

2016

## Individuals with Dementia in Respite Care: Longitudinal Changes in Anxiety, Social Engagement, and Problem Behaviors

Rachael Elizabeth Mills

*Louisiana State University and Agricultural and Mechanical College*

Follow this and additional works at: [https://repository.lsu.edu/gradschool\\_theses](https://repository.lsu.edu/gradschool_theses)



Part of the [Social Work Commons](#)

---

### Recommended Citation

Mills, Rachael Elizabeth, "Individuals with Dementia in Respite Care: Longitudinal Changes in Anxiety, Social Engagement, and Problem Behaviors" (2016). *LSU Master's Theses*. 3762.

[https://repository.lsu.edu/gradschool\\_theses/3762](https://repository.lsu.edu/gradschool_theses/3762)

This Thesis is brought to you for free and open access by the Graduate School at LSU Scholarly Repository. It has been accepted for inclusion in LSU Master's Theses by an authorized graduate school editor of LSU Scholarly Repository. For more information, please contact [gradetd@lsu.edu](mailto:gradetd@lsu.edu).

INDIVIDUALS WITH DEMENTIA IN RESPITE CARE:  
LONGITUDINAL CHANGES IN ANXIETY,  
SOCIAL ENGAGEMENT,  
AND PROBLEM BEHAVIORS

A Thesis

Submitted to the Graduate Faculty of the  
Louisiana State University and  
Agricultural Mechanical College  
in partial fulfillment of the  
requirements for the degree of  
Master of Social Work

in

The School of Social Work

by  
Rachael E. Mills  
B.S., Louisiana State University, 2014  
May 2016

## **ACKNOWLEDGMENTS**

First, I would like to acknowledge and thank my thesis chair, Dr. Scott Wilks. You provided for relentless guidance, time, and support throughout this journey for which I am immensely thankful. I would also like to thank my thesis committee members, Dr. Juan Barthelemy and Dr. Cecile Guin for the amount of time and dedication they spent on helping me with this educational journey. I would also like to thank Jennifer Geiger for helping to guide me through all of the statistical data.

To my friends and family: thank you for supporting and tolerating me all along the way. I appreciate all of the times each of you allowed me to discuss my thesis, the findings, and all of the information I found interesting about Alzheimer's disease. I could not have done this without your constant love and support. Thank you.

## TABLE OF CONTENTS

ACKNOWLEDGMENTS .....	ii
ABSTRACT.....	iv
CHAPTER 1: INTRODUCTION.....	1
CHAPTER 2: LITERATURE REVIEW .....	4
Explicating Dementia and Alzheimer’s Disease.....	4
Conceptualization of Anxiety .....	9
Conceptualization of Social Engagement .....	11
Conceptualization of Problem Behaviors .....	12
Conceptualization of Charlie’s Place.....	13
Historical Foundation of Adult Day Centers .....	15
Application to Charlie’s Place .....	16
Purposes, Research Questions, and Hypotheses.....	17
CHAPTER 3: METHODS .....	19
Design and Sampling .....	19
Instrumentation .....	19
Data Analysis .....	21
CHAPTER 4: RESULTS.....	22
Sample Characteristics.....	22
Anxiety, Social Engagement, and Problem Behavior.....	23
CHAPTER 5: DISCUSSION AND IMPLICATIONS.....	25
Summary of Results.....	25
Implications for Practice.....	26
Limitations and Future Research .....	27
CHAPTER 6: CONCLUSION .....	29
REFERENCES .....	30
APPENDIX: IRB APPROVAL FORMS .....	34
VITA.....	37

## **ABSTRACT**

Individuals with Alzheimer's disease (AD) and dementia commonly referred to as persons with dementia (PWD), often experience behavioral and psychological symptoms as a result of the disease process. With no cure for AD and no way to prevent the onset of this disease, studies are analyzing methods to manage the symptoms of this disease. Previous literature on the effect of social adult day models is limited, especially pertaining to particular symptoms linked to this disease. This study explored three presenting symptoms associated with AD: anxiety, problem behaviors, and social engagement. Using a secondary data analysis, a sample of 30 participants from Charlie's Place Activity and Respite Center located in Baton Rouge, LA were observed and analyzed to determine if this adult day center would have an impact on the PWD's levels of anxiety, problem behaviors, and social engagement.

## CHAPTER 1: INTRODUCTION

In the United States in 2015, an estimated 5.3 million people were living with Alzheimer's disease, yet there are still no curative methods or ways to prevent the onset of the disease (Alzheimer's Association, 2016). Many people living with Alzheimer's disease or another form of dementia exhibit psychological and behavioral problems that can become a burden to both the individual and his or her caregiver. In addition to the onset of memory loss, an individual with Alzheimer's disease can experience symptoms such as agitation, anxiety, depression, social withdrawal, and problem behaviors (Alzheimer's Association, 2015a). The purpose of this longitudinal study is to determine the effect of adult day centers on the levels of anxiety, problem behaviors, and social engagement of persons with Alzheimer's disease or other types of dementia.

Caregivers are a vastly overlooked population in need of assistance, especially those caring for someone with a form of dementia such as Alzheimer's disease (AD). According to the Alzheimer's Association (2015b), in 2014 an estimated 85% of all caregivers for persons with dementia consisted of family members, equating to nearly 15.7 million people (Alzheimer's Association, 2015b). The amount of unpaid care provided by family caregivers consisted of 17.9 billion hours of voluntary care (Alzheimer's Association, 2015b). According to the Alzheimer's Association (2015b), the billions of hours of unpaid care is worth nearly \$217 billion. The slow progression of AD causes a steady cognitive decline that often results in an individual's inability to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs), which are needed for one to function independently (Alzheimer's Association, 2016). Some of the daily tasks associated with caregiving can include managing medications, feeding, transporting, and grooming (Alzheimer's Association, 2016). The around-the-clock care that

persons with dementia are in need of can create situations in which the caregiver begins to exhibit signs of caregiver stress or burden (Alzheimer's Association, 2015b).

Caregiver burden, as defined by Hall et al. (2014), is any stressors related to taking care of a family member or friend undergoing a chronic illness. Caring for someone with AD or dementia can result in a high level of caregiver burden that can generate biological, psychological, and social problems among the caregivers (Hall et al., 2014). When unaddressed, caregiver stress can cause health problems such as anxiety, depression, or insomnia and can also lead to feelings of irritability or anger towards their loved one afflicted by AD (Alzheimer's Association, 2016). Due to the cognitive and physical decline that AD and dementia perpetuates, higher levels of caregiver stress are attributed to the progression of these diseases (Hall et al., 2014). According to the Alzheimer's Association (2016), caregivers of persons with dementia are 3.5 times more likely to state that the most difficult problem related to caregiving is the exacerbation of their own health related issues. Additionally, the Alzheimer's Association (2016) found that mental distress was regarded as high or very high in 60% of AD and dementia caregivers and another 40% of caregivers were found to be battling depression related to caregiving. Furthermore, in 2014 there was an estimated cost of \$9.7 billion associated caregiver health issues (Alzheimer's Association, 2016). The risk of caregivers developing a psychological or physical ailment can result in high burnout rates, which can diminish the quality of care for the individual with AD or dementia (Alzheimer's Association, 2016).

One of the many interventions targeting caregiver burden are respite centers, commonly referred to as adult day centers (MetLife Mature Market Institute, 2010). In 2010, the MetLife Mature Market Institute assessed 4,601 medical and social adult day centers across the United States. The study found that these adult day centers served nearly 260,000 participants and

caregivers combined (MetLife Mature Market Institute, 2010). One of the most common reasons for client enrollment was due to the need for caregiver respite (MetLife Mature Market Institute, 2010). It was observed that both participants and caregivers benefited from many of the adult day centers. One main way these adult day centers helped caregivers was that they allowed the caregiver to continue working, while at the same time providing resources and programs to help alleviate some of the stressors associated with caring for persons with dementia (MetLife Mature Market Institute, 2010). The study indicated that nearly 70% of these adult caregiving programs provided educational opportunities for caregivers, 58% offered support groups, and 40% ran individual counseling sessions (MetLife Mature Market Institute, 2010). Additionally, it was determined that 80% of participants attended adult day centers for a full work-hour day and nearly 46% attended five days per week (MetLife Mature Market Institute, 2010). This is important because it demonstrates how caregivers are able to continue working while providing care for their loved ones (MetLife Mature Market Institute, 2010). Having adult day centers that persons with AD or dementia can attend is a way to alleviate some of the stressors related to caregiver burden.

The subsequent sections of the literature review will evaluate current literature on Alzheimer's disease and dementia. Next, the outcomes of anxiety, problem behaviors, and social engagement in relation to AD and dementia will be explicated. Following will be a discussion explaining the conceptualization of the adult day center Charlie's Place. Lastly, the historical foundation of adult day centers will be explained, along with the study's purpose, research questions, and hypotheses.



## CHAPTER 2: LITERATURE REVIEW

### Explicating Dementia and Alzheimer's Disease

In order to conduct a study with individuals with Alzheimer's disease (AD) and dementia, it would be important to explicate the disease first. Major neurocognitive disorder, commonly known as *dementia*, is a broad term for the overall symptoms pertaining to the decline in cognitive ability. Dementia causes significant impairment in both activities of daily living (ADLs) and instrumental activities of daily living (IADLs; American Psychiatric Association, 2013). ADLs include tasks that are needed to take care of one's body, such as feeding, bathing, and dressing; IADLs include more complex tasks needed to maintain independence, such as managing finances and doing housework. There are a number of different cognitive disorders under the category of dementia, but the three most common forms of dementia are AD, vascular dementia, and dementia with Lewy Bodies (Alzheimer's Association, 2015a). AD is a neurocognitive disorder that causes the deterioration of neurons in the brain resulting in problems with memory, language, judgment, and behavior (Alzheimer's Foundation of America, 2015).

According to the American Psychiatric Association (2013), four criteria must be met before someone can be diagnosed with AD. These include the presence of mild or major neurocognitive disorder, a gradual onset of cognitive impairments, criteria meeting either probable or possible AD, and the disease is not better explained by other neurological and biological diseases (American Psychiatric Association, 2013). The symptoms for mild neurocognitive disorder are typically memory loss and problems with IADLs, while major neurocognitive disorder yields a significant decline in the ability to perform ADLs. One main distinguishing factor AD has from other types of dementia is that there must be very clear signs

of major cognitive decline persisting over a period of time (American Psychiatric Association, 2013). Further, in order to meet the requirement of probable AD the gene for AD must be present. Possible AD would be diagnosed if there were no linking gene present (American Psychiatric Association, 2013). The reason for the differentiation between probable and possible AD is due to the fact that the diagnosis of AD can only be certain upon examination of an autopsy (American Psychiatric Association, 2013).

Symptoms of Alzheimer's disease most commonly emerge after the age of 65 and progress for the remainder of one's lifetime ("Alzheimer's Disease," 2011). While the cause is still unknown, AD's greatest risk factor is age (American Psychiatric Association, 2013). In the United States, 53% of those living with AD are between the ages 75-84 and those over 85 years make up 40% of the AD population (American Psychiatric Association, 2013). Individuals diagnosed with AD usually have a life expectancy of about ten years, but this can range from two to 20 years (Alzheimer's Foundation of America, 2015). Currently, more than 5.3 million people in America live with AD, and with no cure the number of people with this disease continues to grow. It is projected that by the year 2025 there will be a 40% increase in individuals living with AD (Gaugler, James, Johnson, Scholz, & Wevue, 2015). As of 2015, Louisiana has nearly 82,000 people living with AD and this number is expected to increase 34.1% by the year 2025 (Gaugler et al., 2015). The projected increase of cases of AD is indicative of the importance of planning for the future and understanding the problems that can be caused by the disease.

Additionally, the individuals participating in this study are being taken care of by their primary caregivers within the home. In 2013, 15.5 million caregivers provided in-home care to a loved one with AD or dementia, amounting to approximately 17.7 billion hours of voluntary care (Gaugler et al., 2015). In the United States the number of nursing home beds amounts to nearly

1.6 million. Of that, the number of nursing home beds accounted for in Louisiana is 35,533 (Gaugler et al., 2015). In 2012, Harris-Kojetin, Sengupta, Park-Lee, and Valverde (2013) indicated that 48.5% of nursing home residents consisted of those with AD or dementia, but Gaugler et al. (2015) stated that this number has increased to nearly 60%. With the vast amount of people providing in-home care for someone with AD or dementia, along with the increasing percentage of nursing home beds allocated to individuals with dementia, it is important for social work to understand the mental, social, and behavioral health of these individuals. Constructs related to these types of health constitute the outcomes of this study. For the sake of brevity, the remainder of this thesis will refer to people with AD or dementia as persons with dementia (PWD).

It is evident that PWD experience changes in memory due to the nature of this disease and behavior problems often accompany the memory changes. Older adults without a major or mild cognitive disorder generally have a cognitive decline that increases 1-2% per year, while PWD have a progression rate of 10-15% each year (Henry et al., 2012). Because the onset of AD is gradual, changes both with memory and behavior can be outlined in early, middle, and advanced stages. As the Alzheimer's Association (2015a) states, during the beginning stages PWD are generally self-sufficient, in that one begins experiencing only minor problems with memory. As a result, difficulty with IADLs ensues. For example, PWD may begin to forget things such as paying monthly bills or taking regularly scheduled medications, but might still be able to drive or continue with his or her career (Alzheimer's Association, 2015a). The early stages of AD can last for several years and because PWD are predominantly functionally independent with minor changes in memory, the signs of AD may not be recognized (Alzheimer's Association, 2015a).

During the middle stages of AD, greater changes in memory begin to occur. The stark decline of functional memory along with difficulty performing ADLs often contributes to definable behavioral problems in this stage (Alzheimer's Association, 2015a). Once simple tasks become burdensome, PWD start to rely on the assistance of his or her caregiver to function in everyday activities such as deciding what to wear or remembering to brush one's teeth (Alzheimer's Association, 2015a). Problem behaviors appear to peak during the middle stages of AD and begin to diminish during the last and most advanced stages as PWD lose any ability to verbally or physically communicate. As indicated by Roth et al. (2003), problematic behaviors among PWD are most prominent with moderate dementia and become less severe as the stages and symptoms of dementia progress.

The decline in memory along with problematic behaviors can lead to changes in social engagement for PWD. As the disease progresses, PWD begin to participate less frequently in social activities, which may no longer be seen as enjoyable. In a study by Farrell et al. (2014), 236 participants with mild-to-moderate AD were assessed to determine if they had trouble with finding the correct words when speaking and how this affected social engagement. Fifty-two percent of the participants stated they had problems with effectively communicating. The participants also reported lower satisfaction in activities they previously enjoyed in addition to decreased participation in social activities (Farrell et al., 2014). It was concluded that the participants with AD that experienced difficulty when speaking participated in social activities less frequently and indicated that these activities were no longer as gratifying as they were before the onset of AD (Farrell et al., 2014). Furthermore, a study by Henry et al. (2012) sought to determine whether social behavior differed among those with early dementia, mild cognitive impairment, and people who aged normally. The study examined social appropriateness,

inappropriateness, stereotyping, and prejudice. It was found that the controls and the participants with mild cognitive impairment did not differ significantly, while those with early dementia displayed the highest signs of inappropriate social behavior (Henry et al., 2012). The findings were attributed to the deterioration of cogent memory, rather than trouble with memory recall (Henry et al., 2012). Findings from this study indicated that behavior problems related to social situations could occur in the earliest stages of AD, which can have a negative effect on interpersonal relationships for PWD (Henry et al., 2012).

It should be noted that these changes in personal interaction for PWD have a direct effect on their relationship with a caregiver. Though PWD may be faced with increased difficulty and dissatisfaction when participating in social and leisure activities, the progression of dementia severely impacts relationships with the person's caregivers. In a longitudinal study, the effects of behavioral problems among PWD were examined (Gaugler, Kane, Kane, & Newcomer, 2005). It was determined that problems in behavior directly correlated with increased caregiver stress as well as increased levels of depression. Furthermore, a study by Linde, Denning, Matthews, and Brayne (2014) stated that all of the symptoms of behavioral and psychological symptoms in dementia (BPSD) were associated with higher levels of caregiver burden and disturbed the overall happiness of caregivers. Another study, by Perren, Schmid, Herrmann, and Wettstein (2007), assessed behavioral problems in PWD and the effects it has on their caregiving spouses. The study found that the caregivers had a higher tendency of avoiding their partners that exhibited higher levels of problematic behaviors (Perren, Schmid, Herrmann, & Wettstein, 2007). The study by Fauth (2013), which evaluated 177 caregivers and their spouses with dementia, categorized BPSD by frequency of occurrence, level of intensity, and distress. It was found that the most prevalent behavioral symptoms that were assessed using the

Neuropsychiatric Inventory consisted of apathy, depression, and agitation (Fauth, 2013). The most apparent physical changes were in appetite, motor behaviors, and apathy; the most distressing symptoms were delusions, agitation and irritability (Fauth, 2013). Furthermore, the study presented that the most prevalent symptoms according to the Revised Memory and Behavior Problems Checklist were related to memory problems, and the least frequent behavioral symptoms among PWD were disruptive behaviors (Fauth, 2013). Though problems with memory were most frequent and disruptive symptoms were least frequent among the PWD, the most distressing symptoms to the caregivers were the disruptive symptoms. As indicated by this study, though behavioral problems may not occur as often as memory problems, these have a direct correlation of the relationship between PWD and his or her caregiver and therefore require particular attention (Fauth, 2013).

### **Conceptualization of Anxiety**

Though PWD may experience many symptoms related to overall mental health, the main focus pertaining to mental health in this thesis is anxiety. This is because anxiety is remarkably prevalent in this population. Before discussing the prevalence of anxiety within this population, it is important to discuss the prevalence within the general population of the country. Of the anxiety disorders, generalized anxiety disorder (GAD) is listed as the most prevalent, affecting nearly 6.8 million Americans (National Institute of Mental Health, n.d.). Obsessive-compulsive disorder (OCD) and panic disorder follow behind GAD as the second and third leading forms of anxiety disorders (American Psychiatric Association, 2013). GAD, which affects twice as many women as men, typically includes symptoms such as feelings of restlessness, becoming easily fatigued, trouble concentrating, irritability, muscle tension, and sleep disturbance (American Psychiatric Association, 2013; National Institute of Mental Health, n.d.). According to the

American Psychiatric Association (2013) in order to meet the criteria for GAD one must exhibit signs of the following six criteria: excessive anxiety or worry present for at least six months, difficulty controlling the worry, having three of the six previously described symptoms, symptoms causing significant distress, and that the disorder is not due to another medical condition or other mental disorders.

While the etiology of anxiety disorders is largely unknown, onset usually occurs in early adulthood affecting between 5.7% and 9% of all cases for a lifetime (American Psychiatric Association, 2013; National Institute of Mental Health, n.d.). A study by Gonçalves and Byrne (2012) sought to test the age of onset for GAD. The study analyzed a sample of 8,841 Australians between the ages of 16-86 years, of which 3,178 people were between the ages of 55-85. In the age range of 55-85 years, 227 participants presented a lifetime prevalence of GAD. The study found that less than one tenth of those with GAD were diagnosed with the disorder over the age of sixty (Gonçalves & Byrne, 2012). According to the American Psychiatric Association (2013), in the United States GAD typically occurs more frequently in those of European origin over and above people of Asian, African, Native American, or Pacific Islander descent. One cross sectional study that examined anxiety rates among a sample of 330 adults 65 years and older found that when compared to older white adults, African American adults were less likely to be classified as anxious and less likely to be taking psychotropic medications (Kim, Morales, & Bogner, 2008).

After reviewing different empirical data, while many people with AD showed significant signs of anxiety, the prevalence of GAD constituted a small percentage among those with AD because they did not meet the criteria outlined in the DSM-V. For example, the study by Chemerinski, Petracca, Manes, Leiguarda, and Starkstein (1998) assessed 398 AD patients for

GAD and only 5% of the patients presented symptoms that qualified for this disorder. While only a small portion met the criteria for GAD, the authors noted that those with GAD presented much more severe symptoms for anxiety, depression, and behavioral problems than the AD patients without GAD. Chemerinski et al. (1998) also referred to a study that found GAD has a prevalence of 1.9% among adults 65 and older implying that GAD among those with AD is two to four times more likely to occur than with older adults without AD (Blazer, George, & Hughes, 1991). Another study examined two different samples with AD over a period of five years; one group consisted of 62 participants and the other group with 75 (Ferretti, McCurry, Logsdon, Gibbons, & Teri, 2011). The study sought to examine overall anxiety symptoms, not just GAD. It was concluded that 68% to 71% of the participants displayed symptoms of anxiousness with worry, apprehension, and irritability, all of which were the most prevalent symptoms (Ferretti et al., 2011). The study found that only 5% to 6% presented symptoms for GAD that met the criteria for the DSM-V (Ferretti et al., 2011). These studies demonstrate that those who have AD are at higher risk for developing GAD and the possibility for worsening symptoms of anxiety. The current study will follow the understanding of anxiety as cited in the previous paragraph, focusing on the symptoms of anxiety and not the disorder itself.

### **Conceptualization of Social Engagement**

As indicated by the Alzheimer's Association (2015a), PWD in the early stages of AD may experience slight behavioral changes such as feeling more anger or embarrassment due to the frustration of knowing they are beginning to experience memory problems. As a result, this can sometimes lead to isolation (Alzheimer's Association, 2015a). The article by van der Linde, Denning, Matthews, and Brayne (2014) analyzed 62 studies related to the BPSD. In relation to PWD, the study found patterns of symptoms pertaining to affectivity, psychosis, hyperactivity,



and euphoria. Of these symptoms it was stated that PWD exhibited affective behavioral symptoms, particularly dysphonia and anxiety, most frequently in early stages of AD and dementia (van der Linde, Dening, Matthews, & Brayne, 2014).

### **Conceptualization of Problem Behaviors**

As a result of the inability to perform simple daily tasks, PWD can become easily angered or frustrated (Alzheimer's Association, 2015a). Throughout the middle stages of AD, PWD may experience problematic behaviors as a result of declining communication skills. PWD begin having more difficulty expressing coherent thoughts or concerns and deciphering conversations among others, thus making communication less effective and more challenging (Alzheimer's Association, 2015a). Common problem behaviors that arise during the middle stages of AD are anxiety, depression, repetitive behaviors, irritability, altered sleep patterns, physical/verbal outbursts, and a tendency to continually wander (Alzheimer's Association, 2015a). As the Alzheimer's Association (2015a) states, these challenging behaviors are due to the brain's inability to retrieve, synthesize, or apply information effectually. Nearly 90% of PWD experience at least one behavioral or psychotic symptom during the middle stages of AD. During this gradual transition from mild to advanced dementia, it is common for PWD to experience any of the following behavioral problems: agitation, aggression, hallucinations, delusions, wandering, or sundowning (Alzheimer's Association, 2015a). The study by Linde, Dening, Matthews, and Brayne (2014) noted that the most prominent symptoms of hyperactivity, which were irritability and aggression, were more commonly displayed during the later stages of AD and dementia (Proitsi et al., 2011).

## **Conceptualization of Charlie's Place**

The independent variable of this study involves participants attending Charlie's Place Activity and Respite Center located in Baton Rouge, LA, which is a branch of Alzheimer's Services of the Capital Area. Alzheimer's Services, also located in Baton Rouge, was founded in 1983 when a local nurse and neurologist recognized a growing problem with AD and dementia ("Alzheimer's Services," 2015a). Alzheimer's Services is a non-profit organization that serves ten parishes in South Louisiana assisting over 15,000 individuals with AD and dementia in addition to educating and providing support for caregivers ("Alzheimer's Services," 2015a) The mission of Alzheimer's Services is to support, teach, and provide help to all of those affected by AD and dementia ("Alzheimer's Services," 2015b.). The types of programs Alzheimer's Services provides consist of educational programs and training sessions on AD and dementia, services and activities supporting caregivers and those with memory impairment, a resource library, a telephone help-line, and Charlie's Place Respite Center ("Alzheimer's Services," 2015d.).

Charlie's Place first opened in Baton Rouge, LA, in 2007. The day center provides respite to caregivers allowing them to have a day to themselves while knowing their loved one is in a safe environment. The participants at Charlie's Place are generally in the early stages of AD or dementia ("Alzheimer's Services," 2015c). In order to attend the respite center, the participants must be ambulatory, continent, and must be able to feed themselves. No more than fifteen participants can attend Charlie's Place per day and each client is permitted to attend a maximum of two days per week ("Alzheimer's Services," 2015c). Additionally, because Charlie's Place is a social model respite center rather than a medical model, it does not provide any medical services to participants. The mission and purpose of Charlie's Place is to encourage

client socialization through various stimulating activities, some of which may include physical exercise; therapeutic activities, such as music or arts/crafts; socialization; mentally stimulating games; lunchtime; and rest (“Alzheimer’s Services,” 2015c). One unique aspect regarding Charlie’s Place is its structural similarity to a comfortable home, i.e. the atmosphere of the living room and kitchen areas resembles that of a house. It is not unusual for clients to exhibit anxiety, social, and behavioral problems; therefore Charlie’s Place’s staff is highly trained to manage a range of difficult and problematic behaviors. T. Durham, the respite care coordinator at Charlie’s Place, stated that working at Charlie’s Place is a dynamic job that requires training to effectively manage these types of behaviors (personal communication, July 27, 2015). A client may have ten good days without any problems and on the eleventh day they may exhibit stress or anxiety, which can be displayed with aggressive outbursts. An example of problematic behavior shown at Charlie’s Place was a client’s resistance to getting in his wife’s car because he thought he is at home and did not want to leave. Durham also stated that clients who have trouble communicating their needs effectively often display aggressive behavior as a result (personal communication, July 27, 2015). These examples indicate a progression of AD and dementia among clients. The activities that Charlie’s Place provides are ways in which the staff manages these types of behaviors. Popular methods to manage problem behaviors and promote socialization among the participants are exercise, discussion groups about who the clients were in the past, and themed socials (Durham, personal communication, July 27, 2015). Through these specialized AD care techniques, Charlie’s Place has become a beneficial adult day center by affectively promoting client well-being and aiding caregivers with respite time.

## **Historical Foundation of Adult Day Centers**

The type of program relevant to Charlie's Place is referred to as a social model day program, but before discussing what this type of model entails the general principles and historical foundation of this model must be explained. Throughout the United States the main variations between adult day programs center on the differentiations between the social and medical models. Generally, the social model is a type of respite program that is geared toward keeping the client an active member of the community ("National Adult Day," n.d). The day programs that adopt the social model are typically open five days a week during regular business hours and their purpose is to provide older adults with a safe environment where they are able to socialize and interact with people their age ("National Adult Day," n.d.). Though it is not uncommon for a social day center to have an on-staff nurse, the medical model usually consists of a larger interdisciplinary team with doctors, nurses, physical therapists, etc. Another main difference between the two models is that a social model is commonly private pay, while a medical model usually accepts Medicaid or Medicare (Alzheimer's Association, 2015a).

In a study conducted by the MetLife Mature Market Institute (2010), 4,601 adult day centers, both social and medical, were analyzed to determine overarching commonalities between the facilities. Among several of the findings, the outcome most significant to this study centered on the relevancy of AD and dementia. With the finding that nearly half of day centers' recipients consisting of those with AD and dementia, it has been demonstrated that adult day programs are the forerunners in caring for this client population (MetLife Mature Market Institute, 2010). Additionally, it was found that roughly 90% of all centers provided activities that encouraged cognitive stimulation, about 80% allowed for memory training activities, and 75% delivered educational programs regarding AD and dementia (MetLife Mature Market

Institute, 2010). With the type of respite care adult day programs are able to provide, it is likely that nursing home placement will be delayed for those with AD and dementia (“National Adult Day,” n.d).

Adult day centers are moderately new establishments in the United States. The origin of adult day centers dates back to the 1930s in England when Dr. Marjory Warren first initiated a rehabilitation hospital specialized for the care of older adults (Brubaker, 2014). Then in 1957, Dr. Lionel Cosin of Cowley Road Day Hospital in England established the very first adult day hospital (Irvine, 1994; “National Adult Day,” n.d). Around the same time as Dr. Cosin, English doctor Eric Brooke began to recognize the twofold problem of medical and social ailments among older adults (Howell, 1976). With the influence of these three British doctors, headway was made in the development of geriatric care. Thus, a model of Dr. Cosin’s adult day hospital was adopted in a North Carolina hospital in the 1960s (“National Adult Day,” n.d). Shortly after, in 1970, Byberry State Hospital in Pennsylvania closed and reopened as an adult day center. The number of adult day centers in the United States began to rapidly grow, with about 300 centers established within the ten years of the first opening (“National Adult Day,” n.d). In order regulate adult day centers and run them in a more uniform manner, the National Adult Day Services Associated was formed in 1979. As of 2014, there were 5,685 day programs in the United States and that number continues to grow (“National Adult Day,” n.d).

### **Application to Charlie’s Place**

Charlie’s Place offers a variety of activities geared towards clients who are experiencing the early stages of AD and dementia. These activities have the potential to influence a positive outcome on the health of the clients who partake in them. More specifically, the structure of Charlie’s Place as a social day program could have a positive impact in reducing or managing

client anxiety and behavioral problems, while increasing social engagement. Because Charlie's Place provides a structured and safe environment where clients can participate in various daily activities, a client's level of anxiety may be reduced. The reason for this is that a client who is in the early stages of AD and dementia may feel anxious about activities, such as meal preparation, because they no longer remember the steps to prepare a meal. Charlie's Place could alleviate some of the stress and anxiety of such activities (Femia, Zarit, Stephens, & Greene, 2007). Additionally, because Charlie's Place is a social model, one of its main goals is to provide various activities that incorporate and encourage socialization. In doing this, Charlie's Place may reduce client isolation while maintaining his or her independence (SeniorCare.com, 2015). Lastly, the issue of behavioral problems could be regulated with continuous activities, including those that incorporate cognitive stimulation (SeniorCare.com, 2015). For someone who is inclined to become restless or agitated, the structured activities such as exercise or music therapy may provide a way for that client to refocus reducing the tendency towards problematic behavior.

### **Purposes, Research Questions, and Hypotheses**

The purpose of this study is to evaluate whether attending a social model adult day center, such as Charlie's Place, will have an impact on the levels of anxiety, social engagement, and problem behaviors among PWD.

The research questions for this thesis are as follows:

- **R<sub>1</sub>**. Will regular attendance at Charlie's Place impact anxiety levels among PWD?
- **R<sub>2</sub>**. Will regular attendance at Charlie's Place impact social engagement among PWD?
- **R<sub>3</sub>**. Will regular attendance at Charlie's Place impact problem behaviors among PWD?

Based on the previously discussed literature, the hypotheses for this thesis are as follows:

- **H<sub>1</sub>**. Regular attendance at Charlie's Place will impact anxiety levels of PWD as shown by the Hamilton Anxiety Rating scale.
- **H<sub>2</sub>**. Regular attendance at Charlie's Place will impact social engagement of PWD as shown by the Index for Social Engagement.
- **H<sub>3</sub>**. Regular attendance at Charlie's Place will impact problem behaviors of PWD as shown by the Revised Memory and Problem Behaviors Checklist.

## **CHAPTER 3: METHODS**

### **Design and Sampling**

This thesis conducted a secondary data analysis. The data were collected using an interrupted time-series model collected by Dr. Scott Wilks. Before beginning the study, approval by the LSU institutional review board (IRB) and Alzheimer's Services was obtained. The target population for this study was the clients of Charlie's Place. The data were gathered from Charlie's Place over a 24-month period. First, to recruit participants the executive director of Alzheimer's Services emailed and directly spoke with the caregivers of the clients at Charlie's Place to explain the purpose of the research study. Because of the nature of dementia, consent forms were signed by the caregivers of the clients of Charlie's Place and collected by the Alzheimer's Services staff executive director. Two staff members of Charlie's Place were trained to collect the data by observing the participating client and completing observation based on empirical data.

Attached to the questionnaire was a cover letter that explained the purpose of the study and researcher contact information. To ensure confidentiality, the questionnaire used a unique, numerical code for each participant. The questionnaire captured data related to demographics and empirical measures relating to the health and wellness concerns of the participants. Throughout the 24-month period, data was collected by passively observing the participants in four to six different intervals. The staff completed the data instrument in an isolated area apart from other Charlie's Place staff and clients.

### **Instrumentation**

Client demographic information consisted of number of visits to Charlie's Place, age, sex, race, marital status, education level, and stage of AD.



The Hamilton Anxiety Rating Scale (HAM-A), developed by Dr. M. Hamilton (1959), is a 14-item, 5-point Likert scale with response choices ranging from *not present* to *very severe*. Due to the nature of the interview, the 14<sup>th</sup> item pertaining to the interviewee's behavior was not included. The HAM-A is used to measure client anxiety by assessing cognitive functions, such as anxious mood, tension, fears, insomnia, intellectual, depressed mood, as well as somatic functions such as muscular, sensory, cardio symptoms, respiratory, GI symptoms, genitourinary, and autonomic symptoms (Vaccarino, 2008). Each question within the HAM-A presents a score ranging from 0-5; a higher global score indicates greater levels of anxiety among the client.

The Index of Social Engagement (ISE) is a 6-item, 5-point Likert scale with response choices ranging from *never* to *always*. The ISE was developed by Mor et al. (1995) to assess client interactions, ease of structured activities, ease of self-initiated activities, establishing own goals, involvement in community of facility, and acceptance of invitations to group activities. The ISE score ranges from 0-6, with a higher global score indicating more advanced social engagement (van Beek, Frijters, Wagner, Groenewegen, Ribbe, 2011).

The Revised Memory and Problem Behaviors Checklist (RMPBC) is a 23-item dichotomous questionnaire that measures problem behaviors of PWD (APA, 2015). The RMPBC was created by Teri et al. (1992) and consists of two subscales. One scale measures the frequency of problem behaviors among PWD, while the other measures the reactions of these problems by the caregivers. The latter is not being observed because this thesis is only examining PWD. The questionnaire is usually a Likert scale format, but the scale has been modified in order to assess the client's behaviors during the most recent visit at Charlie's Place. Questions on the RMPBC are related to memory problems, affect, and disruptive behaviors (APA, 2015). The

RMPBC presents one total global score ranging from 0-23. A higher global score indicates a higher occurrence of problematic behaviors.

### **Data Analysis**

The reported descriptive statistics were gathered from all sample demographics, which are nominal levels of measurement except for age and MMSE score, which are interval levels of measurement. Descriptive statistics were also used to report the global scores from the three standardized empirical scales used in this study, which are parametric levels of measurement. The different interval points for each of the scales will determine if the global scores are significantly different. In order to check for significant differences on a specific measure's global score between the different paired data points, a repeated measures ANOVA was run. If the ANOVA outcome was determined to be significant, post-hoc analysis deciphered between which pair(s) of data points was the group significantly different.

## CHAPTER 4: RESULTS

### Sample Characteristics

Sample characteristics are reported in Table 1.

Table 1: Sample Characteristics

Variable	<i>N</i>	%	<i>M</i>	<i>SD</i>
Age			80.37	7.83
MMSE Score			15.67	5.23
Sex Male				
Male	16	53.30		
Female	14	46.70		
Race				
Caucasian	23	76.70		
African American	6	20.00		
Hispanic/Latino	1	3.30		
Marital Status				
Married	19	63.30		
Widowed	11	36.70		
Education Level				
High School/GED	9	31.03		
Bachelor's Degree	9	31.03		
Some College	5	17.24		
Master's Degree	4	13.79		
PhD	2	6.90		
Stage of AD				
Mild	14	46.70		
Moderate	8	26.70		
Severe	6	20.00		
Very Mild	2	6.70		

At the baseline, the total number of participants for the study consisted of 30 people, 53.30% men and 46.70% women. The vast majority of participants were Caucasian (76.70%), followed by African American (20.00%) and Hispanic/Latino (3.30%). Additionally, the mean age of the total participants was 80.37( $SD = 7.83$ ). Of the total number of participants, 63.30% were married and 36.70% widowed. In regards to educational level, 31.03% of participants received their high school diploma or GED and another 31.03% received their bachelors' degree.

This was followed by those who received some college (17.24%), and those participants who received their masters (13.79%). The severity of AD was measured in four stages: very mild (6.70%), mild (46.70%), moderate (26.70%), and severe (20.00%). Lastly, participant MMSE score had a mean of 15.67( $SD = 5.23$ ).

### **Anxiety, Social Engagement, and Problem Behavior**

Although data were collected over a period of 24 months in ten-week intervals, only the first three data intervals presented a sample size sufficient enough to analyze the data. At the baseline assessment there were a total of 30 participants, then at the second follow-up interval there were 24 participants, and 21 participants are interval three. For each category of anxiety, problem behavior, and social engagement repeated measures ANOVA was run. Additionally, the data analyzed for each of these categories were deemed statistically significant at the 0.05 level.

All repeated measure ANOVA results are reported in Table 2. Through the observation of participants by trained staff members, it was hypothesized that regular attendance at Charlie's Place would impact anxiety levels of PWD as shown by the Hamilton Anxiety Rating scale. After the ANOVA was run among the three intervals, none of the paired time intervals were significant  $F(2, 40) = 2.08, p = .14$ ; anxiety among participants remained the same over time. Mauchly's sphericity test indicated that the assumption of sphericity was not violated,  $\chi^2(2) = 5.27, p = .07$ . Therefore, uncorrected ANOVA results were utilized.

Furthermore, it was hypothesized that regular attendance at Charlie's Place would impact social engagement of PWD as demonstrated by the Index for Social Engagement. Mauchly's sphericity test indicated that the assumption of sphericity was not violated,  $\chi^2(2) = 2.24, p = .33$ . Therefore, uncorrected ANOVA results were utilized, which indicated statistical significance between the means for at least one pair of analyses,  $F(2, 40) = 3.45, p = .04$ . After analyzing the

pairwise comparisons to determine which two points were statistically significant, it was found that the mean social engagement scores between intervals one and three were significantly different. Social engagement significantly declined from the baseline to interval three.

Lastly, it was hypothesized that regular attendance at Charlie’s Place would impact problem behaviors as shown by the Revised Memory and Problem Behaviors Checklist.

Mauchly’s sphericity test indicated the assumption of sphericity was violated,  $\chi^2(2) = 16.52, p = .00$ . Because  $\epsilon = .63$ , the Greenhouse-Geisser correction was used  $F(1.27, 25.30) = 3.18, p = .08$ .

These results indicated that problem behaviors remained the same over time.

Table 2: Repeated Measure ANOVA Results

Variable	$df_w$	$df_e$	$F$	$p$
Anxiety	2.00	40.00	2.08	.14
Problem Behaviors <sup>a</sup>	1.27	25.30	3.18	.08
Social Engagement	2.00	40.00	3.44*	.04

\* $p < .05$

<sup>a</sup> Greenhouse-Geisser correction used

## CHAPTER 5: DISCUSSION

### Summary of Results

As previously demonstrated, the changes in the levels of anxiety and problem behaviors among PWD attending Charlie's Place were non-significant. This shows that neither anxiety nor problem behaviors decreased in participants attending the adult day center. Social engagement was statistically significant, meaning that it significantly differed among participants between at least one pair of intervals. Social engagement decreased between intervals one and three and showed no significant results between one and two or two and three. The reason for the decrease in social engagement may be attributed to the fact that AD causes a regression in memory and often results in a decline in social activity (Alzheimer's Foundation of America, 2015). This study's results of a decrease in social engagement coincides with the previously mentioned literature, such as the by Farrell et al. (2014) which concluded that a decline in participant socialization was because of memory regression.

Although etiology related to the impact of adult day centers on PWD's levels of anxiety, social engagement, and problem behavior is limited, the findings of this study related to other pieces of literature. As discussed in the literature review, it is very common for PWD to experience higher levels of anxiety and problem behaviors in addition to having a decline in social engagement (Chemerinski et al., 1998; Farrell et al., 2014; Roth et al., 2003;). The study by Roth et al. (2003) indicated that problem behaviors among PWD are extremely prevalent among those in the middle stages of AD. Farrell et al. (2014) determined that persons with mild to moderate AD had decrease in social and previously pleasurable activities. Although there is not extensive research on GAD and AD, studies such as Chemerinski et al. (1998) and Blazer, George, and Hughes (1991) found that participants with AD exhibited higher levels of anxiety

than individuals without AD. In addition to this study's findings, these studies further indicate that anxiety, problem behavior, and social engagement may not change due to the deteriorating nature of AD.

### **Implications for Practice**

As the above literature indicates, there is limited research on the affects of adult day centers on PWD experiencing anxiety, social engagement, and problem behaviors. As indicated by this study's results, if PWD attending adult day centers does not decrease anxiety or problem behaviors, the potential for caregiver burnout could increase. In a study by Hall et al. (2014), researchers sought to determine whether increased symptoms associated with AD and dementia caused greater stress in their caregivers. After evaluating 100 participants with mild to moderate AD and their caregivers, Hall et al. (2014) determined that caregivers who presented with higher levels of depression correlated with PWD's level of cognition, behavior disturbances, and level of independence. Another study, by Yeager, Hyer, Hobbs, and Coyne (2010), assessed the level of caregiver burden in relation to the stages of AD and the associated symptoms of the disease. The study similarly found that caregiver burden increased as cognitive and physical independence of those with AD declined (Yeager et al., 2010). As these two studies indicate, those caring for PWD may be at risk for caregiver stress or burnout. Therefore, social workers may need more rigorous education regarding the signs of caregiver burnout and how to address these issues with the caregivers. Further, when working with caregivers of PWD it is important to note that even if adult day centers do not have a significant impact on the participants' levels of anxiety, social engagement, or problem behaviors, having PWD attend day centers can help relieve caregiver stress by giving respite to the caregivers (MetLife Mature Market Institute, 2010). It is important that social workers be educated on how to work with the growing

population of PWD and be familiar with the cognitive and behavioral aspects that change an individual's personality and how this could potentially affect their caregivers.

Although there were no significant improvements in anxiety and problem behaviors and there was a decline in social engagement among participants, this may not be indicative of the quality of care provided by Charlie's Place. Due to the progressive, degenerative nature of AD and dementia, participant improvement may never be an attainable goal. Because AD and dementia progress with time, the likelihood of seeing significant improvements in these categories could continuously be unsatisfied. In order to successfully work with PWD and their caregivers, social workers should have extensive education on the problematic symptoms of AD and dementia. With more than 5 million people in America living with AD and still no cure, social workers need to recognize the prevalence of the disease and advocate for solutions (Alzheimer's Association, 2016). The findings of this study along with other similar literature implicates the importance of planning for the future and understanding the problems that can be caused by AD and dementia. In order to help the PWD and their caregivers to fully understand the disease process along with techniques to help manage symptoms, social workers could provide psychoeducation.

### **Limitations and Future Research**

Some of the limitations of this study include its small sample size (N = 30). The reason the sample size was restricted to such a small number was partly due to the fact that Charlie's Place has a limit of fifteen clients per day. Additionally, the small sample size can also be attributed to the drop out rate due to the nature of the disease. In order to attend Charlie's Place, the PWD must be ambulatory, continent, and able to self-feed. Due to the nature of AD, as the disease progresses and the client's cognitive faculties decline, they are not eligible to attend



Charlie's Place. With a larger adult day center, a greater sample size would likely be possible because the clientele population would be bigger and there would be fewer limitations on attending qualifications.

In addition to the study's small sample size there was also a lack of random sampling and a lack of a comparison group. Because Charlie's Place is a closed group, random sampling was not used. Another agency was contacted as a means for a control group, but was unresponsive. This demonstrates a sampling bias within the study. Due to a lack of random sampling, the population addressed in this study may be underrepresented and may not be an accurate representation of the population of PWD as a whole (Taylor-Powell, 2009)

Another limitation to this study is how many days per week the participants are able to attend Charlie's Place. Because participants can only attend this day center a maximum of two days per week, this could limit the possibility of influence on anxiety, social engagement, and problem behavior. Conducting this study at an adult day center where participants can attend up to seven days per week could allow for more rigorous information to be gathered. Because of the aforementioned nature of AD and dementia, 10 week intervals of data collection may have been too intermittent to note any significant changes. Future studies on respite care should collect data in more frequent intervals.

## CHAPTER 6: CONCLUSION

The purpose of this thesis was to determine the effect of the social adult day center Charlie's Place on the levels of anxiety, problem behaviors, and social engagement of PWD. The study began with a literature review using previous research to explicate the disease process of AD and dementia and how it affects the individual along with his or her caregiver. The literature review continued with a conceptualization of outcomes assessing anxiety, problem behavior, and social engagement in relation to AD. Then the literature review conceptualized Charlie's Place, followed by the historical background of adult day centers. The methods section outlined in this thesis demonstrated that this thesis used a secondary data analysis. Further, data were gathered over a period of 24-months by observing participants at Charlie's Place in four to six different intervals and completing patient demographics and the aforementioned scales. As shown in the results section, it was determined that both anxiety and problem engagement in participants neither increased nor decreased, while social engagement declined from interval one to interval three. As previously stated, the number of people in the United States with AD continues to increase and there is a need to understand how to manage the symptoms that often ensue with the development of this disease. Because there is limited research pertaining to PWD attending adult day centers, this thesis added to the body of knowledge by assessing a few of the symptoms associated with AD.

## REFERENCES

- Alzheimer's Association. (2015a). *What is dementia?* Retrieved from <http://www.alz.org/what-is-dementia.asp> .
- Alzheimer's Association. (2015b). *Alzheimer's disease caregivers*. Retrieved from [http://act.alz.org/site/DocServer/caregivers\\_fact\\_sheet.pdf?docID=3022](http://act.alz.org/site/DocServer/caregivers_fact_sheet.pdf?docID=3022) .
- Alzheimer's Association. (2016). *2015 Alzheimer's facts and figures*. Retrieved from <http://www.alz.org/facts/> .
- Alzheimer's Disease and Education Referral Center (2011). *Alzheimer's disease fact sheet*. Retrieved from [http://www.nia.nih.gov/sites/default/files/alzheimers\\_disease\\_fact\\_sheet\\_0.pdf](http://www.nia.nih.gov/sites/default/files/alzheimers_disease_fact_sheet_0.pdf) .
- Alzheimer's Foundation of America. (2015). *About Alzheimer's*. Retrieved from <http://www.alzfdn.org/AboutAlzheimers/definition.html> .
- Alzheimer's Services of the Capital Area. (2015a). History. Retrieved from <http://www.alzbr.org/explore.cfm/aboutus/history/> .
- Alzheimer's Services of the Capital Area. (2015b). Mission Statement. Retrieved from <http://www.alzbr.org/explore.cfm/aboutus/missionstatement/> .
- Alzheimer's Services of the Capital Area. (2015c). Charlie's Place and Respite Center. Retrieved from <http://www.alzbr.org/charliesplace.cfm> .
- Alzheimer's Services of the Capital Area. (2015d) Programs and Services. Retrieved from <http://www.alzbr.org> .
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5<sup>th</sup> ed.). Arlington, VA: American Psychiatric Publishing.
- American Psychological Association. (2015). *The Revised Memory and Behavior Problems Checklist*. <http://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/memory-behavior.aspx> .
- Blazer, D., George, L.K., Hughes, D. (1991) The epidemiology of anxiety disorders: an age comparison. *Anxiety in the Elderly*. pp. 17-30.
- Brubaker, J. (2014). The birth of a new specialty: Geriatrics. *The Journal of Lancaster General Hospital*, 3(3). Retrieved from <http://www.jlgh.org/Past-Issues/Volume-3---Issue-3/The-Birth-of-a-New-Specialty.aspx> .

- CaringKind the Heart of Alzheimer's Caregiving. (2015). Social vs. medical model day programs.  
<https://www.alznyc.org/nyc/searchforservices/socialmedical.asp#.VeHLbBNVikp> .
- Chemerinski, E., Petracca, G., Manes, F., Leiguarda, R., & Starkstein, S. E. (1998). Prevalence and correlates of anxiety in Alzheimer's disease. *Depression and Anxiety*, 7(4).
- Farrell, M. T., Zahonde, L. B., Stern, Y., Dorrejo, J., Yeung, P., & Cosentino, S., (2014). Subjective word-finding difficulty reduces engagement in social leisure activities in Alzheimer's disease. *Journal of the American Geriatrics Society*, 62(6), 1056-1063.
- Fauth, E. A. (2013) Which behavioral and psychological symptoms of dementia are the most problematic? Variability by prevalence, intensity, distress ratings, and associations with caregiver depressive symptoms. *International Journal of Geriatric Psychiatry*, 28(7), 263-271.
- Femia, E., Zarit, S., Stephens, M., & Greene, R. (2007). Impact of adult day services on behavioral and psychological symptoms of dementia. *Gerontologist*, 47(6), 775-778.
- Ferretti, L., McCurry, S., Logsdon, R., Gibbons, L., & Teri, L. (2001). Anxiety and Alzheimer's disease. *Journal of Geriatric Psychiatry and Neurology*, 14(1). 52-58.
- Gaugler, J., James, B., Johnson, T., Scholz, K., Weuve, J. (2015). *2014 Alzheimer's disease facts and figures*. Retrieved from [http://www.alz.org/downloads/Facts\\_Figures\\_2014.pdf](http://www.alz.org/downloads/Facts_Figures_2014.pdf) .
- Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer R. (2005). The longitudinal effects of early behavior problems in the dementia caregiving career. *Psychology and Aging*, 20(1), 100-116.
- Gonçalves, D. C., & Byrne, G. J. (2012). Sooner or later: age at onset of generalized anxiety disorder in older adults. *Depression and Anxiety*, 29(1), 29-46.
- Hall, D., Wilkerson, J., Lovato, J., Sink, K., Chamberlain, D., Alli, R., & ... Shaw, E.G. (2014). Variables associated with high caregiver stress in patients with mild cognitive impairment or Alzheimer's disease: Implications for Providers in a Co-Located Memory Assessment Clinic. *Journal of Mental Health Counseling*, 36(2), 145-159.
- Hamilton, M. (1959).The assessment of anxiety states by rating. *British Journal of Medical Psychology* 32:50-55.
- Harris-Kojetin, L., Sengupta, M., Park-Lee, E., Valverde, R. (2013). Long-term care services in the United States: 2013 overview. *National Center for Health Statistics. Vital Health Stat*, 3(37). [http://www.cdc.gov/nchs/data/nsltcp/long\\_term\\_care\\_services\\_2013.pdf](http://www.cdc.gov/nchs/data/nsltcp/long_term_care_services_2013.pdf) .

- Henry, J. D., von Hippel, W., Thompson, C., Pulford, P., Sachdev, P., & Brodaty, H. (2012). Social behavior in mild cognitive impairment and early dementia. *Journal of Clinical & Experimental Neuropsychology*, 34(8), 806-813.
- Howell, T. (1976). Aspects of the history of geriatric medicine. *Section of the History of Medicine*, 69. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1864279/pdf/procrsmed00029-0083.pdf> .
- Irvine, R. (1994). Obituary: Lionel Cosin. *The Independent*. Retrieved from <http://www.independent.co.uk/news/people/obituary-lionel-cosin-1369765.html> .
- Kim, Y., Morales, K., & Bogner, H. (2008). Patient ethnicity and the identification of anxiety in elderly primary care patients. *Journal of the American Geriatric Society*, 56(9), 1626-1630.
- MetLife Mature Market Institute. (2010). The MetLife national study of adult day services. Retrieved from <https://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-adult-day-services.pdf> .
- Mor, V., Branco, K., Fleishman, J., Hawes, C., Phillips, C., Morris, J., et al.(1995). The structure of social engagement among nursing home residents. *Journal of Gerontology: Psychological Sciences*, 50B, 1-8.
- National Adult Day Services Association. (n.d.a). About adult day services. Retrieved from <http://nadsa.org/learn-more/about-adult-day-services/> .
- National Adult Day Services Association. (n.d.b) Historical highlights. Retrieved from <http://nadsa.org/learn-more/historical-highlights/> .
- National Institute of Mental Health. (n.d.). Generalized anxiety disorder among adults. <http://www.nimh.nih.gov/health/topics/generalized-anxiety-disorder-gad/index.shtml> .
- Perren, S., Schmid, R., Herrmann, S., & Wettstein, A. (2007). The impact of attachment on dementia-related problem behavior and spousal caregivers' well-being. *Attachment & Human Development*, 9(2), 163-178.
- Potvin, O., Forget, H., Grenier, S., Prévile, M., & Hudon, C. (2011). Anxiety, depression and 1-year incident cognitive impairment in community-dwelling older adults. *Journal of the American Geriatrics Society*, 59(8), 1421-1428.
- Proitsi P., Hamilton G., Tsolaki M., et al. (2011). A multiple indicators multiple causes (MIMIC) model of behavioural and psychological symptoms in dementia (BPSD). *Neurobiol Aging*, 32(3), 434-442.
- Roth, D. R., Burgio, L. D., Gitlin, L. N., Gallagher-Thompson, D., Coon, D. W., Belle, S. H., & ... Burns, R. (2003). Psychometric analysis of the revised memory and behavior

- problems checklist: factor structure of occurrence and reaction ratings. *Psychology and Aging*, 18(4), 906-915.
- SeniorCare.com. (2015). Benefits of adult day care. Retrieved from <http://www.adultdaycare.org/resources/benefits-of-adult-day-care/> .
- Taylor-Powell, E. (2009). What is sampling bias? Retrieved from <http://www.uwex.edu/ces/4h/evaluation/documents/Whatissamplingbias.pdf> .
- Teri, L., Truax P., Logsdon R., Uomoto, J., Zarit, S., & Vitaliano, P.P. (1992). Assessment of Behavioral Problems in Dementia: The Revised Memory and Behavior Problems Checklist (RMBPC). *Psychology and Aging*, 7,4, 622-31.
- Vaccarino, A. H. (2008). Symptoms of anxiety in depression: assessment of item performance of the Hamilton Anxiety Rating Scale in patients with depression. *Depression & Anxiety* (1091-4269), 25(12), 1006-1013.
- van Beek, A., Frijters, D., Wagner, C., Groenewegen, P., Ribbe, M. (2011). Social engagement and depressive symptoms of elderly residents with dementia: A cross-sectional study of 37 long-term care units. *International Psychogeriatrics*, 23(4), 625-633.
- van der Linde, R., Denning, T., Matthews, F., & Brayne, C. (2014). Grouping of behavioural and psychological symptoms of dementia. *International Journal of Geriatric Psychiatry*, 29(6), 562-568.
- Yeager, C. A., Hyer, L. A., Hobbs, B., & Coyne, A. C. (2010). Alzheimer's disease and vascular dementia: The complex relationship between diagnosis and caregiver burden. *Issues in Mental Health Nursing*, 31(6), 276-384.

APPENDIX: IRB APPROVAL FORMS

ACTION ON PROTOCOL APPROVAL REQUEST



Institutional Review Board
Dr. Robert Mathews, Chair
130 David Boyd Hall
Baton Rouge, LA 70803
P: 225.578.8692
F: 225.578.5963
irb@lsu.edu | lsu.edu/irb

TO: Scott Wilks
Social Work
FROM: Robert C. Mathews
Chair, Institutional Review Board
DATE: January 14, 2014
RE: IRB# 3455
TITLE: Program Evaluation of Charlie's Place Respite Center

New Protocol/Modification/Continuation: New Protocol

Review type: Full \_\_\_ Expedited X Review date: 1/15/2014

Risk Factor: Minimal X Uncertain \_\_\_ Greater Than Minimal \_\_\_

Approved X Disapproved \_\_\_

Approval Date: 1/15/2014 Approval Expiration Date: 1/14/2015

Re-review frequency: (annual unless otherwise stated)

Number of subjects approved: 125

Protocol Matches Scope of Work in Grant proposal: (if applicable) \_\_\_

By: Robert C. Mathews, Chairman [Signature]

PRINCIPAL INVESTIGATOR: PLEASE READ THE FOLLOWING -
Continuing approval is CONDITIONAL on:

- 1. Adherence to the approved protocol, familiarity with, and adherence to the ethical standards of the Belmont Report, and LSU's Assurance of Compliance with DHHS regulations for the protection of human subjects\*
2. Prior approval of a change in protocol, including revision of the consent documents or an increase in the number of subjects over that approved.
3. Obtaining renewed approval (or submittal of a termination report), prior to the approval expiration date, upon request by the IRB office (irrespective of when the project actually begins); notification of project termination.
4. Retention of documentation of informed consent and study records for at least 3 years after the study ends.
5. Continuing attention to the physical and psychological well-being and informed consent of the individual participants, including notification of new information that might affect consent.
6. A prompt report to the IRB of any adverse event affecting a participant potentially arising from the study.
7. Notification of the IRB of a serious compliance failure.
8. SPECIAL NOTE:

\*All investigators and support staff have access to copies of the Belmont Report, LSU's Assurance with DHHS, DHHS (45 CFR 46) and FDA regulations governing use of human subjects, and other relevant documents in print in this office or on our World Wide Web site at http://www.lsu.edu/irb

## Application for Approval of Projects Which Use Human Subjects

This application is used for projects/studies that cannot be reviewed through the exemption process.



Institutional Review Board  
 Dr. Robert Mathews, Chair  
 130 David Boyd Hall Baton  
 Rouge, LA 70803 P:  
 225.578.8692  
 F: 225.578.5983  
[irb@lsu.edu](mailto:irb@lsu.edu) | [lsu.edu/irb](http://lsu.edu/irb)

-- Applicant, Please fill out the application in its entirety and include two copies of the completed application as well as parts A-E, listed below. Once the application is completed, please submit to the IRB Office for review and please allow ample time for the application to be reviewed. Expedited reviews usually takes 2 weeks. Carefully completed applications should be submitted 3 weeks before a meeting to ensure a prompt decision.

-- A Complete Application Includes All of the Following:

- (A) Two copies of this completed form and two copies of part B thru F.
- (B) A brief project description (adequate to evaluate risks to subjects and to explain your responses to Parts 1&2)
- (C) Copies of all instruments to be used.  
 \*If this proposal is part of a grant proposal, include a copy of the proposal and all recruitment material.
- (D) The consent form that you will use in the study (see part 3 for more information.)
- (E) Certificate of Completion of Human Subjects Protection Training for all personnel involved in the project, including students who are involved with testing or handling data, unless already on file with the IRB. Training link: (<http://phrp.nihtraining.com/users/login.php>)
- (F) IRB Security of Data Agreement: (<https://sites01.lsu.edu/wp/ored/files/2013/07/Security-of-Data-Agreement.pdf>)

1) Principal Investigator\*:  Rank

\*PI must be an LSU Faculty Member

Dept:  Ph:  E-mail:

2) Co Investigator(s): please include department, rank, phone and e-mail for each

IRB# <u>3455</u> LSU Proposal # _____
Full <input type="checkbox"/> Expedited <input checked="" type="checkbox"/>
<input checked="" type="checkbox"/> Complete Application <input checked="" type="checkbox"/> Human Subjects Training <input checked="" type="checkbox"/> IRB Security of Data Agreement

3) Project Title:

4) Proposal Start Date:  5) Proposed Duration Months:

6) Number of Subjects Requested:  7) LSU Proposal #:

8) Funding Sought From:

**STUDY APPROVED BY:**  
 Dr. Robert C. Mathews, Chairman  
 Institutional Review Board  
 Louisiana State University  
 130 David Boyd Hall  
 225-578-8692 / [www.lsu.edu/irb](http://www.lsu.edu/irb)

Approval Expires: 1/14/2015

**ASSURANCE OF PRINCIPAL INVESTIGATOR** named above

I accept personal responsibility for the conduct of this study (including ensuring compliance of co-investigators/co-workers) in accordance with the documents submitted herewith and the following guidelines for human subject protection: The Belmont Report, LSU's Assurance (FWA00003892) with OHRP and 45 CFR 46 (available from <http://www.lsu.edu/irb>). I also understand that copies of all consent forms **must be maintained at LSU for three years after the completion of the project.** If I leave LSU before that time, the consent forms should be preserved in the Departmental Office.

Signature of PI *Scott E. Wilks, PhD* Date 01-03-14

**ASSURANCE OF STUDENT/PROJECT COORDINATOR** named above. If multiple Co-Investigators, please create a "signature page" for all Co-Investigators to sign. Attach the "signature page" to the application.

I agree to adhere to the terms of this document and am familiar with the documents referenced above.

Signature of Co-PI (s) \_\_\_\_\_ Date \_\_\_\_\_



**ACTION ON PROTOCOL CONTINUATION REQUEST**



Institutional Review Board  
Dr. Dennis Landin, Chair  
130 David Boyd Hall  
Baton Rouge, LA 70803  
P: 225.578.8692  
F: 225.578.5983  
[irb@lsu.edu](mailto:irb@lsu.edu) | [lsu.edu/irb](http://lsu.edu/irb)

**TO:** Scott Wilks  
Social Work

**FROM:** Dennis Landin  
Chair, Institutional Review Board

**DATE:** September 2, 2015

**RE:** IRB# 3455

**TITLE:** Program Evaluation of Charlie's Place Respite Center

**New Protocol/Modification/Continuation:** Continuation

**Review type:** Full  Expedited  **Review date:** 9/2/2015

**Risk Factor:** Minimal  Uncertain  Greater Than Minimal

**Approved**  **Disapproved**

**Approval Date:** 9/2/2015 **Approval Expiration Date:** 9/1/2016

**Re-review frequency:** (annual unless otherwise stated)

**Number of subjects approved:** 125

**LSU Proposal Number (if applicable):** 41229

**Protocol Matches Scope of Work in Grant proposal:** (if applicable)

**By:** Dennis Landin, Chairman 

**PRINCIPAL INVESTIGATOR: PLEASE READ THE FOLLOWING –  
Continuing approval is CONDITIONAL on:**

1. Adherence to the approved protocol, familiarity with, and adherence to the ethical standards of the Belmont Report, and LSU's Assurance of Compliance with DHHS regulations for the protection of human subjects\*
2. Prior approval of a change in protocol, including revision of the consent documents or an increase in the number of subjects over that approved.
3. Obtaining renewed approval (or submittal of a termination report), prior to the approval expiration date, upon request by the IRB office (irrespective of when the project actually begins); notification of project termination.
4. Retention of documentation of informed consent and study records for at least 3 years after the study ends.
5. Continuing attention to the physical and psychological well-being and informed consent of the individual participants, including notification of new information that might affect consent.
6. A prompt report to the IRB of any adverse event affecting a participant potentially arising from the study.
7. Notification of the IRB of a serious compliance failure.
8. SPECIAL NOTE:

*\*All investigators and support staff have access to copies of the Belmont Report, LSU's Assurance with DHHS, DHHS (45 CFR 46) and FDA regulations governing use of human subjects, and other relevant documents in print in this office or on our World Wide Web site at <http://www.lsu.edu/irb>*

## VITA

Rachael Mills was born and raised in Baton Rouge, Louisiana where she attended elementary St. George Catholic School and high school at St. Joseph's Academy. Rachael graduated from Louisiana State University with a Bachelor of English Literature and a minor in social work in May 2014. She continued her education at Louisiana State University and is a candidate to receive her Master of Social Work degree in May 2016. Rachael currently resides in Baton Rouge, Louisiana and plans to work in gerontology with a specific interest in Alzheimer's disease.