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Fostering compassionate care for persons with Alzheimer's disease in nursing facilities.

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FOSTERING COMPASSIONATE CARE FOR PERSONS WITH ALZHEIMER'S DISEASE LIVING IN NURSING FACILITIES

by

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M.S.S.W., University of Louisville, 2012

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DEDICATION

This dissertation is dedicated to those affected by Alzheimer's disease and their caregivers.

ACKNOWLEDGEMENTS

I was 7 years old when I first learned about Alzheimer's disease. It was the Spring of 1992, and after a traumatic fall that resulted in a broken hip, my maternal grandmother started to show signs of confusion and behavioral changes. She was 75 years old at the time, and several doctors attributed these changes to her age. As she continued to decline, and her behaviors worsened, we were finally given a diagnosis: Alzheimer's disease. I did not know at the time the extent to which her diagnosis would impact me, the rest of my childhood, and how I learned to understand caregiving. From the onset of the disease to the final days, I watched as my mother took care of my grandmother day in and day out. My mother would work all day at her job, come home and make dinner for me, and then spend the rest of her evening taking care of my grandmother. Alzheimer's is not a disease that simply impacts the person, but the persons' family, friends, and communities but most importantly, it is the caregiver that is often impacted the most. These early experiences taught me that the caregiving journey could be difficult and arduous, so I want to acknowledge the work of caregivers for persons with Alzheimer's disease. In particular, I would like to say thank you to three caregivers that have taught me so much along the way- Margie, Zelda, and Doris.

I would also like to thank my committee. Each of you has given me the support that I needed along the way. Annatjie, you are the MENTOR. I am not sure I would have made it without your help and encouragement. You are so brilliant and amazing, and I am

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ABSTRACT

FOSTERING COMPASSIONATE CARE FOR PERSONS WITH ALZHEIMER'S DISEASE LIVING IN NURSING FACILITIES

Sam Gilbert Cotton

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The aim of this dissertation study was to examine the impact of the implementation of a new Compassionate Care (CC) curriculum on the quality of care provided by Certified Nursing Assistants (CNAs) to residents with Alzheimer's disease (AD). More specifically, this dissertation used Kirkpatrick's model of evaluation to assess the reactions, learning, and behavior change of the CNAs exposed to the curriculum, and ultimately the impact of the curriculum on the stress levels of residents with AD. To accomplish this, we had two studies that aligned with the Kirkpatrick model of evaluation.

For Study #1, the evaluation of the compassionate care curriculum (Kirkpatrick Levels One, Two, and Three), the following hypotheses guided the study: ***Hypothesis 1:*** *After completion of the compassionate care curriculum by the CNA experimental group, CNAs will show a significantly higher increase in knowledge, caregiving self-efficacy, caregiving satisfaction and a significantly higher reduction in feelings of affiliate stigma than the CNAs who completed the current standard curriculum (control group).*

For Study #2, Evaluation of the Compassionate Care Curriculum (Kirkpatrick Level Four), the following hypotheses were used to guide the study: ***Hypothesis 1a:*** *Residents with AD from the experimental nursing facility will have a different 12-week agitation change trajectory from the residents with AD from the control nursing facility.* ***Hypothesis 1b:*** *Residents with AD from the experimental nursing facility will have a different 12-week salivary cortisol change trajectory from the residents with AD from the control nursing facility.* ***Hypothesis 2a:*** *Differences in change in CNAs knowledge, confidence, satisfaction and affiliate stigma will have a differential effect on the 12-week agitation trajectories of residents with AD in the experimental and control nursing facilities.* ***Hypothesis 2b:*** *Differences in change in CNAs knowledge, confidence, satisfaction and stigma and differences in residents with AD agitation will have a differential effect on the 12-week salivary cortisol trajectories of residents with AD in the experimental and control nursing facilities.*

Methods: The study included an experimental and control nursing facility. The sample of residents with AD from the two facilities, including a convenient sample of 25 residents from the experimental group and 27 from the control group. All the CNAs who took care of the residents with AD that took part in the study were also included in the study for a total of 99 CNAs, 48 in the experimental group and 51 in the control group.

At baseline, prior to the implementation of the curriculum, data were collected on the demographics of the CNAs along with their pre-test on AD knowledge, self-efficacy, caregiving satisfaction, and affiliate stigma for both the experimental and control groups. At the 12-week period, after the curriculum and care groups were implemented, data on

AD knowledge, self-efficacy, caregiving satisfaction, and affiliate stigma were collected again for both groups.

After equivalency between the two groups was tested, a two-way mixed method MANOVA was utilized to examine how scores changed for all of the dependent variables. For this study, the focus of the analysis was to examine whether there was a significant difference over time (within-subjects), whether there were differences between the control and experimental groups (between-subjects), and whether there was an interaction effect between time and group, indicating if the groups change differently over time.

The second study examined the final element of the Kirkpatrick model, namely stress levels of residents with AD. This study was conducted by testing a hybrid multilevel growth model.

Results: CNAs changes in terms of their knowledge of AD, self-efficacy, caregiving satisfaction and affiliate stigma were analyzed to understand the impact the compassionate care curriculum had on the CNAs, using levels 1, 2 and 3 of the Kirkpatrick Evaluation Model. For AD knowledge, we saw a significant increase in scores from baseline to 12 weeks for the experimental group while the control group remained the same over the 12-week period. Self-efficacy for the experimental group improved between baseline and 12-weeks but deteriorated slightly for the control group. Caregiver satisfaction showed a slight improvement at 12-weeks for both groups, yet the experimental group showed a trend of greater improvement than the control group. For the experimental group, feelings of affiliate stigma declined between baseline and 12-weeks, while the control group remained similar at the 12-week period.

From the Kirkpatrick model, level 4 examined outcomes. This study focused on the stress outcomes of the residents with AD, specifically agitation and salivary cortisol levels. All models built showed that the experimental group performed better in reducing agitation and reducing salivary cortisol levels. The final models were able to show how the changes in the CNAs specifically affected these positive outcomes. CNA knowledge and self-efficacy had the most impact on changing agitation levels, and CNA knowledge and agitation levels had the most impact on salivary cortisol levels.

Conclusions: The results of this study showed that integrating a compassionate care curriculum into the work that CNAs perform with persons with AD can lead to positive outcomes on CNAs knowledge, self-efficacy, caregiving satisfaction, affiliate stigma and a reduction of agitation and cortisol levels in persons with AD. This has implications for the way we conceptualize the type of care that is provided by CNAs to persons with AD in nursing facilities. Currently, CNAs are trained to only provide traditional basic nursing care focuses primarily on the basic needs of the person such as attending to activities of daily living. While traditional basic nursing care is important, it should be supplemented with compassionate care for persons with AD. Compassionate care (CC) emphasizes the bond between the caregiver (the CNA) and the care receiver (the person with AD) and their journey together. CC can also provide CNAs with skills to respond to the changes that the person with AD experiences as they decline.

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CHAPTER I: PROBLEM STATEMENT

Alzheimer's Disease (AD) is a progressive neurodegenerative disorder that affects cognition and daily functioning (Liang et al., 2016). It is characterized by what it strips from persons suffering in its grasp. It progressively destroys the ability to eat, walk, bathe and dress. It slowly erodes memories and perceptions of time, along the way, taking pieces of one's identity. The changes experienced by persons with AD contributes to an inability to recall the context of what is occurring, which in turn, invites delusions, anxiety, and at times agitation. As the brain undergoes changes, persons with AD slowly retreat from the realities of this world and into a world of their own. In some instances persons with AD are labeled the "living dead" and their last years are referred to as "the funeral that never ends" (Behuniak, 2011).

As the sixth leading cause of death in the United States (Centers for Disease Control and Prevention, 2017), AD kills more persons each year than prostate and breast cancer combined (Alzheimer's Association, 2018). It is the only disease in the top contributors of death for which we have no prevention or cure and no means of slowing its progression (Alzheimer's Association, 2018). The average time lapse between an individual exhibiting any symptoms of the disease and receiving the diagnosis is 2.8 years (Brookmeyer, Corrada, Curriero, & Kawas, 2002). Currently, one in 10 persons aged 65 and older have a diagnosis of AD-type dementia (Alzheimer's Association, 2018). Between 2000 and 2014, there was an 89% increase in deaths attributed to the

disease. During this time frame, deaths from AD nearly doubled while reported deaths of the number one killer, cardiovascular disease, declined (Alzheimer's Association, 2018). The disease affects 5.5 million persons in the United States and every 66 seconds a person is diagnosed with AD (Centers for Disease Control and Prevention, 2017). In Kentucky, home to just over 4 million people, the story is similarly dire. Kentucky is ranked 18th in the nation for AD mortality (United States Department of Health and Human Services Centers for Disease Control, 2018). There are 71,000 persons or 1.6 % of the population diagnosed with AD in Kentucky, and this number is projected to increase by 21.1% to 86,000 persons by 2025 or 1.9% of the population (Alzheimer's Association, 2018).

As Alzheimer's disease progresses cognition, including language, thought, memory, executive function, judgment, attention, perception, and the ability to live a purposeful life changes and it becomes difficult for persons with AD to live a normal life (National Research Council, 2000). Behavior changes and daily living concerns caused by the disease creates problems for caregivers to provide care and engagement in a meaningful way (Beck, Ortigara, Mercer, & Shue, 1999). Estimates suggest that aggression occurs in roughly 40% to 60% of persons living in facilities such as nursing homes (Corbett, Smith, Creese, & Ballard, 2012). These behaviors are related to greater overall impairment in functioning and short survival time (Weiner, Hynan, Bret, & White, 2005). The focus of care shifts to keeping persons with AD safe and managing activities of daily living.

As a result, more persons with AD and other forms of dementia are receiving care from formal care providers in nursing home facilities (Gaugler, Fang, Davila, & Shippee,

2014). According to a study by the Centers for Disease Control and Prevention, in 2014 there were 1,369,700 current residents in nursing homes with more than half having AD or related dementia (Harris-Kojetin et al., 2016). Having an AD diagnosis increases the chance that an individual will be admitted to a nursing home. It is predicted that an estimated 4% of the general population will be admitted into a nursing home by age 80 compared to 75% of persons with AD at the same age (Alzheimer's Association, 2018).

Within nursing homes in the United States, Certified Nursing Assistants (CNAs) are predominately charged with providing care to persons with AD. It is estimated that more than 600,000 CNAs provide direct care that includes personal and activities of daily living (ADL) support for the 1.4 million persons with AD that live in nursing facilities in the United States (U.S. Census Bureau, 2015). The work performed by CNAs is arduous and challenging due to the complexities of providing care to persons with AD. The profession experiences high levels of turnover and issues with recruitment from burnout and job dissatisfaction (Sengupta, Ejaz, & Harris-Kojetin, 2012).

The bulk of the care provided by CNAs in nursing facilities is described as basic nursing care (Pennington, Scott, & Magilvy, 2003; Reinhard, Young, Kane, & Quinn, 2003; Stombaugh & Judd, 2014; U.S. Department of Health and Human Services, 2002; Wiener, Squillace, Anderson, & Khatutsky, 2009). Basic nursing care is task-oriented and designed to meet the essential needs of the person (U.S. Department of Health and Human Services, 2002). It is defined as basic infection control, bathing, bed-making, safe patient handling, elimination assistance, nutrition and fluids, personal hygiene and grooming, and vital signs (Stombaugh & Judd, 2014; U.S. Department of Health and Human Services, 2002; Wiener et al., 2009). Certification for CNAs is federally

mandated and includes 75-hours of basic nursing care that will be explained in more detail later in this chapter. (Reinhard et al., 2003; Wiener et al., 2009).

Compassionate Care

CNAs receive limited dementia training, and therefore, are often ill-prepared to provide care to persons with AD (Chu, Wodchis, & McGilton, 2014; Pennington et al., 2003). In Kentucky, CNAs who are employed at nursing homes only receive 10 hours of specific dementia training, as part of their license certification (Kentucky Adminstrative Regulations, 2006; Patient Protection and Affordable Care Act, 2010). The content of this training is primarily focused on the process of providing basic nursing care specifically to persons with AD (Kentucky Adminstrative Regulations, 2006; Patient Protection and Affordable Care Act, 2010). Additionally, a portion of the training focuses on how to understand and communicate with persons with AD (Kentucky Adminstrative Regulations, 2006; Patient Protection and Affordable Care Act, 2010). The training CNAs receive in dementia care is insufficient to provide the care persons with AD require as the disease progresses (Sengupta, Harris-Kojetin, & Ejaz, 2010).

Due to the complexities of the disease, persons with AD needs more than just basic nursing care. They need care that will allow them to flourish. Flourishing refers to the experience of a life going well and represents a combination of feeling good and functioning effectively (Huppert & So, 2013), with high levels of emotional, psychological, and social well-being (Keyes, 2005). For persons with AD this may not look like it would in a highly functioning individual, but it represents living within an optimal range of human functioning (Fredrickson & Losada, 2005). It is a state of existence where disease or impairment co-exists with dignity and quality of life. The

conceptualization of flourishing differs in part from many definitions of health in that the expectation of freedom from disease, disability, high cognitive and physical functioning and active engagement with life (Rowe & Kahn, 1998) are not required in order to flourish.

In order to train CNAs to provide care that allows persons with AD to flourish and improve patient outcomes it is recommended that CNA training hours be increased (Trinkoff, Storr, Lerner, Yang, & Han, 2017). This curriculum should supplement the existing mandated training CNAs receive and provide a deeper understanding of the journey that persons with AD experience as they progress through the disease. CNAs have expressed that they felt inadequately prepared for real-life resident care and requested additional training (Sengupta et al., 2010).

Compassionate Care (CC) refers to care that promotes and allows persons with AD to flourish by improving the dyadic relationship between the CNA and persons with AD. It is achieved by focusing on the physical and mental health of persons with AD including neurological, cognitive, general health and psychosocial factors, and also factors that are more dynamic, such as the physical and social environment and the changing needs and states within persons with AD (Norton, Allen, Snow, Hardin, & Burgio, 2010). Improving the dyadic relationship between persons with AD and their caregiver contributes greatly to improved physical and mental health outcomes (Pickering, Nurenberg, & Schiamberg, 2017). CC is a response to suffering, distress or discomfort that is associated with disease or decline in mental and physical functioning (Tierney, Seers, Tutton, & Reeve, 2017). CC respects the dignity of persons with AD by providing the task-oriented care needed to ensure safety and physical functioning as well

as the care needed to support mental health, as the disease progresses. CC is deliberate and intentional in its focus to alleviate pain and suffering while also promoting that persons with AD can flourish throughout their lifespan. This is achieved through the implementation of enhanced responses to behaviors and situations that persons with AD exhibit. It includes deeper caregiver and care-receiver relationships where the caregiver has the ability to communicate in a manner that promotes positive energy within and between persons with AD and their families (D. Cohen, 2000).

While definitions for CC vary (Dewar, Adamson, Smith, Surfleet, & King, 2014; Schantz, 2007; von Dietze & Orbb, 2000) most include the relief of suffering as a key concept. The concept of relieving suffering is distinguishable from related concepts such as kindness, empathy, sympathy, and pity. In order to provide CC, caregivers must have the ability to be open, alert, and sensitive to suffering, and also take action to alleviate or prevent suffering from continuing (Gilbert & Choden, 2013). While CNAs are trained to alleviate suffering following task-oriented procedures, the standard protocol focused on basic nursing care fails to highlight compassionate caregiving that promotes human flourishing. This model requires that the CNA not only changes personal attitudes, beliefs and actions in working with persons with AD but also have a desire to infuse CC in the larger organization or health care system. Current CNA training programs do not spend enough time to allow CNAs to understand the complexities of providing CC.

The goal of this study is to develop a CC curriculum for CNAs in nursing facilities and evaluate how the delivery of such a curriculum will improve care to persons with AD in nursing facilities. In order to understand the complexity of the disease, including its origin, treatment, and care, this chapter outlines the history of AD,

the development of pharmaceuticals, and the history of care provisions to older adults from home care to the growth of institutional care.

The History of Alzheimer's Disease

To fully understand the lack of compassionate care for persons with AD, one must first examine the characterizations of the disease throughout history. Since the origins of the disease, persons with AD have often been stigmatized and portrayed as less than human for the way that the disease contributes to their decline both mentally and physically. To begin unraveling the story of dementia and understand how the disease came to be misunderstood and stigmatized, one must start with the development of the ancient medical structure.

Dementia in Antiquity (approximately 476 BC- 1453 AD)

During antiquity, everyday life was met with natural disasters, fatal disease and a never-ending series of warfare. Medical practice, during this time, was heavily predicated on the use of magic and sacred ritual. According to the Greeks, the healing god Aesculapius was considered the highest authority of medicine (Stanton, 1999; Zilboorg & Henry, 1941). Mythological writings dating back to around 1500 BC suggest that Aesculapius was the son of Apollo and his mortal mistress Coronis. According to the narrative, in a fit of rage Apollo killed Coronis upon learning she was pregnant. He took the baby after her death and gave him to a centaur to learn the ancient art of healing (Stanton, 1999). Subsequently, temples were erected in Aesculapius's name, and a high order of priests carried out a series of rituals to heal the ill. Until Hippocrates' time, laymen were not permitted to administer any treatment. Only specialized clergy was allowed to administer medical treatment (Roman, 2003; Zilboorg & Henry, 1941).

Treatment at the temple included a combination of acts on the part of both the patient and the priests. In most cases, the patient would be required to sleep near the temple and dream of the God appearing to them. Based on the interpretation of this dream, there were various remedies of fermented mixtures that were used to cure the ailment and rites that included ceremonies involving both music and dance (Roman, 2003). As early as the Neolithic period, humans understood the utility of plants and other substances found in the wild that could be mixed to alleviate pain, nausea, and other maladies (Hillman, 2014).

Within the confines of the medical temples and Greek society, physical ailments were the only diseases that were treated. Little consideration was given to mental disorders, and no treatment was provided if an individual suffered from mental illnesses or the symptoms associated with cognitive decline that we know today (Cilliers & Retief, 2009). Interestingly, some persons with various forms of mental illness were granted a higher status within society and viewed as having special powers. They were often used to interpret dreams and assist clergy in providing treatment to those with physical ailments within the temples of Aesculapius (Zilboorg & Henry, 1941). Around the same period that the Greeks were receiving treatment delivered in the name of Aesculapius, the ancient Egyptians developed a precise art to the care and preparation of the dead, known as mummification, which was believed to assist the person in their journey to the after-life. Little thought was given to the brain during this process of mummification. In fact, this vital organ was deemed so insignificant that it was extracted through the nose using a hook and discarded immediately after death (Wickens, 2015). Other writings from the time also suggest that the brain was viewed simply as a vessel for moving mucus from

the body to the nose (Wickens, 2015).This was in contrast to views on the heart, which was viewed as the center of all things good (Wickens, 2015). As different historical scholars began to articulate theories about cognitive decline and aging, the location of mental capacities would change dependent on the popular theory of the time (Boller & Forbes, 1998). While ancient Egyptians were not concerned with the brain, hieroglyphics from around 2000 BC suggest that they were aware of cognitive decline and associated this decline with one's age. However, this theory was predicated on the notion that the heart and diaphragm were the seats of mental capacities (Boller & Forbes, 1998).

The first formal descriptions of dementia are commonly attributed to Pythagoras (ca. 570-490 BC). He was an often-controversial figure within Greek history and primarily known as a philosopher and mathematician. Pythagoras is primarily known as the inventor of a theorem bearing his name that states that the square of a hypotenuse is equal to the sum of the squares of the other two sides (Ingram, 2014). While Pythagoras produced no formal writings, reports from his contemporaries provide insight into his work (Huffman, 2014). The long history of formalizing clinical descriptions of dementia begins with Pythagoras' construction of a delineation of the human lifespan into five distinct phases corresponding with ages 7, 21, 49, 63, and 81 (Halpert, 1983). Each phase is marked by defining characteristics. The last two phases Pythagoras termed *senium*, referred to the increasing mental decline that occurred in this phase for most humans. This was also a time when the body began to enter into a state of decline and decay (Halpert, 1983). Pythagoras equated *senium* as similar to the period of infancy and childhood (Berchtold & Cotman, 1998; Halpert, 1983). Pythagoras, furthermore, commented on the fact that it was rare during this time to live to old age with the average

life expectancy during this time frame being only 30 years (Roman, 2003). In other writings detailing Pythagoras' work, the word *imbecility* is attributed to the process of cognitive decline (Halpert, 1983). By the 19th century, this term would evolve to become used as a derogatory term for persons with intellectual disabilities (Trent, 1995).

During the Greco-Roman era (ca. 332-395 BC), mental health was studied from both the medical perspective and detailed in the literature. Scholars have noted that there is a difference in these conceptualizations of mental health with medical writings focusing primarily on the biological mechanisms involved while contemporary literature from this time period focused primarily on the supernatural or divine origins of the disease (Cilliers & Retief, 2009). Homer's epic poem *The Odyssey*, written near the end of the 8th century, describes the theory regarding the connection between age and cognitive ability. In *The Odyssey*, readers are introduced to King Laertes of Ithaca, the father of the titular character Odysseus. Homer writes of Laertes prestigious role as a physically vigorous war hero (Homer, 1996). When Odysseus returns to his home in Ithaca twenty years after first leaving to fight in the Trojan war, he finds his father in a much different state (Homer, 1996). To distinguish Laertes condition from other psychological diseases, Homer places emphases on his memory, particularly his long-term memories (Homer, 1996). For example, Laertes is described as an individual that despite his wealth and prestige, decides to spend his days in the gardens of the city and sleeping in barns since this is where his fondest childhood experiences occurred. Laertes seems unaware of any short-term memory that he has gained in the twenty years since Odysseus first left, and this is reiterated in a passage where Odysseus identifies himself to his father by pointing

to a scar that he obtained during childhood as well as reciting the number of trees that the duo planted together in the gardens decades ago (Homer, 1996).

Descriptions of dementia are equally present in Greek mythology suggesting that the disease was considered an aspect of life. Mythology was commonly used to explain any phenomenon that was not understood at the time. In one myth, Tithonus is described as handsome but mortal, and he is married to the goddess of dawn Eos. As a gift to her husband, Eos pleads with Zeus to make her husband immortal. Her wish is granted. However, she failed to ask that he keep his youth. Thus, Tithonus continued to age, despite his immortality and began showing features of dementia including incessant talk that was unintelligible to his wife. When Eos could no longer stand watching her husband's decline, she turned him into a grasshopper (Bulfinch, 2014). While the mythology does not offer a formal name for dementia, only a description, it can be ascertained from the moral of the story, that as Tithonus aged, despite his newfound immortality, his behaviors and mannerisms were similar to an "aging mind" that we now refer to as cognitive decline (J. Jones & Jones, 2010).

Legal writings further reveal social commentary on the perceived nature of cognitive decline during antiquity. While only fragments of his writings still exist today, Solon (630-530 BC) is known for generating reforms in Athens by developing revisions to codified laws. Solon is credited with foraging a reform to end political and moral decline. In regards to dementia, Solon determined that old age was one factor that could contribute to impaired judgment and thus, persons might not have a sound mind to make decisions (Boller & Forbes, 1998).

While a trend towards describing the symptoms of dementia was apparent in literature, scholars, and philosophers after Pythagoras continued to posit theories about the nature of the brain and cognitive decline. Nearly two centuries after Pythagoras detailed the life stages previously described, Hippocrates (ca. 460-370 BC) demarcated his own medical classification. Hippocrates is known as one of the most influential medical doctors of all times. Hippocrates work is still utilized within the medical field (Breitenfeld, Jurasic, & Breitenfeld, 2014). There are 60 known works that are credited to Hippocrates. However, it is commonly believed that much of his writing was written by his students (Porter, 2004). Hippocrates does not provide an exact characterization of dementia; however, many scholars often equate the use of the term *paranoia* to the same definition that Pythagoras provides for imbecility (Berchtold & Cotman, 1998; Halpert, 1983). It has been suggested that the absence of the terms cognitive decline or dementia is due to the common perception that it was intertwined with old age (Roman, 2003). Since Hippocrates did not provide direct commentary for mental decline, it is difficult to determine whether paranoia was an accurate description of dementia. However, it should be noted that the Hippocratic cannon postulated that all illnesses could be attributed to an imbalance in the four cardinal body fluids. During this time, ancient Greeks held that there were four cardinal body fluids, often referred to as humours, and four primary and opposite fundamental qualities known as hot, cold, wet and dry. This theory posited that each humour was connected to a mental state and thus, an imbalance would contribute to certain declines or behaviors (Boller & Forbes, 1998; Jouanna, Eijk, & Allies, 2012; Porter, 2004).

Hippocrates' work was central to the development of medicine. Until his work, the field of medicine was not organized, and treatment of conditions was largely performed by religious leaders or clergy. Furthermore, given the emphasis on religion, there was not an emphasis on scientific inquiry (Porter, 2004). Thus, Hippocrates work with identifying humours is important since this led to the prevention and treatment of physical conditions. For example, if the imbalance occurred within the individual's blood system, such as a buildup of toxins, then bloodletting was recommended as a suitable treatment for this ailment (Porter, 2004).

Despite Hippocrates work in medicine, the debate about the nature of the mind persisted within philosophy. Plato (ca. 429-347 BC) and his student, Aristotle (ca. 384-322 BC) wrote about the correlation between age and cognitive decline. Aristotle's most notable work in the field of psychology is *De Anima*, which provides a broad overview of his theories on the nature of living things (Shields, 2016). In particular, it is clear from Aristotle's writings that there is a perception that cognitive decline as one ages is an inevitable condition. Furthermore, Aristotle disagreed with Hippocrates theory that the brain (or head) was the center of mental functioning. Instead, Aristotle arrived at the conclusion that the heart was the source of mental faculties and life.

Contribution to the debate about the nature of mental capacity and old age was also provided by Cicero (ca. 106-43 BC). Cicero was a Roman philosopher, known as a great orator who primarily studied the law. By the time that Cicero was writing, the connection between old age and cognitive decline was generally accepted. However, Cicero disagreed with the prevailing notion that cognitive decline, which he referred to as senile debility, was an inherent nature of old age. Instead, Cicero argued that only those that

were of weak constitution suffered from senility, thus adding an element directly correlated to one's morality (Boller & Forbes, 1998). Furthermore, Cicero believed that cognitive decline could be prevented, primarily by one staying active and keeping an active mind (Boller, Bick, & Duyckaerts, 2007). This, Cicero believed, was the key to avoiding the disease.

Roman physician Celsus (ca. AD 14-37), who translated significant medical works from Greek to Latin, is thought to have been the first to employ the terms *dementia* and *insanity* as medical terms in *De Medicina* (Berrios, 1990; Roman, 2003). Celsus, influenced by the work of Hippocrates, divided insanity into three different categories that included melancholia, phrenitis, and dementia. Each was determined by a different cause (Roman, 2003). Prior to the work of Celsus, many mental disorders were characterized under the same phenomenon given the overarching symptomology. From the work of Celsus, we know that he was continuously on a search for the most effective drugs for his patients (Hillman, 2014).

Galen (ca. AD 129 -200), the Greek physician is known as a prolific writer, having completed 21 volumes of work of an estimated 1,000 pages each. His writings are heavily influenced by the work of Hippocrates (P. N. Singer, 2016; Wickens, 2015). More of Galen's writings have survived by comparison to those physicians and philosophers writing prior to this time (Hillman, 2014). In one of his voluminous encyclopedias, the physician listed *morosis*, his word for dementia, as a mental disease linked to the brain (Berchtold & Cotman, 1998; Schäfer, 2005). In his description of *morosis*, he characterized that disease by stating, "some who in the knowledge of letters and other arts are totally obliterated; indeed they can't even remember their own names" (Berchtold

& Cotman, 1998). Given that he was heavily influenced by the work of Hippocrates, Galen's writings posit that old age itself was considered a disease given the process that persons experience (Berchtold & Cotman, 1998; Halpert, 1983; Schäfer, 2005). Furthermore, Galen conjectured that disorders, such as cognitive impairment, could be related to diseases or processes in other organs in the body, a theory that was first posited by Hippocrates (Boller & Forbes, 1998). While most of Galen's work was a continuation of previous scholars, Galen distinguished himself from others in that he went a step further to prove the theories that he wrote about. Despite the fact that these were rare practices during this time, writings show that Galen performed scientific experiments and dissection which provided more concrete knowledge about the human body (Wickens, 2015).

Galen's work comes at the end of the Greco-Roman period. By the time he was writing and producing scientific evidence, the decline of the empire had already started. From the works of this period, it can be ascertained that dementia was established as a normal process of aging. Epidemics, disease, and death due to lack of resources were a part of life.However, it was viewed that if one survived to old age cognitive decline would inevitably occur.

By the 5th century (AD), due to a shifting political landscape and a decline in power, the Western Roman Empire was largely considered a failed state (Philippides, 1980). Despite these major losses, the Eastern Roman Empire, known primarily today as the Byzantine Empire, continued on and lasted from approximately 330 AD to 1453 AD (Philippides, 1980). Much of the research and scholarly work during this time was an extension on the work that had been developed during the Greco-Roman period.

The roots of gerontology begin to take shape during the Byzantine Empire (Lascaratos & Poulakou-Rebelakou, 2000). We know through the work of Aetius of Amida, that by the 6th century (AD) , there were physicians that treated the aging population, simply referred to as the "aged" (Poulakou-Rebelakou, Kalantzis, Tsiamis, & Ploumpidis, 2012). The emphasis on providing specialty care to older adults is particularly interesting given that during the Byzantine Empire there is the first known movement towards a desire to appear more youthful. In particular, Empress Zoe is credited with starting this trend, as she continued to search for elixirs and remedies to appear much younger during her 60s (Panas, Poulakou-Rebelakou, Kalfakis, & Vassilopoulos, 2012). The detailed accounts of Zoe's quest for youth are noteworthy in that it provides insight into Byzantine pharmacology. Medicinal practices during this time grew to be heavily predicated on the use of plants. Unlike their predecessors, the Byzantine's began to cultivate plants that were known more for their medicinal properties (Scarborough, 2002).

Aging was not the only concern during this period as the significant medical discourse during this time period was focused on the Justinian Plague (around 542 AD), the cause of which we now know to be *yersinia pestis*, the same bacteria responsible for the Bubonic plague (Drancourt et al., 2004). This pandemic was devastating to the population, and an estimated 13% of the world population succumbed to death from the outbreak (W. Rosen, 2007). Detailed descriptions and theories about the plague were postulated by Paul of Aegina and provided the foundation for understanding more about dementia and memory loss. Paul recorded a number of persons that were struck by the plague also exhibited memory loss as the disease progressed. Building upon the work of

Hippocrates, Paul suggested that this memory loss, or as modern descriptions term it, dementia, was due to the buildup of certain fluids in the humours (Poulakou-Rebelakou et al., 2012).

While dementia was viewed as only a symptom of the plague, other historians began to take notice of cognitive decline through their observations of the Emperors. Surviving historical texts from the Byzantine Empire suggests that dementia was not uncommon among Emperors that lived into older age. There was a number of persons that lived to be 70 years or older (Poulakou-Rebelakou et al., 2012). Records from this period are extremely detailed, and it was not unusual for historians to document an Emperor across their lifespan. These detailed, longitudinal texts provide accounts that suggest symptoms that are hallmarks of the different forms of dementia. From Justine I (518-527 AD) all the way to Andronicus II Palaeologus (1282-1328 AD), there are accounts of dementia, or at the very least some mention of cognitive decline. For example, analysis of documents pertaining to Justin I (518-527) notes the leader's remarkable decision-making skill in governing and military matters while later texts suggests that his cognitive abilities deteriorated to the point where his nephew Justinian carried out many of his obligations (Poulakou-Rebelakou et al., 2012). Sadly, Justinian would later suffer a similar fate, as historians described the onset of mental decline that forced his wife, Theodora to carry out his duties (Poulakou-Rebelakou et al., 2012). Even famed Empress Zoe, known for her incessant need to appear young and exuberant, was described in later years as suffering from many of the symptoms that we now know are characteristics of dementia (Poulakou-Rebelakou et al., 2012).

This period provides us with commentary about specific historical persons that suffered from the disease. We know their names, their work, and what their lives were like before and after the disease. This is important because it is the first surviving chronicle of cognitive disease. This period is also particularly important due to the development of more standardized pharmacological interventions that were developed to treat physical ailments, but there is no mention of treating cognitive decline.

In tracing the origins of characterizations of dementia in the writings of scholars of antiquity in this section provides an understanding of how misunderstanding and stigma became attached to the disease. The earliest surviving documents illustrate that the brain was secondary to the heart, which was considered the soul and primary hub for all thought. Little was known about the functions of the brain. Although medicines for physical ailments such as pain and nausea were being developed in antiquity, the lack of understanding of dementia and cognitive decline delayed a search for treating or curative medicine for cognitive decline. Examination of this period also provides an understanding of how the field of medicine developed. From the origins of the temples devoted to Aesculapius, whereby persons presented with ailments and were provided with treatment the focus was on physical ailments, not mental ailments, firmly establishing medicine as a separate field.

Medieval era (approximately 5th century to the 16th century)

Commentary on what is now known as AD and other forms of dementia continued intermittently until the Middle Ages. However, any progress that was made stalled during the Medieval period. The lack of writings and depictions of the disease during this period can be attributed to two primary causes: the rise of the Church and the

rapid spread of the Black Plague. The Catholic church became a formidable force during the Middle Ages, and its stances on scientific research contributed to a decline in research (Carruthers, 2008).

During this time, the Church rose as a powerful force and ultimately contributed to the decline in the status of medicine, science and the work of scholars from these fields (Logan, 2002). The clergy was the ultimate authority over knowledge and reasons leaving little room for those that disagreed, such as physicians and scientists. The Black Plague spread quickly throughout much of Europe and was the foremost cause for any public health concerns (J. Kelly, 2005). Given this, the only known existing essay on the disease during this time was written by Franciscan Friar Roger Bacon. During his life, Bacon was known for his use of empirical methods and his push towards scientific reason. He was subsequently imprisoned for his views (Brophy, 1963). While in solitary confinement just before his death, he wrote '*Methods of Preventing The Appearance of Senility,'* in which he describes old age and links the loss of memory and cognition to the posterior part of the brain (Brophy, 1963). Furthermore, Bacon described persons as being without reason, and essentially without the capacity for thought. While Bacon does not provide justification for his argument, this is the first publication that linked memory and cognition to a specific portion of the brain.

Despite the lack of literature on dementia from the Medieval period, what is noteworthy is the prominence that was placed on memory, particularly by the church. For the medieval period, great emphasis was placed on collective memory (Brenner, Cohen, & Franklin-Brown, 2013). Works of art and writings, particularly those rooted in Christian ideology are filled with allegories and metaphors (Carruthers, 2008). Take for

example, '*Hypnerotomachia Poliphili,'* which in English translates to Poliphilo's Strife of Love in a Dream, which comes at the end of the Medieval period. The book has been attributed to many authors and is written in a rather bizarre mix of Latinate Italian. It remains an important work because of its overuse of imagery and is an example of Medieval allegory of the moral perils of love (Trippe, 2002). The original versions of the books were adorned with large wood etchings that depicted scenes from the story. The same feelings are conjured through the work of Medieval artist Giotto. His scene of the Nativity or the Crucifixion of Rimini utilizes similar themes and approaches ("Giotto Di Bondone," 2017).

These works are important because the use of imagery allows people to form memories of the images depicted. By and large, during the Medieval period, persons were illiterate, so it would stand to reason that building memory based on these images was important. Scholars argued that building a collective memory during this period was not merely a byproduct of the lack of education for most persons. Instead, it could be viewed under the auspices of the goals of the Church (S. Katz, 2013). Use of collective memory assisted in developing a moral and just population. Ethics were built through the development of these memories. Even the clergy was taught the importance of memory and trained to eat and drink while reading scripture in hopes of retaining the properties of the text they were studying (S. Katz, 2013).

The maintenance of memory was so desired that it was often lauded through the descriptions of influential persons by noting their ability to remember. For example, Thomas Aquinas, the priest, who was respected and renowned during the Medieval period, is still often described as both excellent at recalling information and morally

superb (Carruthers, 1990). The implications in these statements are that one's moral identity is inherently connected to their ability to remember.

For our discussion of dementia, this emphasis on building memory created a lasting impact. First, it was predicated on this concept that everyone should have the capacity to build memory. Regardless of one's educational status, there was an expectation that if you heard a sermon or any number of stories that were contained with religious text, you would be able to recount it orally to others. Memory was not directed through intellect or physiology. The inability to complete such tasks was viewed as a moral deficit. While the Medieval period is often known as the dark era for the lack of philosophical and scientific inquiry, for characterizations of dementia it would prove to have damning effects in that the stigmatization of not being able to remember was a moral defect.

Dementia During the Enlightenment Period (17th -18th Century)

As the Enlightenment period began paving the way for modern developments, public health began receiving more attention. In the Medieval era, record keeping became an accepted way of providing information about the population at large. Major cities such as London kept records on vital statistics, such as prevalent diseases that physicians reported treating and the causes of death of its citizens. In smaller towns, records were often less detailed with brief descriptions of ailments. As the Medieval period ended, and the world shifted towards increasing discovery and innovation, more emphasis was placed on naming diseases and providing an overview of the symptoms commonly associated with specific diseases. With increasing longevity, scholars were taking note of

concerns about public health in part through an analysis of the existing records (Pagden, 2013) .

This renewed interest in science paved the way for many important discoveries within the medical field. Surgical procedures, while still rudimentary by modern standards, were implemented as medical interventions by the mid-1600's (Gay, 1966). During this time frame, the practice of bloodletting and similar procedures was still used. By 1661, the development of the microscope allowed physicians and scholars to view microscopic structures that were previously not accessible. The discovery of blood circulation led to the use of blood transfusion for many diseases. By the mid-1700's, inoculation for diseases such as smallpox were in use. It was indeed a time of rapid development for many diseases and interventions.

Classification of medical terminology also developed through the course of the 17th to 18th centuries. Dementia was now characterized by a grouping of diverse terms such as *imbecility*, *amentia*, *phrenesis*, and most commonly, *senility*. This would change with the publication of a classification of mental disorders entitled '*Nosographie philosophique ou méthode de l'analyse appliquée à la medicine'* by physician Phillippe Pinel (Wallace & Gach, 2010). Originally written in 1798 and widely embraced, Pinel coined the term dementia to define the broad characteristics of cognitive decline. Pinel differentiated between delusion and manic behaviors, which were previously associated solely with cognitive decline. Pinel argued that persons with dementia were without the capacity for logic and decision-making. While much of the depictions are dated and used antiquated terminology, Pinel was the first to provide a lengthy analysis of the loss of memory, cognitive function, and the notion that dementia was a progressive disease

(Wallace & Gach, 2010). Hence, prior to Alzheimer's presentation, Pinel was predominately credited with providing an overview of cognitive decline.

By the 17th and 18th centuries, characterizations of the disease would permeate cultural works as well. Whether in comedy or tragedy the disease was portrayed as a representation of the curse of getting old. This period marked a shift towards the Enlightenment period. Thus, literature during this time reflected the movements towards social commentary and often included satirical works. The depictions of dementia varied from serious soliloquies to the use of ironic humor to portray the failures of the mind that are associated with the disease (Boller & Forbes, 1998).

Renowned playwright William Shakespeare provided several allusions to the devastation caused by dementia in his plays. Shakespeare's works 'As You Like It,' 'Hamlet,' and 'King Lear' all contain soliloquies that explore a character's thoughts relating to the aging process. In 'As You Like It,' Shakespeare introduces the concept of dementia in direct correlation to becoming old in the following passage from Scene 2, Act 7 (W. Shakespeare, 1623), as follows:

"With spectacles on nose and pouch on side
His youthful hose, well saved, a world too wide
For his shrunk shank; and his big manly voice,
Turning again towards childish treble, pipes
And whistles in his sound. Last scene of all
That ends this strange eventful history
Is second childishness and mere oblivion
Sans teeth, sans eyes, sans teeth, sans everything."

Unlike medical scholars of the time, Shakespeare also made clear distinctions between senility as portrayed in 'King Lear,' and the differing accounts of delirium associated with madness as exhibited by Lady Macbeth in 'Macbeth.' This was unusual for this time period because most physicians believed that these forms of cognitive decline were the same. In 'King Lear' Act IV, Scene 7, the featured character explores his memory loss (W. Shakespeare, 1606), as follows:

"I am a very foolish fond old man,

Fourscore and upward, not an hour more nor less;

And, to deal plainly,

I fear that I am no in my perfect mind.

Methinks I should know you, and know this man;

Yet I am doubtful for I am mainly ignorant

What place this is; and all the skill I have

Remembers not these garments; not I know not

Where I did lodge last night… (…) Am I in France?"

Dementia is also mentioned within the fictional world of 'Gulliver's Travels.' First published in 1726, Jonathan Swift's book is a satirical work that targeted nearly everyone of prominence from the Church to the Monarchy and quickly became a bestselling novel (Ingram, 2014). At the time, Swift's hard-hitting satire was widely controversial prompting the author to publish the book under the moniker given to the titular character, Gulliver.

On his third journey, toward the end of the book, Gulliver travels to the colony of Luggnagg. Upon arriving, Gulliver observes, "The Luggnaggians are polite and generous

people," yet it is the Struldbrugs, a group of persons living in the colony that really capture his attention, for the Struldbrugs are said to be immortal (Swift, 1726). Initially, Gulliver is enamored by this concept stating "I freely own myself to have been struck with inexpressible delight, upon hearing this account"; the idea that anyone would have the opportunity to live forever without fear of death was an extraordinary idea (Swift, 1726). His initial thrill regarding the ability to live forever is quickly deflated after meeting several Struldbrugs, for it seems that immortality, in this case, was marred by the problems with which it is associated (Swift, 1726).

As the story progresses, Gulliver soon learns that the Struldbrugs are profoundly disabled by their lack of memory as they age through observations of these immortal persons. It is remarked that those that lose their memories entirely fair the best since this loss comes without feelings of sorrow. These encounters left Gulliver shaken, and he concluded that the Struldbrugs were a mortifying sight, one that no longer evokes envy regarding their immortality (Swift, 1726).

In a horrific twist of fate, nearly a decade after Swift penned these descriptions of dementia; he wrote a letter to a friend stating "I have entirely lost my memory… I can hardly understand one word I write" (Ingram, 2014). Correspondence such as this letter along with writings of his friends and colleagues have left many scholars to suggest that Swift suffered from AD or another form of dementia (Bewley, 1998; Ingram, 2014). However, this has been largely debated in recent decades, as some scholars argue that Swift's symptoms as described were more in alignment with Pick's disease, a rare form of progressive dementia, that affects the frontal lobes of the brain (Bewley, 1998; Crichton, 1993; Lorch, 2006). By 1742, Swift was declared incompetent, and

subsequently, all of his affairs were handled by caregivers. He passed away from the disease two years later (Bewley, 1998; Ingram, 2014).

The incorporation of dementia into the themes of these cultural works illustrated key concepts in the discourse about the historical conceptions of dementia even though these were fictional accounts. The way in which dementia was depicted as being intrinsically related to old age demonstrated that by this time, the correlation between the two was solidified. These depictions presented a dark side of dementia that further contributed to the stigmatization of the disease.

Modern Descriptions of Alzheimer's disease (the 1900's- Present)

On November 4th, 1906, Dr. Alois Alzheimer stood before attendees of the 37th meeting of the South West Germany Society of Psychiatry in Tubingen, Germany and delivered an extraordinary address regarding the disease that would eventually bear his name (Cipriani, Dolciotti, Picchi, & Bonuccelli, 2011; Goedert & Ghetti, 2007; Maurer & Maurer, 2003). As he took the stage, Alzheimer began his address, entitled 'On a Peculiar, Severe Disease Process of the Cerebral Cortex', by thanking his former employer, Professor Emil Sioli, for allowing him to present the accumulation of clinical notes and tissue collections from the autopsy on his former patient, known only as Auguste D (Alzheimer, 1907; Maurer & Maurer, 2003; Maurer, Volk, & Gerbaldo, 1997).

The room was quiet as Alzheimer began his speech with the following, "From a clinical perspective my Auguste D. case already offered such a distinctive clinical picture that it would not be classified among any of the known illnesses. I will describe it to you in what follows" (Maurer & Maurer, 2003).

Alzheimer first encountered Auguste nearly five years earlier as a patient who had presented at the Asylum for the Insane and Epileptic, a psychiatric facility in Frankfurt (Cipriani et al., 2011; Maurer & Maurer, 2003; Maurer et al., 1997). Alzheimer served as an assistant physician and had worked under the mentorship of Sioli to improve the conditions at the facility. On his first day, Alzheimer was appalled by the horrid conditions and wrote, "Some patients appeared with pockets filled with all sorts of waste, others had masses of paper and writing materials hidden all over the place and in big packets under their arms." By the time Auguste D. was admitted to the facility, Alzheimer, Sioli, and their colleague Dr. Franz Nissel had initiated policies to ensure all patients were fed, bathed, rooms were cleaned and not used as isolation rooms when possible, and duration baths were established to calm and reduce the agitation of patients (Maurer & Maurer, 2003). In 1901, these approaches were considered progressive in the treatment of persons with mental illness. Traditionally, psychiatric institutions had been separated from medical hospitals. Classical treatment included bloodletting and cathartics. However, these methods were slowly being replaced with non-restraints and moral therapy which had first been introduced by Philippe Pinel in the mid-1800's. Pinel was well respected in the psychiatric community, known for his nosological classification of all diseases including senile dementia (Bynum, 2008).

For Auguste, the facility would become home for the final five years of her life. At 51 years of age, Auguste exhibited a rapid decline in functioning that was uncharacteristic given her family history and with no known cause. Eight months prior to admission, Auguste exhibited no symptoms (Cipriani et al., 2011). Her husband, a railway clerk, could no longer provide for her care forcing him to admit her. A review of

her medical records indicated that at the time of admittance she suffered from paranoia, delusions and hallucinations, along with progressively declining cognitive impairment (Cipriani et al., 2011; Goedert & Spillantini, 2006; Hippius & Neundorfer, 2003). During one of his first assessments, Alzheimer sat with her while she ate her midday meal and recorded the following interaction:

"At midday Auguste D. had cauliflower and pork for lunch.

Alzheimer- What are you eating?

Auguste D.- Spinach!

She chewed the meat.

Alzheimer- What are you eating now?

Auguste D.- First I eat the potatoes and then the horseradish." (Maurer & Maurer, 2003)

On this first encounter, he continued his observations by showing her several objects. After a short span of time, Auguste no longer knew what the objects were that she had been shown (Maurer & Maurer, 2003). Her short-term memory seemed completely erased. When Alzheimer offered her a pencil to write her name on a sheet of paper, she could barely scribble out the A in Auguste before stopping and entering into a confused state (Maurer & Maurer, 2003). While Auguste was initially not at ease with Alzheimer's presence, this changed overtime, and they were able to form a bond that was based on their mutual experiences growing up in the same town in Germany (Maurer et al., 1997).

The disease that had no name would continue to haunt Auguste as her condition worsened. Clinical notes by Alzheimer and other physicians provided a first-hand account of the horrors that Auguste was suffering. Whatever this disease was, its onset

had been quick, and its symptoms were intense. Often, Auguste would shout in agony succumbing to her fear that someone was attempting to kill her while other times she would sit quietly, alone and stare blankly into space (Maurer & Maurer, 2003; Maurer et al., 1997). She would pace and speak unintelligibly often directed to her husband and her child, despite their absence. Her memories seemed distorted as if someone was slowly chipping away at their contents. Sleep was disrupted as she would often pace or sit up in her bed in lieu of resting. On occasion, she was known to go into the main room of the facility, where other patients congregated, grab their faces and strike them violently with her hands (Cipriani et al., 2011; Maurer & Maurer, 2003).

In his experience as a physician, Alzheimer had encountered similar cases in other patients, yet, he was intrigued due to the manifestation of these symptoms in someone much younger. At the time, such behaviors were exhibited by persons much older than Auguste's 51 years (Maurer et al., 1997). Given the age of his previous patients, Alzheimer had hypothesized that this form of mental decline was associated with the thickening of the blood vessels of the brain, known as atherosclerosis (Maurer & Maurer, 2003).

As was customary for the time, Alzheimer's primary course of treatment included an approach to reduce the patient's agitation. Assessments were completed through talking with patients and records indicated that Alzheimer did this frequently. Alzheimer did extensive research on the therapeutic effects of warm and mild baths that extended over several hours, and in some cases, days, to soothe and calm extremely agitated patients (Maurer & Maurer, 2003). Alcohol was to be administered in mild doses for its calming properties. Not unlike modern facilities, for Auguste, and other patients at the asylum,

pharmaceuticals were used and considered to be useful in working with agitated patients. It was common practice to use 2 to 3 grams of Chloral Hydrate, a sedative, to manage behavior. With this treatment, no injection was needed, and therefore, patients in Auguste's condition would not need to be confined to receive treatment (López-Muñoz, Ucha-Udabe, & Alamo, 2005).

On at least one occasion, Alzheimer had to fight to keep Auguste at the asylum. Her husband could no longer pay the fees to keep her at the facility, and a plan was put in place to transfer her to another asylum. Knowing her importance to his work, Alzheimer was able to negotiate for her to stay (Maurer & Maurer, 2003). By 1903, Alzheimer had accepted a new position working as head of the anatomy lab at the Royal Psychiatric Clinic. However, he had not forgotten his patient and continued to track her progress (Hippius & Neundorfer, 2003). On April 9th, 1906, Alzheimer received a call that Auguste had passed away, he immediately requested her brain be sent him for further research so that he could complete a histological analysis (Hippius & Neundorfer, 2003; Maurer & Hoyer, 2006). Using silver staining, developed by his colleague, Max Bielschowsky, Alzheimer was able to clearly describe the senile plaques and neurofibrillary tangles in the patient's brain (J. Jones & Jones, 2010). His analysis revealed what is now considered pathological hallmarks of the disease (D. H. Small & Cappai, 2006). It should be noted that by the time that Alzheimer made his discovery, dementia, as a general term to describe the loss of memory as one ages, was utilized within the medical lexicon, and both Phillipe Pinel and Jean-Etienne Esquirol had provided characterizations of the disease (Cipriani et al., 2011). Furthermore, the presence of plaques and tangles were also noted in the literature, however, neither had

been connected as a marker of cognitive decline (Cipriani et al., 2011). Thus, when Alzheimer made the connection between these two elements and posited that Auguste's decline was due to the plaques and tangles that formed in her brain, his theory changed the dominant view regarding senile dementia.

On that day in November 1906, as Alzheimer finished presenting his slides that included the histological analysis, he posited not only the connection between the plaques and tangles and the memory loss and bizarre behaviors of his patient but also shattered the notion that dementia was only related to old age. When he was finished with his presentation, he anticipated a lively discussion. Yet was met with unexpected silence. He had, after all, just explained, in his professional opinion, the details of a potentially rare disease for the very first time. It was customary for the chair of the meeting to bring forth any questions from the audience, however, on this occasion, the audience seemed preoccupied (Cipriani et al., 2011; Dahm, 2006; Hippius & Neundorfer, 2003). The facilitator inquired about questions and comments, and the audience remained silent. Alzheimer left the podium feeling perplexed by the lack of response (Maurer & Maurer, 2003).

Today the story of a seemingly rare disease, to use Alzheimer's words, would make the front pages of all the major news outlets. However, coverage of Alzheimer's presentation was limited, with the Tubinger Chronicle only noting the following, "Dr. Alzheimer from Munich gave an account of a peculiarly severe disease process, which caused significant shrinkage of the nerve cells within four and a half years" (Maurer & Maurer, 2003). Alzheimer's presentation had been overshadowed by a formidable foe namely, the psychoanalytic movement. By 1906, names like Freud, Adler, and Jung were

making waves, and the psychiatric community was, in effect, seduced with the idea of psychosexual development and talk therapy. Sitting in the audience at the conference was C.G. Jung, a collaborator of Sigmund Freud, and a proponent of psychoanalytic theory. His presence contributed to the shift in focus to the psychological aspect in the often tense debates that ignited during the conference (Maurer & Maurer, 2003). The debate erupted into the equivalent of an academic shouting match centered around a lecture presented the previous May by Professor Gustav Aschaffenburg from Cologne. This lecture was a provocative criticism of Freudian theory that centered on compulsive masturbation. This was followed by a presentation on a proposed modification that the author termed psychosynthesis. The presenting opinions of these scholars ignited a lively debate among the crowd including a heated exchange between members of the audience and Jung regarding the principles of psychoanalytics (Maurer & Maurer, 2003).

While the audience contributed to the increasing debate surrounding Freudian theory, the disease that Alzheimer described seemed to be lost, much like the memory of his patient. Despite the initial setback incurred at the conference, Alzheimer was undeterred and published an article based on his findings in 1907 entitled, "A Characteristic Serious Disease of the Cerebral Cortex" (Alzheimer, 1907; Strassing & Ganguli, 2005). In the years that followed, a number of other publications noted the histological symptoms of patients discovered post-mortem with descriptions of behaviors similar to Auguste D. when they were alive. A year after Alzheimer's publication, his Italian co-worker Francesco Bonfiglio described a second patient with similar symptoms and presenting behaviors (Cipriani et al., 2011). In In 1909, the case of Auguste D. was once again presented along with three other cases of similar origin, at the Psychiatric Clinic of the

German University of Prague, focusing on a detailed description of histopathological changes in dementia (Cipriani et al., 2011).

In the end, it was German psychiatrist Emil Kraepelin that introduced the eponym 'Alzheimer's disease' in the eighth edition of the Handbook of Psychiatry published in 1910 (Hippius & Müller, 2008). Kraepelin was an esteemed, well-respected psychiatrist, that spent most of his career developing a classification of psychiatric disorders (Bynum, 2008). In his text, Kraepelin separated AD from presenile dementia, citing it as a separate disease, a theory that contemporary research has since overturned (Cipriani et al., 2011).

Despite Kraepelin's contention that this was a separate, potentially new disease, it should be noted that it is unclear what, if any, discussions that Alzheimer and Kraepelin had about the nature of the disease and its classification. Since Kraepelin's publication in 1910, scholars have speculated his motivation for naming the disease after Alois Alzheimer (Hippius & Neundorfer, 2003). Kraepelin would have been aware of the other scholars working in the field to define the disease. It could be that Kraepelin did in earnest believe that Alzheimer had discovered a new disease, one that needed to be, for clinical purposes, separated from presenile dementia (Beach, 1987; Goedert & Ghetti, 2007). It is also worth noting that Alzheimer worked in Kraepelin's lab in Munich and closely collaborated with him during his time in Munich (Maurer et al., 1997). Furthermore, it was Kraepelin who encouraged Alzheimer to present his findings at a scientific meeting in Tubingen (Hippius & Neundorfer, 2003). Thus, his motivation may have been the rivalry between his lab and that of Pick in Prague, where Fischer worked (Goedert & Ghetti, 2007). This has led many scholars to suggest that the eponym Alzheimer's disease is not accurate (Boller & Forbes, 1998).

Regardless of Kraepelin's motivations, giving this disease a name did little to bring it to the collective consciousness in terms of a matter pertinent to public health. Even with Kraepelin's stature in the psychiatric community, senile dementia continued to be considered a byproduct of aging, and little attention was given to cases of early-onset dementia (Lock, 2014). Furthermore, after his death in 1915, Alzheimer was remembered more for his histological acumen and his intensive work ethic than for the disease that carried his name (Ballenger, 2006). Thus, in the intervening years, after Kraepelin introduced the term Alzheimer's disease, there was little research occurring regarding the disease (Hippius & Neundorfer, 2003). Alzheimer's research culminated in other researchers replicating Alzheimer's observations and initial histological analysis of the patient's brain specimen's post-mortem.

Paradoxically, Alzheimer's discovery is situated during a time of increasing medical innovation and insight. Prior to the advances in medicine made during the late 19th and early 20th centuries, the lifespan of persons with many chronic conditions was short and debilitating. By 1897 Felix Hoffman, a German chemist, synthesized Aspirin, a drug that now has implications in the daily lives of persons worldwide (Van Dulken, 2001). In 1907, Alfred Bertheim and Paul Ehrlich began the era of antibiotic chemotherapy, by developing arsphenamine to be used to treat the infection associated with syphilis (Parascandola, 2009). This paved the way for the development of penicillin in 1928 by Alexander Fleming (Ligon, 2004). These innovations produced significant improvements for the quality of life and the human condition. Furthermore, these discoveries and others contributed to the extension of the human lifespan. However, a tension between the progressive medical techniques being developed and the mental health system at the time

created notable tension due to the historical mistreatment of persons with mental illness and cognitive impairment. By the early 19th century, older adults with AD were often grouped together with adults of all ages that had cognitive impairments such as intellectual disabilities and Down syndrome (Trent, 1995). Persons with any form of cognitive impairment were known as *imbeciles*, *idiots*, or *feeble-minded* and their condition was often thought to be connected to moral decay or impurity (Trent, 1995). This led to many individuals, including those with AD to be institutionalized in, often, deplorable conditions much like the one that Alzheimer encountered when he first arrived to work at the Asylum for the Insane and Epileptic.

AD remained in the dark, both metaphorically and quite literally, due to the cascading effect of several, significant factors. First, senile dementia has primarily been viewed as a byproduct of aging. If one survived the array of maladies and diseases that killed most persons before the prevalence of modern medicine, they would surely succumb to the afflictions associated with old age (Bishop, 1904). Second, as previously stated, although AD was noted in the literature it was not until the mid-20th century that scholars refocused their attention to the disease as falling under the umbrella of dementia rather than senile dementia. Dementia was viewed as a product of aging, one that was largely associated with old age given that a distinction between the decline in acuity that accompanies normal aging and the decline seen in persons with dementia was not clearly formulated. Hence, early scholars and researchers arrived at the conclusion that this was an inevitable condition. The fact that this was a circumstance of living to old age meant that this disease could not possibly be cured and thus, preventative medical interventions were not explored.

This characterization of cognitive decline permeated scientific inquiry through time, even today, nearly 116 years later. AD and other forms of dementia are inherently tied to the process of aging which has an impact on the disease in terms of funding, research, and stigma. AD research is far behind that of other diseases of public health concern, particularly if one examines the funding that is allocated each year through the National Institute of Health.

Current Characterizations of Alzheimer's Type Dementia. Alzheimer's Disease is now classified as a neurocognitive disorder (NCD) with major or mild subtypes. The term "dementia," is still used in settings due to custom, familiarity with the term, and continuity of medical data (American Psychological Association, 2013). The term dementia is used as an umbrella term to describe a decline in cognitive ability that is severe enough to impede activities of daily living. Currently, there exist several known neurobiological causes of dementia. Furthermore, each type of dementia has different patterns of symptoms and brain abnormalities, with some similarities between specific forms of dementia. AD is by far the most commonly diagnosed form of dementia, which accounts for an estimated 60% to 80% of all cases (Alzheimer's Association, 2018; Centers for Disease Control and Prevention, 2017). This is followed by vascular dementia, dementia with Lewy bodies (DLB), Parkinson's disease dementia and mixed dementia, which is the presence of abnormalities of more than one cause of dementia (Alzheimer's Association, 2018). Rarer cases of dementia include frontotemporal lobar degeneration (FTLD), Creutzfeldt-Jakob disease, and normal pressure hydrocephalus (Alzheimer's Association, 2018).

AD is defined by a distinct pathology that includes the presence of senile plaques (SPs) composed of beta amyloid (Aβ) and neurofibrillary tangles (NFTs) consisting of tau (Esiri, 2007; Harrington, 2012). The human brain contains tens of billions of neurons. These are cells that control and transmit information through a series of electrical and chemical signals (Whalley, 2001). Neurons are critical in providing information to different parts of the human body to maintain and function properly. Amyloid plaques within the brain are found within spaces between neurons. The plaque consists primary of abnormal deposits of a brain protein fragment known as beta-amyloid (Aβ) (DeKosky, 2003). It is not currently known whether these plaque buildups are the cause of AD or a result of the disease's progression. Inside neurons, neurofibrillary tangles (NFTs) are also a hallmark sign of the presence of AD (Serrano-Pozo, Frosch, Masliah, & Hyman, 2011). NFTs are clumps of the protein tau, and when an individual suffers from Alzheimer's disease, tau undergoes an abnormal transformation that causes it to detach from microtubules and stick to tau molecules (DeKosky, 2003; Serrano-Pozo et al., 2011). This results in the formation of clumps of tangles. Finally, there is a loss of neural connections when the synaptic connections between certain groups of neurons stop working and thus, begin to degenerate, causing cell death (Whalley, 2001). Unlike cells in other parts of the human body, neurons do not divide, and when they die, they are not replaced by new ones. While the loss of neural connections is present within the disease, it is simply unknown if the loss of neural connections is related to the buildup of amyloid plaques and tau. Furthermore, researchers are currently examining if there are other abnormalities in the brain that could provide new insights into the disease (DeKosky, 2003).

Under a microscope, the presence of beta amyloid plaques is detected as extracellular deposits while the accumulation of the tau protein occurs at the intracellular level (Harrington, 2012). The current prevailing theory, of which most medical research and development is predicated, is that Aβ deposition is the primary lesion that contributes to Alzheimer's disease and that neurofibrillary tangles are secondary, perhaps caused by the presence of Aβ. (Penke, Bogar, & Fulop, 2017; Sajjad, Arif, Shah, Manzoor, & Mustafa, 2018).

The presence of the two compounds are not the only changes that appear within the brain. Typically, the weight of the brain decreases anywhere from 100-200 grams as the disease takes over, with atrophy showing in the temporal, parietal, and frontal lobes along with the hippocampus (Poirier & Gauthier, 2014). As these sections of the brain begin to atrophy, the ventricular system becomes enlarged (Budson & Solomon, 2016). Furthermore, the neurochemistry of the brain is altered and a deficit of acetylcholine, a neurotransmitter, is consistently found in persons with AD (Budson & Solomon, 2016).

Despite the understanding of these changes occurring within the brain, there are conflicting accounts of what produces the pathology of the disease. There are many questions that are the focal point of active research, such as: Does the presence of plaques and tangles represent the essence of the disease? Or: Are plaques and tangles merely byproducts of the disease process? Furthermore, even if the answer to either one of these questions is affirmative, this does not establish what causes this pathology in the brain to occur (Poirier & Gauthier, 2014).

Current research within the AD field is focused on pinpointing the trajectory of the disease as this could lead to potential pharmaceutical interventions. As to what causes

these changes in the brain to occur, there have been a plethora of studies that have pointed to everything from excessive air pollution (Moulton & Wei, 2012) to sleep disorders (Cipriani, Danti, Vedovello, Nuti, & Lucetti, 2014), and even, aluminum (Kawahara, 2005) as being the culprits in causing AD while social engagement (Krueger et al., 2009), diet (Gu, Luchsinger, Stern, & Scarmeas, 2010; Luchsinger, Noble, & Scarmeas, 2007), and exercise (Coelho et al., 2013; Yaffe, 2010), have all been touted as preventative measures for decreasing cognitive decline. The results of these studies and others similar in content are often sensationalized in the popular media, which often leads to stereotypes (Kirkman, 2006) all the while, there is still so much that is unknown regarding the disease.

Symptoms and Behaviors Associated with AD. As previously noted, AD has profound effects on the brain and its' ability to function and communicate with the rest of the body. This results in decline in activities of daily living to behaviors that are both disruptive and, often, harmful. Persons with mild AD experience profound memory loss that affects many of the activities of daily living. Person with AD may wander and become lost in environments that should be familiar. Social interactions may become difficult as persons with mild AD can become lost in conversation and ask the same questions repeatedly. Routine activities may take longer than usual to complete. Furthermore, persons may have difficulty with familiar tasks related to money management such as paying bills or receiving change back from a cashier. Family members and friends may notice increased changes in the individual's demeanor and behaviors. As the disease progresses, the presence of behavioral symptoms, such as agitation and aggression, are commonly associated with moderate AD. These behaviors

are related to greater overall impairment in functioning and short survival time (Weiner et al., 2005).

As time progresses, persons with moderate AD may experience more profound effects. The memory loss experienced in the mild impairment stage may worsen, and persons may lose the functional capacity to communicate, to reason, and participate in abstract thought. As memory loss worsens, persons with moderate AD may not be able to recognize family members, friends or care providers. They may have issues with completing multi-step tasks such as putting on clothes or preparing meals. Moreover, as confusion sets in the individual may develop paranoia, delusional thoughts, and in some instances, act in an agitated or aggressive manner. Estimates suggest that aggression occurs in roughly 40% to 60% of persons living in facilities such as nursing homes (Corbett et al., 2012).

In the final stages of the disease, persons with severe AD are increasingly dependent on others for care and require increased sleep. Furthermore, as their body begins to shut down from the effects of the disease, they may experience weight loss from the lack of appetite or difficulty swallowing. The person with AD may suffer seizures; this can be attributed to gliosis and neuronal injury in the brain as a result of the dementia process. If they are confined to bed, they may experience skin infections from decreased mobility.

While each individual's journey with AD is different, the aforementioned stages provide a brief overview of the progression of the disease and how it affects the individual's ability to function. For some individuals, the process is swift, while others

must endure a long and painful journey. In some cases, persons with AD pass within 3 years of diagnosis, while others suffer for as long as 20 years (Brookmeyer et al., 2002).

The Development of Pharmaceuticals

For as long as humans have been aware of illness and disease, they have tried to develop treatments and cures. Today, after decades of scientific discovery, most medications are chemically synthesized compounds that are created and tested in labs, and then approved for mass production by federal regulating bodies (Liebenau, 1987). However, the origins of medicines are rooted in the use of simple solutions that were historically readily available such as plants and, in some cases, animal compounds. Many cultures maintained records of medications that were most effective for treating common ailments. China was by far the most sophisticated in their approach. By 1100 BCE, China developed and documented at least one dozen treatments for common ailments (Leung, 2006). By the 16th century, this significantly increased to more than 1,900 different remedies (Leung, 2006).The first pharmacopeia, known as *the De Material Medica*, is estimated to have been written in the first century CE and is attributed to Dioscorides. Little is known about the scholar except that he was thought to be from Greece, and a botanist (Eadie, 2004). In India, Ayurveda is a medical system that was developed around 5000 years ago. Within its structure remedies included herbs and other substances found in nature. The first medicinal documentation in English that is known is *The English Physician*, published in 1652 by Nicholas Culpeper (Culpeper, 2016). It is noteworthy for its comprehensive categorization of medicinal herbs and their usages.

The late 1800's and early 1900's was a time of increased medical innovation and discovery. In the case of tetanus, a series of discoveries led to the understanding of

tetanus bacillus, the development of antitoxin, and the use of a vaccine to ward off this infectious disease (Porter, 1999). The case of tetanus is only one case study that represents the overarching development of pharmaceuticals.

The movement toward increased research marks a shift in thought about medical practices. The field of medicine, and physicians were less equated with the mysticism than in previous centuries. This shift can also be attributed to the development in the understanding of modern organic chemistry. Before the 1800's, chemists posited that compounds that were obtained from humans and other living organisms were gifted with what they termed a *vital force*; this was in part to distinguish from inorganic compounds. The underlying theory was that these compounds could only be produced within living organisms, thus making them unique. This changed in 1828 when Fredrich Wöhler made a profound discovery in which he could produce the organic chemical *urea*, a constituent of urine, from the entirely inorganic compound, ammonium cyanate (Porter, 1999).

From Small Apothecaries to Big Pharma

The current pharmaceutical industry can be traced from two primary sources, all of which emerged during the late 1800's through the early 1900's. Today, pharmaceutical companies such as Pfizer, Johnson & Johnson, GlaxcoSmith Kline, and Merck are international, Fortune 500 companies (Malerba & Orsenigo, 2015). Yet, during the 1800's, their origins were far humbler, as each of these companies started as a family-owned apothecary (Liebenau, 1987). As medications during this time predominately consisted of herbs and other plant compounds, an apothecary was managed by persons skilled in the trade of mixing combinations of herbs, minerals, and other commonly found items to produce solutions or pastes in the treatment of a variety

of ailments (Malerba & Orsenigo, 2015). Other remedies that were used included morphine and quinine. Eventually, these smaller apothecaries were replaced as it became easier to manufacture drugs in mass. Thus, many of these apothecaries transitioned from natural products to developing and manufacturing medications on a larger scale (Malerba & Orsenigo, 2015).

While there are many companies today that started as apothecaries and eventually developed into medication manufacturing, many companies such as Bayer and Pfizer started as dyestuff and chemical companies. With the pharmaceutical market showing steady growth these companies established research labs and applied for patents for drugs (DiMasi, Hansen, & Grabowski, 2003). By the 1930's, these companies were established drug developers, yet they developed slowly. In 1930, most medications were still procured without a prescription. People suffering from a malady could go into a pharmacy, explain their symptoms, and receive a compounded drug. During this period physicians were also dispensing medications directly to their patients (Freeman & Louçã, 2002).

In the 1920s and 1930s both penicillin and insulin were discovered and manufactured, albeit at a modest scale. The Second World War provided a major stimulus to the developing pharmaceutical industry, with requirements for the large-scale manufacture of analgesics and antibiotics and increasing demands from governments to undertake research to identify treatments for a wide range of conditions. The post-war period from the 1950s to the 1990s saw major advances in drug development with the introduction of new antibiotics, new analgesics, such as acetaminophen and ibuprofen, and completely new classes of pharmaceuticals such as oral contraceptives, beta-

blockers, benzodiazepines and a wide range of novel anti-cancer medicines (Chandler Jr., 2005; Liebenau, 1987).

Commercializing Medication

As the decades passed, pharmaceutical companies such as Pfizer and Eli Lilly became more prominent. It was during this time that pharmaceutical sales began to be heavily promoted. Drugs were marketed to doctors with the intent to spur more prescriptions and sales. Doctors were financially rewarded by the pharmaceutical companies for promoting their products (Chandler Jr., 2005).

The rise of big pharmaceutical companies was also bolstered through marketing directly focused on potential consumers. Until the mid-1980's print and digital marketing to consumers were not common. When print marketing, in magazines and newspapers began, there were federal regulations that stated that drugs could not be touted as a miracle cure for ailments, and all of the side effects of the medication had to be listed at the bottom of the advertisement to safeguard the public. Furthermore, the Food and Drug Administration enacted a provision in 1969 requiring that all advertising had to be both fair and balanced (Chandler Jr., 2005). In 1986, the first commercial advertisement for medication was filmed that directly targeted consumers. This opened the door for more medications to be marketed directly to consumers without the need to market to physicians (J. Li, 2014)

The following is an example of consumer pharmaceutical advertising that highlights the problem with direct marketing to consumers. Seldane (generic: terfenadine) was first approved for use in 1985. The drug was an antihistamine used to treat allergies, hives, and other allergic inflammatory conditions without causing

drowsiness. In the first commercial that aired in 1986 for Seldane, the name of the drug could not be used, but the marketing campaign urged consumers to ask their doctor about a new drug that could help them if they were suffering from allergies. This was a way of getting around the FDA regulation. By all accounts, the campaign was successful. It was estimated the drug sales for Seldane were roughly $34 million, and several years after the advertisement first aired, sales were estimated at $800 million. However, by 1998, Seldane was completely removed from the market (Geier, 1998). Throughout the 12 years that it was on the market, the FDA received numerous complaints and inquires because, as it would later be revealed, the drug interacted with several antifungal drugs (generics: ketoconazole and itraconazole), several antibiotics (generics: E.E.S, E-Mycin, Ery-Tab; clarithromycin; azithromycin) and a popular ulcer medication (cimetidine) (Geier, 1998). This interaction included serious heart abnormalities and contributed to 8 known deaths. Citing this, the FDA finally pulled the drug from the market (Geier, 1998). The 1980's and 1990's saw more leniency in pharmaceutical advertising regulations that allowed the name and proposed benefits of drugs to appear in advertisements (J. Li, 2014).

Medications and Alzheimer's Disease

Living with AD in a nursing facility often proves difficult for the person with AD, their family, and for those providing care to them. Feeling disconnected from family and in a foreign setting can lead to unrest. Confused by the unfamiliar faces of the ever-changing stream of staff providing direct care, agitation may ensue. Agitation has been defined as "inappropriate verbal, vocal, or motor activity that is not judged by an outside observer to be an obvious outcome of the needs or confusion of the individual" (Cohen-

Mansfield, 2001). Given the nature and severity of the behaviors of persons with AD, psychotropic medications are often the first line intervention for those living in nursing facilities, even though it has been recommended that they should be avoided in patients with dementia (Borda, 2006; Gentile, 2010).

Often known by their generic names, drugs such as Seroquel, Abilify, and Risperidone are commonly used to treat aggression, agitation, and delusions. Furthermore, these medications can be prescribed to persons with AD in nursing facilities to combat the behaviors often associated with the disease (Borda, 2006). While administering dosages of one or more of these medications can prove helpful in calming down an agitated or aggressive resident in a nursing facility, these medications are not without side effects. Antipsychotic medication use in older adults with AD can contribute to an increase in cognitive decline, increase in falls, metabolic changes such as hyperglycemia and diabetes, and dysphasia (Garrard, Chen, & Dowd, 1995). The most alarming side effect from the use of antipsychotic medications is the increase in mortality of those who take them. This evidence is based on 17 placebo-controlled trials over a 6 to 12-week time frames. While significant changes were shown in participant's levels of agitation and aggression, there was a 1.6-1.7 increased risk for mortality in the groups that received antipsychotic medications (C. G. Ballard, Gauthier, Cummings, & Lyketsos, 2009). Causes of death in these studies varied, however, most were attributed to cardiovascular or infectious events. This evidence has led the Food and Drug Administration (FDA) to issue black box warnings to several anti-psychotic medications, including Risperidone**,** indicating that these medications have severe or life-threatening adverse effects (Lenzer, 2005). Currently, there are no FDA approved antipsychotic

medications for use with persons with dementia, including AD (C. G. Ballard, Waite, & Birks, 2006).

The big problem is that many of the published articles promoting drugs are written by researchers working on behalf of pharmaceutical companies. One example of this is Janssen Pharmaceutica's research and marketing of Risperidone (Lenzer, 2005) which was shown effective and safe by their researchers. Janssen Pharmaceuticals is a subsidiary of the Johnson & Johnson company, considered an American institution. Although primarily known as the manufacture of staple household products, such as baby oil, baby powder, and shampoos Johnson & Johnson actually makes 91% of it's profit from medical devices and drugs, not from consumer products. Production of Risperidone began in 1994 and was intended to replace Haldol, which came off-patent in 1986 (Colpaert, 2003). Part of the marketing strategy for Risperidone was to make it the "top choice" of medications for Medicaid run programs for older adults in state nursing facilities. By 2005, the FDA issued black box warnings on several anti-psychotic medications, including Risperidone. The company continued to promote Risperidone for unapproved usages, including for older adults with dementia, to physicians prescribing medications in nursing home settings as a safe and efficient drug but unfortunately, that was not the case. In 2012, Johnson & Johnson reached a $181 million consumer fraud settlement that included 36 states along with the District of Columbia (Thomas, 2012). The company was also accused of minimizing and concealing the risks associated with

the medication's use. These events were purported to occur after the FDA issued their black box warning on the medication (El Haj et al., 2016).

In addition to the black box warnings, and the fines imposed on companies, there are other provisions established to prevent the misuse of antipsychotic medications in nursing homes. Primarily known as OBRA-87, the Omnibus Budget Reconciliation Act of 1987 requires that new long-term care residents be assessed for mental illness and nonpharmacological treatments be used to manage behaviors (M. Kelly, 1989). This law was added after repeated concerns were expressed in the media and among leaders in the geriatric field that medication management was dangerous in most long-term care facilities. OBRA-87 took effect in October 1990 and provided guidelines for state surveyors to determine nursing home compliance with federal regulations (Anderson & Bjorklund, 2009). Persons transitioning into nursing facilities for long-term care must undergo the Pre-admission Screening and Resident Review (PASRR) to ensure that they are not inappropriately placed in long-term care (Madhusoodanan, Nwedo, Brenner, & Mirza, 2014). PASRR as a federal mandate brings states in accordance with the Supreme Court decision, Olmsted vs. L.C., which held that all persons have the right to live in the least restrictive setting possible (United States Reports, 1999) . PASRR requires that 1) all applicants to a Medicaid-certified nursing facility be evaluated for mental illness and/or intellectual disability; 2) be offered the most appropriate setting for their needs (in the community, a nursing facility, or acute care settings); and 3) receive the services they need in those settings. While the PASSR provisions exist at the federal level, many states including Kentucky, include exemptions to these rules. Residents being admitted directly from hospitals are exempt from screening and furthermore, persons that have a diagnosis

of dementia or intellectual disability are exempt from PASSR (Madhusoodanan et al., 2014).

In Kentucky, in most long-term care facilities, antipsychotic medications are still prescribed on a regular basis. Between the end of 2011 and the end of the first quarter of 2017 roughly 19.1% of persons living in Kentucky long-term care facilities received antipsychotic medications compared to the national average of 15.7% (Monroe & Ceballos, 2017). The use of antipsychotic medications in nursing facilities in Kentucky poses another overarching concern about the state of older adults with AD and other forms of dementia. CNAs are also primarily responsible for the care and behavior management of these individuals. Therefore, appropriate training of CNAs is warranted (Molinari et al., 2017).

The first medication brought to the market for AD was Cognex (generic: tacrine). It was developed by neuroscientist William Summers. Early reports of the medication were marked by Summers unconventional approaches to development and research (Kolata, 1992; Leary, 1991). From his research, Summers felt that AD needed to be targeted with a medication that could block or reduce the production of acetylcholinesterase. Without any funders or backing, Summers invested $90,000 of his own money into the production of a tacrine pill that could be brought to market. In 1981, in an experiment to test the drug, Summers administered the medication to 12 of his patients that had AD (Jebelli, 2017). As he did not know what dose would be of benefit to the patients, they received varying dosages intravenously (Jebelli, 2017). Hours after administering the drug, Summers noted a marked difference in his patient's cognitive abilities (Jebelli, 2017). Despite these findings which were published in 1986, the FDA

was initially reluctant to approve the medication, citing its potential for causing liver disease (Leary, 1991). Later reports suggested that Summers findings could not be replicated (Kolata, 1992).

Even today, the available options that exist for AD are only for managing the effects of the disease, including behaviors, if the patient is in the mild to moderate stages of the disease. Medications including Cognex (generic: tacrine), Razadyne (generic: galantamine), Exelon (generic: rivastigmine), and Aricept (generic: donepezil) are commonly used to treat mild to moderate stage AD. These medications are known as cholinesterase inhibitors and work by preventing the breakdown of a specific brain chemical, acetylcholine (G. Small & Bullock, 2011). Acetylcholine is critical for the processes of memory and thinking. These medications work because they augment acetylcholine and act as neurotransmitter augmentation therapy (G. Small & Bullock, 2011; Wattmo, Minthon, & Wallin, 2016). However, as the disease progresses, it is not as affected by these medications.

For persons progressing to the moderate to severe stages of the disease, there is another medication known as Namenda (generic: memantine) that are commonly prescribed. Both Namenda and Aricept are used for the severe stages of the disease (Plosker & Lyseng-Williamson, 2005). Namenda is an N-methyl D-aspartate (NMDA) antagonist. The basis of Namenda is that it contributes to the regulation of glutamate, a brain chemical allowing for better cognition and global functioning (Zhou & Danbold, 2014). Another pharmaceutical approach to this disease is Namzaric, which is a combination of Namenda and Aricept.

To summarize, as of 2018, we have 5 medications on the market that are available, and this is the extent to which pharmaceutical treatments are available for a disease that is the 6th overall leading cause of death in the United States. The medications do not stop the disease itself nor do these medications aggressively slow the disease. The medications can only show some effects on mitigating the behaviors associated with the disease.

Providing Care to Older Adults: From Home Care to Growth of Institutions

To fully conceptualize the current status of care for persons with AD in the United States, we must understand the origins of caregiving. Care for older adults during much of the history has been provided in the home. Families were expected to provide the daily care for their older family members. In return, any property or financial means of the individual was bequeathed to the family (Gawande, 2014). Often, it was customary for generations of one family to live together, or at the very least, within close proximity and often, this reflected customs that were derived from the family's country of origin (Benjamin, 1993). Given this arrangement, nearly all care was delivered in the home, and in many situations by either family members or other natural caregivers. If persons found themselves without family support or care, there were accommodations that could be made to assist the aging individual. For example, in some instances, the town would supplement another family to provide care. Alternatively, if the individual had their own home, they might barter goods for someone to come and provide them with support (Lacey, 1999). However, by the mid-19th century, this began to shift due to the development of the medical model of care and changes in familial structures (Gawande, 2014).

This shift first began in larger cities in the United States, as the colonial model of providing care in-home and development of a barter system were not always possible. Moving to a city, however, often required leaving family, and therefore, a support system. Furthermore, by the late 1800's, persons were having fewer children, and therefore, less reliable sources of support as they aged (L. E. Jones & Tertilt, 2006). The lack of support, particularly as persons aged, would make way for the development of almshouses. Almshouses originated in England in the 10th century and were designed to be used by the indigent that could not afford other accommodations. For many centuries almshouses were available only for the deserving poor or persons in the community who were deemed in good moral standing (Goose, Caffrey, & Langley, 2016). Known for being crowded and unsanitary, and with abusive support staff, the almshouse was often the last resort for many (S. Katz, 2013). The widely referenced, Quincy Report of 1821, offers a description of the care provided to these persons who were often considered the lowest of society for they had nowhere else to turn (M. B. Katz, 1984; S. Katz, 2013). Furthermore, a review of the 1865 almshouse census records indicates that the average age of the institutionalized in the almshouse was just under 50 years of age (Lacey, 1999).

By the late 19th century, there were other options for care in addition to the almshouses. Private, charitable homes began to be developed to provide services in many cities across the United States. Furthermore, the rise of mental institutions and hospitals were also developing during this time (Trent, 1995). Many of the charitable houses of the time that accepted older adults were limited to white persons of the

Protestant faith with little or no impairments. There were long waiting lists for rooms at these facilities with many persons waiting years to receive support (Lacey, 1999).

In the United States, home care began to diminish particularly after World War I. This period reflected a number of interrelated factors that would change the fabric of care provided to older adults, including those with AD. The end of the war brought new challenges to public health as returning soldiers presented with disabilities, as a result of their service, that needed to be addressed (Linker, 2011; Murphy, 2014). Due to the technological advances that resulted from the Industrialization Revolution, persons began to live longer. Between1900 and 1920 the older adult population grew dramatically. The estimates suggest that this population grew from about 3 million persons to about 5 million persons (Hobbs & Stoops, 2002). Furthermore, the number of persons aged 85 years and older increased from 100,000 to 300,000 persons (Hobbs & Stoops, 2002).

During this time, public health became an increasing concern due to the rapid urbanization that occurred at the beginning of the century. Persons were living in cities in increasing numbers, and the concern regarding the spread of infectious disease led to this newfound concern (Armstrong, Conn, & Pinner, 1999). Also, the rapid increase in the older adult population created a systematic breakdown of the provision of care for this population. The increase of older adults coupled with the turbulent financial years of the Great Depression created a need for external sources of care as it became increasingly difficult for families to provide the support to aging family members as they had once done (Haber, 1993).

The deplorable conditions witnessed in almshouses and mental facilities were also a cause for concern. There were limited regulations regarding specific care for older

adults, and those with cognitive impairments such as AD. The Social Security Act of 1932 was developed to pave the way for a better structure for institutionalizing care for older adults. Initially, the act was designed to provide independence to the aging population of American citizens (Haber, 1993). The Social Security Act of 1932 contributed to the decline and subsequent closures of almshouses across the United States (Haber, 1993; M. B. Katz, 1984).

In response to the closure of almshouses privately owned boarding houses began to develop in each state due to federal funding provisions. While some of these houses provided excellent care, this was not always the case with some providing care on par with the almshouses that they replaced. Further, the regulations for these care providers during this time were limited. In the end, care was inconsistent, and furthermore, there was simply not enough privately-owned houses for this to be a sustainable safety net for older adults (Lacey, 1999).

By the 1950's, this led to housing older adults and those with AD in state mental hospitals across the nation even though the initial purpose of these hospitals was to provide acute care to persons with psychiatric illness. These facilities were never designed to provide long-term care, and therefore, this form of care was ultimately not sustainable (Haber, 1993; Haber & Gratton, 1993). This led to the development of nursing facilities or skilled nursing facilities, to provide care specifically to older adults and those with cognitive impairments such as AD. The need for more sustainable, long-term care coupled with the growing interest in developing an aging-related industry led to a surge in nursing home facilities. Between 1963 and 1980, it is estimated that more than one million new nursing home beds were added to provide care to this population (Doty,

Liu, & Wiener, 1985; Vladeck, 1980). The original nursing home model was based on the institutional care model (E. Goffman, 1968). In this model, emotional and cognitive experiences and autonomy were disregarded (Doll, Cornelison, Heath, & Syme, 2017). This model promoted uniformity in all aspects of life, was directed by a single authority and was conducted in the same place. Staff carried out daily duties that were regimented under a single plan that sought to fulfill the official aim of the institution (Wiersma & Dupuis, 2010).

The changes that led to the increases in long-term care facilities did not ensure the quality of care. Furthermore, many of these facilities were subsidized with government funding. By 1975, Medicaid paid over $5 billion dollars for nursing home care each year (Lacey, 1999). During the 1970's and early 1980's, there were various published accounts that called into question the care that was provided to persons in nursing facilities. Stories of nursing home fires, of residents dying from bedsores, and food poisoning were widely described in reports given to government officials and in the media (Hawes, 2003). Despite the nature of these concerns and the amount of government funding allotted to nursing facilities, these facilities remained largely unregulated until the late-1980 were when the Nursing Home Reform Provisions of 1987 were passed in Congress (Zhang & Grabowski, 2004).

Currently, long-term care for persons with AD has come a long way from the unsafe and often-deplorable conditions mentioned in this section. However, this is not to suggest that more improvements are not needed. Behaviors such as delusions, outbursts, and aggression are symptomatic of AD. Chemical and physical restraints have many times been utilized in these situations to make the individual more manageable (Fossey et

al., 2006). Furthermore, a large portion of persons with dementia living in nursing facilities receives substantial doses of tranquilizers for behavioral symptoms. This was instituted despite the literature suggesting only modest results along with high placebo effects and, in some scenarios, adverse side effects for those persons (Fossey et al., 2006).

The Development of the Nurse Aide Profession

The care provided to persons with AD is often characterized as either delivered by informal or formal providers. In 2014 alone, nearly 16 million family members and other caregivers provided an estimated 18 billion hours of unpaid caregiving to persons with AD and other forms of dementia. Although, more persons with AD and other forms of dementia are receiving care from formal care providers in nursing home facilities (Gaugler et al., 2014). CNAs make up an estimated 60% of the employees in an average nursing home in the United States (Trinkoff et al., 2013).

In nursing homes, CNAs provide functional assistance to residents in all aspects of their daily care. CNAs are charged with completing tasks to support residents with activities of daily living. These tasks range from personal care support to administering medication. CNAs receive minimal training and low pay for a stressful job many times managing problematic symptoms and behaviors. As a result, burnout and turnover are common for these front-line workers (J. Rosen, Stiehl, Mittal, & Leana, 2011). Many of the issues that are faced by CNAs today are a direct result of their history of volunteer service and marginalization within the nurse field which will be discussed next.

A Volunteer Reserve Is Formed. The need for nurse's aides, the precursor to CNAs, developed during the United States entry into World War I in April of 1917. The

use of heavy artillery and machine guns posed new challenges as the carnage left soldiers with debilitating wounds, fractures, and infection. The American Red Cross, tasked with filling positions to take care of the soldiers on the front lines, recruited nurses from across the United States (M. M. Jones, 2012). However, the need far exceeded the nursing professionals that were available. In Britain, the Voluntary Aid Detachment (VAD was developed in 1909 by the Red Cross to fill these gaps in the workforce (While, 2014). It would subsequently serve as a model for the volunteers that would be needed in the United States. While nurses and other trained medical professionals were actively recruited for the war effort, the Red Cross also began to seek volunteers in the form of nurse's aides. These volunteers had little or no medical background and were often women recruited from middle to upper-class backgrounds (While, 2014).

The initial criteria for volunteer nurse aides were for practical purposes. All applicants had to be between the ages of 25 and 35, unmarried, in good health and capable of hard physical labor. Applicants could not have German or Austrian relationships by birth or marriage. Furthermore, applicants could not be daughters, mothers, or wives of anyone serving in the United States Army, Navy, states or abroad. Vaccinations against smallpox along with inoculations against typhoid and paratyphoid were required. Prospective nurse aides were also required to have graduated from or be willing to take a specific course in elementary hygiene and home care of the sick. These were the only required preparation for the role (While, 2014).

World War I depleted the number of nurses in the United States that were necessary to provide care within hospitals. The drain on human resources required the Red Cross to continue to recruit actively and train nurse's aides to fill the roles once

occupied by graduate level nurses. Training courses for hospital care for nurse's aides were implemented in Red Cross sites across the nation to help prepare nurse aides. Many of the requirements that were previously mandated were removed to accommodate those persons that might be interested but did not meet the established care criteria (Hallett, 2014; Yen, 2012).

From the onset, the utilization of a voluntary force of workers presented unique challenges to the American Nursing Association and the Red Cross. The field of nursing had established standardization and professional training. Highly regarded institutions of education offered nursing degree programs. Yet, many of the volunteer nurse aides had little experience in healthcare or any field for that matter. Training for volunteer nurse aides was limited during this time. This, in part, can be attributed to the tension between wanting to deploy professional, experience nurse aides as opposed to volunteer nurse aides. This tension played out between the Red Cross and the Federal government throughout the war, and the role of the nurse aide was never clear. The President of the American Red Cross, Jane Delano, at the time, was adamant in her opposition to the use of volunteer nurse aides from the beginning of the War. However, by the War's end, Delano along with key organizations such as the American Hospital Association (AHA) understood that the need for nurse aides outweighed the risks of using volunteers. Federal provisions were put in place to activate the reserve of volunteer nurse aides that had been recruited. These reserves were never used as the War ended after the provisions were enacted. Nurse aides, after the War, remained a volunteer position that fell within the purview of the Red Cross. After WWI, many of the training programs enacted by the Red

Cross throughout the United States remained inactive until there was cause for their need during the beginning of WWII (Hallett, 2014; Irwin, 2013).

Current Training and Workforce Development for Nurse Aides. Due to their status as volunteer workers, nurse aides did not emerge as a profession with rules or formal training until the mid-20th century. The profession was formalized by the Nursing Home Reform Provisions of the Omnibus Budget Reconciliation Act of 1987 (known as OBRA-87) (Code of Federal Regulations, 2012). OBRA-87 established the requirement for a 75-hour nurse aide training that included at least 12 hours of continuing education and competency evaluation program for those persons employed as nurse aides in long-term care facilities (Han, Trinkoff, Storr, & Lerner, 2014; Klauber & Wright, 2001). Each state was tasked with creating and implementing its own curriculum and testing system (Klauber & Wright, 2001). In Kentucky, this has been implemented as a 75-hour course along with 16 hours of hands-on clinical training. Currently, only 4 of the 75 mandatory hours focus on dementia care.

With the introduction of the Affordable Care Act of 2010, more mandated education was required. Specifically, section 6121 requires six 1-hour modules, known as *Hand in Hand*, covering 7 areas including: 1) understanding the world of dementia; 2) the person and the disease; 3) what is abuse; 4) listening and speaking; 5) being a person with dementia, actions and reactions; 6) preventing abuse; and 7) being with a person with dementia making a difference (Patient Protection and Affordable Care Act, 2010).

Table 1 delineates an overview of the current curriculum mandates in each state and how they are implemented. This table does not include the *Hand in Hand* training that is

a requirement in all long-term care facilities that receive federal funding and review. Only additional dementia training to Hand in Hand is included in the table.

Table 1

CNA Training by State

CNA Training by State (Patient Protection and Affordable Care Act, 2010)			
State	Statute or Regulations Related to Nurse Aide Training Citations	Hours Required for Nurse Aide Certification	Dementia Training Required?
Alabama	1. Federal Code of Regulations: CFR Title 42, Vol. 3, 483.	Total Instruction: 75 hours Includes: 16 hours of clinical experience	N/A
Alaska	1. Alaska Administrative Code, Title 12, 44.835.	Total Instruction: 140 hours	N/A
Arizona	1. Arizona Admin Code § R4-19-802 (2014)	Total Instruction: 120 hours Includes: 40 hours of classroom instruction, 20 hours of instructor-supervised skills practice and 40 hours of instructor-supervised clinical experience	N/A
Arkansas	1. Ark. Code Ann. § 20-10- 705 (2005) 2. Ark. Code R. 016.06.07-IV (2012)	Total instruction: minimum of 90 hours	15 hours of training related to Alzheimer' disease and dementia if working in a long-term care facility.
California	1. Cal. Health. & Safety Code. 1263 (2002) 2. Cal. Health. & Safety Code. 1337.1 (2013) 3. Cal. Health. & Safety Code. 1337.3 (2013) 4. Cal. Code. Regs. tit. 22 § 71835 (2013) 5. Cal. Code Regs. tit. 22 § 71847 (1992)	Total instruction: 150 hours Includes: 100 hours of clinical hours	2 hours initial dementia training for nurse aides working in skilled or intermediate care facilities and five hours annually after the initial training.
Colorado	1. 3 Colo. Code Regs. § 716- 1:11-5 (2014)	Total Instruction: 75 hours Includes: 16 hours of clinical experience	N/A
Connecticut	1. Connecticut Department of Public Health Regulations, Public Health Code, Chapter IV, Title 19-13-D8t.	Total Instruction: 100 hours Includes: 50 hours of clinical experience	N/A
Delaware	1. 16-3000-3220 Del. Admin. Code § 2.0 (2013)	Total Instruction: 150 hours Includes: 75 hours of clinical experience	6 hours of dementia-specific training during each 24-month certification period.
District of Columbia	1. D.C. Mun. Regs. tit. 29, § 3204 (2014)	Total Instruction: 120 hours Includes: 75 hours of clinical experience	16 hours of nurse aide training must include topics related to Dementia care as part of standard certified nurse aide training.

CNA Training by State (Patient Protection and Affordable Care Act, 2010)			
Florida	1. Florida Administrative Code, Rule Chapter: 64B9-15.	Total Instruction: 120 hours Includes: 40 hours of clinical experience	N/A
Georgia	1. Alliant GMCF, Nurse Aide Program Overview.	Total Instruction: 85 hours Includes: 24 hours of clinical experience	N/A
Hawaii	1. Hawaii Administrative Rules, Title 16, Chapter 89A 2. Med-QUEST Division, Certification Programs, "State Certified Nurse Aide Training Program" (May 2004)	Total Instruction: 100 hours Includes: 70 hours of clinical experience	N/A
Idaho	1. Health Professions Program, Idaho Division of Professional-Technical Education, "How to Start a Nursing Assistant Course."	Total Instruction: 120 hours Includes: 32 hours of clinical experience	N/A
Illinois	1. Ill. Admin. Code tit. 77, § 395.150 (2013) 2. Ill. Admin. Code tit. 77, § 395.300 (2013)	Total Instruction: 120 hours Includes: 40 hours of clinical experience	12 hours of nurse aide training must include topics related to Dementia care as part of standard certified nurse aide training.
Indiana	1. 410 Ind. Admin. Code 16.2-3.1- 14 (2013)	Total Instruction: 105 hours Includes: 75 hours of clinical experience	Staff in nursing facilities who have regular contact with residents must have a minimum of 5 hours of dementia-specific training within the first 6 months of employment or within 30 days for those assigned to the Alzheimer's and dementia special care unit. All nurse aides are to do three-hours annual dementia specific continuing education for recertification.
Iowa	1. 441 Iowa Ad- min. Code r. 81.16 (2014)	Total Instruction: 75 hours Includes: 30 hours of clinical experience	16 hours of nurse aide training must include topics related to Dementia care as part of standard certified nurse aide training.
Kansas	1. Kansas Administrative Regulations 28-39-165.	Total Instruction: 90 hours Includes: 45 hours of clinical experience	N/A
Kentucky	1. Kentucky Administrative Regulations, Title 907, Chapter 1, Section 450.	Total Instruction: 75 hours Includes: 16 hours of clinical experience	N/A
Louisiana	1. La. Admin. Code tit. 48, § 10015 (2012)	Total Instruction: 80 hours Includes: 40 hours of clinical experience	Dementia training must be included in nurse aide training but hours are not specified.
Maine	1. 10-144 Me. Code R.110, § 8.C (2014)	Total Instruction: 180 hours Includes: 70 hours of clinical experience	12 hours per year in-service training, which must include some training in providing services to residents with cognitive impairment.
Maryland	1. Md. Code Regs. 10.07.02.40 (2014)	Total Instruction: 100 hours Includes: 40 hours of clinical experience	N/A
Massachusetts	1. Code of Massachusetts Regulations, Title 105.156.320.	Total Instruction: 75 hours Includes: 16 hours of clinical experience	N/A

CNA Training by State (Patient Protection and Affordable Care Act, 2010)			
Michigan	1. Michigan Department of Community Health, Bureau of Health Professions, Nurse Aide Training Curriculum.	Total Instruction: 75 hours Includes: 16 hours of clinical experience	N/A
Minnesota	1. Follows Federal Code of Regulations: CFR Title 42, Vol. 3, 483.	Total Instruction: 75 hours Includes: 16 hours of clinical experience	N/A
Mississippi	1. Follows Federal Code of Regulations: CFR Title 42, Vol. 3, 483.	Total Instruction: 75 hours Includes: 16 hours of clinical experience	N/A
Missouri	1. Mo. Rev. Stat. § 198.082 (1988) 2. Mo. Code Regs. Ann. Tit. 19 § 30-84.010 (2014)	Total Instruction: 175 hours Includes: 100 hours of clinical experience	Dementia training must be included in nurse aide training, but hours are not specified.
Montana	1. Montana Department of Public Health and Human Services, Quality Assurance Division, Certification Bureau, State Plan for the Nurse Aide Training and Competency Testing Program.	Total Instruction: 75 hours Includes: 25 hours of clinical experience	N/A
Nebraska	1. 172 Neb. Admin. Code ch. 108 § 003 (2014)	Total Instruction: 75 hours Includes: 16 hours of clinical experience	N/A
Nevada	1.Nev. Admin. Code § 632.758 (1992)	Total Instruction: 75 hours	N/A
New Hampshire	1. New Hampshire Code of Administrative Rules, Chapter Nur 10, Section Nur 704.09	Total Instruction: 100 hours Includes: 60 hours of clinical experience	N/A
New Jersey	1. N.J. Stat. Ann. § 26:2M-7.2 (2012)	Total Instruction: 90 hours Includes: 40 hours of clinical experience	N/A
New Mexico	1. New Mexico Administrative Code, 8.312.2.21	Total Instruction: 75 hours	N/A
New York	1. 10 N.Y. Comp. Codes. R. & Regs. § 415.26 (2010)	Total Instruction: 100 hours Includes: 30 hours of clinical experience	Dementia training must be included in nurse aide training, but hours are not specified.
North Carolina	1. North Carolina Department of Health and Human Services, Division of Health Service Regulation, Center for Aide Regulation and Education, State Approved Curriculum for Nurse Aide I Training.	Total Instruction: 75 hours Includes: 16 hours of clinical experience	N/A
North Dakota	1. North Dakota Administrative Code, 33.07.06.02.	Total Instruction: 75 hours Includes: 16 hours of clinical experience	N/A
Ohio	1. Ohio Admin. Code 3701-17- 07.1 (2012)	Total Instruction: 75 hours Includes: 16 hours of clinical experience	For nurse aides working in specialty units, 12 hours per year including dementia-related continue education is required.
Oklahoma	1. Okla. Stat. Ann. tit. 63, § 1-1951 (2013) 2. Okla. Admin. Code § 310:677-11-4 (2009)	Total Instruction: 75 hours Includes: 16 hours of clinical experience	N/A

CNA Training by State (Patient Protection and Affordable Care Act, 2010)			
Oregon	1. Oregon Administrative Code, 851-061-0090.	Total Instruction: 150 hours Includes: 75 hours of clinical experience	N/A
Pennsylvania	1. Pennsylvania Department of Education, Application for Approval of Nurse Aide Training and Competency Evaluation Program, June 2012	Total Instruction: 80 hours Includes: 37.5 hours of clinical experience	N/A
Rhode Island	1. R.I. Admin. Code 31-5-26 Appendix II (2012)	Total Instruction: 100 hours Includes: 20 hours of clinical experience	Dementia training must be included in nurse aide training but hours are not specified.
South Carolina	1. South Carolina Department of Health and Human Services, Department of Facility Services, South Carolina Nurse Aide Training Program Packet, "Guidelines for Nurse Aide Program Training Approval."	Total Instruction: 75 hours Includes: 16 hours of clinical experience	N/A
South Dakota	1. Admin. R. S.D. 44:04:18:15 (1995)	Total Instruction: 75 hours Includes: 16 hours of clinical experience	Dementia training must be included in nurse aide training, but hours are not specified.
Tennessee	1. Tennessee Annotated Code 68-11-209	Total Instruction: 75 hours Includes: 35 hours of clinical experience	N/A
Texas	1. Tex. Health & Safety Code Ann. § 250.0035 (2011) 2. 40 Tex. Ad- min. Code § 94.3 (2013) 3. 40 Tex. Ad- min. Code § 94.9 (2013) 4. 40 Tex. Ad- min. Code § 1.1929 (2004)	Total Instruction: 100 hours Includes: 40 hours of clinical experience	Nurse aides are required to complete 24 hours in-service education every two years which includes training in the care of patients with Alzheimer' disease.
Utah	1. Utah Administrative Code, Rule R432-45.	Total Instruction: 100 hours Includes: 24 hours of clinical experience	N/A
Vermont	1. Vermont Board of Nursing, Administrative Rules, Part 16.12.	Total Instruction: 80 hours Includes: 30 hours of clinical experience	N/A
Virginia	1. 18 Va. Ad- min. Code § 90-25-140 (2014) 2. 18 Va. Ad- min. Code § 90-26-40 (2014)	Total Instruction: 120 hours Includes: 40 hours of clinical experience	Dementia training must be included in nurse aide training, but hours are not specified.
Washington	1. Wash. Ad- min. Code § 246-841-100 (2008) 2. Wash. Ad- min. Code § 246-842-100 (1991)	Total Instruction: 85 hours Includes: 50 hours of clinical experience	N/A
West Virginia	1. West Virginia Department of Health and Human Resources, Bureau for Public Health, Office of Health Facility Licensure and Certification, Nurse Aide Educational Program, Criteria and Guidelines.	Total Instruction: 120 hours Includes: 55 hours of clinical experience	N/A
Wisconsin	1. Wis. Admin. Code Trans. § 129.07 (2008) 2. Wis. Admin. Code Trans. § 129.08 (2011)	Total Instruction: 120 hours Includes: 32 hours of clinical experience	Dementia training must be included in nurse aide training, but hours are not specified.
Wyoming	1. Wyoming State Board of Nursing, Administrative Rules and Regulations, Ch. II, Section 5(b)	Total Instruction: 75 hours Includes: 16 hours of clinical experience	N/A

This analysis shows that 31 states along with the District of Columbia are more than meeting the federal requirements training. This analysis also illustrates that the state of Kentucky still lacks in terms of consideration of updating nurse aide training. In a review of other states, most have updated state CNA training regulations in the last 10-15 years to reflect best practices. In Kentucky, the last changes that were implemented to nurse aide training on a state-wide level were with the provisions that were included in OBRA-87 in 2006 (Hawes, 2003). It is also important to consider that there have been numerous changes in terms of our understanding of the impact and nature of AD since the time that OBRA-87 was implemented. Several states have addressed this by requiring that nurse aide training to include hours and clinical supervision in providing care for persons with AD. Other states not only include AD training at the onset of nurse aide training but also require continuing education each year. It has been shown that better trained CNAs who are more capable of performing tasks provide better care (Han et al., 2014). The Institute for Medicine recommended that training hours for CNAs should at a minimum be 120 hours and that the certified nursing assistant certification exam directly assesses competence in the care of older people (Institute of Medicine, 2008).

Summary

Alzheimer's is a devastating disease that affects over 5 million persons in the United States, and it will continue to increase as the baby boomer generation ages (Alzheimer's Association, 2018). It is a disease without a cure or validated ways to slow down its progression (Alzheimer's Association, 2018). The challenges faced today in providing care for persons with AD are very much rooted in the historical characterizations of the disease. This has affected the care of persons and even the way

that medications are developed for those facing the disease. CNAs have emerged as the primary caregivers for persons with AD living in nursing home settings. The education provided to CNAs, while adequate in understanding the basic nursing care of persons with AD fails to teach CNAs how to provide compassionate care. This new level of training is needed in order to give CNAs the tools to overcome the societal stigma that follows the disease and develop a stronger bond with patients and their workplace.

While this chapter served as an introduction to the challenges of the disease and furthermore, provided a foundation for understanding its' unique complexities, subsequent chapters will focus on building a new approach to providing compassionate care for persons with AD.

1

CHAPTER II: LITERATURE REVIEW

This chapter introduces a theoretical framework for conceptualizing AD. It provides insight into the need for compassionate care and the stress associated with CNA caregiving. Specifically, theories of disablement and symbolic interactionism are discussed. The chapter also includes learning theories that were used to inform the development of the compassionate care curriculum, specifically cognitive learning theory and social learning theory. Also, Kirkpatrick's evaluation model is discussed as a framework for the evaluation of the new curriculum. The chapter concludes with a conceptual hypothetical model that was used to investigate the effectiveness of the compassionate care curriculum in reducing the stress levels of persons with AD in nursing facilities.

It should be noted that the theoretical framework explored does not reflect all the major paradigms that exist related to AD, the nature of the disease as a disability, learning about caregiving or the actual process of caregiving. However, the theories that were selected for inclusion provide a solid foundation for conceptualizing the complexities of providing compassionate care.

Theoretical Frameworks for Conceptualizing Alzheimer's disease

AD is both debilitating and disabling for the individual suffering from the disease. Understanding how persons with AD respond to physical and mental changes and their new identity becomes an important aspect of any AD-related social research. Hence,

understanding the perspective of persons with AD, provided the foundation for developing a compassionate care curriculum that could provide tools and skills to CNAs to care for persons with AD.

Theories examined included theories of disablement and symbolic interactionism. These theories were chosen because they conceptualize the complexities that contribute to the environment of the individual living with AD. Both theories conceptualize AD as a disability and a loss of the individual's personhood. Theories of disablement focus primarily on the process that the individual undergoes from being a functional, productive member of society to becoming a person with a disability (S. Nagi, 1964, 1991). Symbolic Interactionism (SI) provides a conceptualization of how persons with AD and those around them interact post-diagnosis of AD (Blumer, 1969; Stryker, 1980).

Theories of disablement

A progressive disease, Alzheimer's impacts the individual in a way that is particularly devastating. Persons with AD are not only confronted with the challenges of the disease but also with the feelings associated with loss of functions. Theories of disablement provide a framework within the field of disability research to give an understanding regarding the process of change that occurs as an individual is faced with their disability.

Saeed Nagi was the first to conceptualize disability as a process (S. Nagi, 1964). In Nagi's model, disablement is defined as any chronic or acute condition that has an impact on the individual's performance and functioning (S. Nagi, 1964, 1991; S. Z. Nagi, 1976). This framework is based on four interrelated concepts termed active pathology, impairment, functional impairment, and disability (S. Nagi, 1964, 1991). Active

pathology is the result of trauma, infection or illness, neurological diseases or any other etiology. In this case, active pathology includes AD. Impairment is the resulting loss or the abnormality of the anatomical, physiological, mental or emotional nature. For AD, this would include many of the symptoms of the disease such as memory loss, confusion, and disruption of sleep patterns due to the histological abnormalities of AD. Functional limitations refer to the restrictions in performing basic activities of daily living. This would include the limitations that are often faced by persons with AD as the disease progresses. It includes the loss of participating in personal care, shopping, and even eating. In Nagi's model, the culminating process of these factors leads to disability (S. Nagi, 1964, 1991; Saad & Judith, 1980).

Framing the development of AD as a process that leads to disability provides an understanding of how a person with AD might conceptualize the disease as it progresses. Faced with the prospect of disability due to AD, the individual processes the change in status within their world, from an able-bodied person to a person living with a disability. For the person with AD this can also contribute to a feeling of loss of self, particularly as the disease progresses (S. Nagi, 1964, 1991). For example, persons with AD may not have the capacity to complete the activities that once provided them with enjoyment. Additionally, persons may be viewed by their family as needing increased support and care. The increased loss of independence can be overwhelming to the person with AD. Overall, in the early stages of the disease, while the person is still very much aware of their situation, this can contribute to depression and behaviors associated with this loss of identity (Hausner, 2004).

Nagi's model is limited in several areas that need to be addressed. At the time of its development, the model did not account for external factors such as environment or the societal implications of disability. Initially, the model did not focus on the effects that disablement had on a persons' health (Jette, 1997). Furthermore, Nagi's model has not been specifically applied to AD research, only general forms of disability. The model also does not focus on any of the precipitating factors that lead to a person's disability. However, Nagi's model provides a foundation for understanding the internal process that the person with AD undergoes related to their disease. Since its original introduction to the scholarly work in the field of disability and disablement, it has been modified to address some of the limitations associated with the model.

One limitation of Nagi's model was addressed in the 1990's by scholars Verbrugge and Jette (Branch, 1996). While the original model provides a foundational understanding of the disablement process, Verbrugge and Jette expounded upon this by examining the precipitating factors that lead to a persons' disability (Verbrugge & Jette, 1994). Through this adaptation, disability or disabling conditions such as AD are classified as dysfunctions within the human body. However, externalities or internal crises could either speed up the decline in functioning or stabilize it depending on the nature of the situation (Verbrugge & Jette, 1994). This provides a foundation for understanding how persons faced with impending loss of function can manage given their environment in addition to the actual physical and biological concerns that are brought upon by the disease (Verbrugge & Jette, 1994).

As an individual with AD faces their eventual prognosis, understanding the transition to disability becomes important in providing care and support to not only the

individual but their family as well (Verbrugge & Jette, 1994). In order to understand this transitional process, theories of disablement provide a foundation for conceptualizing the imminent disability that one faces (Verbrugge & Jette, 1994). Furthermore, these frameworks also address the significant stigma that is often associated with cognitive decline and loss of function within society (Verbrugge & Jette, 1994).

Symbolic interactionism

Theories of disablement provide a foundation for understanding how an individual undergoes the journey from functioning to disability. However, how the individual interacts and responds to their situation is also an essential consideration that must be made when conceptualizing the impact of AD. Symbolic Interactionism (SI) focuses on how the individual interacts within their own unique system (Blumer, 1969; Stryker, 1980). AD affects the ability to perform activities of daily living and erases many memories, which, in turn, can also strip away the sense of identity. Take, for example, a 68-year old grandmother that has recently been diagnosed with AD. Although she may have cared for her grandchildren for a number of years, as the disease progresses she won't be able to continue in the same way she did in the past. The loss of memory and ability to function in activities of daily living creates a loss of a sense of self. Utilization of the theory of SI can provide an understanding of this individual's journey and how she attributes meaning to her life and interactions with her family given her diagnosis (Ariotti, 1999).

To understand the way in which a person interacts with their environment, SI provides both a foundation and an intricate understanding of the social interaction process

that humans engage in. SI also provides an understanding of how these interactions can change over time given the progression of the disease (Blumer, 1969).

First developed by George Herbert Meade and later articulated and expanded upon by his student, Herbert Blumer, SI was first introduced in the 1920's (Blumer, 1969). However, its origins reside in the work of renowned sociologist Max Weber (Segre, 2014). Given its origins in sociological theory, SI, at its core emphasizes the interactions and their subsequent meanings between individuals. SI has applicability for many populations and is not solely focused on persons with AD. However, it provides a deeper understanding of how the individual is involved in their environment. SI is predicated on the understanding that all persons engage in their environment in some way (Blumer, 1969; Stryker, 1980).

SI is the process in which persons make meaning of their circumstances through interactions with the systems that surround them. Underlying SI is the emphasis not simply on social behavior, but on a deeper level, how the behavior is constructed (Stryker, 1980). SI provides an in-depth understanding of social interaction (Blumer, 1969; Stryker, 1980). It is not viewed as a byproduct of an individual's need to attribute meaning to the world around them (Dennis, 2011). From engagement with others, the individual develops and attributes meaning to actions, items and even other humans in their environment (Blumer, 1969; Stryker, 1980).

It is important to consider that the foundations of SI are built upon three separate, yet interrelated concepts (Blumer, 1969; Stryker, 1980). The first concept is that human beings act towards items in their environment based on the meanings attributed to these items (Dennis, 2011). For example, all humans respond accordingly to their mothers or

fathers since there is meaning associated with these persons within society (Dennis, 2011). The second concept of SI posits that the meaning attributed to humans and objects is derived from social interaction (Blumer, 1969; Stryker, 1980). The meaning attributed to these figures (mother and father) arises from the social engagement process. Lastly, these meanings undergo a process of continuous revision as the individual continues to engage within their environment (Blumer, 1969; Stryker, 1980).

This brings us back to the example of the recently diagnosed 68-year old with AD. Through her interactions with her family, she had conceptualized her role as being that of a caregiver to both her adult children and her grandchildren. These social interactions gave her purpose and meaning in her life. Hence, when the disease renders her unable to do these activities any longer, she not only loses these interactions but loses her role within her family as well. The disease in effect informs the way she will define, interpret and react to the new situation and make meaning based on her perceptions. This is an example of how symbolic interactionism can help in understanding the roles or identity that persons attribute to themselves, and the loss that AD inflicts as it progresses (Waldrop, Clemency, Lindstrom, & Clemency, 2015).

From this perspective, persons are rational actors that continuously engage with each other. Given these circumstances, individual's behavior will be shaped by these interactions. Furthermore, given this emphasis on interaction, it is assumed that social actions are representations of the social structures that are prevalent within the societal system. Hence, these are hidden motivations that contribute to one's construction or meaning-making. The process of meaning-making is viewed on a continuous spectrum. Interactions change over time between actors within the system. Therefore, this alters the

meaning that the individual attributes to the circumstance. Meaning making is as much a contextual phenomenon as it is continuous (Blumer, 1969). Within different interactions with different actors, persons can take on new roles or gain new perceptions about oneself (Blumer, 1969).

From the lens of SI, social interaction is a cornerstone of the world in which we live (Dennis, 2011). Humans engage with each other through verbal and non-verbal contact. For an individual with AD, this process takes on new meaning. Communication and ways of self-expression increasingly deteriorate as the disease progresses. Thus, AD can have a powerful impact on the role of the individual within society as well as how persons with AD interact and engage with those around them.

Symbolic interactionism and stigma. The concept of stigma was first developed in depth by Goffman (Erving Goffman, 1986). His work has been applied to many different conditions including mental illness, AIDS and epilepsy. Goffman posits that stigma originates when an individual has an undesirable attribute that discredits them within society (Erving Goffman, 1986). For persons with AD, the disease becomes an attribute from which they cannot separate and contributes to them experiencing stigma within society. The stigmatization of persons with AD, as outlined in Chapter 1, is rooted in the historical conceptions of dementia and the way that person with AD are treated in society can be described in more depth using symbolic interactionism.

As previously stated, humans engage with each other in a constant loop of communication where interactions are being perceived in different ways by all parties that are engaged in the interaction (Blumer, 1969).As the disease progresses, persons living with AD do not meet the norms of society. They often behave in ways that are

challenging for others. This impacts the person's ability to interact with others. For example, an individual with AD may be unwilling to shower regularly. Norms of our culture dictate that this is an activity of daily living that is important and is valued. When others in society encounter the un-showered, perhaps disheveled individual, then they do not know how to respond. This challenges the way that they believe that person typically behave.

For caregivers, the stigma associated with the disease is often profound and results in what Goffman defines as affiliate stigma (Erving Goffman, 1986). Caregivers derive their role from essentially providing care to the person with Alzheimer's disease. This means that the individual, while not directly inflicted with the disease, feels the stigma associated with providing care to someone with the disease. This can be a contributing factor to the caregiver's burnout and their feelings of frustration as they too feel stigmatization. This, in turn, affects the quality of care that the individual with AD receives.

Theoretical Frameworks for Understanding Learning Processes

While the previous section explored two theories that provide a theoretical framework to understand persons living with AD, it is also important to consider how to implement curriculum and training for working with persons with the disease. CNAs are charged with providing direct care to persons with AD in nursing home settings. Understanding how these professionals develop skills disseminated through training is important. Theories of learning provide a framework for understanding how persons process information and provide a framework for best practices in disseminating information that can be retained and utilized (Spring, 2010).

Learning is a complex process that requires not only obtaining information but also the transference of the information into tangible, measurable behaviors (Hergenhahn, 1976). Hence, learning should not simply involve passive dissemination of information from instructor to the learner. Instead, learning is characterized primarily by changes in behavior (Spring, 2010). Hence, for learning to be successful, the learner must not only process the information provided but also translate it into observable behaviors. Learning theories are cogent frameworks consisting of established concepts and ideas that provide explanations of how people learn (Spring, 2010).

Within educational psychology, there exist several types of theories of learning that present different perspectives and highlight different components that are viewed as critical to the learning process. The utilization of contrasting learning theories is useful in the development of curriculum (Spring, 2010). The following section will highlight two theories of learning, cognitive and social, how the theory conceptualizes learning, and the processes involved in learning to be effective. Moreover, these particular theories were chosen due to their contributions to conceptualizing motivation and learning.

Cognitive Learning Theory

The cornerstone of cognitive-based learning theory rests on the notion that to change an individual's behavior; their cognition must first be changed (Bush, 2006). Therefore, foundations of cognitive learning theory focus primarily on the learner and their internal processes of learning (Braungart & Braungart, 2003). Since learning is viewed as an internal process, persons in the learning environment will process the information provided differently and in their own way due to their own, unique set of experiences (Bush, 2006). Under cognitive-based learning, transference of learning is

achieved through understanding, with an emphasis on the notion of learning to learn (Braungart & Braungart, 2003). Once this process is changed through a learning experience, it becomes an inherent process by which the learner begins to implement the tools or strategies that have previously been disseminated through education or training (Braungart & Braungart, 2003).

Given the emphasis on the internal processes of the learner, it might be assumed that individual reward is necessary to reinforce the transition from taking knowledge and implementing it into practice, however, this is not the case. Instead, it is more important to consider the learner's motivation for learning and furthermore, their overall goals as it relates to the material at hand (Braungart & Braungart, 2003; Bush, 2006). Understanding this information about the learner requires an understanding of the experiences and unique skill set that the individual brings to the learning process. Without these insights, the instructor will not be able to engage with the learner. This has obvious implications for the utilization of the material disseminated.

Within cognitive based theories, there exist different models to explain how information is retained and applied by the learner. One model, known as the information-processing model of memory functioning, offers a schema of memory organization that follows a path of linear stages (Leonard, 2002). The first stage, operationalized as attention, requires that the learner engages in the external stimuli provided in the educational opportunity. In this stage, the learner should be able to respond to the instructor with feedback, questions, and overall engage in behaviors that illustrate their attention to the material (Braungart & Braungart, 2003). If the learner is not engaged in the attention stage or seemingly receptive to the material, it is suggested that the

instructor try again later when the learner is more apt to be attentive to the material. The second stage of the model is characterized as processing (Braungart & Braungart, 2003). During this stage, the learner is processing the information using their preferred mode of learning. Hence, it becomes increasingly important to understand whether the learner aligns more with audio, visual, or application modes of learning. In the third stage, the learner moves from processing the information provided to storing information into their short-term memory, known as memory storage (Braungart & Braungart, 2003). At this stage, information is ascertained through learning and either disregarded or moved into long-term memory for utilization. The final stage within this model is the action phase. This stage is predicated on the previous stage in that learners will either eliminate the information learned or put it into action (Braungart & Braungart, 2003). However, the model does not end in the final stage. The learner may find that after some time they have issues with retrieving the learned material or that they have retrieved the information incorrectly (Leonard, 2002). This requires part of the process to start over, as the learner will need to modify the information if this happens and an instructor or another learner corrects them (Braungart & Braungart, 2003). Understanding this process is useful in the creation of curriculum since it provides a framework for how the learner processes and retrieves information and converts this into actions.

Under the cognitive learning framework, it should also be noted that persons are thought to understand and process the information provided through making meaning and relating the information to experiences or other portions of information that have already retained (Leonard, 2002). This becomes helpful in understanding how the individual retains the information that is provided.

Cognitive-based learning theories have relevance to this study in that it provides a framework for understanding the motivation for learning and how learned behaviors become a continuous, inherent mechanism. Through this framework, it is important to provide learners with a clear understanding of why the material is important. For CNAs working with persons with AD, this will be emphasized through the need to provide compassionate care to the individual. Furthermore, cognitive theories of learning reiterate the importance of understanding the learner's motivations, goals, and life experiences. These have an impact on the way in which the learner not only processes information but also how information is translated into actions.

Social Learning Theory

In contrast to the internal processes that are emphasized in cognitive-based learning, theories of social learning postulate that persons learn through their social environment. First developed by Albert Bandura, the foundations of social learning theory are built on the understanding that the learner's environment and interactions with other learners is most important in building a body of knowledge that can be transferred into behaviors (Bandura, 1977, 1986). With the emphasis on the learner's environment, social learning theory suggests that modeling from others is the most important impetus to changing behavior (Bandura, 1986). Furthermore, the individual learner does not have to be reinforced under this framework. Known as vicarious reinforcement, the theory posits that if a learner witnesses a role model or other learner in their environment receiving praise or positive attention, then this will reinforce the behavior. Reward, however, is not always necessary for the learner to adopt the behavior since viewing the

action will undoubtedly have an impact regardless of whether the role model receives praise or reinforcement (Bandura, 1977, 1986).

In his seminal work, Bandura outlined a four-step model that delineates the process of social learning (Bandura, 1977, 1986). Given that it focuses on the internal processes that an individual learner undergoes to participate in and benefit from social learning, it is aligned with models under cognitive forms of learning as previously elucidated. The first step in Bandura's model is the attentional phase (Bandura, 1977). This phase is necessary for learning to occur and is the point at which the individual learner observes a role model engaging in the behavior. The role model is an individual that the learner views as a competent and reliable leader in the environment (Bandura, 1986). The next step is the retention phase in which the learner observes the role model in action and then processes the behavior observed. The third step is the reproduction phase. The learner copies the behaviors that have been observed from the role model. Reproduction of the behaviors in this phase are strengthened if the learner goes through the process of mental rehearsal, an immediate reenactment of the behavior, and if the learner receives corrective feedback from the role model (Bandura, 1977). The final step is the motivation phase where the learner is motivated to complete the behavior. This model reflects Bandura's conception of the learner as being the primary agent in the social environment by which all the observations and subsequent behaviors are filtered given the learner's experiences and motivations (Bandura, 1977, 1986).

For developing a curriculum that CNAs can use effectively, social learning theory provides an understanding of how persons perceive their environment as a tool of learning. Persons observe behaviors of others within the environment and depending on

the feedback of the observable behavior, will implement it. Furthermore, social learning theory highlights the need for going further than simply disseminating information to learners. Instead, learners can actively observe behaviors in their environment and then, implement these behaviors if they seem appropriate.

Kirkpatrick Model of Evaluation

The purpose of this dissertation study is to introduce a CC curriculum that incorporates the theories of learning and therefore a model for evaluation is needed. The Kirkpatrick Model of Evaluation was first introduced in the late 1950's by David Kirkpatrick as a process of evaluation to determine whether newly adopted models of training or a new curriculum produces the intended results and objectives (D. L. Kirkpatrick, 1959a, 1960). The structure of the model allows for understanding how learners understand and adopt the curriculum to their practice. The model was later expanded on and refined through a number of scholarly literature by Kirkpatrick and his son (D. L. Kirkpatrick & Kirkpatrick, 2005; J. Kirkpatrick, 2005). The model is widely used in evaluation studies (Campbell & Mather, 2018; Farjad, 2012; C. Jones, Fraser, & Randall, 2018; Praslova, 2010; Simpson & Scheer, 2016). The Kirkpatrick model can be applied during any stage of evaluation, including before, during or after the implementation of training (C. Jones et al., 2018).

The Kirkpatrick model denotes 4 levels of evaluation that will be utilized in the study (D. L. Kirkpatrick, 1960; J. Kirkpatrick, 2005). They are as follows: Level 1- Reaction, explores to what degree participants react favorably to the learning event; Level 2- Learning, explores to what degree participants acquire the intended knowledge, skills, and attitudes based on their participation in the learning event; Level 3- Behavior,

explores to what degree participants apply what they learned during the training when they are back on the job; and, Level 4- Results, explores to what degree outcomes occur as a result of the learning event and subsequent reinforcement (D. L. Kirkpatrick, 1960; J. Kirkpatrick, 2005).

The first level, *reaction*, focuses on the reaction of the learners to the delivered content (D. L. Kirkpatrick, 1959b). Reaction to the training is important for two primary reasons. First, it enables the learners to become part of the process. Second, the feedback solicited from learners can be used in future iterations of the development of the content (D. L. Kirkpatrick, 1959b; J. Kirkpatrick, 2005). Given the research discussed in the aforementioned section, empowering CNAs to provide feedback to the content that is provided in the curriculum will become a valuable asset, particularly during the pilot-testing phase.

After determining the learners' reaction to the training, *learning* is the second level of evaluation (D. L. Kirkpatrick, 1959a). It is important to measure how learners understand the concepts and techniques that were provided in training. This can often be achieved through a skill-based knowledge test that is taken at the pre- and post-time intervals (Reio, Rocco, Smith, & Chang, 2017).

In level three of Kirkpatrick's model, there is a shift in focus from learning to *transfer* (J. Kirkpatrick, 2005). The focus of this level is on the job performance of the learner and how they were able to implement the material that was delivered through the training (Reio et al., 2017). This level is critical as results cannot be assessed (level 4) if the learners have not transferred their learning in behavior changes that are measured by the organization (Reio et al., 2017). This level is considered more time consuming than

the previous levels since it requires the organization to examine the behaviors of the learners and assess whether transference of learning has occurred (J. Kirkpatrick, 2005).

Finally, the model culminates with the fourth level- results. In this context, results mean the assessment of the desired outcomes of the curriculum. (C. Jones et al., 2018). This can be the most challenging level of the model to assess and measures the actual organizational change that occurred as a result of the training (Reio et al., 2017). Studies that utilize all four levels of the model provide comprehensive evaluations (C. Jones et al., 2018).

Conceptual Hypothetical Model

Utilizing the presented theories as a foundation, a conceptual hypothetical model was developed. The purpose of this proposed model is to provide an understanding of how the stress of persons with AD living in nursing facilities can be improved by the implementation of a compassionate care curriculum for CNAs. Figure 1 shows the proposed model along with an overview of the variables that are included in the model.

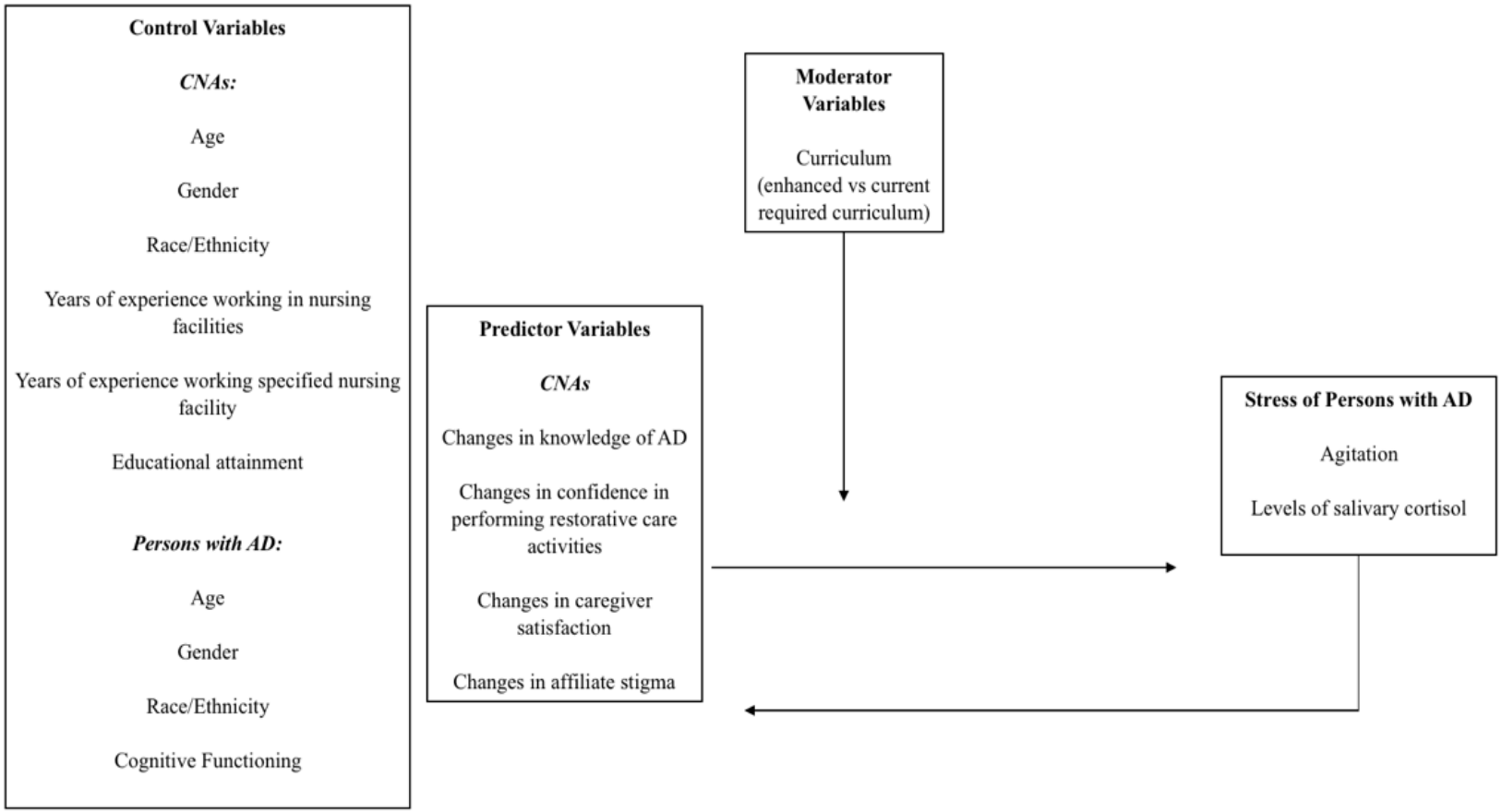


Figure 1. Conceptual Hypothetical Model

Operationalization of Conceptual Model Variables

The following provides an overview and justification for all variables that were included in the conceptual hypothetical model.

Control Variables. To focus on the impact of a CC curriculum in how to care for residents with AD living in nursing facilities, a variety of variables served as control variables for the study. These variables were divided into those that focused specifically on CNA characteristics and those that focused specifically on the characteristics of persons with AD.

CNA characteristics. The following CNA characteristics were controlled for:

Age of CNAs. It is important to control for age of the CNAs that are providing care to persons with AD. Age-related values exist within helping professions including CNAs. Persons from younger age cohorts tend to be more open to change, while older age cohorts report being more set in their current ways of providing care (Caplan & Bull, 1992). Age is also related to job and training experience (Onnismaa, 2008). CNAs that are older, by virtue, had more experience and therefore, are more likely to respond to difficult situations in a more positive way (Onnismaa, 2008).

CNA Gender. Gender could influence the way in which the CC curriculum is implemented, and persons with AD are cared for. The CNA workforce is predominately comprised of females (United States Department of Health and Human Services Centers for Disease Control, 2018). Females in helping professions, such as CNAs, tend to exhibit higher levels of empathy than their male colleagues (Williams, 1989). Furthermore, this level of empathy displayed can lead to higher rates of emotional fatigue and exhaustion (Williams, 1989). Females often choose to enter into helping professions,

such as the CNA profession, for different reasons than men (Byrne, 2008). This could potentially impact care because females and males could interact differently with the residents with AD.

CNA Race/Ethnicity. Reports have indicated that while persons of color make up roughly one-quarter of the total United States workforce across all fields and professions, within the CNA workforce, African Americans make up over one-third of the workforce (United States Department of Health and Human Services Centers for Disease Control, 2018). It has also been suggested that factors related to disparities between races can increase job strain (Chaudhuri, Yeatts, & Cready, 2013; Hurtado, Sabbath, Ertel, Buxton, & Berkman, 2012). In a study specifically looking at factors of jobs strain, it was found that there were differences in black CNAs and white CNAs. More specifically, black CNAs felt they had less control over their work (Hurtado et al., 2012). Furthermore, black CNAs in the study reported earning $2.58 less per hours than white CNAs (Hurtado et al., 2012). These factors contributed to higher feelings of job strain that could lead to differential interactions with residents with AD (Hurtado et al., 2012).

Years of experience working in nursing facilities. For nursing facility staff and administrators, experience in the field is often correlated to higher scores on the core quality measures as stipulated by CMS (Krause, 2012). In general, within the nursing profession, years of experience is correlated to higher feelings of competency in providing care (Takase, 2013). Hence, overall years of work experience can have an impact on the care that residents in the facility receive on a daily basis.

Years of experience in specified nursing facility. The number of years that the CNAs worked in the specified nursing facility was seen as important, particularly

considering the impact that staffing turnover has on the structure of the facility and the care received by residents (Castle, Engberg, R., & Men, 2007). This should be differentiated from the number of years that the individual has worked in the field in total since turnover and facility changes are common within the CNA profession. Furthermore, it is assumed that each facility has its own culture, work environment, and expectations. Becoming a part of this unique culture is important to both workers and the residents they serve. Studies have shown that the number of years working in a specific nursing home settings can have a positive impact on nursing facility workers perceived feelings of self-efficacy (Pfister et al., 2013).

Educational attainment. Education attainment included only formal education received by the CNAs (Griscti & Jacono, 2006). CNAs are required to have a high school diploma (Montgomery, Holley, Deichert, & Kosloski, 2005), with some being more qualified. Education attainment impacts the care they provide to persons with AD, with more education providing a positive effect on the quality of care (Coogle, Parham, & Rachel, 2011).

Characteristics of residents with Alzheimer's disease. As with the considerations to control for variables related to the CNAs, there are important control variables to consider in relation to the characteristics of residents with AD.

Age of persons with AD. As people age, they are more predisposed to having AD. Both gender and age are the most significant predictors of developing the disease (Vina & Lloret, 2010). Thus, the prevalence rate of the disease is much higher for those persons aged 85 and older than it is for persons 65 and older (Centers for Disease Control and Prevention, 2017). Furthermore, it has been shown that persons with AD who are 85

years and older are more prone to exhibit the various behavioral symptoms that are often associated with the disease (Furuta, Mimura, Isono, Sugai, & Kamijima, 2004). Hence, the older the residents with AD, the more complicated the care can be. Age is also connected to other chronic conditions that the individual may be predisposed to in addition to AD, including, cataracts, hearing loss, high blood pressure, or cardiovascular disease (Salive, 2013). If a person with AD has one or more other chronic conditions, this will require increased care.

Gender of persons with AD. From the onset of AD research, it was established that the disease disproportionately affects women (Farrer et al., 1997). This early research has been expounded upon in subsequent decades, making it clear that while there is a debate about why more women are diagnosed with AD, the fact remains that there is a difference between genders (Vina & Lloret, 2010).

Gender has an impact on the interactions between residents in a nursing home and staff. In a study of interactions between staff and residents, it was noted that female residents did not initiate interactions with male staff (Lindesay & Skea, 1997). Some critical feminist gerontological theories suppose that women spend most of their lives feeling disenfranchised and not valued within society (hooks, 2000). These feelings of inferiority might transfer into their lives within any long-term care facility (Lindesay & Skea, 1997).

Race/ethnicity of persons with AD. An individual's race/ethnicity may have an impact on their care. Minorities in society are often marginalized and these disparities extend to the care that they receive in the nursing facility. One study focused on social engagement showed that while a majority of nursing home residents showed low social

engagement, there was a difference for racial/ethnic minorities. When compared to white residents, minority residents were between 30% and 40% less likely to show overall high social engagement (Y. Li & Cai, 2014).

Cognitive Functioning. Identifying cognitive functioning assists in understanding where the person with AD is in the trajectory of the disease (Silverberg et al., 2011). More care is needed for those with higher levels of cognitive decline (Silverberg et al., 2011). The goal is to ensure that all residents receive the same quality of care, regardless of their mental acuity.

Predictor Variables. Predictor variables include changes in knowledge of Alzheimer's disease; changes in confidence in performing restorative care activities; changes in caregiver satisfaction; and, changes in affiliate stigma. They are explained in more detail below.

Changes in knowledge of Alzheimer's disease. According to the Kirkpatrick model after the reaction to the curriculum, learning is the second level of evaluation (J. Kirkpatrick, 2005). It is important to measure how learners understood the concepts and strategies for providing care that was included in the delivered curriculum. It was anticipated that an increase in knowledge would have an impact on care. From the literature, we know that education has a direct positive impact on the quality of care provided by CNAs (Trinkoff et al., 2017; Yeatts, Cready, Swan, & Shen, 2010).

Changes in confidence in performing restorative care activities. Following Kirkpatrick's model, there is a shift in focus from learning to the transference of skills through behavior (J. Kirkpatrick, 2005). The focus on this variable was to determine if

CNAs moved past the learning processes to utilize the information that they were provided via the curriculum.

From the literature, we know that an increase in education and experience correlated with higher performance in restorative care activities (Castle et al., 2007). Based on increased training and more experience with working with the needs of this population, it was anticipated that CNAs would have more confidence in their abilities to provide compassionate care.

Changes in confidence in performing restorative care activities are connected to Bandura's social cognitive theory (Bandura, 1986). It was posited that self-efficacy is an important factor for behavioral change to occur. Through the process of feeling more confident in their abilities, it was assumed that nurse aides would want to use the skills they developed during their exposure to the curriculum.

Changes in Caregiver Satisfaction. The relationship between the care receiver and the caregiver can be a special bond, one that the caregiver will cherish long after the care receiver has passed away. However, in those moments when caregiving is particularly difficult when the individual with AD is at their lowest moment, caregiving can be particularly challenging. All of this can have an impact on caregiver satisfaction. The conceptual model included the impact that caregiver satisfaction from the perspective of the CNAs would have on the care of residents in the nursing facilities.

Caregiver satisfaction is the alternative to caregiver fatigue (Figley, 1995). Figley states that caring comes with a cost that can manifest in a negative way that includes fatigue (Figley, 1995). Therefore, fatigue often is the direct result of trauma and stress-related exhaustion that occurs in helping professions such as that of CNAs (Sabo, 2006).

This is particularly true as the caregiver's life becomes more intertwined with the individual that they are providing care to and can intensify based on the circumstances. For example, caregivers can experience secondary trauma based on the individual's circumstances (Sabo, 2006). Fatigue can be related to many of the activities that nursing aides are faced with, including providing care to persons with AD when they are not adequately educated with tools and techniques to help in this care. This fatigue can contribute to negative care for persons with AD, particularly if the CNA does not have the adequate skills to cope with their feelings. Adequate skills, in this context, are those skills that are needed to provide a truly compassionate approach to caregiving. Thus, caregiver satisfaction is achieved when the CNA is equipped to deal with the exhaustion and stress that is accompanied by the process of providing care to persons with AD. Satisfaction is not limited to the opposite of compassion fatigue. Satisfaction also includes the feelings of reward that are often accompanied by caregiving. Thus, for caregivers, there is also this understanding that while caregiving can be burdensome and difficult, that it also provides a rewarding experience.

Changes in Affiliate Stigma. Stigma is defined as an "attribute, behavior, or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one" (Erving Goffman, 1986). Goffman described not only the stigmatization that persons with disabilities, such as AD suffer, but also the stigma that extends to persons that associated with stigmatized persons; this is known as affiliate stigma.

It has been shown that caregivers and family members experience stigma and both function and wellness are affected (Kahn, Wishart, Randolph, & Santulli, 2016).It has also been found that stigma by association related to AD is especially high in the delivery of services and in the lives of persons with AD (Werner & Heinik, 2008). The purpose of the compassionate care curriculum was to contribute to a decrease in the affiliate stigma of the CNAs.

Moderator Variable. The curriculum served as the moderator variable in this study. The control group continued with their traditional care and the experimental group engaged with the compassionate care curriculum.

Traditional Curriculum. The control group received no additional training and continued with care per norm. This included providing residents with AD basic nursing care. All CNAs went through the mandatory certification program which included 75 hours of basic nursing care and had participated in Hand in Hand training through CMS (Kentucky Adminstrative Regulations, 2006; Patient Protection and Affordable Care Act, 2010). As it is mandated that basic nursing care is supplemented with 12 hours of training each year, CNAs at the control facility participated in required training on topic areas such as lifting, toileting, administering medication, and other areas that would assist them in providing the task-specific areas of basic nursing care.

Compassionate Care Curriculum. The development of the curriculum followed a problem-based learning approach (Barrows & Tamblyn, 1980), presented in a format that allowed for collaborative adult learning to take place (Schapiro, 2003), within the context of on-the-job learning (Khan, Khan, & Khan, 2011). Problem-based learning has two fundamental assertions: 1) learning through problem-solving is more effective for

creating a body of knowledge usable in the future than traditional memory-based learning; and 2) health team skills most important for patients are problem-solving skills, not memory skills (Barrows & Tamblyn, 1980). Adult learning is guided by the assumptions that for learning to be meaningful and significant, it should be self-directing, draw on past and present experiences as a resource for learning, address problems, and situations learners are currently facing, be based in relationship and in community, and be both a cognitive and an affective experience (Schapiro, 2003). On-the-job learning is focused on supporting the organization to increase performance and develop workers that will be satisfied with their jobs and stay in the job for a longer period of time (Khan et al., 2011).

The content was presented in an online modular format, starting with didactic overviews, and then followed by case studies to highlight the content. Eight online modules were developed that focused on three primary areas: 1) the disease and its impact; 2) compassionate caregiving for persons with Alzheimer's disease; and 3) caring for the caregiver. For all CNAs that participated in the study, it took approximately 8 hours spread out across one week for the modules to be completed.

After the completion of the online modules, all CNAs participated in hands-on learning and support, by participating in compassionate care groups. These groups were held at the nursing facility where the CNAs were employed in order to receive additional on-the-job support. Each hour-long group session began with a brief didactic focused on a set of difficult behaviors the CNAs in the facility decided they needed the most help with. As part of the brief 15-minute didactic presentation, interventions were discussed that could be used to address these behaviors. The rest of the hour was used to discuss

specific residents who were demonstrating these behaviors. Strategies that could work for the specific residents were explored in the context of group learning where everyone contributed to the discussion and provided insight. A specific behavior management care plan for the residents discussed was then written up and shared with all CNAs. During the first month, these groups were held twice a week at different times to allow for as many CNAs to participate as possible. The next two months, these groups were held once a week on different days, again to allow for as many CNAs to participate as possible. These compassionate care groups allowed for the development of a strong care community within the nursing home and better collaboration between CNAs in the coordination of care for persons with AD at the facility.

Outcome Variables. The following are the two outcome variables in the conceptual model defining the stress of persons with AD.

Stress of Person with AD: Agitation. The model culminates in an examination of the stress of the person with AD living in the nursing facilities and receiving care from CNAs. Stress of the person with AD was measured by agitation and levels of salivary cortisol. When a person with AD is stressed, this can manifest as agitation (Hooker et al., 2002). Agitation is attributable to the stress a person feels as they begin to decline as a result of the disease. Personhood is the very embodiment of the individual's character, and often with AD, this is stripped away, making it particularly difficult for caregivers to deal with the AD patient. If a person with AD feels as though their needs are not being met or if they are challenged to do certain tasks that make them feel uncomfortable, this could result in anxiety. Take, for example, a resident that no longer prioritizes showering or bathing. When they were fully functioning, prior to the disease, this was more than

likely a priority and part of their activities of daily living. However, as the disease progresses, they might no longer value participation in this activity. Or the act of taking a shower or bath might be so physically difficult for them that they might fear participation in this activity. If the individual is pushed to engage in this activity, this could cause anxiety that results in negative behaviors. Thus, the purpose of the CC curriculum was to generate a decrease in stress for the resident by introducing a more compassionate approach rather than forcing the individual to engage in the activity because of technical and administrative procedural rules.

Stress of Person with AD: Salivary Cortisol. Lastly, levels of salivary cortisol were measured in the person of AD. Cortisol is an essential hormone in the regulation of the stress response along the hypothalamic-pituitary-AD renal (HPA) axis, and salivary cortisol has been used as a measure of free circulating cortisol levels (Maruyama et al., 2012; Smith & Vale, 2006). Measuring cortisol levels in persons with AD has been established as a way to better understand the stress that the person is undergoing on a biological level (Woods et al., 2008). As a biomarker, salivary cortisol is a simple and non-invasive way of measuring a persons' level of stress. Salivary cortisol testing has been a successful way to measure emotional variables in patients with AD (de la Rubia Orti et al., 2018).

Summary

This chapter provided an overview of the literature that was relevant to the primary components of this dissertation. Overviews of established theoretical perspectives were discussed as it pertains to persons with AD, CNAs that are providing care to persons with AD and theories of learning to assist in the development of the

project. Furthermore, a hypothetical, theoretical model was developed to conceptualize the theories and how they will impact stress for persons with AD living in nursing facilities.

CHAPTER III: METHODOLOGY

The aim of this study was the implementation and evaluation of a newly developed CC curriculum for CNAs. This chapter focuses on the methodology of the study. In order to evaluate the effectiveness of the compassionate care curriculum, the study was broken down into two parts. The first part of this study focused on the evaluation of CNA training in nursing facilities, specifically the first three levels of Kirkpatrick's model, namely Reaction, Learning, and Behavior. The second part of this study focused on level four of the Kirkpatrick model, which examined results in the form of the stress outcomes of residents with AD.

Study #1: Evaluation of the Compassionate Care Curriculum (Kirkpatrick Levels One, Two, and Three)

Research Design and Hypothesis

Study #1 utilized a quantitative pre-post control group design to examine changes in CNAs knowledge, self-efficacy, caregiver satisfaction and affiliate stigma over a 12-week period. The experimental group was exposed to the newly developed compassionate care curriculum, with the control group being exposed to the standard curriculum that is currently used in Kentucky. The following specific aim and research hypothesis guided study #1:

Aim 1: To determine if the CNA compassionate care curriculum for nursing home residents with AD is better than the current standard curriculum to increase the following

attributes of CNAs: knowledge of AD, caregiving self-efficacy, feelings of caregiving satisfaction, and feelings of affiliate stigma.

Hypothesis 1: *After completion of the CNA compassionate care curriculum by the experimental group, CNAs will show a significantly higher increase in knowledge, caregiving self-efficacy, caregiving satisfaction and a significantly higher reduction in feelings of affiliate stigma than the CNAs who completed the current standard curriculum.*

Sample

This study included an experimental facility and a control facility in Kentucky, both part of Signature HealthCARE which is a healthcare and rehabilitation company with 118 locations in 10 states and over 17,000 employees. Both facilities were urban, with the experimental facility located in Jefferson County, and the control facility in Fayette County. Both were small size nursing facilities. According to the CMS quality measures, both the experimental and control facility scored 4 out of 5 on staffing at baseline. For quality of resident care, both facilities scored 4 out of 5 at baseline. Neither facility had any penalties for the past 3 years. All CNAs at these two facilities who took care of the residents with AD that took part in the study were included in the sample for a total of 99 CNAs, 48 in the experimental group and 51 in the control group.

Measures

Demographics. The following demographics of CNAs were collected to ensure equivalency between the CNAs in the experimental and control groups:

Age. The age of the CNA.

Gender. The gender of the CNA.

Race/Ethnicity. The race/ethnicity of the CNA.

Years of experience working in nursing facilities. The number of years that the CNA has worked specifically in nursing facilities.

Number of years' experience in specified nursing facility. The number of years that the CNA has worked in the current facility that is a part of the study.

Educational attainment. The number in years that the CNAs received formal educational training.

Learner outcome measures. The following measures were used to examine CNA learner specific attributes and changes:

Learner Satisfaction. The learner satisfaction survey was administered after the completion of the curriculum program to determine CNAs satisfaction with the program. This was only administered to CNA learners that were part of the experimental group. The learning satisfaction survey consisted of 3 items, rated on a scale ranging from 1 (not satisfied at all) to 5 (very satisfied).

AD knowledge. AD knowledge was measured using the AD Knowledge Scale (ADKS). The ADKS is a 30-item, true/false scale and covers the following topic areas: risk factors, assessments, and diagnosis, symptoms, course, life impact, caregiving, treatment and management. Reliability for the ADKS has shown that reliability is acceptable (test-retest correlation = .81; internal consistency reliability = .71) and has been validated as a tool for assessing knowledge of all types of caregivers and in different settings (Carpenter, Balsis, Otilingam, Hanson, & Gatz, 2009).

CNA Self-Efficacy. Self-efficacy was measured using the Nursing Assistants' Self-Efficacy for Restorative Care Activities (NASERC). The NASERC is a measure that determines nursing assistants' confidence in performing restorative care activities in

nursing home settings. This is a 10-item measure that was administered to CNAs after they have completed the curriculum to determine their confidence in performing tasks in working with residents with AD. Alpha coefficients for the NASERC ranged from .80 to .91 (Resnick & Simpson, 2003).

Caregiving Satisfaction. Caregiving satisfaction was measured by the Revised Caregiving Appraisal scale also known as the RCAS (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989). It measures the extent to which caregiving is a source of fulfillment and self-esteem by examining the acceptance of subjective burden, caregiver satisfaction, and caregiving impact. The reliability of the RCAS is high for the general population (Cronbach alpha=.90).

Affiliate Stigma. Affiliate stigma was measured using the Affiliate Stigma Scale. The Affiliate Stigma Scale emanates from Goffman's understanding of stigma (Erving Goffman, 1986). Affiliate stigma is defined as self-stigmatization that an individual faces when they associate or affiliate with a stigmatized population (Mak & Cheung, 2008). For CNAs, this is the feeling of the stigma that they feel by working with a marginalized population. The Affiliate Stigma Scale contains three unidimensional domains: cognition (7 items), affect (7 items) and behavior (8 items), rated on a 4-point Likert scale. A higher score on the scale indicates a higher level of affiliated stigma. The use of this scale to determine self-stigma with caregivers has been supported with a Cronbach alpha for this population ranging between .85 and .94. (Chang, Su, & Lin, 2016).

Data Collection

At baseline, prior to the implementation of the curriculum, and after 12-weeks, data were collected on the demographics of the CNAs along with their pre-test on AD

knowledge, self-efficacy, caregiving satisfaction, and affiliate stigma for both the experimental and control groups. At the 12-week period, after the curriculum and care community meetings were implemented, data on AD knowledge, self-efficacy, caregiving satisfaction, and affiliate stigma were collected again for both groups. During this time, data were also collected on learning satisfaction, only for the CNAs in the experimental group.

Power Analysis

An a priori power analysis was performed with G*Power (Faul, Erdfelder, Buchner, & Lang, 2009) with the alpha level for the MANOVA analysis set to .05 and a correlation of .50 to achieve power of .80 and a medium effect size, which suggested a total sample size of 76 (38 in the experimental group and 38 in the control group) to detect a significant model. For this study, we had 48 CNAs that were part of the experimental group and 51 CNAs that were part of the control group for a total of 99 CNAs in the study. Therefore, we met the power requirement for the study.

Analysis

Analysis of this study used a repeated measures approach. This type of analysis is appropriate when the same group of people are pre-tested and post-tested on a dependent variable.

All data collected was examined for missing values, outliers and distribution form, to determine if it would meet the assumptions of the appropriate tests for the planned analysis. As this is a study utilizing a control group, it was first important to test for equivalence between the two groups at baseline. Where appropriate, either Chi-square

tests or independent samples t-tests were completed on all the demographic and dependent variables at baseline.

After equivalency was tested, a two-way mixed design MANOVA was utilized to examine how scores changed for all of the dependent variables after implementation of the CC curriculum. A two-way mixed design MANOVA is appropriate when there is both within-subjects and between-subject's factors. For this study, the focus of the analysis was to examine whether there was a significant difference over time (within-subjects), whether there were differences between the control and experimental groups (between-subjects), and whether there was an interaction effect between time and group, indicating if the groups change differently over time.

For this study, there were two points of data collection: at baseline and 12 weeks after the beginning of the curriculum and compassionate care group. There were four dependent variables: knowledge of AD, self-efficacy of restorative care activities, caregiving satisfaction, and affiliate stigma.

Study #2: Evaluation of the Compassionate Care Curriculum (Kirkpatrick Level Four)

Research Design and Hypothesis

The second study examined the final element of the Kirkpatrick model, namely stress levels of residents with AD. This study was conducted by testing a hybrid multilevel growth model, as detailed in Chapter 2 Figure 10, with a three-nested level structure. According to Singer and Willet (2003), a study examining growth over time must include at least 3 waves of data collection. This study fulfills this requirement as it

utilized data collected from residents with AD that looked at changes between baseline, 6 weeks and 12 weeks.

The outcome variable used in this model was operationalized as stress experienced by residents with AD over a 12-week period. Stress was operationalized as agitation and salivary cortisol levels. Therefore, the model was treated as a hybrid model where the model was first built with agitation as the outcome variable of interest. After this model was built, agitation was moved to a predictor and tested in the second model where salivary cortisol levels became the outcome variable.

Multilevel modeling, many times referred to as hierarchical linear modeling, is an appropriate statistical technique to analyze data that is clustered. Multilevel modeling assumes that there is a hierarchical structure in the data set and that units of observation fall into groups or clusters. For this study, the three clusters or levels were as follows: level 1 referred to the three measurement occasions for each resident with AD, level 2 referred to the residents with AD, and level 3 referred to the CNAs providing care to the residents with AD. Figure 13 illustrates the levels of the model. The advantage for using multilevel modeling in data that is clustered like this is the ability to examine the distinct effect of the predictors at each level, by allowing for the separation of the variance that is occurring at each level.

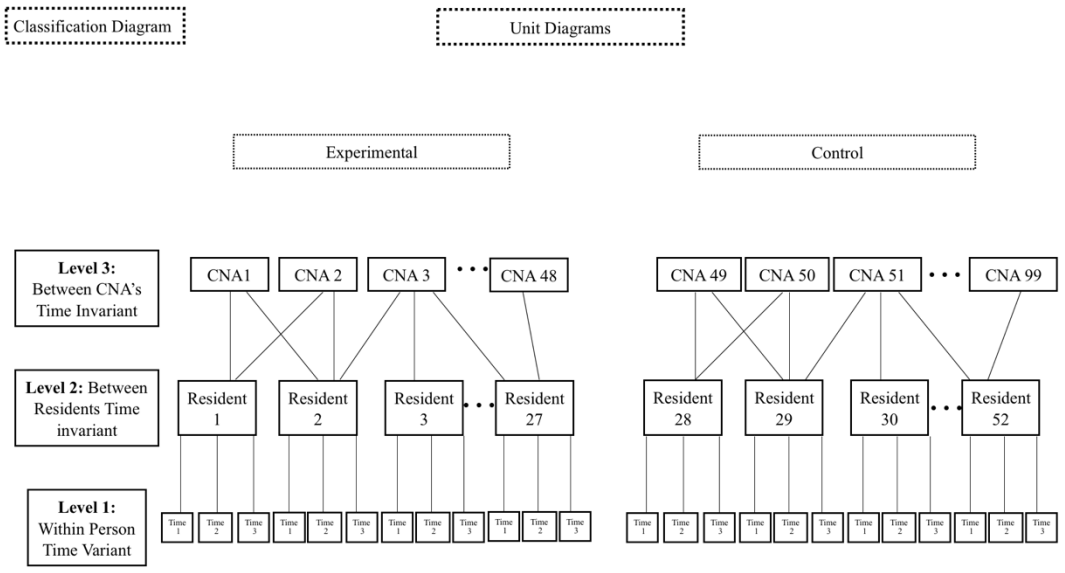


Figure 2. Data Structure

Traditional multilevel modeling is used to analyze data that is purely hierarchical in nature meaning that each lower-level unit belongs to a single higher-level unit (Chung & Beretvas, 2012). However, this approach ignores the fact that often, longitudinal data is not structured in a pure hierarchical way. Given that within each nursing facility, residents with AD are cared for by many different CNAs, this is a multiple membership model (Chung & Beretvas, 2012). In multiple membership models, the lower level units do not belong to only one higher level unit. Instead, the lower level units are nested within multiple higher-level units. Thus, the residents with AD were nested within the CNAs. This specific type of multiple membership model is also referred to as a two-way cross-classified data structure. It is important to note that in multiple membership models, data will vary dependent on the degree to which the lower level units belong to the higher-level units.

In clustered data, it is important to account for dependence or correlation among responses in the same unit or cluster. Utilizing multilevel modeling allows this

dependence or correlation to be explicitly modeled. One primary difference between multilevel modeling and traditional regression analysis is that multilevel modeling allows random effects such as random intercept and slopes or random coefficient for each unit. Multilevel modeling can also make use of all available outcomes data in the estimation of the model parameters because it treats time in a flexible manner (J. D. Singer & Willett, 2003). This is particularly important given the type of study subject, namely persons with AD at the end of life. It was, therefore, possible to keep data from study participants, even if circumstances might change and they had to end their participation within the 12-week period of the study. However, all study participants were able to remain in the study.

The study analysis followed a two-step approach. As part of step 1, we identified an aim 1 that focused only on a two-level multilevel structure where measurement points over time were identified as level 1 and persons with AD identified as level 2. The only level 2 predictor that was added in the model was group status. This same analysis could have been completed as part of a time series mixed ANOVA analysis where time is treated as the within effect, and the group status is treated as the between effect.

As part of step 2, the researcher identified an aim 2 that focused on a three-level cross-classified structure where level 1 and level 2 stayed the same as in step 1. However, in this step, level 3 was added and included the impact of the CNAs on the outcome variables connected to the residents. This type of analysis can only be completed in a multilevel model environment. The reason for this two-step approach was to illustrate the power of multilevel modeling in this type of dataset where data from both residents and CNAs need to be considered for a complete understanding of change in the outcome

variable. Not only can the effect of changes in CNA knowledge, self-efficacy, caregiver satisfaction, and affiliate stigma be evaluated without any variance constraints but also CNA impact on each individual resident can be weighted according to the time spent with each resident over the 12-week period.

The following research hypotheses were tested, which captured the multilevel growth aspects of the CNAs and persons with AD. Aim 1 focused on the two-level multilevel structure while aim 2 focused on the three-level cross-classified model.

Aim 1: To determine if residents with AD from an experimental nursing facility differ in their stress levels from residents with AD from a control nursing facility, after the implementation of a compassionate care curriculum in the experimental nursing facility.

Hypothesis 1a: *Residents with AD from the experimental nursing facility will have a different 12-week agitation change trajectory than the residents with AD from the control nursing facility.*

Hypothesis 1b: *Residents with AD from the experimental nursing facility will have a different 12-week salivary cortisol change trajectory than the residents with AD from the control nursing facility.*

Aim 2: To determine if differences in change in CNAs knowledge of Alzheimer's disease, caregiver confidence, caregiver satisfaction, and stigma will have a differential effect on the 12-week stress trajectories of residents with AD in the experimental and control nursing facilities. For the hypotheses related to aim 2, the background characteristics for CNAs and residents with AD were controlled for, when the model required it.

Hypothesis 2a: *Differences in change in CNAs knowledge, confidence, satisfaction and affiliate stigma will have a differential effect on the 12-week agitation trajectories of residents with AD in experimental and control nursing facilities.*

Hypothesis 2b: *Differences in change in CNAs knowledge, confidence, satisfaction and stigma and differences in residents with AD agitation will have a differential effect on the 12-week salivary cortisol trajectories of residents with AD in experimental and control nursing facilities.*

Sampling

The CNA sample for study #2 included all the CNAs that took part in study #1. The resident sample for study #2 was drawn from residents with AD in the two nursing homes where the CNAs worked. In the experimental facility there was a total of 50 residents with AD, and in the control facility, there was a total of 45 residents with AD. The sample from each nursing home included a convenience sample of 25 residents from the experimental group and 27 residents from the control group, for a total of 52 residents from both nursing homes. The selection of participants was based on their availability and the willingness of their caregiver or legal authorized representative to consent to their participation. For the purposes of selecting the sample, Rapid Cognitive Screening (RCS) was used. As described in the measures section, this screening tool score is between 0 and 10, with 0 indicating severe dementia and 10 indicating normal cognitive functioning. The original intention of using the RCS was only to include residents that scored 0-5 (indicating dementia) on the RCS. However, in our control group, there was one individual that scored a 6. After further discussion with the facility, it was determined

that this individual would remain a part of the study sample, due to concerning behavior manifestations.

Power Analysis

In multilevel modeling, there exist sample size requirements for each level of the model (Snijders, 2005). In terms of power, while higher samples sizes at all levels are important, the primary concern is the sample size at the highest level. Power for level 1 depends on the number of measurement occasions, while power for level 2 depends on the number of residents with AD, and power for level 3 depends on the amount of CNAs that participate (Snijders, 2005).

Statistical power concerns in multilevel modeling are complicated as the power differs for fixed effects vs. random effects as a function of effect size, intraclass correlation, and the number of groups and cases per group (J. Cohen, Cohen, West, & Aiken, 2003). With the significance level set at 0.05, the intra-class correlation at a small size of 0.05, which is recommended for health and mental health research (Spybrook, Raudenbush, Liu, Congdon, & Martinez, 2008), the model wanted to detect at least a medium effect size (0.04) and achieve at least 80% power. At the highest level of the model, at least 20 units were needed for adequate power (Kreft & De Leeuw, 1998). For this study, level 3 (CNAs) included 99 CNAs, meeting the main requirement for power. Level 2 (residents) included 52 residents and level 1 (time) had 156 measurement occasions.

Operationalization of variables

The variables included in this study were provided a priori as part of the development of a conceptual framework that was delineated in Chapter 2. In this chapter, the variables are operationalized.

Control variables. To focus solely on the impact of enhanced training on the care of residents with AD living in nursing facilities, a variety of control variables formed part of the study. These variables were divided into segments that focus specifically on CNA characteristics and the characteristics of the persons with AD.

Nursing Aide Characteristics. The same CNA demographics that were described in Study #1 were used as control variables in this study, namely: age, gender, race/ethnicity, years of experience as a CNA, number of years' experience in specified nursing facility and number of years of formal education.

Residents with AD Characteristics. The following characteristics of the residents with AD were controlled for:

Age. The age of the residents with AD.

Gender. The gender of the residents with AD.

Race/ethnicity. The race/ethnicity of the residents with AD.

Cognitive Functioning. Cognitive functioning was measured by the Rapid Cognitive Screen (RCS), a brief screening tool consisting of 5 questions that is used in a variety of settings for the detection of cognitive impairment (Malmstrom et al., 2015). Scores on the RCS range from 0 -10, with 0 indicating severe dementia and 10 indicating normal cognitive functioning. A score between 0-5 indicates dementia, a score between 6-7 indicates mild cognitive impairment, and a score between 8-10 indicates normal

cognitive functioning. The RCS includes 3-items from the St. Louis University Mental Status (SLUMS) exam, which is a commonly used assessment tool for determining cognitive decline. Validation studies show that the RCS predicts dementia with a sensitivity of 0.89 and a specificity of 0.94 (Malmstrom et al., 2015).

Predictor Variables. The following training related CNA variables have been noted to impact the stress of residents with AD. The CNA predictor variables included changes in AD knowledge, self-efficacy, caregiving satisfaction, and affiliate stigma. All these variables were operationalized as part of Study #1.

Moderator Variable. The moderator variable was defined as the following between the experimental and control groups.

Traditional Curriculum. This included all of the basic nursing care curriculum and training that CNAs received in the control group.

Compassionate Care (CC) Curriculum. In addition to the basic nursing care training that all CNAs receive, the CC curriculum focused specifically on AD and consisted of 8 online modules and participate in the care groups. All the CNAs in the experimental group participated in the CC curriculum.

Outcome Variables. The following measures were utilized to determine if there was a reduction of stress for residents with AD.

Agitation. The Cohen-Mansfield Agitation Inventory (CMAI) was used to measure agitation. This rating inventory was developed in 1986, consisting of 29 agitated behaviors each on a 7-point scale. The CMAI has been used in nursing home settings (Cohen- Mansfield, Marx, & Rosenthal, 1989).The CMAI is considered a reliable scale with a Cronbach's alpha score of .92 (Zare, Shayeghian, Birashk, & Afkham, 2012).

Subscales include disruptiveness, aggressive behavior, physically non-aggressive behavior and verbally non-aggressive behavior (Whall et al., 1999). Each person's subscale scores can be combined into a total score (Whall et al., 1999). For the purposes of this study, a total score was used. On the CMAI, scoring ranges from a 1 indicating that the behavior has never occurred to a 7 indicating that the behavior occurs several times an hour.

Salivary cortisol levels. Salivary cortisol has recently emerged as a novel biomarker for psychosocial stress responsiveness within the sympathetic adrenomedullary (SAM) system (Maruyama et al., 2012; Smith & Vale, 2006). The literature supports the use of these tests in that it is relatively inexpensive and non-invasive when compared to other biomarker testing. Salivary cortisol levels were collected using a testing kit from Peak Biometrics (PeakBiometrics, 2018). The kit utilized a smartphone and adaptive equipment that quickly analyzed each sample on site.

Data Collection

The same data that were collected from CNAs during study #1 was used for study #2. For the residents with AD, data were collected at baseline that included the resident demographics, CMAI scores, and cortisol levels. The demographics of the residents were collected from the nursing facility administration. As the CMAI is an inventory that uses a rating scale, CNAs that worked with the residents that were part of the study were asked to complete the measure based on the resident's behaviors. The facility administrator determined which CNA would be the most appropriate person to complete the inventory. The same CNA was used to complete the CMAI at baseline, six weeks and 12 weeks after the implementation of the curriculum. For the cortisol testing, each

resident's saliva was collected using a salivette that the resident was able to bite onto and produce a small amount of saliva. The salivette was then placed in a secured Ziplock bag labeled with the resident's confidential ID and no other identifying information. After samples were collected from each resident participating in the study, the samples were analyzed at the facility. The analysis involved taking the saliva sample and piping it on to a test strip. The test strip was then placed in a smartphone reader that was connected to an iPhone with an app designed by Peak Biometrics to read the cortisol levels from the test strip. After the read-out was produced from the app, the sample was discarded onsite in one of the facility's biohazard containers.

Analysis

Initial descriptive analysis of the data was conducted using IBM SPSS Statistics 25. To prepare the data for analysis, the data were organized into three files that included the following: the CNA data, the resident data and another file that included the weights for the amount of time each CNA worked with each resident. To correctly fit the CNA data to the resident data, it was important to track the proportion of time each CNA worked with each resident. Therefore, each resident with AD had 5 columns (the maximum number of CNAs working with one resident) reserved containing the identification codes for each CNA that provided care along with a proportion of time spent with the resident. These proportions were referred to as weights. The data were collected from the facility administrators.

The three files were merged into one file and then restructured to a vertical file, where each resident in the study had multiple cases in the file that represented each measurement occasion where data were collected. Final model variables in the vertical

file were inspected for the form by inspecting the distribution of CNA-level and resident-level variables. The data were then analyzed with MLwiN 3.2, a program designed specifically for this type of analysis (Rabash, Steele, Browne, & Goldstein, 2009).

Model fit was accomplished with Bayesian modeling. First, Iterative Generalized Least Squares (IGLS) was used, followed by Markov Chain Monte Carlo (MCMC) estimation to estimate a baseline (Kreft & De Leeuw, 1998). MLwiN utilizes a Metropolis Hastings sampling method to sample diffuse preceding distributions. For the chains to converge to the distribution of interest, a burning period was used. The chains were then a dependent sample of values from the distribution of interest. In accordance with using Markov chain Monte Carlo (MCMC) estimation, a burn-in of 500 and a chain of 20,000 (Chung & Beretvas, 2012) were used. As a result of dependence, a suggested effective sample size (ESS) of 250 is a statistical convention for model convergence (Steele, 2008). With the 20,000 chain, the ESS of 250 was met.

After the data was restructured, aim 1 and aim 2 were met by first building a two-level model (Model 1a and 1b) and then building a three-level model (Model 2a and 2b). Both these models were developed using a random intercept model. The following steps were used: a) Fitting the unconditional model which described the level of agitation/saliva cortisol across all residents (Model 2Aa and 2Ab); b) fitting the unconditional growth model depicting the extent of agitation/cortisol across all residents across time (Model 2Ba and Model 2Bb); c) fitting the main effects to explain the changes in the dependent variables (Model 2Ca and Model 2Cb); and d) fitting the interaction effects of time with the main effects to explain the change over time (Model

2Da and Model 2Db); To create a parsimonious model, control variables and predictor variables that did not contribute to the model were removed.

Human Subjects Protection

The study was approved by the Institutional Review Board at the University of Louisville, as well as the Signature Healthcare research committee. The approved informed consent and assents contained detailed information about the study, the possible risks and benefits and the amount of time it would take to complete the survey. The study did not involve the use of deception, drugs or devices, covert observation, special participant populations, induction of mental and/or physical stress, procedures that may cause physical harm to the participant, issues commonly regarded as socially unacceptable, or procedures that might be regarded as an invasion of privacy.

At the beginning of the program, at the experimental nursing facility, prior to starting the implementation of the curriculum, a member of the research team took as much time as needed to explain the informed consent to the CNAs and then had them sign the document. A copy of the informed consent was provided to each CNA. The process was the same for CNAs at the control nursing facility. The exception was that they did not receive the curriculum and they were only asked to participate in the surveys.

For the residents with AD, an assent was used. The study was explained to the resident prior to the beginning of the study. Due to the nature of the residents participating in this study, the study was explained again at the beginning of each session. When a resident with AD could not verbalize their consent, a member of the research team contacted the legally authorized representative (LAR). The LAR was a member of the resident's family. The LAR was asked to participate in the informed consent

procedures. The same procedure was used to explain the study to the LAR that was used to explain the study to the participants. It was explained to all participants that they were not going to be compensated for their participation. They were also told that they might withdraw from the study at any time without penalty.

Once data were collected from a participant, a unique identifying number was assigned to the participant at the time of enrollment in the study, to ensure confidentiality. Data from this study were not shared outside of the research team.

All methods of data collection were done at the convenience of the participants in the project. The risks involved in this study were minimal. However, they were addressed. The term "risk" refers to psychological or physical injury, social, legal, and financial harm (Dunn & Chadwick, 1999). For the CNA, participation in the curriculum and care groups could have contributed to emotional discomfort. The expectation was that the curriculum and participation in care groups would contribute to more quality care, however, it could have the unintended consequence of making the CNAs more aware of limitations in their skill set. Furthermore, there was a risk that someone might have felt uncomfortable answering one or more questions on the surveys that were part of the study. For the residents with AD, obtaining their saliva for cortisol testing could have caused discomfort and additional stress, depending on where they were at in the trajectory of the disease and their behaviors.

Summary

This chapter delineated the methodological approach and analysis plan for the two studies through a discussion of the research questions, the research design, sampling,

operationalization of measures, and the methods of analysis. The following chapter will detail the results of the two separate studies delineated in this chapter.

CHAPTER IV: RESULTS

The aim of this dissertation study was to examine the impact of the implementation of a new CC curriculum on the quality of care provided by CNAs to residents with AD. More specifically, the study used Kirkpatrick's model of evaluation to assess the reactions, learning, and behavior change of the CHNs exposed to the curriculum, and ultimately the impact of the curriculum on the stress levels of residents with AD.

Findings related to the following research aims are described in this chapter: ***Study #1, Aim 1:*** *To determine if the CNA compassionate care curriculum for nursing home residents with AD is better than the current standard curriculum to increase the following attributes of CNAs: knowledge of AD, caregiving self-efficacy, feelings of caregiving satisfaction, and feelings of affiliate stigma;* ***Study #2, Aim 1:*** *To determine if residents with AD from an experimental nursing facility differ in their stress levels from residents with AD from a control nursing facility, after the implementation of a compassionate care curriculum in the experimental nursing facility;* ***Study #2, Aim 2:*** *To determine if differences in change in CNAs knowledge of Alzheimer's disease, caregiver confidence, caregiver satisfaction, and stigma will have a differential effect on the 12-week stress trajectories of residents with AD in the experimental and control nursing facilities.* This chapter describes data preparation activities and preliminary analysis, describes the study sample, details the model building process and presents the results.

Data Preparation and Preliminary Analyses

Data Screening

Data was screened for missing values and outliers. As MLwin cannot handle missing data, all data was checked to ensure that there was no missing data from each file. All data necessary from each research participant (both CNAs and residents) were collected. Therefore there was no need to take any further actions related to missingness. No outliers were detected.

Creating one horizontal data file

All data from the study were entered into three separate SPSS files. The first SPSS horizontal file contained the data from the residents with AD. A horizontal file is structured in a way where one participant has one row in the file with all the data over time presented on the one row with different labels indicating the different time periods. The resident file included the control variables (age, gender, ethnicity, and rapid cognitive screening scores) along with the outcome variables (agitation and cortisol levels). The residents with AD data file was used to describe the resident sample.

The second horizontal file contained the CNA specific data and included the control variables (number of years working in nursing facilities, number of years working in the specific nursing facility, gender, age, and ethnicity) and the predictor variables (knowledge, self-efficacy, stigma, and caregiving satisfaction). The CNA file was used to answer the questions related to Study #1, and also to describe the CNA sample.

The third horizontal file contained the CNA weights. The most CNAs one resident with AD were exposed to, were five. Therefore, in the CNA file, five variables

were created, namely, CNA1, CNA2, CNA3, CNA4, and CNA5. The weights represented the proportion of exposure time each CNA had with each resident.

For the purpose of matching the data, the resident participant ID was used as the common identifier in all of these horizontal files. Then, the separate data files were merged through an iterative merging process. First, the resident file was merged with CNA weights. Then the CNA file was merged with the combined resident CNA weight file. This last process was a complicated procedure due to the fact that for each resident, data on the CNA predictor and controls had to be calculated as proportional data based on the CNA weights.

Creating the vertical data file

After the horizontal file was merged, it was necessary to develop a vertical file because multilevel modeling requires that data be arranged in a vertical format. Therefore, the horizontal data file was restructured to a vertical data file with multiple rows for each measurement occasion. Essentially, this means that the vertical file was comprised of fewer columns but had more rows than the previous horizontal file.

The vertical data file had five types of variables: 1) level identifiers for measurement occasion (level 1), residents with AD (level 2), and CNAs (level 3); 2) time indicator with values from zero to two denoting baseline, 6-week and 12-week data; 3) control variables for both the residents with AD and the CNAs; 4) CNA predictor variables that included group status, change scores in knowledge, self-efficacy, stigma and caregiving satisfaction; and 5) resident outcome variables that included agitation and salivary cortisol levels. The final file included 156 Level 1 units (measurement occasions) for 52 Level 2 units (residents) being care for by 99 Level 3 units (CNAs).

Description of Sample

The following is an overview of the sample that was part of the study. First, the sample of the CNAs is described after which the sample of residents with AD is described.

Certified Nursing Assistants

Demographics. In order to test the assumption of equivalency between the experimental and control groups, the demographic variables were compared to each other with either an independent sample T-test or a Chi-square test. Table 2 provides an overview of the two groups in terms of age, race/ethnicity, gender, number of years working in nursing facilities, number of years working in the current facility, and number of years of formal education.

Table 2

Comparison of demographic variables (CNAs)

	Experimental Mean (SD)/f	Control Mean (SD)/f	t/ $\chi 2$	P value
Age	34.66 (7.24)	31.93 (6.02)	2.25	0.01
Gender				
Female	45	51	3.28	0.11
Male	3	0		
Race/Ethnicity				
Black	8	9		
White	37	41	1.17	0.55
Hispanic	3	1		
# of years working in nursing facilities	6.29 (4.56)	4.55 (3.24)	2.20	0.03
# of years working in current facility	1.97 (1.29)	1.86 (1.46)	0.38	0.70
# of years of formal education	12.27 (0.67)	12.21 (0.57)	0.44	0.66

From Table 2 it is clear that the control and experimental groups were similar on most demographic variables except for age and the number of years working in a nursing facility. The experimental group was older and worked longer in nursing facilities than the control group. During model testing, specific attention was given to these two variables to investigate if they significantly contributed to the variability in the outcome variables.

Outcome Variables (Study #1). Table 3 shows the comparison of the outcome variables in Study #1 between the two groups at baseline, using independent sample t-tests. As previously denoted, these scores were standardized using a z-score to make for more efficient comparison.

Table 3

Comparison of outcome variables at baseline (CNAs)

	Experimental Mean (SD)/f	Control Mean (SD)/f	t/ $\chi 2$	P value
AD Knowledge	19.58 (3.89)	20.58 (4.08)	-1.25	2.14
Self-efficacy	5.71 (1.19)	5.72 (1.20)	-0.36	0.97
Caregiving Satisfaction	3.02 (0.68)	2.71 (0.62)	2.35	0.21
Affiliate Stigma	2.89 (0.29)	2.93 (0.25)	-0.63	0.52

There were no significant differences between the control and experimental group on their AD knowledge, self-efficacy, caregiving satisfaction or affiliate stigma at baseline.

Residents with AD

Demographic variables. The same equivalency tests were needed to compare the demographic variables residents with AD in the experimental and control groups, using

independent samples T-tests and Chi-Square tests. Table 4 provides an overview of the two groups in terms of age, race/ethnicity, gender, and their rapid cognitive scores.

Table 4

Comparison of demographic variables (Residents with AD)

	Experimental Mean (SD)/f	Control Mean (SD)/f	t/ $\chi 2$	P value
Age	78.47 (7.26)	77.09 (6.01)	0.74	0.46
Gender				
Female	19	18	0.17	1.00
Male	8	7		
Race/Ethnicity				
Black	6	3	0.95	0.69
White	21	22		
Rapid Cognition	2.26 (1.60)	2.76 (1.30)	-1.22	0.22

There were no statistically significant differences between the two groups on any of the demographic variables.

Outcome Variables (Study #2). Table 5 shows the comparison of the outcome variables from Study #2 for the residents with AD at baseline, using independent samples T-tests.

Table 5

Comparison of outcome variables at baseline (Residents with AD)

	Experimental Mean (SD)/f	Control Mean (SD)/f	t/ $\chi 2$	P value
Agitation	132.40 (14.67)	133.12 (10.44)	-0.2	0.84
Salivary Cortisol	0.13 (1.03)	-0.14 (.94)	0.98	0.33

There were no significant differences between the control and experimental group on the agitation of residents with AD as well as their salivary cortisol levels.

Description of CNA Workload.

For the CNAs, an overview of the number of residents that were cared for by each CNA and the proportion of time that was spent with each resident with AD is showed in Table 6.

Table 6

Total Number of Residents Cared for by CNA

Experimental Group			Control Group		
CNA ID	Total Number of Residents Cared for by CNA	Patients cared for by CNA weighted by time	CNA ID	Total Number of Residents Cared for by CNA	Patients cared for by CNA weighted by time
CNA 6	3	0.77	CNA 84	6	3.00
CNA 7	3	0.38	CNA 68	3	0.72
CNA 8	3	0.78	CNA 74	3	0.6
CNA 10	3	0.53	CNA 81	3	0.61
CNA 13	3	0.71	CNA 83	3	1.22
CNA 15	3	0.70	CNA 86	3	1.68
CNA 17	3	1.05	CNA 95	3	1.39
CNA 22	3	0.44	CNA 49	2	0.47
CNA 24	3	0.74	CNA 50	2	0.48
CNA 38	3	1.79	CNA 54	2	0.46
CNA 1	2	0.67	CNA 55	2	0.87
CNA 2	2	0.66	CNA 58	2	0.77
CNA 3	2	0.62	CNA 64	2	0.34
CNA 4	2	0.90	CNA 70	2	0.41
CNA 5	2	0.44	CNA 72	2	0.30
CNA 9	2	1.00	CNA 80	2	0.33
CNA 11	2	0.9	CNA 82	2	0.78
CNA 12	2	0.33	CNA 85	2	0.80
CNA 14	2	0.98	CNA 87	2	0.77
CNA 16	2	0.50	CNA 88	2	0.65
CNA 20	2	0.56	CNA 90	2	0.07
CNA 26	2	0.10	CNA 92	2	0.23
CNA 28	2	0.22	CNA 51	1	0.23
CNA 30	2	0.26	CNA 52	1	0.10
CNA 32	2	0.77	CNA 53	1	0.33
CNA 34	2	0.28	CNA 56	1	0.33
CNA 35	2	1.05	CNA 57	1	0.34
CNA 36	2	0.67	CNA 59	1	0.18
CNA 37	2	0.75	CNA 60	1	0.43
CNA 39	2	0.49	CNA 61	1	0.23
CNA 40	2	0.64	CNA 62	1	0.48
CNA 41	2	0.71	CNA 63	1	0.16
CNA 42	2	0.64	CNA 65	1	0.36
CNA 43	2	0.17	CNA 66	1	0.31
CNA 44	2	0.53	CNA 67	1	0.19
CNA 45	2	0.83	CNA 69	1	0.31

Experimental Group			Control Group		
CNA ID	Total Number of Residents Cared for by CNA	Patients cared for by CNA weighted by time	CNA ID	Total Number of Residents Cared for by CNA	Patients cared for by CNA weighted by time
CNA 46	2	0.31	CNA 71	1	0.07
CNA 47	2	0.18	CNA 73	1	0.76
CNA 18	1	0.84	CNA 75	1	0.06
CNA 19	1	0.35	CNA 76	1	0.23
CNA 21	1	0.52	CNA 77	1	0.35
CNA 23	1	0.23	CNA 78	1	0.22
CNA 25	1	0.19	CNA 79	1	0.17
CNA 27	1	0.30	CNA 89	1	0.15
CNA 29	1	0.06	CNA 91	1	0.06
CNA 31	1	0.15	CNA 93	1	0.25
CNA 33	1	0.33	CNA 94	1	0.45
CNA 48	1	0.37	CNA 96	1	0.46
			CNA 97	1	0.19
			CNA 98	1	0.38
			CNA 99	1	0.50
Mean	2.00	0.56	Mean	1.63	0.49

The second and fifth columns in Table 6 is the total number of residents that each CNA worked with and is irrespective of the proportion of each resident's care that they provided. The third and sixth column examines the number of residents with AD cared for by each CNA this time weighted by the proportions of time spent with each resident. We see that the number of residents cared for by CNA's in the study ranges from 1 resident to 6 residents. The majority of the CNA's provided care to one or two residents that were in the study. We also see that the number of whole residents with AD by CNAs range from 0.07 (CNA 71) to 3.00 (CNA 84).

Study #1: Evaluation of the Compassionate Care Curriculum (Kirkpatrick Levels One, Two, and Three)

Study #1 focused primarily on the differences in the pre and posttest scores of the experimental and control CNA groups, but also investigated the satisfaction of the CNAs with the CC curriculum (Level 1 of Kirkpatrick's model). The hypothesis for study #1 was as follows: *After completion of the CNA compassionate care curriculum by the*

experimental group, the CNAs will show a significantly higher increase in knowledge, caregiving self-efficacy, caregiving satisfaction and a significantly higher reduction in feelings of affiliate stigma than the CNAs who completed the current standard curriculum.

Satisfaction of CNAs with the CC curriculum

The satisfaction of the CNAs is shown in Table 7.

Table 7

Satisfaction of CNAs with CC curriculum

	N	Mean	SD
Overall, how satisfied were you with the Alzheimer's disease curriculum?	48	4.29	0.65
Has this curriculum met your expectations?	48	4.73	0.54
Overall, how satisfied were you with the care groups?	48	4.83	0.38
Overall Mean	48	4.62	0.41

Overall, learners were generally satisfaction with the curriculum (mean=4.29, SD=0.65) and the curriculum met their expectations (mean=4.73, SD=0.54). Learners also reported the highest satisfaction with the care groups (mean=4.83, SD=0.38). The overall mean across all of the satisfaction questions showed that learners were satisfied with the compassionate care curriculum (mean=4.62, SD=0.41).

Differences between pre- and posttest

The multivariate test results of the two-way mixed MANOVA is shown in Table 8.

Table 8

Multivariate Test Results

Effect		F	Hypo-thesis df	Error df	Sig.	Partial Eta Squared	Observed Power
Between Subjects	Group Effect	6.22	4	94	0.001	0.21	0.99
Within Subject	Time Effect	24.48	4	94	0.001	0.51	1.00
	Group*Time	23.59	4	94	0.001	0.50	1.00

The results of the two-way mixed MANOVA showed that there was a significant between subjects group effect between the experimental and control groups, a significant within subjects time effect between baseline and 12-weeks and a significant interaction effect between group and time, showing a large effect size. The univariate test results for the group effect, time effect, and group*time effect are shown in Table 9. Bonferroni corrections were applied to the univariate effects (alpha level divided by 4 dependent variables), resulting in adjusted alpha levels for interpretation purposes.

From Table 9 it is clear that all univariate group effects were significant, indicating that groups were overall different on AD knowledge, self-efficacy, caregiving satisfaction, and affiliate stigma. The effect size was small for all four variables. Furthermore, the time effect showed that the sample changed significantly between pre and post on all four dependent variables. The effect size for AD knowledge was large, and for the other variables, the effect sizes were medium. The experimental and control groups changed differently between pre- and posttest on all four dependent variables. These differences are shown below in Figures 3-6.

Table 9

Univariate Test Results for MANOVA Analysis

Effect		F	Hypo-thesis df	Error df	Sig. (alpha level)	Bonferroni Correction	Partial Eta Squared	Observed Power
Group Effect	Knowledge	3.09	1	97	0.08	0.02	0.03	0.41
	Self-Efficacy	4.21	1	97	0.04	0.01	0.04	0.53
	Caregiving Satisfaction	8.13	1	97	0.01	0.003	0.08	0.81
	Affiliate Stigma	4.67	1	97	0.03	0.01	0.05	0.57
Time Effect	Knowledge	45.72	1	97	0.001	0.0003	0.32	1.00
	Self-Efficacy	19.48	1	97	0.001	0.0003	0.17	0.99
	Caregiving Satisfaction	27.21	1	97	0.001	0.0003	0.22	1.00
	Affiliate Stigma	16.71	1	97	0.001	0.0003	0.15	0.98
Group*Time	AD Knowledge	49.09	1	97	0.001	0.0003	0.34	1.00
	Self-Efficacy	24.96	1	97	0.001	0.0003	0.21	1.00
	Caregiving Satisfaction	1.67	1	97	0.20	0.05	0.02	0.25
	Affiliate Stigma	25.31	1	97	0.001	0.0003	0.21	1.00

As shown in Figure 3 below, at baseline, the experimental group had slightly less knowledge than the control group, although the difference was not significant. The AD knowledge of the experimental group improved between baseline and 12-weeks. The control group showed similar AD knowledge at the 12-week period than what they had at baseline. The time*group interaction effect was significant with a large effect size.

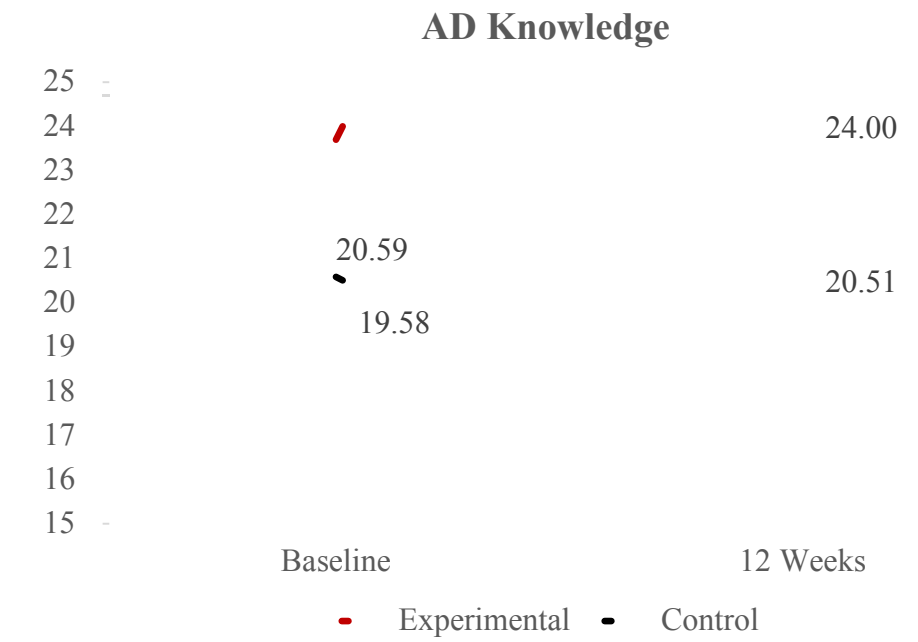


Figure 3. Interaction Effect Between Group and Time for AD Knowledge

Figure 4. Interaction Effect Between Group and Time for Self-Efficacy

The self-efficacy of the two groups were similar at baseline. The self-efficacy for the experimental group improved between baseline and 12-weeks but deteriorated slightly for the control group. The time*group interaction effect was significant with a medium effect size.

At baseline, caregiver satisfaction was slightly higher for the experimental group than the control group, although the difference was not significant. For both groups, there was a slight improvement at 12-weeks in caregiver satisfaction. This improvement was greater for the experimental group. The time*group interaction effect showed a trend with a small effect size.

At baseline, the experimental group felt slightly less affiliate stigma than the control group, although the difference was not significant. The feelings of affiliate stigma for the experimental group declined between baseline and 12 weeks. For the control group, it remained similar at the 12-week period than what they felt at baseline. The time *group effect was significant, with a medium effect size.

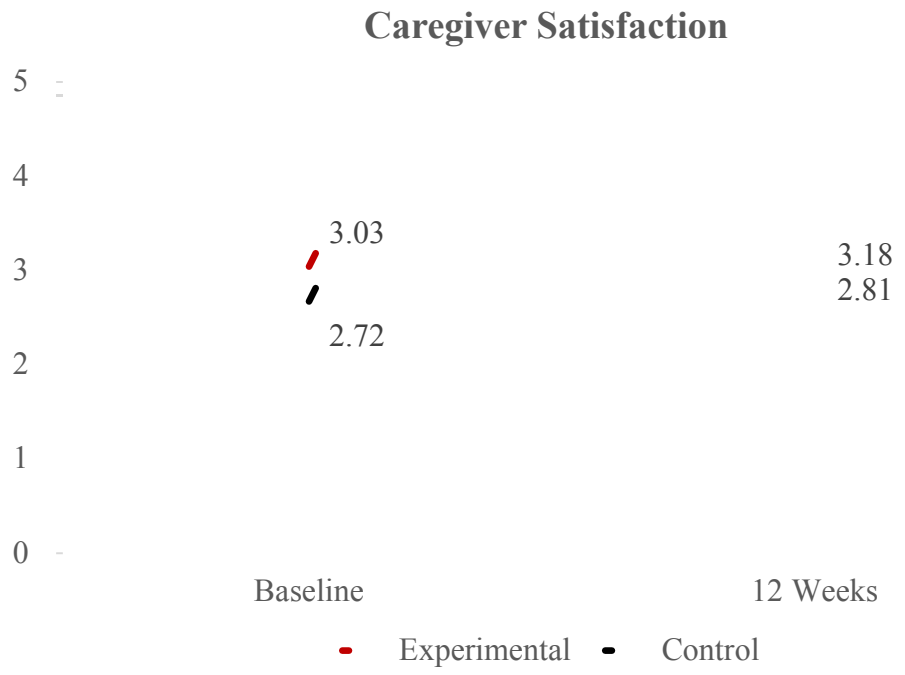


Figure 5. Interaction Effect Between Group and Time for Caregiver Satisfaction

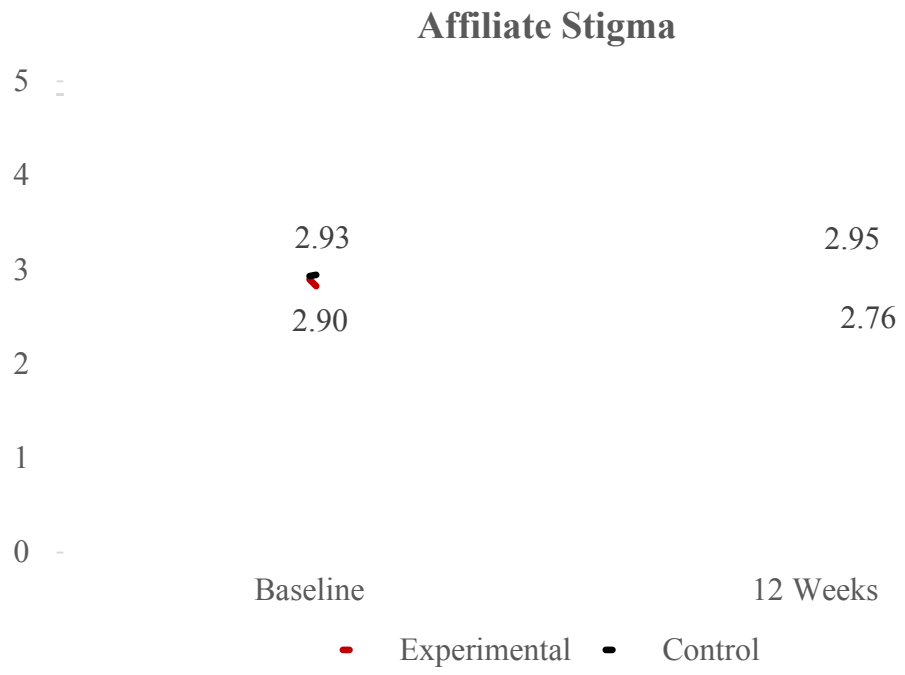


Figure 6. Interaction Effect Between Group and Time for Affiliate Stigma

Study #2: Evaluation of the Compassionate Care Curriculum (Kirkpatrick Level Four)

Study #2 focused primarily on the impact of the compassionate care curriculum on the stress levels of the residents with AD. The hypotheses for study #2 were as follows: ***Hypothesis 1a:*** *Residents with AD from the experimental nursing facility will have a different 12-week agitation change trajectory than the residents with AD from the control nursing facility;* ***Hypothesis 1b:*** *Residents with AD from the experimental nursing facility will have a different 12-week salivary cortisol change trajectory than the residents with AD from the control nursing facility;* ***Hypothesis 2a:*** *Differences in change in CNAs knowledge, confidence, satisfaction, and affiliate stigma will have a differential effect on the 12-week agitation trajectories of residents with AD in experimental and control nursing facilities;* ***Hypothesis 2b:*** *Differences in change in CNAs knowledge, confidence, satisfaction and stigma and differences in residents with AD agitation will have a differential effect on the 12-week salivary cortisol trajectories of residents with AD in experimental and control nursing facilities.*

Model Building

Both agitation and salivary cortisol levels were standardized for this analysis with a mean of 0 and a standard deviation of 1, using the z-score formula. Standardizing scores was to ensure ease of interpretation of the results and is a standard procedure in MLWin.

Assessing the need for the multilevel model. An efficient way to initially assess patterns of change in a study is to graph actual group trajectories for a sample of cases and visually inspect them. For this sample, the whole sample was first graphed collectively and compared between the experimental and control groups in terms of trajectories for changes in agitation (Figures 7-8) and cortisol levels (Figure 9-10). (J. D. Singer & Willett, 2003)

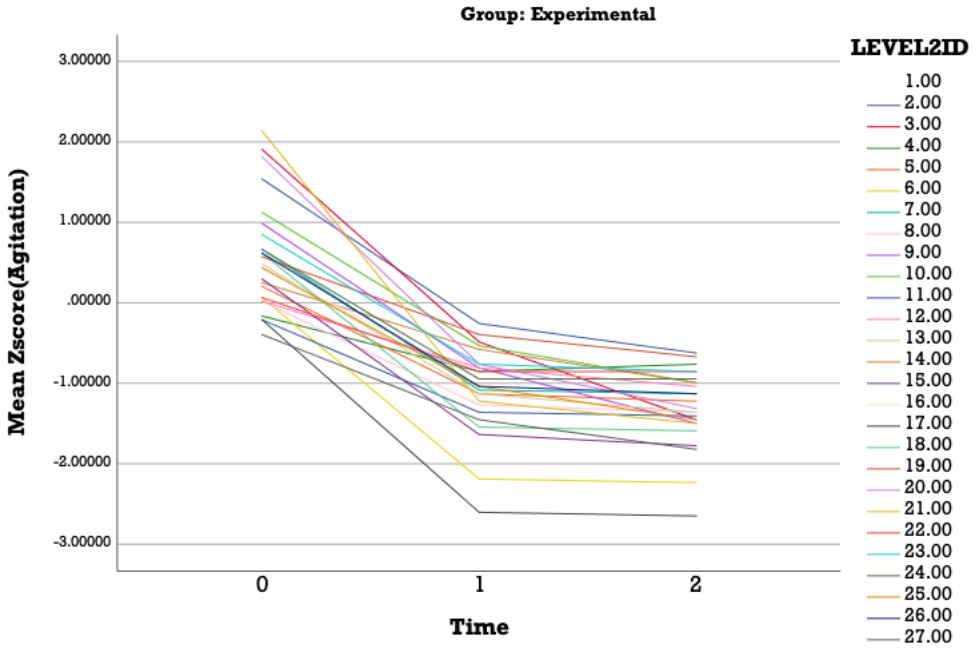


Figure 7. Collected growth trajectories for experimental group on agitation

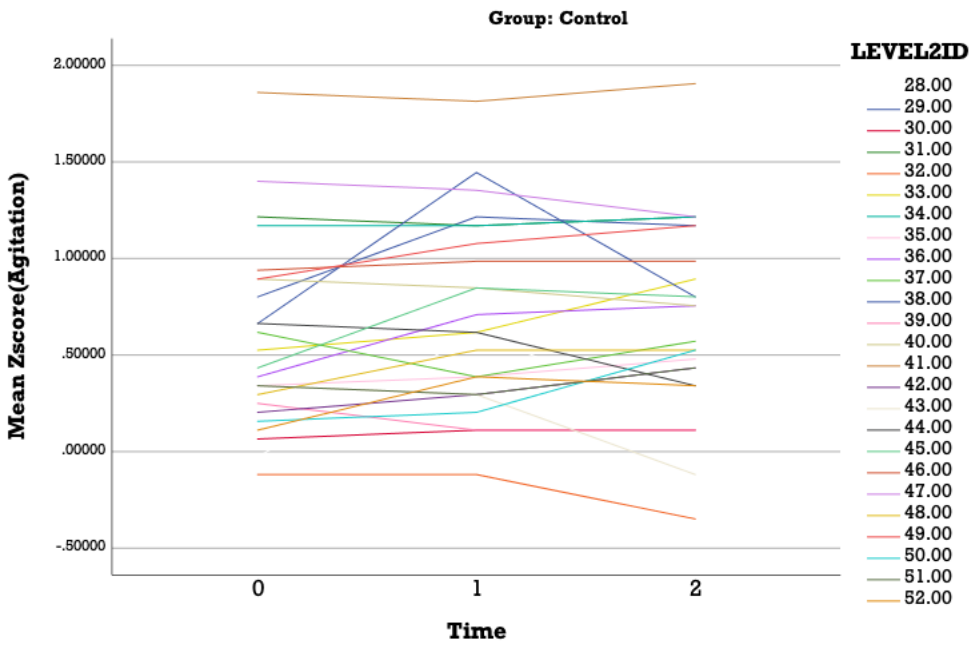


Figure 8. Collected growth trajectories for control groups on agitation

By looking at these collected growth trajectories, it visually appears that residents with AD in the experimental facility where the compassionate care curriculum was implemented reduced their agitation levels. However, the residents with AD in the control facility showed agitation levels that were similar between pre and post assessment, with slightly higher agitation levels at 6 weeks.

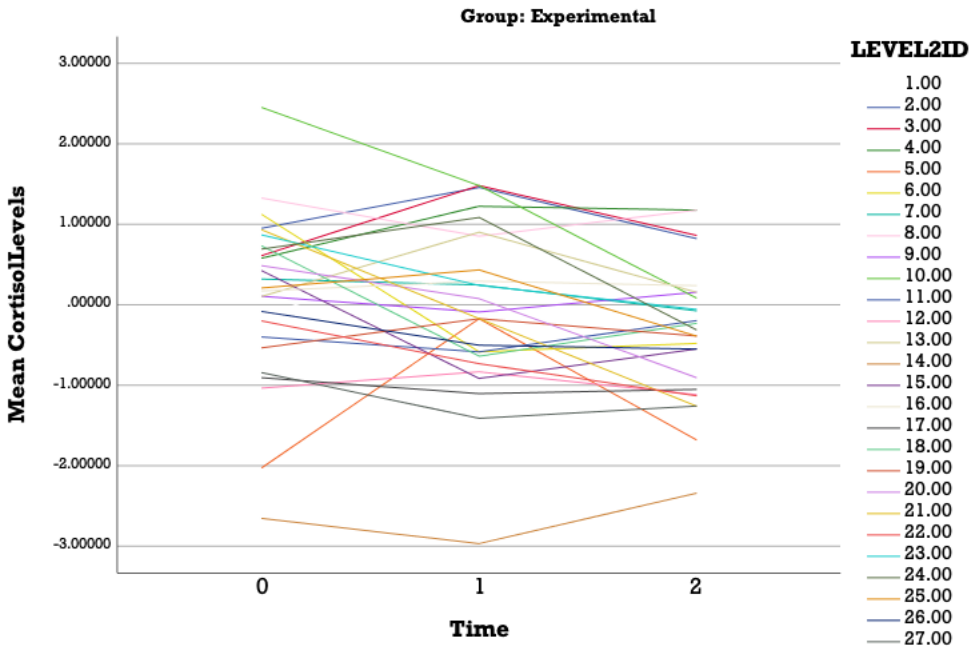


Figure 9. Collected growth trajectories for experimental group on saliva cortisol levels

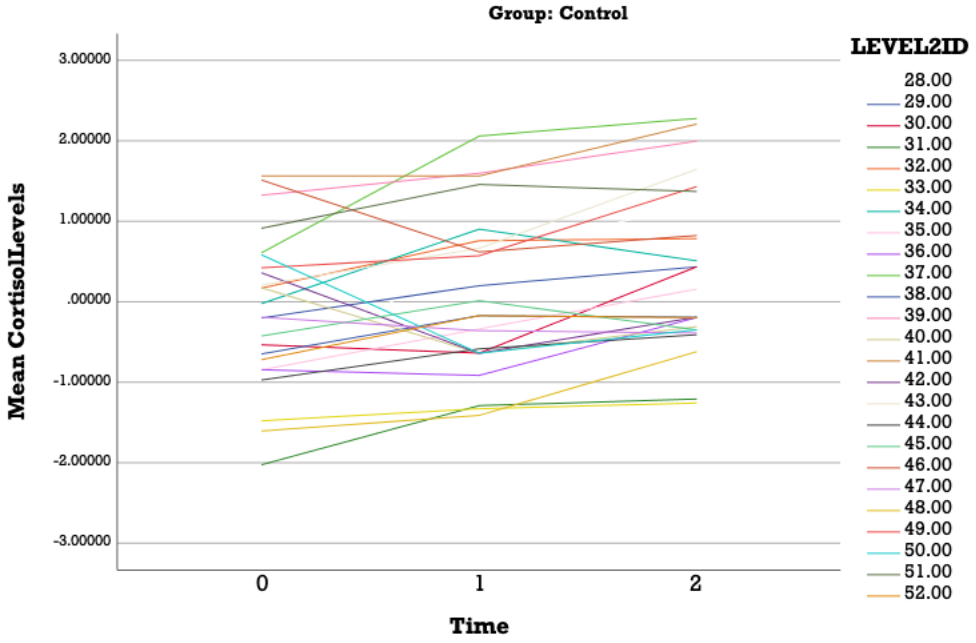
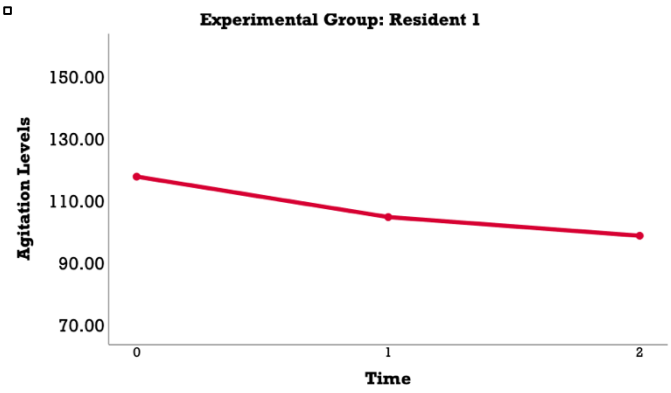


Figure 10. Collected growth trajectories for control group on saliva cortisol levels

By looking at these collected growth trajectories it visually appears that residents with AD in the experimental facility where the compassionate care curriculum were implemented slightly reduced their salivary cortisol levels, peaking at the 6-week assessment. Residents in the control facility showed a slight increase in their salivary cortisol levels, also peaking at the 6-week assessment.

These growth trajectories were also individually plotted and visually inspected for a random sample of 8 from each group. For agitation levels, experimental resident 2 and experimental resident 3 started slightly higher than the control resident 2 and control resident 3. Control resident 2-4 had a slightly flat trajectory compared to some of the residents in the experimental group. Experimental residents 6-8 all started high and by the 6-week time period had agitation levels that decreased and then remained lower at the 12-week time period. Control resident 6 is notable because their agitation levels increased slightly from baseline to 12 weeks. For cortisol levels, experimental residents 15, 18 and 21 showed a sharp decline from baseline to 6-weeks and then showed a continued decline at the 12-week time period. Experimental residents 16 and 17 remained slightly flat across the baseline, 6 week and 12-week time periods. Control residents 15, 19, 20 all showed a slight increase in cortisol levels. Control residents 16, 18 and 22 all showed a slight decline in cortisol levels.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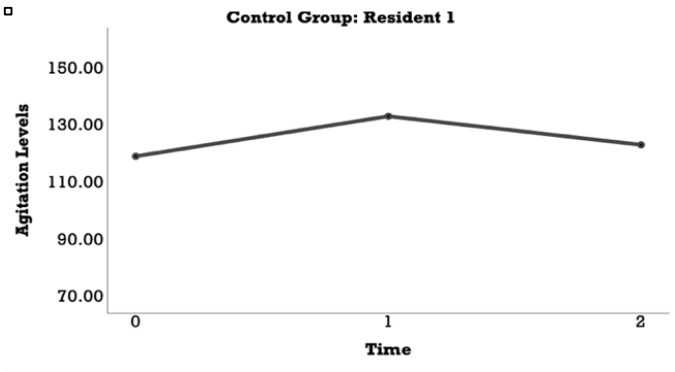
Agitation Levels
150.00
130.00
110.00
90.00
70.00
0
1
2
Time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Agitation Levels
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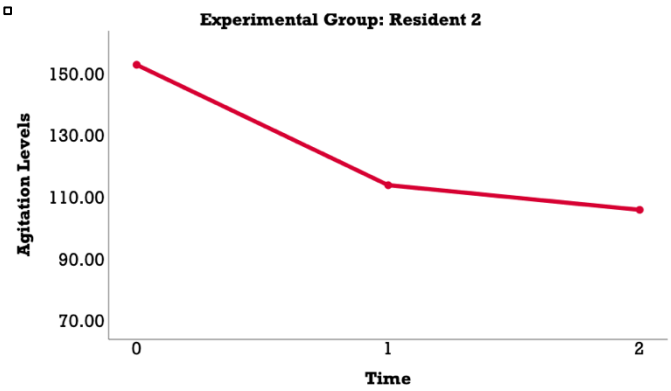
90.00
70.00
0
1
2
Time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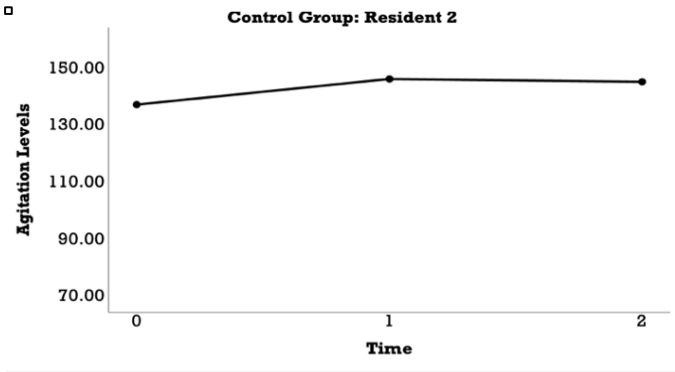
1
2
Time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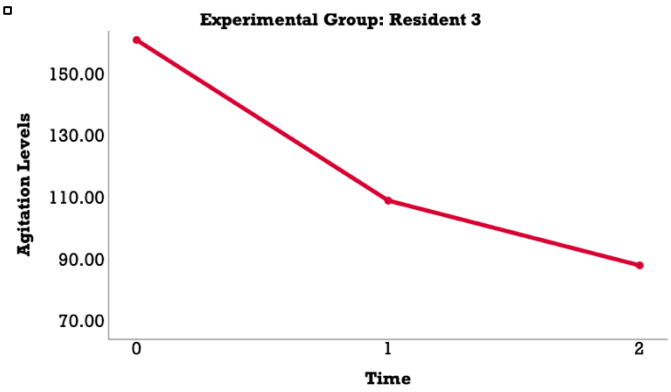
1
2
Time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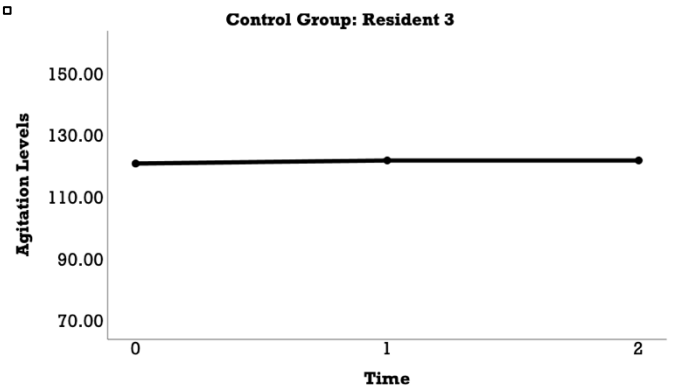
1
2
Time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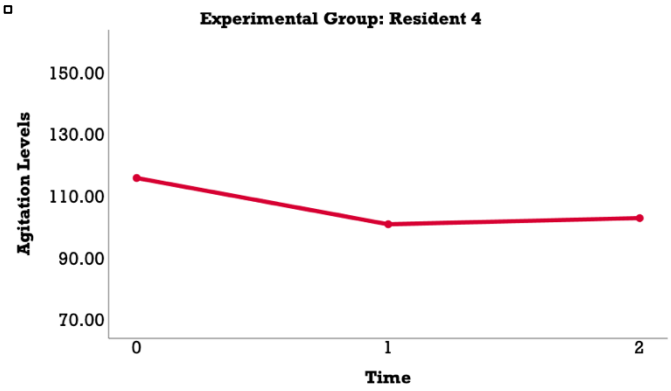
1
2
Time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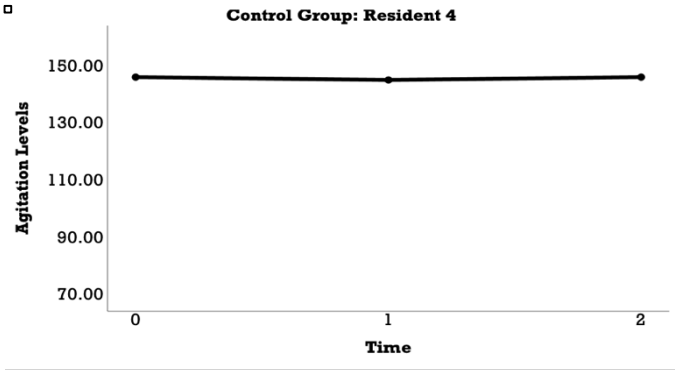
0
1
2
Time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1
2
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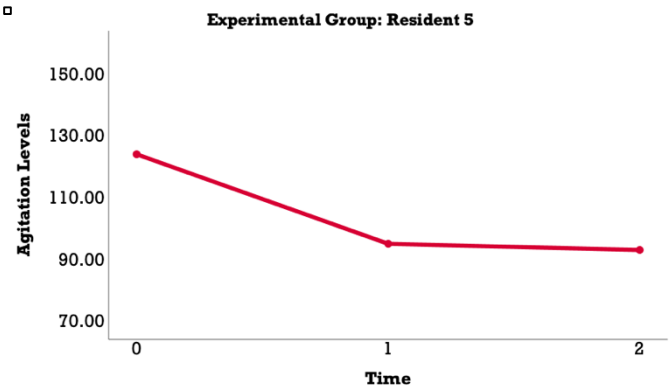
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2
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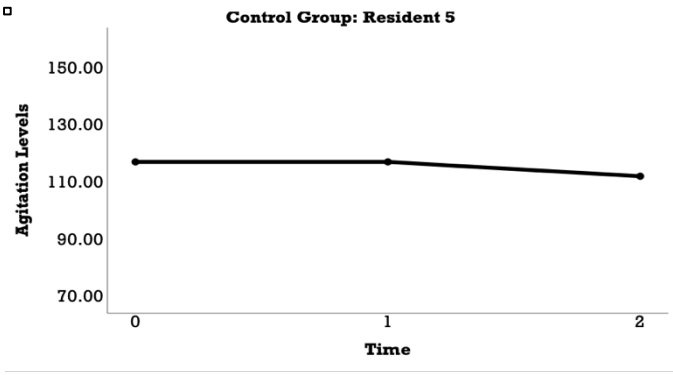
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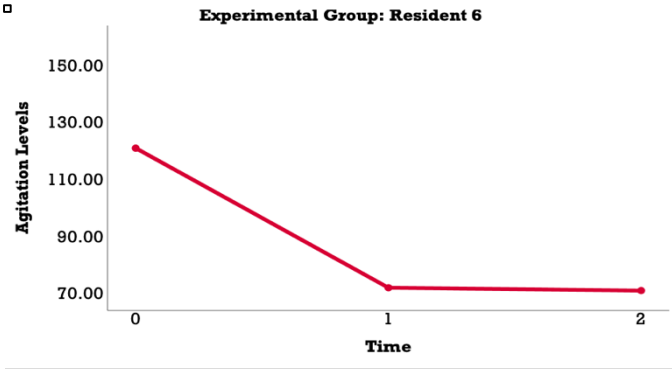
2
Time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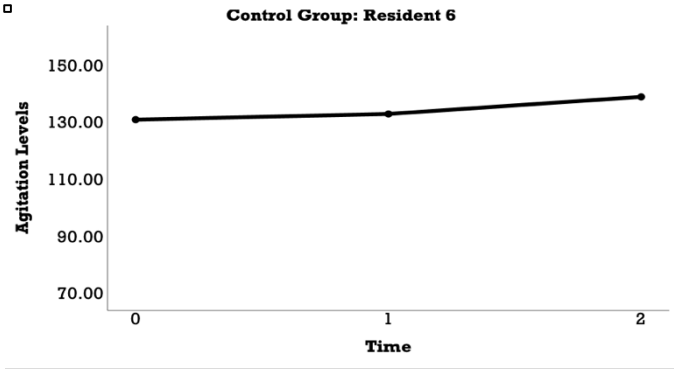
1
2
Time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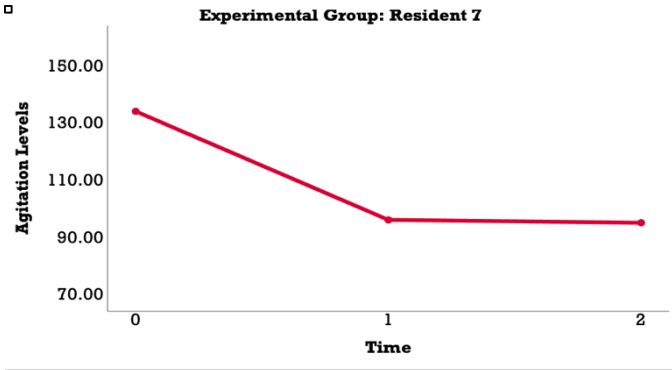
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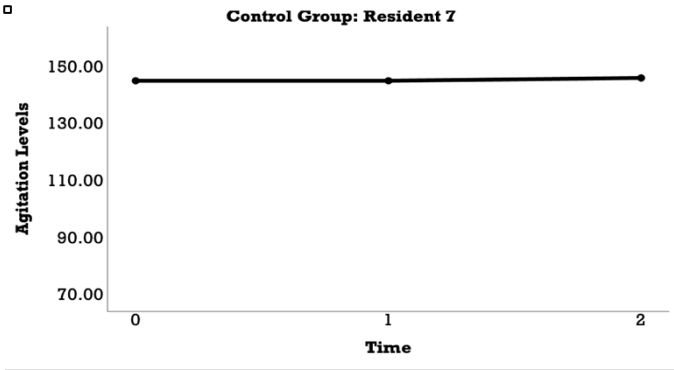
0
1
2
Time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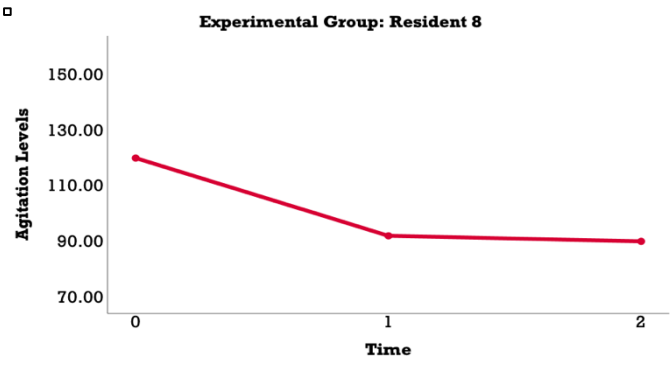
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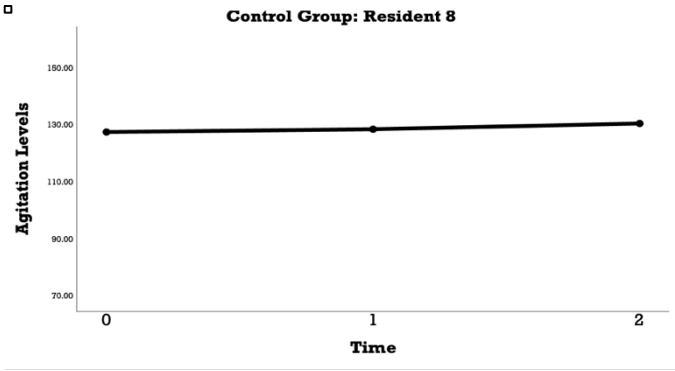
1
2
Time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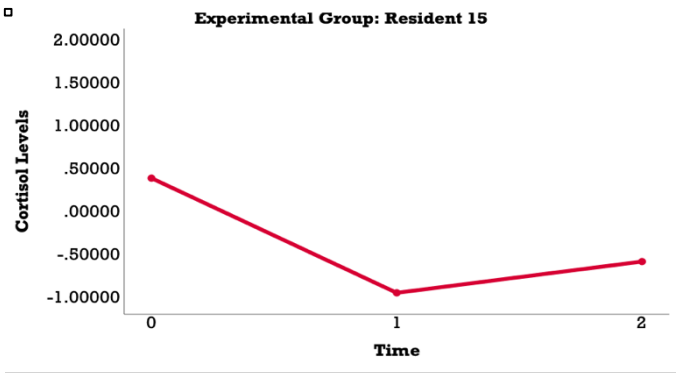
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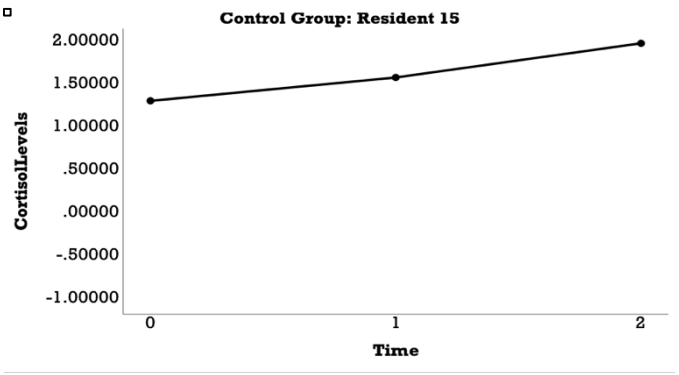
0
1
2
Time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CortisolLevels
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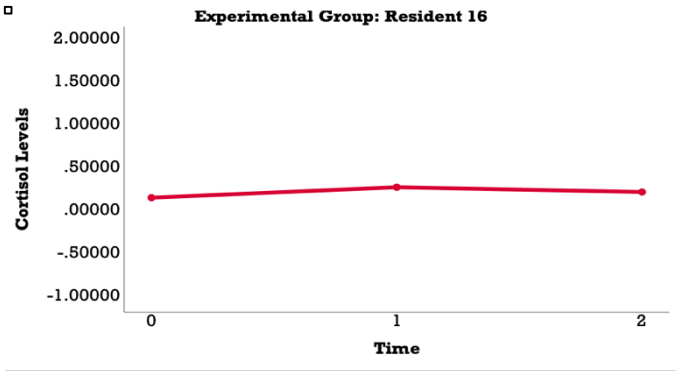
0
1
2
Time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.00000
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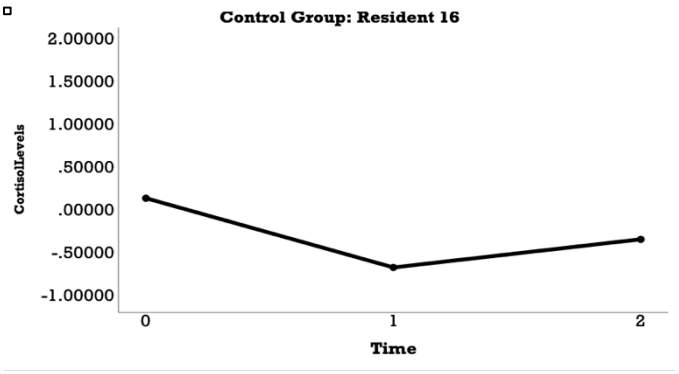
-1.00000
0
1
2
Time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CortisolLevels
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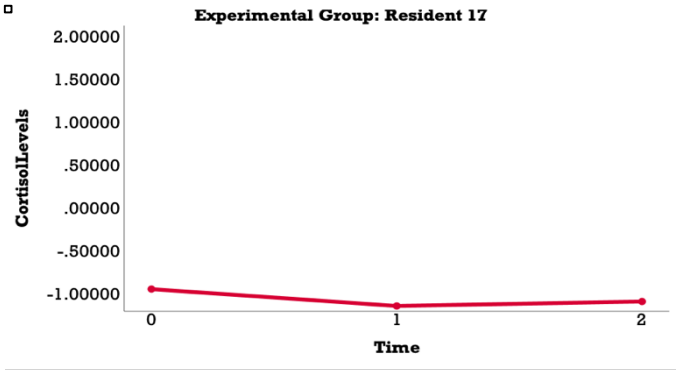
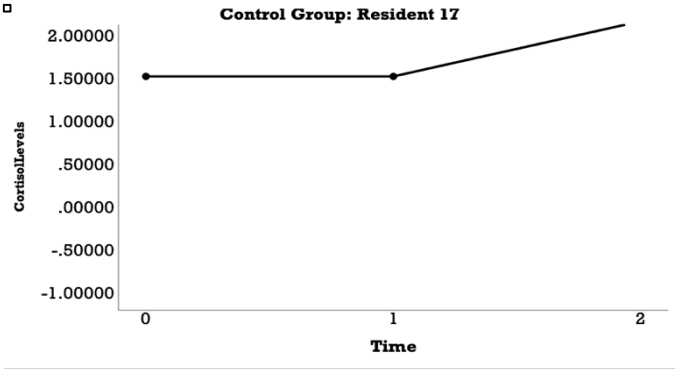
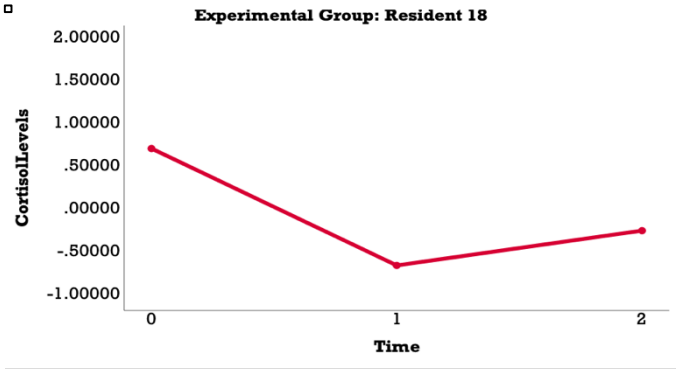
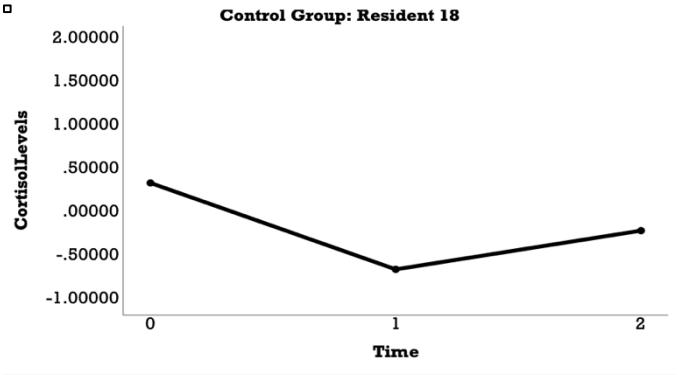
1
2
Time


Experimental Group: Resident 17
CortisolLevels
2.00000
1.50000
1.00000
.50000
.00000
-.50000
-1.00000
0
1
2
Time


Control Group: Resident 17
CortisolLevels
2.00000
1.50000
1.00000
.50000
.00000
-.50000
-1.00000
0
1
2
Time


Experimental Group: Resident 18
CortisolLevels
2.00000
1.50000
1.00000
.50000
.00000
-.50000
-1.00000
0
1
2
Time


Control Group: Resident 18
CortisolLevels
2.00000
1.50000
1.00000
.50000
.00000
-.50000
-1.00000
0
1
2
Time

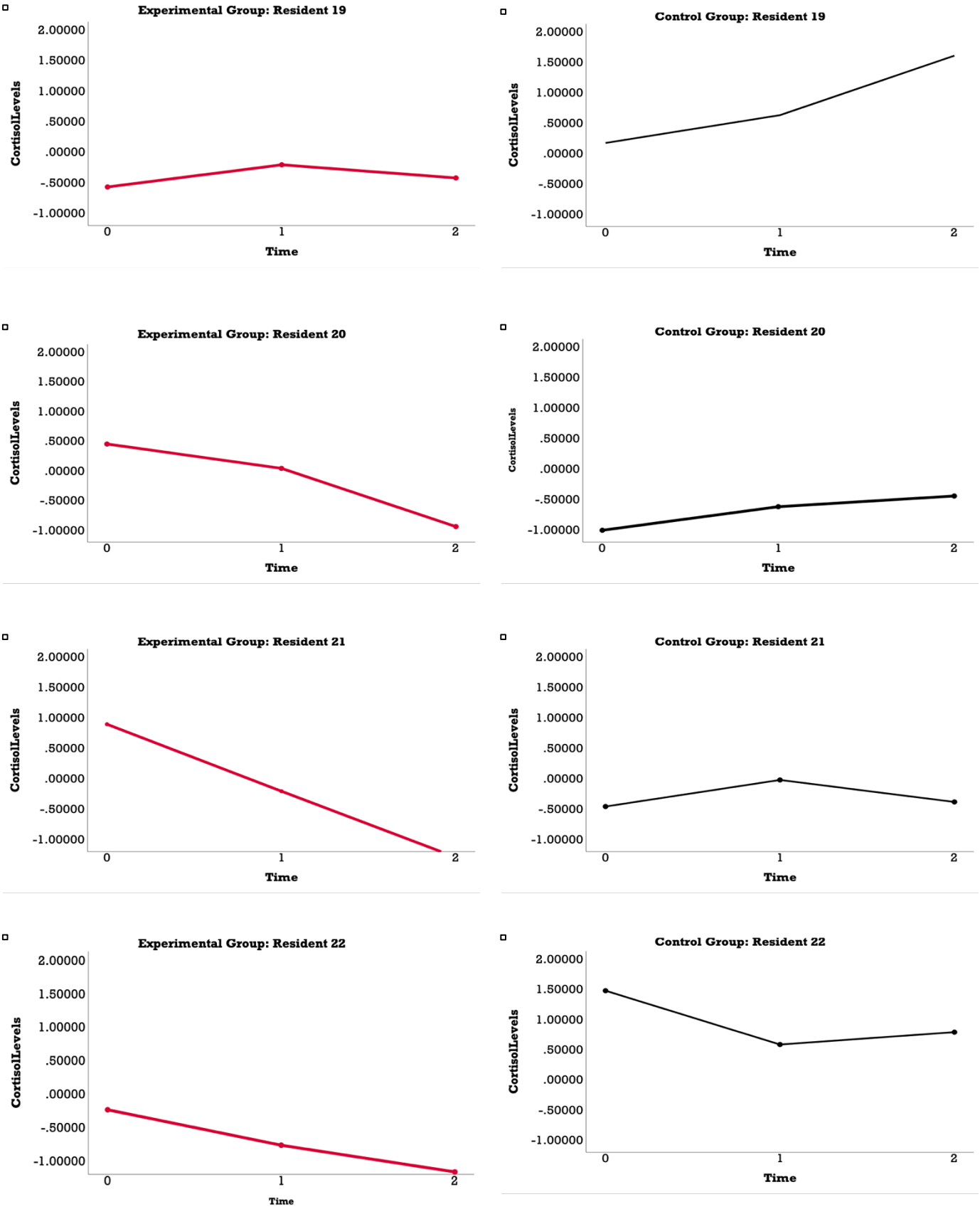


Figure 11. Empirical growth plots for a sample of the study population

Hypothesis 1a: Agitation. Hypothesis 1a focuses on the trajectories of residents with AD in terms of agitation compared to the control group of residents with Alzheimer's disease, without taking into effect the impact the different nurses had on the residents.

Unconditional Model. The first model (Model 1Aa) that was fitted was the unconditional model which described the mean agitation score across all residents irrespective of time. The following equation was used to fit this model.

$$\text{ZAgitation}_{ij} \sim \text{N}\ (XB, \Omega)$$

$$\text{ZAgitation}_{ij} = \beta_{0j}\text{CONSTANT}$$

$$\beta_{0ij} = \beta_0 + u_{0j} + e_{0ij}$$

$$\left[u_{0j}\right] \sim \text{N}(0, \Omega_u) : \Omega_u = \left[\sigma^2_{u0}\right]$$

$$\left[e_{0ij}\right] \sim \text{N}(0, \Omega_e) : \Omega_e = \left[\sigma^2_{e0}\right]$$

Table 10 reveals the estimated intercept, variance components and model fit for the two-level unconditional model using residents with AD at level 2, and measurement points at level 1. There were 52 level 2 units, and 156 level 1 units.

Based on the intercept value, it is estimated that the mean resident with AD is predicted a Z agitation score of 0.004. This estimate does not differ significantly from zero and is expected as the response variable is approximately standardized and therefore has a mean of approximately zero. The between resident variance is estimated at 0.39 (level 2), and the within resident variance is estimated at 0.63 (level 1).

Table 10

Model 1Aa

Parameter	Model 1Aa
Fixed Effects	
ZAgitation	
CONSTANT	0.004 (0.11)
Random parameters	
Level: Level 2 Resident	
Var (CONSTANT)	0.39 (0.13)
Level: Level 1 Time	
Var (CONSTANT)	0.63 (0.09)
DIC:	404.54
pD:	34.81

Note: Standard errors are in parentheses.
***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

The intraclass correlation was calculated using the following formula:

$$ICC = \frac{\sigma_{u0}^2}{\sigma_{u0}^2 + \sigma_{e0}^2}$$

$$= \frac{0.39}{0.39+0.63}$$

$$= 0.38$$

Based on the calculation the ICC is 0.38, suggesting that 38% of the variance in agitation levels was between residents with AD. This supports the need for a multilevel model which accounts for variance both between and within subjects.

The Defiance Information Criterion (DIC) is a likelihood-based measure for comparing models. The DIC combines goodness of fit with model complexity (the number of parameters), to allow for DIC values from different models to be compared directly. The model with the lowest DIC is seen as the best model. If the DIC value

decreases by approximately 10 points, the smaller value is considered to be a significant improvement (Browne, 2009). The DIC for the unconditional model is estimated at 404.54. It is expected that with more variables added to the model, the between and within variances will decrease, and the fit statistic will improve.

Unconditional Growth Model. The unconditional growth model (Model 1Ba) is the unconditional model with the time variable added. It depicts the average agitation scores over time across individuals. The formula used to fit this model, is shown below:

$$\text{ZAgitation}_{ij} \sim \text{N}\,(XB, \Omega)$$

$$\text{ZAgitation}_{ij} = \beta_{0ij}\text{CONSTANT} + \beta_1\text{Time}_{ij}$$

$$\beta_{0ij} = \beta_0 + u_{0j} + e_{0ij}$$

$$\left[u_{0j}\right] \sim \text{N}(0, \Omega_u) : \Omega_u = \left[\sigma^2{}_{u0}\right]$$

$$\left[e_{0ij}\right] \sim \text{N}(0, \Omega_e) : \Omega_e = \left[\sigma^2{}_{e0}\right]$$

In Table 11, Model 1Ba is added for comparison with Model 1Aa.

Table 11

Comparison of Model 1Aa and 1Ba

Parameter	Model 1Aa	Model 1Ba
	Fixed Effects	
ZAgitation		
CONSTANT	0.00 (0.11)	0.46 (0.13)***
Time		-0.45 (0.06)***
	Random parameters	
Level: Level 2 Resident		
Var(CONSTANT)	0.39 (0.13)	0.48 (0.13)
Level: Level 1 Time		
Var(CONSTANT)	0.63 (0.09)	0.42 (0.06)
DIC:	404.54	348.23
pD:	34.81	41.8

Note: Standard errors are in parentheses.
***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

Adding time to the model resulted in an improved model fit (DIC = 404.54 for the unconditional model versus DIC = 348.23 for the unconditional growth model). Model fit was not possible with time as a random effect and had to be added as a fixed effect. With time added to the model, the variance within individuals was reduced from 0.63 to 0.42, but the variance between individuals increased 0.39 to 0.48, showing the need to explain the differences between residents with AD with additional predictors, specifically the intervention that is assumed to have a differential effect on the two groups in the sample. Time was a significant predictor in this model.

Conditional Growth Model. The conditional growth model (Model 1Ca) added group status as a predictor, using the following formula:

$$\text{ZAgitation}_{ij} \sim \text{N}\ (XB, \Omega)$$

$$\text{ZAgitation}_{ij} = \beta_{0j}\text{CONSTANT} + \beta_1\text{Time}_{ij} + \beta_2\text{Experimental}_j$$

$$\beta_{0ij} = \beta_0 + u_{0j} + e_{0ij}$$

$$\left[u_{0j}\right] \sim \text{N}(0, \Omega_u) : \Omega_u = \left[\sigma^2{}_{u0}\right]$$

$$\left[e_{0ij}\right] \sim \text{N}(0, \Omega_e) : \Omega_e = \left[\sigma^2{}_{e0}\right]$$

Table 12 compares the unconditional model with the unconditional growth model and the conditional growth model.

Adding group status to the model resulted in an improved model fit (DIC = 348.23 for the unconditional growth model versus DIC = 328.94 for the conditional growth model). For this model the within person variance stayed the same, but the between person variance was almost all explained by group status. The model also shows that group status was a significant predictor, with the experimental group having significantly less agitation than the control group across time periods.

Table 12

Comparison of Mode1 1Aa, Model 1Ba and Model 1Ca

Parameter	Model 1Aa	Model 1Ba	Model 1Ca
		Fixed Effects	
ZAgitation			
CONSTANT	0.00 (0.11)	0.46 (0.13)***	1.09 (0.11)***
Time		-0.45 (0.06)***	-0.45 (0.06)***
Experimental			-1.23 (0.13)***
		Random parameters	
Level: Level 2 Resident			
Var(CONSTANT)	0.39 (0.13)	0.48 (0.13)	0.06 (0.05)
Level: Level 1			
Time			
Var(CONSTANT)	0.63 (0.09)	0.42 (0.06)	0.43 (0.06)
DIC:	404.54	348.23	328.94
pD:	34.81	41.8	19.05

Note: Standard errors are in parentheses.
***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

Conditional growth model with Interaction Effects. This final model (Model 1Da) added the interaction effects between group and time as a final way to account for the intervention as the groups were hypothesized to change differently over time. The following formula was used for this model:

$$\text{ZAgitation}_{ij} \sim \text{N}(XB, \Omega)$$

$$\text{ZAgitation}_{ij} = \beta_{0ij}\text{CONSTANT} + \beta_1\text{Time}_{ij} + \beta_2\text{Experimental}_j + \beta_3\text{Experimental.Time}_{ij}$$

$$\beta_{0ij} = \beta_0 + u_{0j} + e_{0ij}$$

$$\left[u_{0j}\right] \sim \text{N}(0, \Omega_u) : \Omega_u = \left[\sigma^2_{u0}\right]$$

$$\left[e_{0ij}\right] \sim \text{N}(0, \Omega_e) : \Omega_e = \left[\sigma^2_{e0}\right]$$

Table 13 compares all models.

Table 13

Comparison of all models

Parameter	Model 1Aa	Model 1Ba	Model 1Ca	Model 1Da
		Fixed Effects		
ZAgitation				
CONSTANT	0.00 (0.11)	0.46 (0.13)***	1.09 (0.11)***	0.60 (0.11)***
Time		-0.45 (0.06)***	-0.45 (0.06)***	0.04 (0.06)~
Experimental			-1.23 (0.13)***	-0.28 (0.15)~
Experimental.Time				-0.95 (0.08)***
		Random parameters		
Level: Level 2 Resident				
Var (CONSTANT)	0.39 (0.13)	0.48 (0.13)	0.06 (0.05)	0.15 (0.05)
Level: Level 1 Time				
Var (CONSTANT)	0.63 (0.09)	0.42 (0.06)	0.43 (0.06)	0.19 (0.03)
DIC:	404.54	348.23	328.94	221.25
pD:	34.81	41.8	19.05	39.94

Note: Standard errors are in parentheses.
***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

Adding the interaction effect of group status with time, significantly improved the model fit (DIC=404.54 for the unconditional model, 348.23 for the unconditional growth model, 328.94 for the conditional growth model, and 221.25 for the conditional growth model with main and interaction effects). For this model, the within person variance greatly reduced and the between person variance increased slightly from the previous model. The interaction effect between group status and time was the only significant variable driving this model.

Figure 12 shows the trajectory of agitation over time between the two groups.

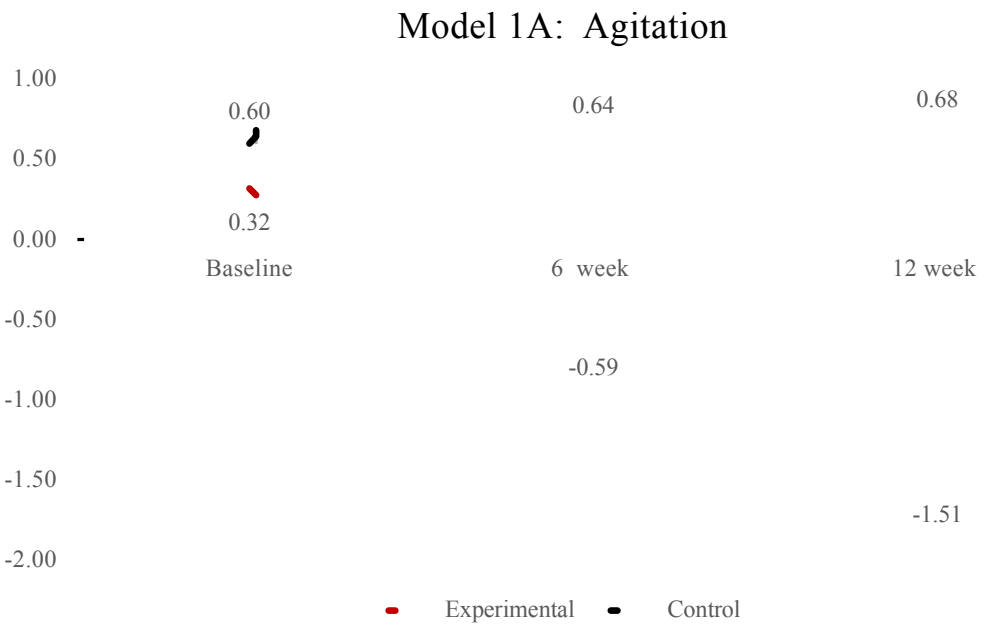


Figure 12. Trajectory of agitation over time between the two groups

ICC was calculated on the final model using the same formula as used with the null model:

$$ICC = \frac{\sigma_{u0}^2}{\sigma_{u0}^2 + \sigma_{e0}^2}$$

$$= \frac{0.15}{0.15+0.19}$$

$$= 0.44$$

This shows that after adding only the group status and time changes to the model, the between residents with AD variance increased. Model 1A was able to demonstrate that residents with AD in the experimental group had a significantly different agitation growth trajectory than the residents with AD in the control group. However, there were differences between the residents with AD that could not be explained simply by being in the experimental or control group. It is hypothesized that the reason for these differences

lie with the CNA's taking care of the residents. Not only was the CNA's influenced differently by the curriculum, but there were also differences in resident characteristics that could have provided a barrier to CNA's to provide compassionate care and rate agitation of the patients in a more favorable manner. Model 2A will investigate these influences on agitation.

Hypothesis 1b: Salivary Cortisol. Hypothesis 1b focuses on the trajectories of residents with AD in terms of salivary cortisol compared to the control group of residents with Alzheimer's disease, without taking into effect the impact the different CNAs had on the residents.

Unconditional Model. The first model (Model 1Ab) that was fitted was the unconditional model which described the mean salivary cortisol levels across all residents irrespective of time. Table 14 reveals the estimated intercept, variance components, and model fit for the two-level unconditional model.

Table 14

Model 1Ab

Parameter	Model 1Ab
Fixed Effects	
ZSalivary Cortisol	
CONSTANT	0.007 (0.13)
Random parameters	
Level: Level 2 Resident	
Var (CONSTANT)	0.73 (0.18)
Level: Level 1 Time	
Var (CONSTANT)	0.29 (0.04)
DIC:	292.55
pD:	46.53

Note: Standard errors are in parentheses.
***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

Based on the intercept value, it is estimated that the mean resident with AD is predicted a Z cortisol level of 0.007. This estimate does not differ significantly from zero and is expected as the response variable is approximately standardized and therefore has a mean of approximately zero. The between resident variance is estimated at 0.73 (level 2), and the within resident variance is estimated at 0.29 (level 1). The intraclass correlation was calculated using the following formula:

$$ICC = \frac{\sigma_{u0}^2}{\sigma_{u0}^2 + \sigma_{e0}^2}$$

$$= \frac{0.73}{0.73+0.29}$$

$$= 0.72$$

Based on the calculation the ICC is 0.72, suggesting that 72% of the variance in cortisol levels was between residents with AD. This supports the need for a multilevel model which accounts for variance both between and within subjects.

The DIC for the unconditional model is estimated at 292.55. It is expected that with more variables added to the model, the between and within variances will decrease, and the fit statistic will improve.

Unconditional Growth Model. The unconditional growth model (Model 1Bb) is the unconditional model with the time variable added. It depicts the average salivary cortisol levels over time across individuals. For this model, time was allowed to have a random intercept and slope on level 2, resulting in a better fit. The model was not able to fit with a random slope on level 1. The formula used to fit this model, is shown below:

$$\text{ZCortisolLevels}_{ij} \sim \text{N}(XB, \Omega)$$

$$\text{ZCortisolLevels}_{ij} = \beta_{0ij}\text{CONSTANT} + \beta_{1j}\text{Time}_{ij}$$

$$\beta_{0ij} = \beta_0 + u_{0j} + e_{0ij}$$

$$\beta_{1j} = \beta_1 + u_{1j}$$

$$\begin{bmatrix} u_{0j} \\ u_{1j} \end{bmatrix} \sim \text{N}(0, \Omega_u): \Omega_u = \begin{bmatrix} \sigma_{u0}^2 & \sigma_{u1}^2 \\ \sigma_{u01} & \end{bmatrix}$$

$$[e_{0ij}] \sim \text{N}(0, \Omega_u): \Omega_u = [\sigma_{e0}^2]$$

In Table 15, Model 1Bb is added for comparison with Model 1Ab.

Table 15

Comparison of Model 1Ab and Model 1B

Parameter	Model 1 Ab	Model 1 Bb
Fixed Effects		
ZSalivary Cortisol		
CONSTANT	0.007 (0.13)	0.01 (0.14)
Time		0.003 (0.06)
Random parameters		
Level: Level 2 Resident		
Var(CONSTANT)	0.73 (0.18)	0.85 (.21)
Var(Time)		0.11 (0.04)
Level: Level 1 Time		
Var(CONSTANT)	0.29 (0.04)	0.19 (0.04)
DIC:	292.55	252.95
pD:	46.53	75.87

Note: Standard errors are in parentheses.
***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

Adding time to the model resulted in an improved model fit (DIC = 292.55 for the unconditional model versus DIC = 252.95 for the unconditional growth model). With time added to this model, the variance within the individuals was reduced from 0.29 to 0.19; however, the variance between persons with AD increased from 0.73 to 0.85. This shows the need to explain the differences between persons with AD with additional predictors, specifically the intervention that is assumed to have a differential effect on the two groups in the sample.

Conditional Growth Model. The conditional growth model (Model 1Cb) added group status as a predictor, using the following formula:

$$\text{ZCortisolLevels}_{ij} \sim \text{N}(XB, \Omega)$$

$$\text{ZCortisolLevels}_{ij} = \beta_{0ij}\text{CONSTANT} + \beta_{1j}\text{Time}_{ij} + \beta_2\text{Experimental}_j$$

$$\beta_{0ij} = \beta_0 + u_{0j} + e_{0ij}$$

$$\beta_{1j} = \beta_1 + u_{1j}$$

$$\begin{bmatrix} u_{0j} \\ u_{1j} \end{bmatrix} \sim \text{N}(0, \Omega_u): \Omega_u = \begin{bmatrix} \sigma_{u0}^2 & \sigma_{u1}^2 \\ \sigma_{u01} & \end{bmatrix}$$

$$\begin{bmatrix} e_{0ij} \end{bmatrix} \sim \text{N}(0, \Omega_u): \Omega_u = \begin{bmatrix} \sigma_{e0}^2 \end{bmatrix}$$

Table 16 compares the unconditional model with the unconditional growth model and the conditional growth model.

Table 16

Comparison of Model 1Ab, Model 1Bb and Model 1Cb

Parameter	Model 1 Ab	Model 1 Bb	Model 1 Cb
	Fixed Effects		
ZSalivary Cortisol			
CONSTANT	0.007 (0.13)	0.01 (0.14)	0.10 (0.19)
Time		0.003 (0.06)	0.003 (0.06)
Experimental			-0.19 (0.30)
	Random parameters		
Level: Level 2 Resident			
Var(CONSTANT)	0.73 (0.18)	0.85 (.21)	0.90 (0.23)
Var(Time)		0.11 (0.04)	0.11 (0.04)
Level: Level 1 Time			
Var(CONSTANT)	0.29 (0.04)	0.187 (0.04)	0.19 (0.04)
DIC:	292.55	252.95	253.98
pD:	46.53	75.87	75.63

Note: Standard errors are in parentheses.
***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

Adding group status to the model did not result in an improved model fit (DIC = 252.95 for the unconditional growth model versus DIC = 253.98 for the conditional growth model). For this model, the within person variance stayed the same, but the between person variance increased from 0.85 to 0.90. Group status was not a significant predictor.

Conditional growth model with Interaction Effects. This final model (Model 1Db) added the interaction effects between group and time as a final way to account for the intervention as the groups were hypothesized to change differently over time. The following formula was used for this model:

$$\text{ZCortisolLevels}_{ij} \sim \text{N}(XB, \Omega)$$

$$\text{ZCortisolLevels}_{ij} = \beta_{0ij}\text{CONSTANT} + \beta_{1j}\text{Time}_{ij} + .\beta_2\text{Experimental}_j + \beta_3\text{Experimental.Time}_{ij}$$

$$\beta_{0ij} = \beta_0 + u_{0j} + e_{0ij}$$

$$\beta_{1j} = \beta_1 + u_{1j}$$

$$\begin{bmatrix} u_{0j} \\ u_{1j} \end{bmatrix} \sim \text{N}(0, \Omega_u): \Omega_u = \begin{bmatrix} \sigma_{u0}^2 \, \sigma_{u1}^2 \\ \sigma_{u01} \end{bmatrix}$$

$$[e_{0ij}] \sim \text{N}(0, \Omega_u): \Omega_u = [\sigma_{e0}^2]$$

Table 17 compares all models.

Table 17

Comparison of All Models

Parameter	Model 1 Ab	Model 1 Bb	Model 1 Cb	Model 1Db
		Fixed Effects		
ZSalivary Cortisol				
CONSTANT	0.007 (0.13)	0.01 (0.14)	0.10 (0.19)	-0.16 (0.19)
Time		0.003 (0.06)	0.003 (0.06)	0.26 (0.07)***
Experimental			-0.19 (0.30)	0.30 (0.27)
Experimental.Time				-0.51 (0.10)***
		Random parameters		
Level: Level 2 Resident				
Var(CONSTANT)	0.73 (0.18)	0.85 (.21)	0.90 (0.23)	0.84 (0.20)
Var(Time)		0.11 (0.04)	0.11 (0.04)	0.05 (0.03)
Level: Level 1 Time				
Var(CONSTANT)	0.29 (0.04)	0.19 (0.04)	0.19 (0.04)	0.19 (0.03)
DIC:	292.55	252.95	253.98	243.95
pD:	46.53	75.87	75.63	66.881

Note: Standard errors are in parentheses.
***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

Adding the interaction effect of group status with time, significantly improved the model fit (DIC=292.55 for the unconditional model, 252.95 for the unconditional growth model, 253.98 for the conditional growth model, and 243.95 for the conditional growth model with main and interaction effects). For this model, the within person variance stayed the same from the previous model and the between person variance decreased slightly. Time was a significant variable in this model along with the interaction effect between group status and time.

Figure 13 shows the trajectory of salivary cortisol over time between the two groups.

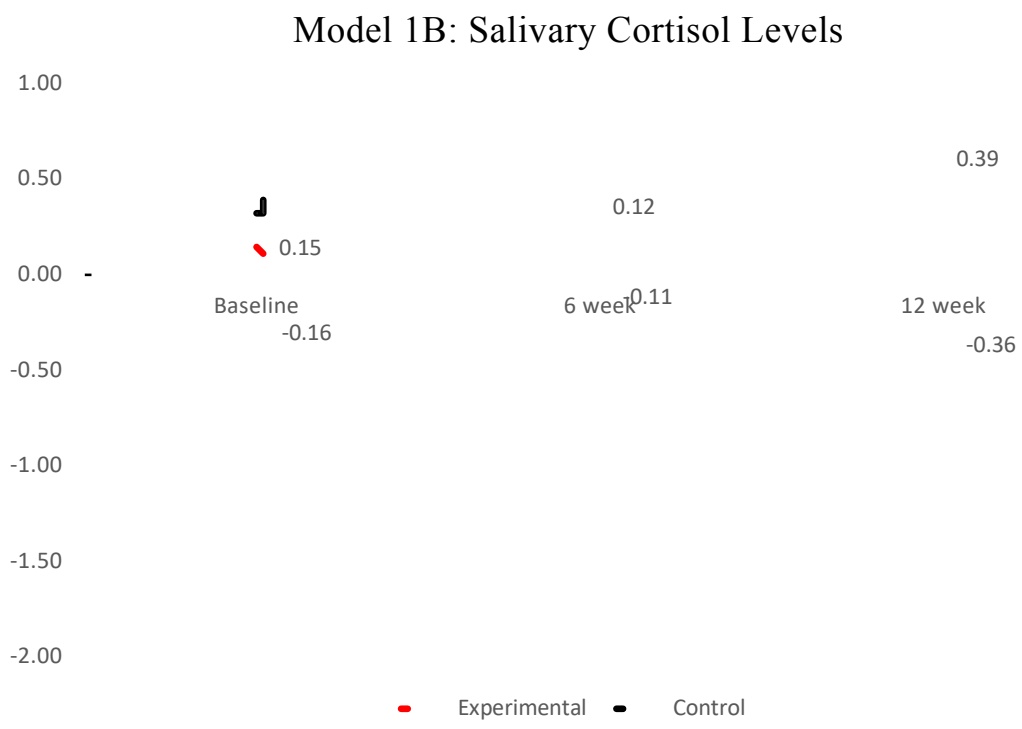


Figure 13. Trajectory of salivary cortisol levels over time between the two groups

ICC was calculated on the final model using the same formula as used with the null model:

$$ICC = \frac{\sigma_{u0}^2}{\sigma_{u0}^2 + \sigma_{e0}^2}$$

$$= \frac{0.84}{0.84+0.19}$$

$$= 0.48$$

This shows that after adding only the group status and time changes to the model, the between residents with AD variance decreased over time. Model 1b was able to demonstrate that persons with AD in the experimental group had a significantly different salivary cortisol growth trajectory than the persons with AD in the control group. The experimental group showed a decrease in cortisol levels over 12 weeks, with the control group showing an increase in cortisol levels.

Hypothesis 2a: Agitation. Hypothesis 2a focuses on the trajectories of persons with AD in terms of agitation compared to the control group, while taking into effect the impact of the different CNAs on the persons with AD.

Unconditional Unclassified Null Model. The first model (Model 2Aa) that was fitted was the unconditional unclassified model. This model only fits the effect of the CNA that had the highest weighted time with a specific resident. The reason for building this model first was to investigate if a classified model where the effect of all CNA's working with a specific resident was modeled, would be a better fitted model. If not, only the effect of one CNA needed to be modelled, resulting in a less complicated model. The following equation was used to fit this model:

$$\text{ZAgitation}_{ijk} \sim \text{N}(XB, \Omega)$$

$$\text{ZAgitation}_{ijk} = \beta_{0ijk}\text{CONSTANT}$$

$$\beta_{0ijk} = \beta_0 + \nu_{0k} + u_{ojk} + e_{0ijk}$$

$$[\nu_{0k}] \sim N\ (0,\ \Omega_v)\text{: } \Omega_v = [\sigma^2_{v0}]$$

$$[u_{0jk}] \sim N\ (0,\ \Omega_u)\text{: } \Omega_u = [\sigma^2_{u0}]$$

$$[e_{0jk}] \sim N\ (0,\ \Omega_e)\text{: } \Omega_e = [\sigma^2_{e0}]$$

Table 18 shows the estimated intercept, variance components, and model fit for the three-level unconditional unclassified model using CNAs at level 3, persons with AD at level 2, and measurement points at level 1. There were 50 level 3 units, 52 level 2 units, and 156 level 1 units.

Table 18

Model 2Aa

Parameter	Model 2Aa
Fixed Effects	
ZAgitation	
CONSTANT	-0.004(0.11)
Random parameters	
Level: Level 3 CNA	
Var(CONSTANT)	0.23 (0.19)
Level: Level 2 Resident	
Var(CONSTANT)	0.19 (0.19)
Level: Level 1 Time	
Var(CONSTANT)	0.63 (0.09)
Var(Time)	
DIC:	403.89
pD:	34.90

Note: Standard errors are in parentheses.
***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

Based on the intercept value, it is estimated that the mean resident with AD is predicted a Z agitation score of -0.004. This estimate does not differ significantly from zero and is expected as the response variable is approximately standardized and therefore has a mean of approximately zero. The between CNA variance is estimated at 0.23 (level 3), the resident with AD variance is estimated at 0.19 (level 2), and the within resident variance is estimated at 0.63 (level 1). The DIC for the unconditional model is estimated at 403.89.

Classified Unconditional Model. The next model that was built was the classified unconditional model. Unlike the unclassified unconditional model, this model took into consideration that one resident received care from multiple CNAs. The following formula was used for this model:

$\text{ZAgitation}_{ij} \sim \text{N}\ (XB, \Omega)$

$\text{ZAgitation}_{ij} = \beta_{0ij}\text{CONSTANT}$

$$\beta_{0i} = \beta_0 + \Sigma_{j \epsilon CNA1(i)}\, w_{i,j}^{(3)} u_{0j}^{(3)} + u_{0,LEVEL2ID(i)}^{(2)} + e_{0i}$$

$$\left[u_{0,CNA1(i)}^{(3)}\right] \sim N\left(0, \Omega_u^{(3)}\right): \Omega_u^{(3)} = [\Omega_{u0,0}^{(3)}]$$

$$\left[u_{0,LEVEL2ID(i)}^{(2)}\right] \sim N\left(0, \Omega_u^{(2)}\right): \Omega_u^{(2)} = [\Omega_{u0,0}^{(2)}]$$

$$[e_{0i}] \sim \text{N}(0, \Omega_e): \Omega_e = [\Omega_{e0,0}]$$

Using a classified model resulted in an improved model fit (DIC = 403.89 for the unclassified unconditional model versus DIC = 395.79 for the classified unconditional model). Given that this model produced a better fit, it was better to build a classified model instead of an unclassified model.

Based on the intercept value, it is estimated that the mean resident with AD is predicted a Z agitation level of 0.002. This estimate does not differ significantly from zero and is expected as the response variable is approximately standardized and therefore has a mean of approximately zero. The between CNA variance is estimated at 0.93 (level 3), the between resident variance is estimated at 0.04 (level 2), and the within resident variance is estimated at 0.61 (level 1). Table 19 shows the classified unconditional model compared to the unclassified unconditional model.

Table 19

Comparison of Model 2Aa (i) and Model 2Aa (ii)

Parameter	Model 2Aa (i)	Model 2Aa (ii)
Fixed Effects		
ZAgitation		
CONSTANT	-0.004(0.11)	0.002 (0.13)
Random parameters		
Level: Level 3 CNA		
Var(CONSTANT)	0.23 (0.19)	0.93 (0.35)
Level: Level 2 Resident		
Var(CONSTANT)	0.19 (0.19)	0.04 (0.05)
Level: Level 1 Time		
Var(CONSTANT)	0.63 (0.09)	0.61 (0.08)
Var(Time)		
DIC:	403.895	395.79
pD:	34.90	31.91

Note: Standard errors are in parentheses.
***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

The intraclass correlation for level 3 was calculated using the following formula:

$$ICC = \frac{\Omega_{u0,0}^{(3)}}{\Omega_{u0,0}^{(3)} + \Omega_{u0,0}^{(2)} + \Omega_{e0,0}}$$

$$= \frac{0.93}{0.93+0.04+0.61}$$

$$= 0.59$$

The intraclass correlation for level 2 was calculated using the following formula:

$$ICC = \frac{\Omega_{u0,0}^{(2)}}{\Omega_{u0,0}^{(3)} + \Omega_{u0,0}^{(2)} + \Omega_{e0,0}}$$

$$= \frac{0.04}{0.93+0.04+0.61}$$

$$= 0.03$$

Based on the calculation the ICC for level 3 is 0.59, suggesting that 59% of the variance in agitation was between CNAs, with the ICC for level 2 showing that there was very little variance between residents left to explain. The reason for this may lie in the fact that the CNAs were responsible for rating the agitation levels of the residents, and that the ratings were more a result of their view on agitation than "true agitation levels" for the residents. The ICC supports the need for a multilevel model which accounts for variance not only between and within residents, but also between CNAs providing care.

The DIC for the unconditional model is estimated at 395.79. It is expected that with more variables added to the model, the between and within variances will decrease, and the fit statistic will improve.

Classified Unconditional Growth Model. The unconditional growth model (Model 2Ca) is the unconditional model with the time variable added. It depicts the average agitation scores over time across individuals. The formula used to fit this model is shown below:

$$\text{ZAgitation}_{ij} \sim \text{N}\ (XB, \Omega)$$

$$\text{ZAgitation}_{ij} = \beta_{0j}\text{CONSTANT} + \beta_{1i}\text{Time}_i$$

$$\beta_{0i} = \beta_0 + \Sigma_{j \epsilon CNA1(i)}\, w_{i,j}^{(3)} u_{0j}^{(3)} + u_{0,LEVEL2ID(i)}^{(2)} + e_{0i}$$

$$\beta_{1i} = \beta_1 + e_{1i}$$

$$\left[u_{0,CNA1(i)}^{(3)}\right] \sim N\left(0, \Omega_u^{(3)}\right): \Omega_u^{(3)} = [\Omega_{u0,0}^{(3)}]$$

$$\left[u_{0,LEVEL2ID(i)}^{(2)}\right] \sim N\left(0, \Omega_u^{(2)}\right): \Omega_u^{(2)} = [\Omega_{u0,0}^{(2)}]$$

$$\begin{bmatrix} e_{0i} \\ e_{1i} \end{bmatrix} \sim \text{N}(0,\ \Omega_e)\ :\ \Omega_e = \begin{bmatrix} \Omega_{e0,0} & \\ \Omega_{e0,1} & \Omega_{e1,1} \end{bmatrix}$$

Table 20 shows the classified unconditional model (Model 2Aa) compared to the classified unconditional growth model (Model 2Ba).

Table 20

Comparison of Model 2Aa (ii) and Model 2Ba

Parameter	Model 2Aa (ii)	Model 2Ba
	Fixed Effects	
ZAgitation		
CONSTANT	0.002 (0.13)	0.01 (0.18)
Time		-0.21 (0.04)***
	Random parameters	
Level: Level 3		
CNA		
Var(CONSTANT)	0.93 (0.35)	2.40 (0.54)
Level: Level 2 Resident		
Var(CONSTANT)	0.04 (0.05)	0.03 (0.04)
Level: Level 1		
Time		
Var(CONSTANT)	0.61 (0.08)	0.75 (0.06)
Covar (Time/CONSTANT		-0.55 (0.06)
Var(Time)		0.38 (0.04)
DIC:	395.79	136.01
pD:	31.91	364.14

Note: Standard errors are in parentheses.
***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

Adding time to the model resulted in an improved model fit (DIC = 136.01 for the unconditional growth model versus DIC = 395.79 for the unconditional model). compared to the unconditional model. Time was added as a random effect on level 1. For this model, the between CNA variance increased from 0.93 to 2.40, the between resident variance stayed the same, and the within person variance increased from 0.61 to 0.77. This model showed that time was a significant variable.

Classified Conditional Growth Model with CNA Predictors. A model was built where both the CNA and resident control variables were added to the unconditional growth model. However, this model showed a worst fit than the unconditional growth model, and none of the control variables were significant. Therefore, this model was not included. The next model built was the conditional growth model with the CNA predictors. Only the predictors that showed significance were included. The following formula was used to build this model:

$$\text{ZAgitation}_{ij} \sim \text{N}\ (XB, \Omega)$$

$$\text{ZAgitation}_{ij} = \beta_{0j}\text{CONSTANT} + \beta_{1i}\text{Time}_i + \beta_2\text{ZSelfEfficacy}_i + B_3\text{ZKnowledge}_i$$

$$\beta_{0i} = \beta_0 + \Sigma_{j\epsilon CNA1(i)}\, w_{i,j}^{(3)} u_{0j}^{(3)} + u_{0,LEVEL2ID(i)}^{(2)} + e_{0i}$$

$$\beta_{1i} = \beta_1 + e_{1i}$$

$$\left[u_{0,CNA1(i)}^{(3)}\right] \sim N\left(0, \Omega_u^{(3)}\right): \Omega_u^{(3)} = [\Omega_{u0,0}^{(3)}]$$

$$\left[u_{0,LEVEL2ID(i)}^{(2)}\right] \sim N\left(0, \Omega_u^{(2)}\right): \Omega_u^{(2)} = [\Omega_{u0,0}^{(2)}]$$

$$\begin{bmatrix} e_{0i} \\ e_{1i} \end{bmatrix} \sim \text{N}(0,\ \Omega_e)\ :\ \Omega_e = \begin{bmatrix} \Omega_{e0,0} & \\ \Omega_{e0,1} & \Omega_{e1,1} \end{bmatrix}$$

Table 21 shows the comparison of the conditional growth model with predictors added in (Model 2Ca) to the previous models.

Table 21

Comparison of Model 2Aa (ii), Model 2Ba, and Model 2Ca

Parameter	Model 2Aa (ii)	Model 2Ba	Model 2Ca
	Fixed Effects		
ZAgitation			
CONSTANT	0.002 (0.13)	0.01 (0.18)	-0.05 (0.13)
Time		-0.21 (0.04)***	-0.18 (0.04)***
ZKnowledge			-0.54 (0.17)***
ZSelfEfficacy			-0.47 (0.19)***
	Random parameters		
Level: Level 3 CNA			
Var(CONSTANT)	0.93 (0.35)	2.40 (0.54)	1.02 (0.70)
Level: Level 2 Resident			
Var(CONSTANT)	0.04 (0.05)	0.03 (0.04)	0.20 (0.20)
Level: Level 1 Time			
Var(CONSTANT)	0.61 (0.08)	0.75 (0.06)	1.29 (0.09)
Covar (Time/CONSTANT		-0.55 (0.06)	-0.96 (0.06)
Var(Time)		0.38 (0.04)	0.65 (0.04)
DIC:	395.79	136.01	111.33
pD:	31.91	34.14	31.58

Note: Standard errors are in parentheses.

***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

Adding in the predictor variables of the change scores of knowledge and self-efficacy to the model resulted in an improved model fit (DIC =111.33 compared to the previous model where DIC=136.01). For this model, the between CNA variance decreased from 2.40 to 1.02, the between resident variance increased from 0.03 to 0.20, and the within person variance increased from 0.75 to 1.29. This model showed that time, and knowledge change scores and self-efficacy change scores were significant variables.

Classified Conditional Growth Model with CNA Predictors and Interactions.

The final model included the predictor variables in the previous model but added in the interaction effects with time. The following formula was used for this model:

$$ZAgitation_{ij} \sim N\ (XB, \Omega)$$

$$ZAgitation_{ij} = \beta_{0j}CONSTANT + \beta_{1i}Time_i + \beta_2 ZSelfEfficacy_i + B_3 ZKnowledge_i + \beta_4 ZSelfEfficacy.Time_i + B_5 ZKnowledge.Time_i$$

$$\beta_{0i} = \beta_0 + \Sigma_{j\epsilon CNA1(i)}\, w_{i,j}^{(3)} u_{0j}^{(3)} + u_{0,LEVEL2ID(i)}^{(2)} + e_{0i}$$

$$\beta_{1i} = \beta_1 + e_{1i}$$

$$\left[u_{0,CNA1(i)}^{(3)}\right] \sim N\left(0, \Omega_u^{(3)}\right): \Omega_u^{(3)} = [\Omega_{u0,0}^{(3)}]$$

$$\left[u_{0,LEVEL2ID(i)}^{(2)}\right] \sim N\left(0, \Omega_u^{(2)}\right): \Omega_u^{(2)} = [\Omega_{u0,0}^{(2)}]$$

$$\begin{bmatrix} e_{0i} \\ e_{1i} \end{bmatrix} \sim N(0,\ \Omega_e)\ :\ \Omega_e = \begin{bmatrix} \Omega_{e0,0} & \\ \Omega_{e0,1} & \Omega_{e1,1} \end{bmatrix}$$

Table 22 compares the final model (Model 2Da) to the previous models.

Adding in the main effects in addition to the interaction effects significantly reduced the DIC for an overall better fit (DIC of 93.57 compared to a DIC of 111.33 for Model 2Ca). For this model, the between CNA variance slightly decreased from 1.02 to 0.99, the between resident variance stayed the same, and the within person variance decreased from 1.29 to 1.18. This model showed that time, knowledge, along with the interaction effect of self-efficacy with time were all significant. The interaction effect of knowledge change with time showed a trend.

Table 22

Comparison of all models

Parameter	Model 2Aa (ii)	Model 2Ba	Model 2Ca	Model 2Da
		Fixed Effects		
ZAgitation				
CONSTANT	0.002 (0.13)	0.01 (0.18)	-0.05 (0.13)	-0.03 (0.14)
Time		-0.21 (0.04)***	-0.18 (0.04)***	-0.18 (0.04)***
ZKnowledge			-0.54 (0.17)***	-0.44 (0.19)***
ZSelfEfficacy			-0.47 (0.19)***	-0.27 (0.21)
ZKnowledge.Time				-0.08 (0.05)~
ZSelfEfficacy.Time				-0.14 (0.05)***
		Random parameters		
Level: Level 3 CNA				
Var(CONSTANT)	0.93 (0.35)	2.40 (0.54)	1.02 (0.70)	0.99 (0.71)
Level: Level 2 Resident				
Var(CONSTANT)	0.04 (0.05)	0.03 (0.04)	0.20 (0.20)	0.20 (0.20)
Level: Level 1 Time				
Var(CONSTANT)	0.61 (0.08)	0.75 (0.06)	1.29 (0.09)	1.18 (0.06)
Covar (Time/CONSTANT			-0.55 (0.06)	-0.87 (0.04)
Var(Time)		0.38 (0.04)	0.65 (0.04)	0.58 (0.03)
DIC:	395.79	136.01	111.33	93.57
pD:	31.91	34.14	31.58	32.11

Note: Standard errors are in parentheses.

***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

Figure 14 shows the knowledge change scores over time for those with change at the 10th and 90th percentile.

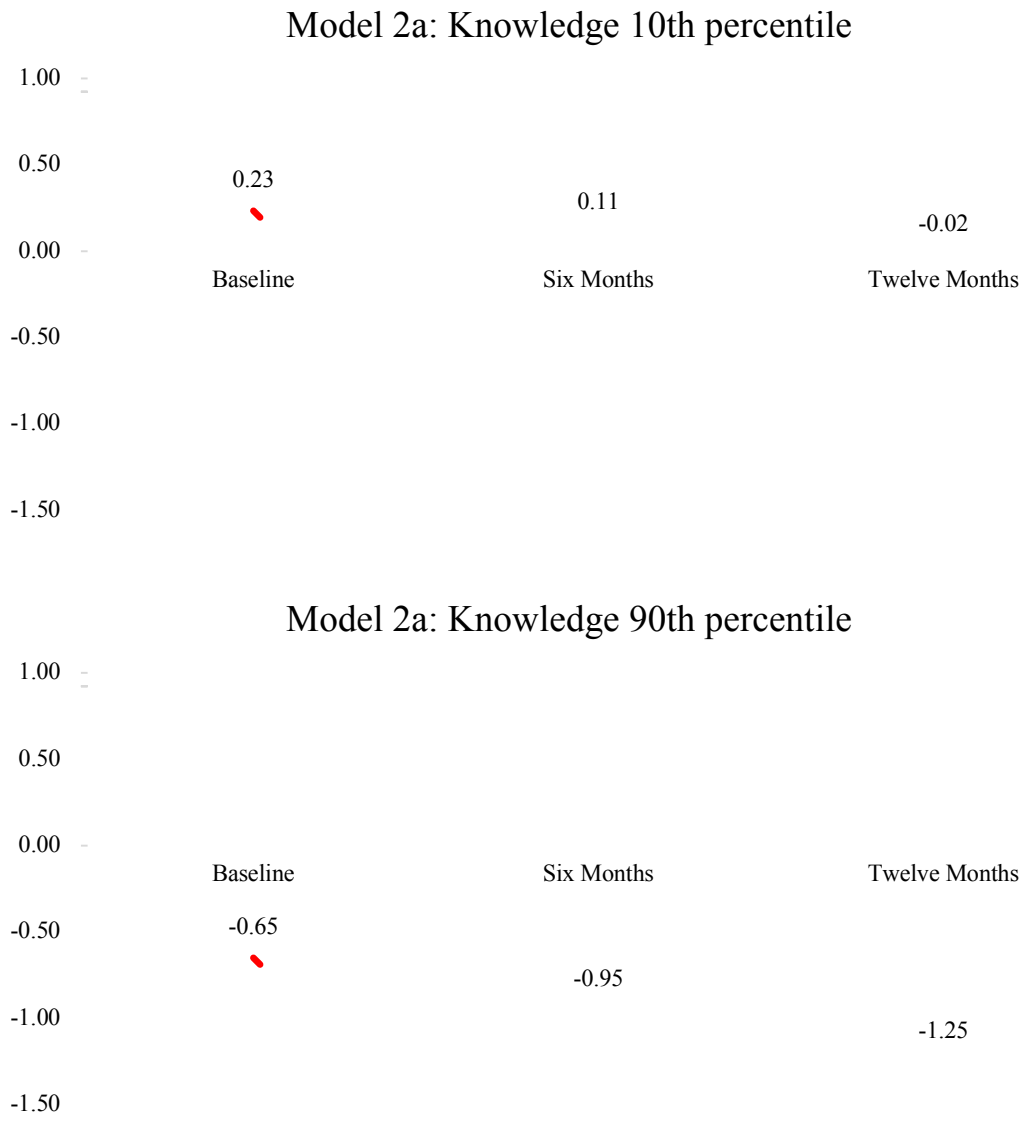


Figure 14. The effect of knowledge change scores and time on agitation

Figure 14 shows even for the CNAs where their change in knowledge was the smallest, agitation levels of residents decreased as a result of this knowledge change. Because these were standardized values, it can be concluded that for CNAs at the 10th percentile of knowledge increase, there was a 0.25 standard deviation decrease in agitation levels. For those where the knowledge change was the highest, agitation levels

of residents decreased more from -0.65 to -1.25, therefore a 0.60 standard deviation decrease in agitation levels. This differential change in agitation levels showed a trend.

Figure 15 shows the self-efficacy change scores over time for those with change at the 10th and 90th percentile.

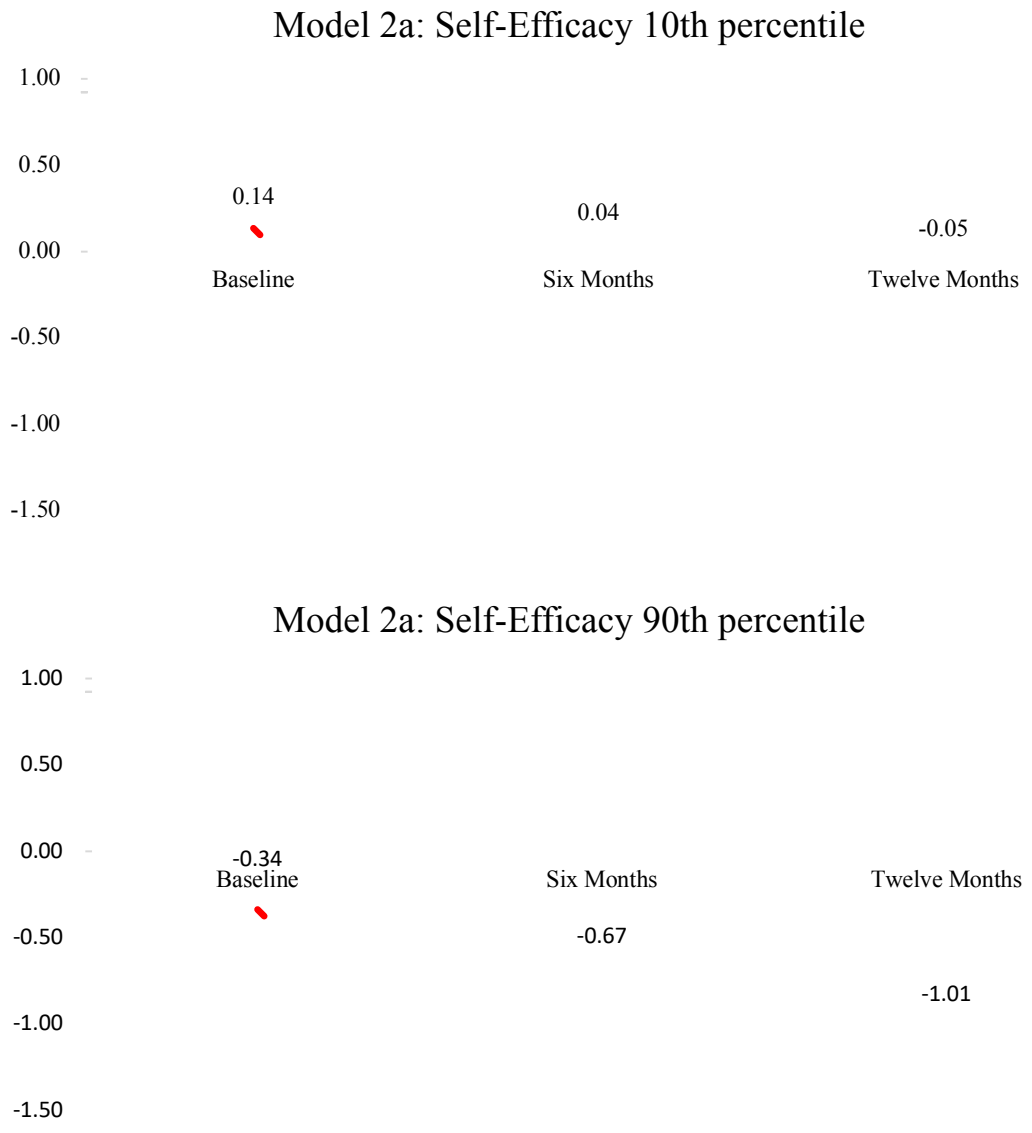


Figure 15. The effect of self-efficacy change scores and time on agitation

Figure 15 shows for the CNAs where their change in self-efficacy were the smallest, agitation levels of residents decreased slightly, from 0.14 to -005 as a result of this self-efficacy change. This change equals a 0.19 standard deviation decrease from baseline to twelve months in agitation levels. For those where the self-efficacy change was the highest, agitation levels of residents decreased more from -0.34 to -1.01 for a standard deviation decrease of 0.67. This differential change in agitation levels was significant.

Hypothesis 1 already showed that CNAs in the experimental groups showed a significantly higher increase in knowledge and self-efficacy over time than the CNAs in the control group who showed almost no change in knowledge and self-efficacy over time. Also, model 1a showed the experimental group had a significant decrease in agitation levels, with the agitation levels for the control group staying the same. From Model 2a it was possible to conclude that the compassionate care curriculum was able to change the knowledge and self-efficacy of CNAs resulting in a decrease in agitation levels for residents with AD.

ICC for level 3 was calculated on the final model using the same formula as used with the null model:

$$ICC = \frac{\Omega_{u0,0}^{(3)}}{\Omega_{u0,0}^{(3)} + \Omega_{u0,0}^{(2)} + \Omega_{e0,0}}$$

$$= \frac{0.99}{0.99+0.20+1.18}$$

$$= 0.42$$

ICC for level 2 was calculated on the final model as well:

$$ICC = \frac{\Omega_{u0,0}^{(2)}}{\Omega_{u0,0}^{(3)} + \Omega_{u0,0}^{(2)} + \Omega_{e0,0}}$$

$$= \frac{0.20}{0.99+0.20+1.18}$$

$$= 0.08$$

This shows that after adding the CNA predictors to the model, the between CNA variance was reduced from 0.59 (null model) to 0.42. The between resident variance slightly increased from 0.03 (null model) to 0.08. However, this between resident variance is much less than the variance that still existed after Model 1a was completed. It is clear that the between resident variance was a product of the characteristics of the CNAs taking care of the residents. The CNAs were influenced differently by the curriculum or lack of exposure to the curriculum. Once these differences were accounted for in the model, the between resident variance decreased.

Hypothesis 2b: Salivary Cortisol Levels. Hypothesis 2b focuses on the trajectories of persons with AD in terms of salivary cortisol compared to the control group, while taking into effect the impact of the different CNAs on the persons with AD.

Unconditional Unclassified Null Model. The first model (Model 2Ab (i)) that was fitted was the unconditional unclassified model. This model only fits the effect of the CNA that had the highest weighted time with a specific resident. The reason for building this model first was to investigate if a classified model where the effect of all CNA's working with a specific resident was modeled, would be a better fitted model. If not, only the effect of one CNA needed to be modeled, resulting in a less complicated model. The following equation was used to fit this model:

$$\text{ZSalivaryCortisolLevels}_{ijk} \sim \text{N}(XB, \Omega)$$

$$\text{ZSalivaryCortisolLevels}_{ijk} = \beta_{0ijk}\text{CONSTANT}$$

$$\beta_{0ijk} = \beta_0 + \text{v}_{0k} + u_{ojk} + e_{0ijk}$$

$$[\text{v}_{0k}] \sim N\ (0,\ \Omega_v)\text{:}\ \Omega_v = [\sigma_{v0}^2]$$

$$[\text{u}_{0jk}] \sim N\ (0,\ \Omega_u)\text{:}\ \Omega_u = [\sigma_{u0}^2]$$

$$[\text{e}_{0ijk}] \sim N\ (0,\ \Omega_e)\text{:}\ \Omega_e = [\sigma_{e0}^2]$$

Table 23 shows the estimated intercept, variance components and, model fit for the three-level unconditional unclassified model using CNAs at level 3, persons with AD at level 2, and measurement points at level 1. There were 50 level 3 units, 52 level 2 units, and 156 level 1 units.

Table 23

Model 2Ab

Parameter	Model 2Ab (i)
Fixed Effects	
ZSalivary Cortisol	
CONSTANT	-0.002 (0.13)
Random Parameters	
Level: Level 3 CNA	
Var(CONSTANT)	0.04 (0.07)
Level: Level 2 Resident	
Var(CONSTANT)	0.70 (0.17)
Level: Level 1 Time	
Var(CONSTANT)	0.29 (0.04)
DIC:	292.61
pD:	46.67

Note: Standard errors are in parentheses.
***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

Based on the intercept value, it is estimated that the mean resident with AD is predicted a Z salivary cortisol levels score of -0.002. This estimate does not differ significantly from zero and is expected as the response variable is approximately standardized and therefore has a mean of approximately zero. The between CNA variance is estimated at 0.04 (level 3), the resident with AD variance is estimated at 0.70 (level 2), and the within resident variance is estimated at 0.29 (level 1). The DIC for the unconditional model is estimated at 292.61.

Classified Unconditional Model. The next model that was built was the classified unconditional model. Unlike the unclassified unconditional model, this model took into consideration that one resident received care from multiple CNAs. The following formula was used for this model:

$$\text{ZSalivaryCortisolLevels}_{ij} \sim \text{N}\ (XB, \Omega)$$

$$\text{ZSalivaryCortisolLevels}_{ij} = \beta_{0ij}\text{CONSTANT}$$

$$\beta_{0i} = \beta_0 + \Sigma_{j \epsilon CNA1(i)}\, w_{i,j}^{(3)} u_{0j}^{(3)} + u_{0,LEVEL2ID(i)}^{(2)} + e_{0i}$$

$$\left[u_{0,CNA1(i)}^{(3)}\right] \sim N\left(0, \Omega_u^{(3)}\right): \Omega_u^{(3)} = [\Omega_{u0,0}^{(3)}]$$

$$\left[u_{0,LEVEL2ID(i)}^{(2)}\right] \sim N\left(0, \Omega_u^{(2)}\right): \Omega_u^{(2)} = [\Omega_{u0,0}^{(2)}]$$

$$[e_{0i}] \sim \text{N}(0, \Omega_e): \Omega_e = [\Omega_{e0,0}]$$

Table 24 shows the classified unconditional model (Model 2Ab (ii)) compared to the unclassified unconditional model (Model 2Ab (i)).

Table 24

Comparison of Model 2Ab(i) and Model 2Ab(ii)

Parameter	Model 2Ab (i)	Model 2Ab (ii)
	Fixed Effects	
ZSalivary Cortisol		
CONSTANT	-0.002 (0.13)	-0.004 (0.13)
	Random Parameters	
Level: Level 3 CNA		
Var(CONSTANT)	0.04 (0.07)	0.17 (0.29)
Level: Level 2 Resident		
Var(CONSTANT)	0.70 (0.17)	0.67 (0.18)
Level: Level 1 Time		
Var(CONSTANT)	0.29 (0.04)	0.29 (0.04)
DIC:	292.61	292.48
pD:	46.67	46.64

Note: Standard errors are in parentheses.
***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

Using a classified model did not result in an improved fit (DIC = 292.61 for the unclassified unconditional model versus DIC = 292.48 for the classified unconditional model). Given that the unclassified unconditional model produced a better fit, it was better to build a simpler unclassified model instead of a classified model.

For the unclassified, unconditional model, the intraclass correlation for level 3 was calculated using the following formula:

$$ICC = \frac{\Omega_{u0,0}^{(3)}}{\Omega_{u0,0}^{(3)} + \Omega_{u0,0}^{(2)} + \Omega_{e0,0}}$$

$$= \frac{0.04}{0.04+0.70+0.29}$$

$$= 0.04$$

The intraclass correlation for level 2 was calculated using the following formula:

$$ICC = \frac{\Omega_{u0,0}^{(2)}}{\Omega_{u0,0}^{(3)} + \Omega_{u0,0}^{(2)} + \Omega_{e0,0}}$$

$$= \frac{0.70}{0.04+0.70+0.29}$$

$$= 0.68$$

Based on the calculation the ICC for level 3 was 0.04, suggesting that 4% of the variance in salivary cortisol levels was between CNAs, while the ICC for level 2 was 0.68, suggesting that 68% of the variance was explained by the residents with AD. The reason for this may be attributed to the fact that salivary cortisol is a biomarker, unlike the agitation scores which were measured on a rating scale by the CNAs, and therefore much more subject to CNA influences.

The DIC for the unconditional model was estimated at 292.61. It was expected that with more variables added to the model, the between and within variances would decrease, and the fit statistic would improve.

Unclassified Unconditional Growth Model. The unconditional growth model (Model 2Bb) is the unconditional model with the time variable added. It depicts the average salivary cortisol levels over time across individuals.

The formula used to fit this model is shown below:

$$\text{ZSalivaryCortisolLevels}_{ijk} \sim \text{N}(XB, \Omega)$$

$$\text{ZSalivaryCortisolLevels}_{ijk} = \beta_{0ijk}\text{CONSTANT} + \beta_{1i}\text{Time}_{ijk}$$

$$\beta_{0ijk} = \beta_0 + \text{v}_{0k} + u_{ojk} + e_{0ijk}$$

$$\beta_{1i} = \beta_1 + e_{1ijk}$$

$$[\text{v}_{0k}] \sim N\ (0,\ \Omega_v)\text{: } \Omega_v = [\sigma_{v0}^2]$$

$$[\text{u}_{0jk}] \sim N\ (0,\ \Omega_u)\text{: } \Omega_u = [\sigma_{u0}^2]$$

$$\begin{bmatrix}\text{e}_{0ijk}\\ \text{e}_{1ijk}\end{bmatrix} \sim N\ (0,\ \Omega_e)\text{: } \Omega_e = \begin{bmatrix}\sigma_{e0}^2 & \\ \sigma_{e01}^2 & \sigma_{e1}^2\end{bmatrix}$$

Table 25 shows the classified unconditional model (Model 2Ab (i)) compared to the classified unconditional growth model (Model 2Bb).

Table 25

Comparison of Model 2Ab (i) and Model 2Bb

Parameter	Model 2Ab (i)	Model 2Bb
Fixed Effects		
ZSalivary Cortisol		
CONSTANT	-0.002 (0.13)	-0.01 (0.15)
Time		0.001 (0.06)
Random Parameters		
Level: Level 3 CNA		
Var(CONSTANT)	0.04 (0.07)	0.04 (0.07)
Level: Level 2 Resident		
Var(CONSTANT)	0.70 (0.17)	0.77 (0.19)
Level: Level 1 Time		
Var(CONSTANT)	0.29 (0.04)	0.46 (0.11)
Covar(Time/CONSTANT)		-0.26 (0.11)
Var(Time)		0.22 (0.09)
DIC:	292.61	269.43
pD:	46.67	44.89

Note: Standard errors are in parentheses.
***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

Adding time to the model resulted in an improved model fit (DIC = 269.43 for the unconditional growth model versus DIC = 292.61 for the unconditional model). Time was added as a random effect on level 1. For this model, the between CNA variance stayed the same, the between resident variance increased from 0.70 to 0.77, and the within person variance increased from 0.29 to 0.46. Time was not a significant variable.

Unclassified Conditional Growth Model with CNA Predictors. A model was built where both the CNA and resident control variables were added to the unconditional growth model. None of the control variables were significant, so this model is not shown. The next model built was Model 2Cb, where CNA predictor variables were added. None of the predictors were significant, but the change in knowledge was kept, as the interaction between knowledge and time was significant in later models. The following formula was used to build this model:

$$\text{ZSalivaryCortisolLevels}_{ijk} \sim \text{N}(XB, \Omega)$$

$$\text{ZSalivaryCortisolLevels}_{ijk} = \beta_{0ijk}\text{CONSTANT} + \beta_{1i}\text{Time}_{ijk} + \beta_{2}\text{Knowledge}_{jk}$$

$$\beta_{0ijk} = \beta_0 + \text{v}_{0k} + u_{ojk} + e_{0ijk}$$

$$\beta_{1i} = \beta_1 + e_{1ijk}$$

$$[\text{v}_{0k}] \sim N\ (0,\ \Omega_v)\text{:}\ \Omega_v = [\sigma^2_{v0}]$$

$$[\text{u}_{0jk}] \sim N\ (0,\ \Omega_u)\text{:}\ \Omega_u = [\sigma^2_{u0}]$$

$$\begin{bmatrix} \text{e}_{0ijk} \\ \text{e}_{1ijk} \end{bmatrix} \sim N\ (0,\ \Omega_e)\text{:}\ \Omega_e = \begin{bmatrix} \sigma^2_{e0} & \\ \sigma^2_{e01} & \sigma^2_{e1} \end{bmatrix}$$

Table 26 shows the comparison of the conditional growth model with CNA predictors added in (Model 2Cb) to the previous models.

Table 26

Comparison of Model 2Ab (i), Model 2Bb, and Model 2Cb

Parameter	Model 2Ab (i)	Model 2Bb	Model 2Cb
	Fixed Effects		
ZSalivary Cortisol			
CONSTANT	-0.002 (0.13)	-0.01 (0.15)	-0.01 (0.15)
Time		0.001 (0.06)	0.001 (0.06)
ZKnowledge			-0.20 (0.16)
	Random Parameters		
Level: Level 3 CNA			
Var(CONSTANT)	0.04 (0.07)	0.04 (0.07)	0.04 (0.6)
Level: Level 2 Resident			
Var(CONSTANT)	0.70 (0.17)	0.77 (0.19)	0.77 (0.19)
Level: Level 1 Time			
Var(CONSTANT)	0.29 (0.04)	0.46 (0.11)	0.50 (0.10)
Covar(Time/CONSTANT)		-0.26 (0.11)	-0.29 (0.09)
Var(Time)		0.22 (0.09)	0.24 (0.09)
DIC:	292.61	269.43	268.88
pD:	46.67	44.89	45.48

Note: Standard errors are in parentheses.
***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

Adding the knowledge change score CNA predictor variable to the model did not result in an improved model fit (DIC =268.88 compared to the previous model where DIC=269.43). For this model, the variance components stayed the same.

Unclassified Conditional Growth Model with CNA Predictors and Agitation. The next model included knowledge from the previous model with the addition of the outcome variable agitation. The following formula was used to create this model:

$$\text{ZSalivaryCortisolLevels}_{ijk} \sim \text{N}(XB, \Omega)$$

$$\text{ZSalivaryCortisolLevels}_{ijk}$$

$$= \beta_{0ijk}\text{CONSTANT} + \beta_{1i}\text{Time}_{ijk} + \beta_2\text{Knowledge}_{jk}$$

$$+ \beta_3\text{Agitation}_{ijk}$$

$$\beta_{0ijk} = \beta_0 + \text{v}_{0k} + u_{ojk} + e_{0ijk}$$

$$\beta_{1i} = \beta_1 + e_{1ijk}$$

$$\beta_{3j} = \beta_3 + u_{3jk}$$

$$[\text{v}_{0k}] \sim N\ (0,\ \Omega_v):\ \Omega_v = [\sigma^2_{v0}]$$

$$\begin{bmatrix}\text{u}_{0jk}\\ \text{u}_{3jk}\end{bmatrix} \sim N\ (0,\ \Omega_u):\ \Omega_u = \begin{bmatrix}\sigma^2_{u0} & \\ \sigma_{u03} & \sigma^2_{u3}\end{bmatrix}$$

$$\begin{bmatrix}\text{e}_{0ijk}\\ \text{e}_{1ijk}\end{bmatrix} \sim N\ (0,\ \Omega_e):\ \Omega_e = \begin{bmatrix}\sigma^2_{e0} & \\ \sigma^2_{e01} & \sigma^2_{e1}\end{bmatrix}$$

Table 27 compares the model (Model 2Db) to the previous models.

Adding agitation to the model produced a significantly better overall model fit (DIC= 268.88 for Model 2Cb compared to 252.32 for Model 2Db). Agitation produced a better fit when it was allowed to vary between residents (Level 2). For this model, the between CNA variance stayed the same, the between resident variance decreased from 0.77 to 0.74 and the within resident variance decreased from 0.50 to 0.31. This model showed that time and agitation were both significant.

Table 27

Comparison of Model 2Ab (i), Model 2Bb, Model 2Cb, and Model 2Db

Parameter	Model 2Ab (i)	Model 2Bb	Model 2Cb	Model 2Db
		Fixed Effects		
ZSalivary Cortisol				
CONSTANT	-0.002 (0.13)	-0.01 (0.15)	-0.01 (0.15)	-0.15 (0.15)
Time		0.001 (0.06)	0.00 (0.06)	0.15 (0.06)**
ZKnowledge			-0.20 (0.16)	-0.03 (0.17)
ZAgitation				0.34 (0.08)***
		Random Parameters		
Level: Level 3 CNA				
Var(CONSTANT)	0.04 (0.07)	0.04 (0.07)	0.04 (0.6)	0.04 (0.07)
Level: Level 2 Resident				
Var(CONSTANT)	0.70 (0.17)	0.77 (0.19)	0.77 (0.19)	0.74 (0.18)
Covar(ZAgitation/CONSTANT)				0.06 (0.06)
Var(ZAgitation)				0.03 (0.02)
Level: Level 1 Time				
Var(CONSTANT)	0.29 (0.04)	0.46 (0.11)	0.5 (0.10)	0.31 (0.09)
Covar(Time/CONSTANT)		-0.26 (0.11)	-0.29 (0.09)	-0.02 (0.09)
Var(Time)		0.22 (0.09)	0.24 (0.09)	-0.01 (0.09)
DIC:	292.61	269.43	268.88	252.32
pD:	46.67	44.89	45.48	50.33

Note: Standard errors are in parentheses.
***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

Unclassified Conditional Growth Model with CNA Predictors and Interactions. The final model included the predictor variables in the previous model but added the interaction effect between knowledge change and time. The following formula was used to build this model:

$$\text{ZSalivaryCortisolLevels}_{ijk} \sim \text{N}(XB, \Omega)$$

$$\text{ZSalivaryCortisolLevels}_{ijk} = \beta_{0ijk}\text{CONSTANT} + \beta_{1i}\text{Time}_{ijk} + \beta_{2i}\text{ZKnowledge}_{jk} + \beta_{3j}\text{ZAgitation}_{ijk} + \beta_4\text{ZKnowledge.Time}_{ijk}$$

$$\beta_{0ijk} = \beta_0 + \nu_{0k} + u_{ojk} + e_{0ijk}$$

$$\beta_{1i} = \beta_1 + e_{1ijk}$$

$$\beta_{3j} = \beta_3 + u_{3jk}$$

$$[\nu_{0k}] \sim N\,(0,\, \Omega_v)\colon\ \Omega_v = [\sigma_{v0}^2]$$

$$\begin{bmatrix} u_{0jk} \\ u_{3jk} \end{bmatrix} \sim N\,(0,\, \Omega_u)\colon\ \Omega_u = \begin{bmatrix} \sigma_{u0}^2 & \\ \sigma_{u03} & \sigma_{u3}^2 \end{bmatrix}$$

$$\begin{bmatrix} e_{0ijk} \\ e_{1ijk} \end{bmatrix} \sim N\,(0,\, \Omega_e)\colon\ \Omega_e = \begin{bmatrix} \sigma_{e0}^2 & \\ \sigma_{e01} & \sigma_{e1}^2 \end{bmatrix}$$

Adding in the interaction between knowledge change and time significantly reduced the DIC for an overall better fit (DIC of 244.23 compared to a DIC of 252.43 for Model 2Db). For this model, the between CNA variance stayed the same, the between resident variance stayed the same, and the within person variance increased slightly from 0.31 to 0.34. This model showed that agitation, along with the interaction effect of knowledge with time were significant. Time as a variable showed a trend towards significance. Table 28 compared Model 2Eb to previous models.

Table 28

Comparison of All Models

Parameter	Model 2Ab (i)	Model 2Bb	Model 2Cb	Model 2Db	Model 2Eb
			Fixed Effects		
ZSalivary Cortisol					
CONSTANT	-0.002 (0.13)	-0.01 (0.15)	-0.01 (0.15)	-0.15 (0.15)	-.08 (0.15)
Time		0.001 (0.06)	0.00 (0.06)	0.15 (0.06)**	0.10 (0.06)~
ZKnowledge			-0.20 (0.16)	-0.03 (0.17)	0.15 (0.18)
ZAgitation				0.34 (0.08)***	0.22 (0.09)*
ZKnowledge.Time					-0.19 (0.07)**
			Random Parameters		
Level: Level 3 CNA					
Var(CONSTANT)	0.04 (0.07)	0.04 (0.07)	0.04 (0.6)	0.04 (0.07)	0.04 (0.07)
Level: Level 2 Resident					
Var(CONSTANT)	0.70 (0.17)	0.77 (0.19)	0.77 (0.19)	0.74 (0.18)	0.74 (0.18)
Covar(ZAgitation/CONSTANT)				0.06 (0.06)	0.06 (0.05)
Var(ZAgitation)				0.03 (0.02)	0.03 (0.02)
Level: Level 1 Time					
Var(CONSTANT)	0.29 (0.04)	0.46 (0.11)	0.5 (0.10)	0.31 (0.09)	0.34 (0.12)
Covar(Time/CONSTANT)		-0.26 (0.11)	-0.29 (0.09)	-0.02 (0.09)	-0.09 (0.12)
Var(Time)		0.22 (0.09)	0.24 (0.09)	-0.01 (0.09)	0.04 (0.09)
DIC:	292.61	269.43	268.88	252.32	244.23
pD:	46.67	44.89	45.48	50.33	51.56

Note: Standard errors are in parentheses.

***p < 0.001; **p < 0.01; *p < 0.05; ~p<0.10

Figure 16 shows the knowledge change scores over time for those with change at the 10th and 90th percentile.

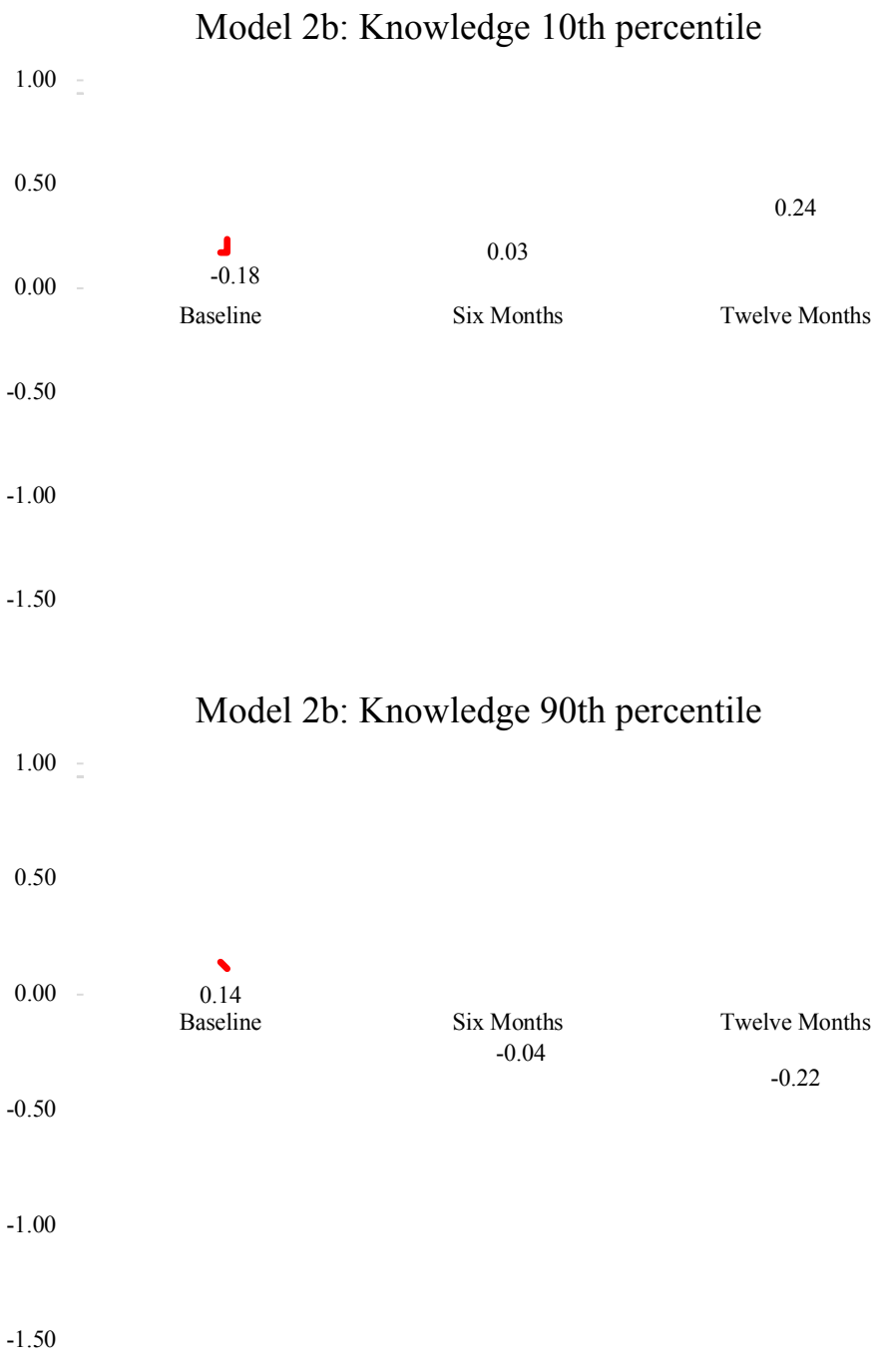


Figure 16. The effect of knowledge change scores and time on salivary cortisol levels

Figure 16 shows that for the CNAs where their change in knowledge was the smallest (10th percentile), salivary cortisol levels of residents increased. Because these were standardized values, it can be concluded that for CNAs at the 10th percentile of

knowledge increase, there was a 0.42 standard deviation increase in salivary cortisol levels. For those where the knowledge change was the highest, salivary cortisol levels of residents decreased from 0.14 at baseline to -0.22 at 12 weeks, therefore a 0.36 standard deviation decrease in agitation levels. This shows the importance of understanding AD disease and increased knowledge of CNAs in reducing the stress of AD residents.

Figure 17 shows the agitation scores over time for those with agitation at the 10th and 90th percentile.

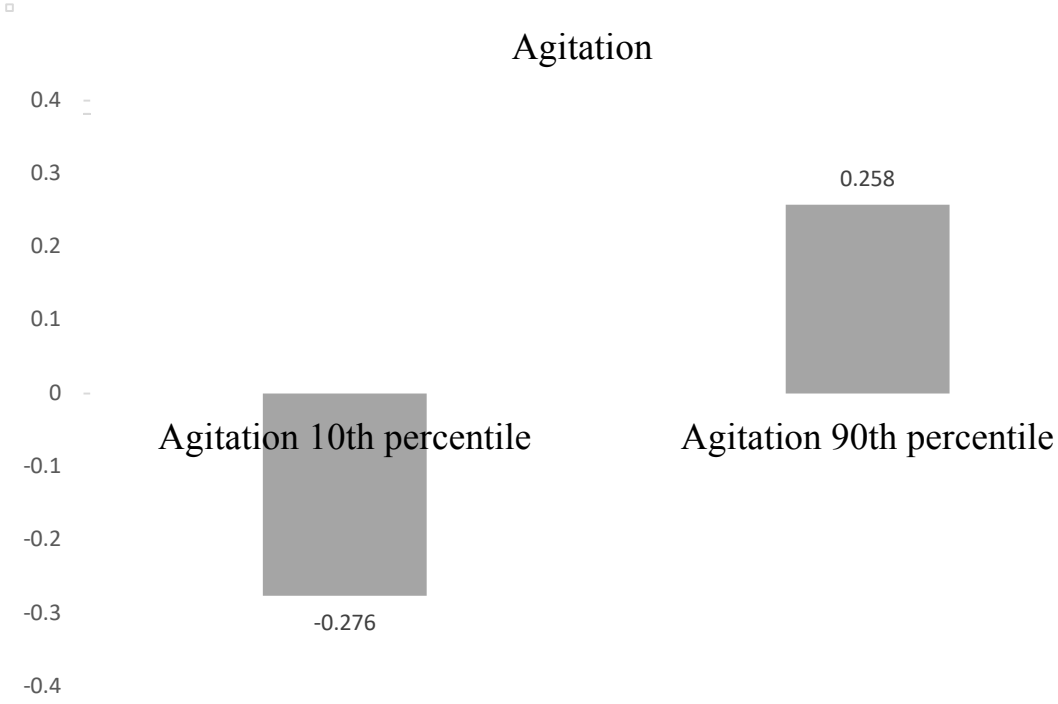


Figure 17. The effect of agitation on saliva cortisol levels

Figure 17 shows that for persons with agitation levels in the 10th percentile, their salivary cortisol levels were lower. For those where agitation levels were the highest (90th percentile), salivary cortisol levels were higher.

Hypothesis 1 already showed that CNAs in the experimental groups showed a significantly higher increase in knowledge than the CNAs in the control group who showed almost no change in knowledge over time. Also, model 1b showed the experimental group had a significant decrease in salivary cortisol levels, with the salivary cortisol levels increasing for the control group. From Model 2b it is possible to conclude that the CC curriculum was able to change the knowledge of CNAs resulting in a decrease in agitation levels, and subsequently a decrease in saliva cortisol levels for residents with AD.

ICC for level 3 was calculated on the final model using the same formula as used with the null model:

$$ICC = \frac{\Omega_{u0,0}^{(3)}}{\Omega_{u0,0}^{(3)} + \Omega_{u0,0}^{(2)} + \Omega_{e0,0}}$$

$$= \frac{0.04}{0.04+0.74+0.34}$$

$$= 0.03$$

ICC for level 2 was calculated on the final model as well:

$$ICC = \frac{\Omega_{u0,0}^{(2)}}{\Omega_{u0,0}^{(3)} + \Omega_{u0,0}^{(2)} + \Omega_{e0,0}}$$

$$= \frac{0.74}{0.04+0.74+0.34}$$

$$= 0.66$$

This shows that after adding the CNA predictors to the model, the between CNA variance reduced slightly from 0.04 (null model) to 0.03. The between resident variance also reduced slightly from 0.68 (null model) to 0.66. However, the between resident variance left with Model 2b was higher than what was left after Model 1b was completed (0.48 for Model 1b compared to 0.66 for Model 2b). More analysis will be needed with additional potential predictors than what was measured with this study to investigate what other predictors could potentially explain these differences between salivary cortisol levels of AD residents. What is, however, clear is that positive changes in knowledge led to significant reductions in agitation, that in turn resulted in reduced salivary cortisol levels. These results showed the value of the CC curriculum to improve the abilities of the CNAs to better care for residents with AD.

Summary

This study utilized the Kirkpatrick model to evaluate the effectiveness of the compassionate care curriculum. The first half of this chapter focused on the first three levels of the Kirkpatrick model of evaluation, namely, reaction, learning, and behavior. To understand the impact of the compassionate care curriculum on the CNAs, we examined changes in their knowledge of AD, self-efficacy, caregiver satisfaction and affiliate stigma at baseline and then after completing the 12-week compassionate care curriculum and participating in the care groups. For AD knowledge, a significant increase

was seen in scores from baseline to 12 weeks for the experimental group while the control group remained the same over the 12-week period. Self-efficacy for the experimental group improved between baseline and 12-weeks but deteriorated slightly for the control group. Caregiver satisfaction showed a slight improvement at 12-weeks for both groups, yet the experimental group showed a trend of greater improvement than the control group. For the experimental group, feelings of affiliate stigma declined between baseline and 12- weeks, while the control group remained similar at the 12-week period.

From the Kirkpatrick model, level 4 examined outcomes. For this study, the focus was on the stress outcomes of the residents with AD, specifically as it relates to agitation and salivary cortisol levels. Two models were built that were able to show that the residents with AD in the experimental group improved in terms of their agitation and salivary cortisol levels after 12 weeks. These two models did not include the impact of the CNAs. This helped us establish that there were changes between the two groups (experimental and control) as a result of the curriculum they were exposed to. The final 2 models were then built that showed the role of the CNAs and how they had an impact on the two groups. We saw that knowledge changes and self-efficacy changes had an impact on the agitation levels of residents with AD. For salivary cortisol levels, it was knowledge changes and agitation scores that had an impact.

Chapter 5 discusses the implications of this study in greater detail. Furthermore, the strengths and limitations, as well as ideas for future research, are described.

CHAPTER V: DISCUSSION

Using the Kirkpatrick model of evaluation and a multilevel modeling methodology, this study examined the use of a CC curriculum with CNA support groups and its' impact on persons with AD living in an experimental and a control nursing facility. The control facility CNAs provided care to persons with AD as usual with no additional training other than the state mandated CNA training program. The experimental nursing facility allowed their CNAs to participate in the CC curriculum. After 12-weeks, this study demonstrated that differences existed between the experimental and control nursing facilities as a result of the introduction of the CC curriculum.

At baseline, before the curriculum was introduced to the experimental facility, analysis was completed to determine if there were differences between the control and experimental groups. For the CNAs in the study, we looked at age, race/ethnicity, gender, number of years working in nursing facilities, number of years working in the current facility, and number of years of formal education. Analysis showed that the control and experimental groups were similar on most demographic variables except that the experimental group was older and worked longer in nursing facilities than the control group. Between the two groups, there were no significant differences between the control and experimental group on their AD knowledge, self-efficacy, caregiving satisfaction or affiliate stigma at baseline.

For the residents with AD, there were no differences in the demographics of the control and experimental group, namely in terms of their age, gender, race/ethnicity, and rapid cognitive screening scores. Furthermore, in terms of the outcome variables at baseline, there were no significant differences between the control and experimental group on the agitation of residents with AD as well as their salivary cortisol levels.

In looking first at the CNAs change scores from baseline to 12 weeks, we saw a significant change in terms of AD knowledge, self-efficacy, caregiver satisfaction and affiliate stigma for those working in the experimental facility compared to those that were at the control facility and not participating in the CC curriculum.

Multilevel models were first built by examining the outcome measures, agitation, and salivary cortisol, without including the impact of the CNAs. By building the models independent of the CNA measures, we were able to demonstrate that the persons with AD in the experimental group showed improvements in terms of their agitation and salivary cortisol levels over the 12 weeks the study took place.

Additional models were constructed to show that the CNAs contributed to this difference between the experimental and control facilities. No control CNA or resident with AD variables were controlled for in the model, as they did not show to have any significant impact on the final outcome. In terms of agitation, analysis showed that knowledge and self-efficacy were the strongest CNA predictors of a decrease in the resident's agitation over time.

In the final salivary cortisol model, we were able to show that knowledge and agitation were the strongest predictors of a decrease in salivary cortisol levels.

Implications for CNA Training in Kentucky

This study has the potential to impact the way we conceptualize the care provided by CNAs. Our current structure of training is rather limiting to the CNAs in that they are not provided with any skill development related to understanding persons with AD and the disease. As a result, we marginalize CNAs in that we do not fully allow them to explore all that the profession can offer. By incorporating the CC curriculum, we can change the conceptualization of care that currently exists within the profession and affect the way persons with AD are cared for.

Changing the Conceptualization of Care

As previously elucidated in Chapters 1 and 2, the way we conceptualization care in the United States in nursing facilities has been largely basic nursing care. We have ignored the relationship between the CNA and the person with AD. Even the movement towards more person-centered care is more focused on the journey of the person and leaves no room for the relationship between these two persons. This mode of thinking ignores the bond that is formed between the CNA and the person with AD. Part of the intent of the CC curriculum is to acknowledge that there is a bond between the CNA and the person with AD and to focus on how to help turn that bond into better care.

We know that conceptualizing care solely as basic nursing care is not working, as evidenced by the current state of long-term care in Kentucky. In terms of long-term care measures, Kentucky is ranked 50th in the nation (AARP, 2017). Unlike other states, such as California and Minnesota, Kentucky does not offer additional training for CNAs working with persons with AD (AARP, 2017). This study demonstrates that with more training and support, the care that CNAs provide can positively affect persons with AD

living in nursing facilities. In particular, this study has policy implications for training regulations for CNAs in Kentucky. As previously stated, the current CNA training in Kentucky follows the minimum training regulations set for by OBRA in 1987 (Code of Federal Regulations, 2012; Hawes, 2003). This training is predicated on basic nursing care, meaning that CNAs are charged with providing care that meets the needs of the persons with AD in terms of their ADLs.

It is also important to note that the purpose of the CC curriculum is not to replace the current trainings that are required for CNAs. Basic nursing care is a necessary component of care. The purpose of this study was to show how care can be enhanced to include compassionate care and the impact that this can have on persons with AD living in nursing facilities. This training adds further content to the CNA training structure. Adding more hours to the certification requirements would be an important step in assisting CNAs with developing the skills that they need to work with persons with AD. Therefore, in addition to advocating for more training for CNAs, we hope to advocate at a state level that the incorporation of more compassionate care, in addition to the current training that is received, would be important for CNAs and the people they care for. Currently, there is no legislative agenda in Kentucky that includes a focus on the amount of training or type of training that CNAs receive.

Future Research

The original research design proposed using eight experimental and eight control facilities for a larger sample. However, due to a number of factors, namely, funding and time limitations we had to reduce the sample size. Furthermore, the original proposal included a sample strategy that focused on exploring the impact of the profit status and

the size of the facility on the outcomes. The outcomes of this study have opened up several areas of future research that will be explored, using the original proposal as a guideline for examining different types of nursing facilities. Therefore, moving forward, it will be important to establish facilities of different sizes and profit status. For this study, we only used facilities that were part of the same health care system and were both considered medium in size. However, to understand further applications of this program, it will be beneficial to compare groups based on profit status and size and to expand the program to other healthcare systems.

In addition to expanding this to nursing facilities in other health care systems, we want to use this information to build a certificate program for compassionate care curriculum designed specifically for CNAs caring for persons with AD. We have explored opportunities on how to offer this with a local technical and community college; therefore, future research of the impact of the curriculum could be tied to this particular set of courses that CNAs from multiple healthcare systems would attend. The premise of this expansion would be to use a micro-credentialing approach to learning care and strategies for working with persons with AD. Micro-credentialing is a competency-based approach to skill development where learners participate in mini or short modules and then demonstrate competency in an area (Berry & Cator, 2016).

Expansion of this project will also include a Project Echo focused on the compassionate care of persons with AD. Project Echo is a telementoring program where professionals interested in learning more about a particular area such as AD can join via a teleconferencing program Zoom (University New Mexico School of Medicine, 2018).

This will allow for the dissemination of the compassionate care curriculum to a wider audience.

Understanding the long-term impact of the compassionate curriculum and the establishment of care groups is also an important area of research that was not addressed in this study. For the purposes of this dissertation, data collection stopped after 12-weeks. Conducting further data collection on the persons from this study will be useful in determining if the introduction of the compassionate care curriculum and the care groups were, in fact, a way to provide better care to persons with AD. Adding this data to the current study will provide a greater understanding of how the CNAs were able to transfer the curriculum into behaviors and the impact that it has on persons with AD.

a include this measure and moreover, examine if CNA stress has an impact on the outcomes of the persons with AD. Given the effective use of salivary cortisol testing for persons with AD in this study, it will be interesting to also examine CNA stress by measuring the cortisol levels of the CNAs that participated in the study.

Conclusion

Strengths of the Study

This study contributes to the research focused on training of CNAs in their work with persons with AD in several critical ways. This study shows that basic nursing care training as mandated by state agencies is only one aspect of the training that CNAs need to for their work at nursing facilities. The results of this study indicate that enhancing mandatory training with a compassionate care curriculum creates a deeper connection between CNA and persons with AD. This connection can improve care delivery and the stress of persons with AD.

Using a control/experimental group design was also a strength in this study. This design allowed a clear understanding of the effect of the intervention and thereby increasing the reliability of the study.

At the beginning of this study, there were concerns that retention would be an issue for the CNAs in the study. However, for this study, we did not have the retention problems that are problematic for many studies involving CNAs.

This study was also strengthened by the collaboration with the healthcare system that we partnered with for the project. From the beginning of the project, the administrators were as accommodating to the project needs as possible. Data were collected without resistance from the administrators. We believe that this allowed us to have a complete set of data without any missingness for both the CNA sample and the persons with AD sample.

Limitations of the Study

While this study contributes to an understanding of the significance of including compassionate care into the training of CNAs working with persons with AD, there are limitations that must be addressed. First, due to time and setting restrictions, we were only able to include two facilities in this study. While we were able to meet the power requirements for our research design, including more facilities in the study will strengthen our findings.

Second, after CNAs at the experimental site were enrolled to participate in this program, we had to close the participation after a certain point despite a desire from more CNA participants to join in the study. While this will be rectified moving forward by the

introduction of a new session of the program at the experimental facility identified in this study, it did limit participation from some CNAs that enrolled in the program late.

Third, the care groups for CNAs were limited in both size and the times they were offered. Arrangements had to be made for the CNAs to come to the sessions and this required coordination with the nursing facility to provide coverage for those attending as it was assumed that this would be part of their shifts at the nursing facility. This meant that not every CNA in the study was available to attend every session.

Summary

The results of this study showed that integrating compassionate care into the work that CNAs do with persons with AD can lead to positive outcomes for CNAs in terms of improved AD knowledge, caregiver self-efficacy, caregiving satisfaction and affiliate stigma. The implementation of compassionate care also greatly impacts the agitation and cortisol levels of persons with AD. This has implications for the way we conceptualize the type of care that is provided by CNAs to persons with AD. Traditional basic nursing care focuses primarily on the basic needs of the person such as attending to activities of daily living. CNAs are trained to only provide this care and other areas are considered outside of their scope. While traditional basic nursing care is important, it should be supplemented with compassionate care for persons with AD. Compassionate care (CC) emphasizes the bond between the caregiver (the CNA) and the care receiver (the person with AD) and their journey together. CC can also provide CNAs with skills to respond to the changes that the person with AD undergoes as they decline.

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APPENDIX A: INFORMED CONSENT AND SURVEYS FOR CNAS FROM THE EXPERIMENTAL GROUP

Subject Informed Consent Document and Research Authorization

FOSTERING COMPASSIONATE CARE FOR INDIVIDUALS WITH ALZHEIMER'S DISEASE

Investigator(s) name & address: Anna C. Faul, PhD & Samantha Cotton, MSSW, 300 E Market St, Suite 200, Louisville KY 40222.

Site(s) where study is to be conducted: Institute for Sustainable Health & Optimal Aging

Phone number for subjects to call for questions: 502-852-5629

Introduction and Background Information

You are invited to participate in a research study that focuses on compassionate care in nursing home settings, specifically focusing on residents with Alzheimer's disease. The purpose of this study is to evaluate a curriculum designed for nurse aides working with residents with Alzheimer's disease. The study is being conducted by Dr. Anna C. Faul, PhD and Sam Cotton, MSSW, ABD**.** The study will take place at eight different nursing facilities in Kentucky.

Approximately 300 subjects will be invited to participate.

Purpose

The purpose of this study is to evaluate a training curriculum delivered to state registered nurse aides (SNRA's) in nursing homes.

Procedures

In this study, you will be asked to participate in eight online modules that will provide you with a foundation about Alzheimer's disease; these modules will focus on three

primary areas: 1.) the disease and its impact, 2.) Compassionate caregiving for individuals with Alzheimer's disease and 3.) Caring for the caregiver. After the completion of these eight modules, you will have the opportunity to participate in hands-on learning and support, known as care groups, within the nursing home where you work. As part of this study, you will complete pre and post-test surveys about your experience with curriculum, your knowledge of Alzheimer's disease and related dementias, and your confidence in performing activities with residents with Alzheimer's disease.

Potential Risks

There are no foreseeable risks other than possible discomfort in answering personal questions. There may be unforeseen risks.

Benefits

Nurse aides may increase their understanding of working with residents with Alzheimer's disease, which could contribute to a transformation within the nursing home towards more compassionate care. The information collected may not benefit you directly. The information learned in this study may be helpful to others.

Payment

You will not be compensated for your time, inconvenience, or expenses while you are in this study.

Revocation of Research Authorization

You may cancel the permission you have given to use and share your protected health information at any time. This means you can tell us to stop using and sharing your protected health information. If you cancel your permission:

- We will stop collecting information about you.
- You may not withdraw information that we had before you told us to stop.
    - We may already have used it or shared it.
    - We may need it to complete the research.
- Staff may ask your permission to follow-up with you if there is a medical reason to do so.

To cancel your permission, you will be requested to complete a written "Revocation of Research Authorization" form located at the end of this document. You may also obtain a copy from your study doctor, designated personnel or from the Human Subjects Protections Program Office website (http://louisville.edu/research/humansubjects/links-to-forms).

Confidentiality

Total privacy cannot be guaranteed. We will protect your privacy to the extent permitted by law. If the results from this study are published, your name will not be made public. Once your information leaves our institution, we cannot promise that others will keep it private.

Your information may be shared with the following:

- Organizations that provide funding at any time for the conduct of the research.
- The University of Louisville Institutional Review Board, Human Subjects Protection Program Office, Privacy Office, others involved in research administration and compliance at the University, and others contracted by the University for ensuring human subjects safety or research compliance
- The local research team
- Researchers at other sites participating in the study (if applicable)
- People who are responsible for research, compliance and HIPAA oversight at the institutions where the research is conducted
- People responsible for billing, sending and receiving payments related to your participation in the study
- Government agencies, such as:
    - Office for Human Research Protections
    - Office of Civil Rights

Security

Your information will be kept private. Any data collected will be stored at the Institute for Sustainable Health & Optimal Aging in secure area in a locked file cabinet.

Voluntary Participation

Taking part in this study is voluntary. You may choose not to take part at all. If you decide to be in this study, you may stop taking part at any time. If you decide not to be in this study or if you stop taking part at any time, you will not lose any benefits for which you may qualify.

You will be told about any changes that may affect your decision to continue in the study.

Contact Persons

If you have any questions, concerns, or complaints about the research study, please contact Samantha Cotton at 502-852-5629.

Research Subject's Rights

If you have any questions about your rights as a research subject, you may call the Human Subjects Protection Program Office at (502) 852-5188. You may discuss any questions about your rights as a research subject, in private, with a member of the Institutional Review Board (IRB). You may also call this number if you have other

questions about the research, and you cannot reach the study doctor, or want to talk to someone else. The IRB is an independent committee made up of people from the University community, staff of the institutions, as well as people from the community not connected with these institutions. The IRB has approved the participation of human subjects in this research study.

Concerns and Complaints

If you have concerns or complaints about the research or research staff and you do not wish to give your name, you may call the toll-free number 1-877-852-1167. This is a 24-hour hot line answered by people who do not work at the University of Louisville.

Acknowledgment and Signatures

This informed consent document is not a contract. This document tells you what will happen during the study if you choose to take part. Your signature indicates that this study has been explained to you, that your questions have been answered, and that you agree to take part in the study. You are not giving up any legal rights to which you are entitled by signing this informed consent document. You will be given a copy of this consent form to keep for your records.

_____	
Subject Name (Please Print)	Signature of Subject Date Signed
_____	_____
__	
Printed Name of Legally	Signature of Legally
	Date Signed Authorized Representative (if
applicable)	Authorized Representative

_____

Authority of Legally Authorized Representative to act on behalf of Subject

*Authority to act on behalf of another includes, but is not limited to parent, guardian, or durable power of attorney for health care.

Printed Name of Person Explaining Consent Form (if other than the Investigator)	Signature of Person Explaining Consent Form	Date Signed

Printed Name of Investigator	Signature of Investigator	Date Signed

List of Investigators:	**Phone Numbers:**
Anna Faul, PhD	502-852-1981
Sam Cotton, MSSW	502-852-5629

REVOCATION OF AUTHORIZATION FOR USE AND DISCLOSURE OF YOUR HEALTH INFORMATION FOR RESEARCH

Return To:

PI Address: 300 E Market St. Suite 200

Louisville KY 40222

OR

Institutional Review Board

MedCenter One, Suite 200

Do not sign this letter unless you are withdrawing from this research. You will be sent confirmation that this notice was received.

To Whom It May Concern:

I would like to discontinue my participation in the research study noted above. I understand that health information already collected will continue to be used as discussed in the Authorization I signed when joining the study.

Your options are (***choose one***):

☐ **Withdraw from Study & Discontinue Authorization:**
Discontinue my authorization for the future use and disclosure of protected health information. In some instances, the research team may need to use your information even after you discontinue your authorization, for example, to notify you or government agencies of any health or safety concerns that were identified as part of your study participation.

☐ **Withdraw from Study, but Continue Authorization:**
Allow the research team to continue collecting information from me and my personal health information. This would be done only as needed to support the goals of the study and would not be used for purposes other than those already described in the research authorization.

_____

Printed Name and Signature of Subject Date Signed

_____

Signature of Subject's Legal Representative (if subject is unable to sign) Date Signed

_____

Printed Name of Subject's Legal Representative

Optional:

I am ending my participation in this study because:

_____

CNA Baseline Survey (Experimental Group)

Participant ID: _____

Part I: Demographics

Please answer the following questions about yourself.

1.) Date of Birth: ____ /_____ /____

2.) Gender:

3.) Do you consider yourself Hispanic? Yes____ No_____

4.) Do you consider yourself primarily:

Black	
American Indian/Native American	
Asian	
White	
Other	

5.) Number of years working in nursing facilities: _____

6.) Number of years working in this specific facility: _____

7.) Number of years of formal educational training: _____

Part II: Alzheimer's Disease Knowledge Scale (ADKS)

Please answer each question by indicating whether the statement is true or false.

1. People with Alzheimer's disease are particularly prone to depression.
    a. True
    b. False
2. It has been scientifically proven that mental exercise can prevent a person from getting Alzheimer's disease.
    a. True
    b. False
3. After symptoms of Alzheimer's disease appear, the average life expectancy is 6 to 12 years.
    a. True
    b. False
4. When a person with Alzheimer's disease becomes agitated, a medical examination might reveal other health problems that caused the agitation.
    a. True
    b. False
5. People with Alzheimer's disease do best with simple instructions given one step at a time.
    a. True
    b. False
6. When people with Alzheimer's disease begin to have difficulty taking care of themselves, caregivers should take over right away.
    a. True
    b. False
7. If a person with Alzheimer's disease becomes alert and agitated at night, a good strategy is to try to make sure that the person gets plenty of physical activity during the day.
    a. True
    b. False
8. In rare cases, people have recovered from Alzheimer's disease.
    a. True
    b. False
9. People whose Alzheimer's disease is not yet severe can benefit from psychotherapy for depression and anxiety.
    a. True
    b. False
10. If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer's disease.
    a. True
    b. False

11. Most people with Alzheimer's disease live in nursing homes.
    a. True
    b. False
12. Poor nutrition can make the symptoms of Alzheimer's disease worse.
    a. True
    b. False
13. People in their 30's can have Alzheimer's disease.
    a. True
    b. False
14. A person with Alzheimer's disease becomes increasingly likely to fall down as the disease gets worse.
    a. True
    b. False
15. When people with Alzheimer's disease repeat the same question or story several times, it is helpful to remind them that they are repeating themselves.
    a. True
    b. False
16. Once people have Alzheimer's disease, they are no longer capable of making informed decisions about their own care.
    a. True
    b. False
17. Eventually, a person with Alzheimer's disease will need 24-hours supervision.
    a. True
    b. False
18. Having high cholesterol may increase a person's risk of developing Alzheimer's disease.
    a. True
    b. False
19. Tremor or shaking of the hands or arms is a common symptom in people with Alzheimer's disease.
    a. True
    b. False
20. Symptoms of severe depression can be mistaken for symptoms of Alzheimer's disease.
    a. True
    b. False
21. Alzheimer's disease is one type of dementia.
    a. True
    b. False
22. Trouble handling money or paying bills is a common early symptom of Alzheimer's disease.
    a. True
    b. False

23. One symptom that can occur with Alzheimer's disease is believing that other people are stealing one's things.
    a. True
    b. False
24. When a person has Alzheimer's disease, using reminder notes is a crutch that can contribute to decline.
    a. True
    b. False
25. Prescription drugs that prevent Alzheimer's disease are available.
    a. True
    b. False
26. Having high blood pressure may increase a person's risk of developing Alzheimer's disease.
    a. True
    b. False
27. Genes can only partially account for the development of Alzheimer's disease.
    a. True
    b. False
28. It is safe for people with Alzheimer's disease to drive, as long as they have a companion in the care at all times.
    a. True
    b. False
29. Alzheimer's disease cannot be cured.
    a. True
    b. False
30. Most people with Alzheimer's disease remember recent events better than things that happened in the past.
    a. True
    b. False

Part III: Self-Efficacy for Restorative Care Activities

These questions are about your confidence in your ability to provide restorative care at this present time. For each question, there is a scale from 1 to 10, with 1 representing no confidence and 10 representing total confidence. Please circle the number that best represents your feelings.

I feel confident that I can provide restorative care activities related to:

1= No confidence										*10= Total Confidence*
Having residents participate in bathing.	1	2	3	4	5	6	7	8	9	10
Having residents participate in dressing.	1	2	3	4	5	6	7	8	9	10
Having residents participate in eating.	1	2	3	4	5	6	7	8	9	10
Having residents participate in a walking program.	1	2	3	4	5	6	7	8	9	10
Having residents participate in a specific exercise program.	1	2	3	4	5	6	7	8	9	10
Having residents participate in toileting activities.	1	2	3	4	5	6	7	8	9	10
Episodes when the resident refuses to participate in specific activities.	1	2	3	4	5	6	7	8	9	10
Days when I am assigned more residents than usual because of staffing issues.	1	2	3	4	5	6	7	8	9	10
When the residents are anxious to get ready for an appointment or a visit from someone.	1	2	3	4	5	6	7	8	9	10
When the family wants me to provide total care.	1	2	3	4	5	6	7	8	9	10

Part IV: CaRegiving Appraisal

	1 Not at all	2 A little	3 Moderately	4 Quite a bit	5 A great deal
Your health has suffered because of the care you must give to the nursing home residents with Alzheimer's disease.	1	2	3	4	5
You are isolated and alone as a result of your caring for the nursing home residents with Alzheimer's disease.	1	2	3	4	5
You will be unable to take care of the nursing home residents with Alzheimer's disease much longer.	1	2	3	4	5
You are very tired as a result of your caring for the nursing home residents with Alzheimer's disease.	1	2	3	4	5
Taking care of the nursing home residents with Alzheimer's disease gives you a trapped feeling.	1	2	3	4	5
Your social life has suffered because you care for nursing home residents with Alzheimer's disease.	1	2	3	4	5
Because of the time you spend with the nursing home residents with Alzheimer's disease, you don't have enough time for yourself.	1	2	3	4	5
You really enjoy being with the nursing home residents with Alzheimer's disease.	1	2	3	4	5
The nursing home residents with Alzheimer's disease pleasure over some little things gives you pleasure.	1	2	3	4	5
Helping the nursing home residents with Alzheimer's disease has made you feel closer to them.	1	2	3	4	5
Taking responsibility for the nursing home residents with Alzheimer's disease. Gives your self-esteem a boost.	1	2	3	4	5
You get a sense of satisfaction from caring for the nursing home residents with Alzheimer's disease.	1	2	3	4	5
Caring for the nursing home residents with Alzheimer's disease gives more meaning to your life.	1	2	3	4	5
You feel about to handle most problems in the care of the nursing home residents with Alzheimer's disease.	1	2	3	4	5
You are pretty good at figuring out what to do about the nursing home residents with Alzheimer's disease.	1	2	3	4	5

	1 Not at all	2 A little	3 Moderately	4 Quite a bit
Other people would discriminate against me if I am with nursing home residents with Alzheimer's disease.	1	2	3	4
My reputation is damaged because I work with nursing home residents with Alzheimer's disease.	1	2	3	4
People's attitude towards me sour when I am with nursing home residents with Alzheimer's disease.	1	2	3	4
Working with nursing home residents with Alzheimer's disease negatively affects me.	1	2	3	4
Working with nursing home residents with Alzheimer's disease makes me think that I am incompetent compared to others.	1	2	3	4
Working with nursing home residents with Alzheimer's disease makes me think that I am lesser than others.	1	2	3	4
Working with nursing home residents with Alzheimer's disease makes me lose face.	1	2	3	4
I feel inferior because I work with individuals with Alzheimer's disease.	1	2	3	4
I feel emotionally disturbed because I work with individuals with Alzheimer's disease.	1	2	3	4
The behavior of residents with Alzheimer's disease makes me feel embarrassed.	1	2	3	4
I feel helpless because I work with nursing home residents with Alzheimer's disease.	1	2	3	4
I feel sad because I work with nursing home residents with Alzheimer's disease.	1	2	3	4
I worry if other would know that I work with nursing home residents with Alzheimer's disease.	1	2	3	4
I am under great stress as I work with nursing home residents with Alzheimer's disease.	1	2	3	4
I avoid communicating with nursing home residents with Alzheimer's disease.	1	2	3	4
I dare not tell others that I work with nursing home residents with Alzheimer's disease.	1	2	3	4
I have cut down on taking nursing home residents with Alzheimer's disease on outings.	1	2	3	4
Because of my work with nursing home residents with Alzheimer's disease, I have reduced my contacts with friends and relatives.	1	2	3	4

When I am with the residents with Alzheimer's disease, I keep an especially low profile.	1	2	3	4
I have reduced my contacts with the nursing home residents with Alzheimer's disease.	1	2	3	4
I dare not participate in activities related to Alzheimer's disease lest others suspect that I work with persons that have the disease.	1	2	3	4
Because of my work with nursing home residents with Alzheimer's disease, I have reduced my contacts with my neighbors.	1	2	3	4

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CNA 12-week Survey (Experimental Group)
Participant ID: _____

Part I: Learning Satisfaction

Please answer the following questions about the Alzheimer's disease curriculum that you recently participated in.

Overall, how satisfied were you with the Alzheimer's disease curriculum?	1 Very Dissatisfied	2 Dissatisfied	3 Neutral	4 Satisfied	5 Very Satisfied

Has this curriculum met your expectations?	1 Much worse than I expected	2 Worse than I expected	3 About what I expected	4 Better than expected	5 Much better than expected

Overall, how satisfied were you with the care groups?	1 Very Dissatisfied	2 Dissatisfied	3 Neutral	4 Satisfied	5 Very Satisfied

Part II: Alzheimer's Disease Knowledge Scale (ADKS)

Please answer each question by indicating whether the statement is true or false.

1. People with Alzheimer's disease are particularly prone to depression.
    a. True
    b. False
2. It has been scientifically proven that mental exercise can prevent a person from getting Alzheimer's disease.
    a. True
    b. False
3. After symptoms of Alzheimer's disease appear, the average life expectancy is 6 to 12 years.
    a. True
    b. False
4. When a person with Alzheimer's disease becomes agitated, a medical examination might reveal other health problems that caused the agitation.
    a. True
    b. False
5. People with Alzheimer's disease do best with simple instructions given one step at a time.
    a. True
    b. False
6. When people with Alzheimer's disease begin to have difficulty taking care of themselves, caregivers should take over right away.
    a. True
    b. False
7. If a person with Alzheimer's disease becomes alert and agitated at night, a good strategy is to try to make sure that the person gets plenty of physical activity during the day.
    a. True
    b. False
8. In rare cases, people have recovered from Alzheimer's disease.
    a. True
    b. False
9. People whose Alzheimer's disease is not yet severe can benefit from psychotherapy for depression and anxiety.
    a. True
    b. False
10. If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer's disease.
    a. True
    b. False

11. Most people with Alzheimer's disease live in nursing homes.
    a. True
    b. False
12. Poor nutrition can make the symptoms of Alzheimer's disease worse.
    a. True
    b. False
13. People in their 30's can have Alzheimer's disease.
    a. True
    b. False
14. A person with Alzheimer's disease becomes increasingly likely to fall down as the disease gets worse.
    a. True
    b. False
15. When people with Alzheimer's disease repeat the same question or story several times, it is helpful to remind them that they are repeating themselves.
    a. True
    b. False
16. Once people have Alzheimer's disease, they are no longer capable of making informed decisions about their own care.
    a. True
    b. False
17. Eventually, a person with Alzheimer's disease will need 24-hours supervision.
    a. True
    b. False
18. Having high cholesterol may increase a person's risk of developing Alzheimer's disease.
    a. True
    b. False
19. Tremor or shaking of the hands or arms is a common symptom in people with Alzheimer's disease.
    a. True
    b. False
20. Symptoms of severe depression can be mistaken for symptoms of Alzheimer's disease.
    a. True
    b. False
21. Alzheimer's disease is one type of dementia.
    a. True
    b. False
22. Trouble handling money or paying bills is a common early symptom of Alzheimer's disease.
    a. True
    b. False
23. One symptom that can occur with Alzheimer's disease is believing that other people are stealing one's things.

a. True
b. False

24. When a person has Alzheimer's disease, using reminder notes is a crutch that can contribute to decline.
    a. True
    b. False
25. Prescription drugs that prevent Alzheimer's disease are available.
    a. True
    b. False
26. Having high blood pressure may increase a person's risk of developing Alzheimer's disease.
    a. True
    b. False
27. Genes can only partially account for the development of Alzheimer's disease.
    a. True
    b. False
28. It is safe for people with Alzheimer's disease to drive, as long as they have a companion in the care at all times.
    a. True
    b. False
29. Alzheimer's disease cannot be cured.
    a. True
    b. False
30. Most people with Alzheimer's disease remember recent events better than things that happened in the past.
    a. True
    b. False

Part III: Self-Efficacy for Restorative Care Activities

These questions are about your confidence in your ability to provide restorative care at this present time. For each question, there is a scale from 1 to 10, with 1 representing no confidence and 10 representing total confidence. Please circle the number that best represents your feelings.

I feel confident that I can provide restorative care activities related to:

Confidence	*1= No confidence*									*10= Total*
Having residents participate in bathing.	1	2	3	4	5	6	7	8	9	10
Having residents participate in dressing.	1	2	3	4	5	6	7	8	9	10
Having residents participate in eating.	1	2	3	4	5	6	7	8	9	10
Having residents participate in a walking program.	1	2	3	4	5	6	7	8	9	10
Having residents participate in a specific exercise program.	1	2	3	4	5	6	7	8	9	10
Having residents participate in toileting activities.	1	2	3	4	5	6	7	8	9	10

Episodes when the resident refuses to participate in specific activities.	1	2	3	4	5	6	7	8	9	10
Days when I am assigned more residents than usual because of staffing issues.	1	2	3	4	5	6	7	8	9	10
When the residents are anxious to get ready for an appointment or a visit from someone.	1	2	3	4	5	6	7	8	9	10
When the family wants me to provide total care.	1	2	3	4	5	6	7	8	9	10

Part IV: Caregiving Appraisal

These questions are about how you feel about the caregiving situation. Please indicate your amount of agreement with each statement.

	1 Not at all	**2 A little**	**3 Moderately**	**4 Quite a bit**	**5 A great deal**
Your health has suffered because of the care you must give to the nursing home residents with Alzheimer's disease.	1	2	3	4	5
You are isolated and alone as a result of your caring for the nursing home residents with Alzheimer's disease.	1	2	3	4	5
You will be unable to take care of the nursing home residents with Alzheimer's disease much longer.	1	2	3	4	5
You are very tired as a result of your caring for the nursing home residents with Alzheimer's disease.	1	2	3	4	5
Taking care of the the nursing home residents with Alzheimer's disease gives you a trapped feeling.	1	2	3	4	5

	1 Not at all	2 A little	3 Moderately	4 Quite a bit	5 A great deal
Your social life has suffered because you care for nursing home residents with Alzheimer's disease.	1	2	3	4	5
Because of the time you spend with the nursing home residents with Alzheimer's disease, you don't have enough time for yourself.	1	2	3	4	5
You really enjoy being with the nursing home residents with Alzheimer's disease.	1	2	3	4	5
The nursing home residents with Alzheimer's disease pleasure over some little things gives you pleasure.	1	2	3	4	5
Helping the nursing home residents with Alzheimer's disease has made you feel closer to them.	1	2	3	4	5
Taking responsibility for the nursing home residents with Alzheimer's disease. Gives your self-esteem a boost.	1	2	3	4	5
You get a sense of satisfaction from caring for the nursing home residents with Alzheimer's disease.	1	2	3	4	5
Caring for the nursing home residents with Alzheimer's disease gives more meaning to your life.	1	2	3	4	5
You feel about to handle most problems in the care of the nursing home residents with Alzheimer's disease.	1	2	3	4	5
You feel reassured about what to do about the nursing home residents with Alzheimer's disease.	1	2	3	4	5
You feel uncertain about what to do about the nursing home residents with Alzheimer's disease.	1	2	3	4	5
You feel that you should be doing more.	1	2	3	4	5
You feel that you could do a better job in caring for the nursing home residents with Alzheimer's disease.	1	2	3	4	5

Part V: Affiliate Stigma Scale

These questions are about how you feel about the working with persons with Alzheimer's disease. Please indicate your amount of agreement with each statement.

	1 Not at all	**2 A little**	**3 Moderately**	**4 Quite a bit**
Other people would discriminate against me if I am with nursing home residents with Alzheimer's disease.	1	2	3	4
My reputation is damaged because I work with nursing home residents with Alzheimer's disease.	1	2	3	4
People's attitude towards me sour when I am with nursing home residents with Alzheimer's disease.	1	2	3	4
Working with nursing home residents with Alzheimer's disease negatively affects me.	1	2	3	4
Working with nursing home residents with Alzheimer's disease makes me think that I am incompetent compared to others.	1	2	3	4

	1 **Not at all**	**2** **A little**	**3** **Moderately**	**4** **Quite a bit**
Working with nursing home residents with Alzheimer's disease makes me think that I am lesser than others.	1	2	3	4
Working with nursing home residents with Alzheimer's disease makes me lose face.	1	2	3	4
I feel inferior because I work with individuals with Alzheimer's disease.	1	2	3	4
I feel emotionally disturbed because I work with individuals with Alzheimer's disease.	1	2	3	4
The behavior of residents with Alzheimer's disease makes me feel embarrassed.	1	2	3	4
I feel helpless because I work with nursing home residents with Alzheimer's disease.	1	2	3	4
I feel sad because I work with nursing home residents with Alzheimer's disease.	1	2	3	4
I worry if other would know that I work with nursing home residents with Alzheimer's disease.	1	2	3	4
I am under great stress as I work with nursing home residents with Alzheimer's disease.	1	2	3	4
I avoid communicating with nursing home residents with Alzheimer's disease.	1	2	3	4
I dare not tell others that I work with nursing home residents with Alzheimer's disease.	1	2	3	4
I have cut down on taking nursing home residents with Alzheimer's disease on outings.	1	2	3	4
Because of my work with nursing home residents with Alzheimer's disease, I have reduced my contacts with friends and relatives.	1	2	3	4
When I am with the residents with Alzheimer's disease, I keep an especially low profile.	1	2	3	4
I have reduced my contacts with the nursing home residents with Alzheimer's disease.	1	2	3	4

	1 **Not at all**	**2** **A little**	**3** **Moderately**	**4** **Quite a bit**
I dare not participate in activities related to Alzheimer's disease lest others suspect that I work with persons that have the disease.	1	2	3	4
Because of my work with nursing home residents with Alzheimer's disease, I have reduced my contacts with my neighbors.	1	2	3	4

APPENDIX B: INFORMED CONSENTS AND SURVEYS FOR CNAS CONTROL GROUP

Subject Informed Consent Document and Research Authorization

FOSTERING COMPASSIONATE CARE FOR INDIVIDUALS WITH ALZHEIMER'S DISEASE

Investigator(s) name & address: Anna C. Faul, PhD & Samantha Cotton, MSSW, 300 E Market St, Suite 200, Louisville KY 40222.

Site(s) where study is to be conducted: Institute for Sustainable Health & Optimal Aging

Phone number for subjects to call for questions: 502-852-5629

Introduction and Background Information

You are invited to participate in a research study that focuses on compassionate care in nursing home settings, specifically focusing on residents with Alzheimer's disease. The purpose of this study is to evaluate a curriculum designed for nurse aides working with residents with Alzheimer's disease. The study is being conducted by Dr. Anna C. Faul, PhD and Sam Cotton, MSSW, ABD. The study will take place at eight different nursing facilities in Kentucky.

Approximately 300 subjects will be invited to participate.

Purpose

The purpose of this study is to evaluate a training curriculum delivered to state registered nurse aides (SNRA's) in nursing homes.

Procedures

As part of this study, you will complete pre and post-test surveys about your experience with the curriculum, your knowledge of Alzheimer's disease and related dementias, and your confidence in performing activities with residents with Alzheimer's disease.

Potential Risks

There are no foreseeable risks other than possible discomfort in answering personal questions. There may be unforeseen risks.

Benefits

Nurse aides may increase their understanding of working with residents with Alzheimer's disease, which could contribute to a transformation within the nursing home towards more compassionate care. The information collected may not benefit you directly. The information learned in this study may be helpful to others.

Payment

You will not be compensated for your time, inconvenience, or expenses while you are in this study.

Revocation of Research Authorization

You may cancel the permission you have given to use and share your protected health information at any time. This means you can tell us to stop using and sharing your protected health information. If you cancel your permission:

- We will stop collecting information about you.
- You may not withdraw information that we had before you told us to stop.
    - We may already have used it or shared it.
    - We may need it to complete the research.
- Staff may ask your permission to follow-up with you if there is a medical reason to do so.

To cancel your permission, you will be requested to complete a written "Revocation of Research Authorization" form located at the end of this document. You may also obtain a copy from your study doctor, designated personnel or from the Human Subjects Protections Program Office website (http://louisville.edu/research/humansubjects/links-to-forms).

Confidentiality

Total privacy cannot be guaranteed. We will protect your privacy to the extent permitted by law. If the results from this study are published, your name will not be made public. Once your information leaves our institution, we cannot promise that others will keep it private.

Your information may be shared with the following:

- Organizations that provide funding at any time for the conduct of the research.
- The University of Louisville Institutional Review Board, Human Subjects Protection Program Office, Privacy Office, others involved in research administration and compliance at the University, and others contracted by the University for ensuring human subjects safety or research compliance
- The local research team
- Researchers at other sites participating in the study (if applicable)
- People who are responsible for research, compliance and HIPAA oversight at the institutions where the research is conducted

• People responsible for billing, sending and receiving payments related to your participation in the study

• Government agencies, such as:

o Office for Human Research Protections

o Office of Civil Rights

Security

Your information will be kept private. Any data collected will be stored at the Institute for Sustainable Health & Optimal Aging in secure area in a locked file cabinet.

Voluntary Participation

Taking part in this study is voluntary. You may choose not to take part at all. If you decide to be in this study, you may stop taking part at any time. If you decide not to be in this study or if you stop taking part at any time, you will not lose any benefits for which you may qualify.

You will be told about any changes that may affect your decision to continue in the study.

Contact Persons

If you have any questions, concerns, or complaints about the research study, please contact Samantha Cotton at 502-852-5629.

Research Subject's Rights

If you have any questions about your rights as a research subject, you may call the Human Subjects Protection Program Office at (502) 852-5188. You may discuss any questions about your rights as a research subject, in private, with a member of the Institutional Review Board (IRB). You may also call this number if you have other questions about the research, and you cannot reach the study doctor, or want to talk to someone else. The IRB is an independent committee made up of people from the University community, staff of the institutions, as well as people from the community not connected with these institutions. The IRB has approved the participation of human subjects in this research study.

Concerns and Complaints

If you have concerns or complaints about the research or research staff and you do not wish to give your name, you may call the toll free number 1-877-852-1167. This is a 24-hour hot line answered by people who do not work at the University of Louisville.

Acknowledgment and Signatures

This informed consent document is not a contract. This document tells you what will happen during the study if you choose to take part. Your signature indicates that this study has been explained to you, that your questions have been answered, and that you agree to take part in the study. You are not giving up any legal rights to which you are entitled by signing this informed consent document. You will be given a copy of this consent form to keep for your records.

Subject Name (Please Print)	Signature of Subject	Date Signed

Printed Name of Legally Authorized Representative	Signature of Legally Authorized Rep	Date Signed

Authority of Legally Authorized Representative to act on behalf of Subject

Printed Name of Person	Explaining Consent Form	Signature of Person Explaining	Date Signed

**Authority to act on behalf of another includes, but is not limited to parent, guardian, or durable power of attorney for health care.*

Printed Name of Person	Explaining Consent Form	Signature of Person Explaining	Date Signed

Printed Name of Investigator Signed	Signature of Investigator	Date Signed

List of Investigators:	**Phone Numbers:**
Anna Faul, PhD	502-852-1981
Sam Cotton, MSSW	502-852-5629

REVOCATION OF AUTHORIZATION FOR USE AND DISCLOSURE OF YOUR HEALTH INFORMATION FOR RESEARCH

Return To:

▫ PI Address: 300 E Market St. Suite 200

Louisville KY 40222

OR

▫ Institutional Review Board

MedCenter One, Suite 200

▪ **Do not sign this letter unless you are withdrawing from this research. You will be sent confirmation that this notice was received.**

To Whom It May Concern:

I would like to discontinue my participation in the research study noted above. I understand that health information already collected will continue to be used as discussed in the Authorization I signed when joining the study.

Your options are (***choose one***):

☐ **Withdraw from Study & Discontinue Authorization:**
Discontinue my authorization for the future use and disclosure of protected health information. In some instances, the research team may need to use your information even after you discontinue your authorization, for example, to notify you or government agencies of any health or safety concerns that were identified as part of your study participation.

☐ **Withdraw from Study, but Continue Authorization:**
Allow the research team to continue collecting information from me and my personal health information. This would be done only as needed to support the goals of the study and would not be used for purposes other than those already described in the research authorization.

_____ _____

Printed Name and Signature of Subject Signed Date

_____ _____

Signature of Subject's Legal Representative (if subject is unable to sign) Signed Date

Printed Name of Subject's Legal Representative Birthdate of Subject

_____

Relationship of Legal Representative to Subject

_____ _____

Subject's Address Subject's Phone Numbe

CNA Baseline and 12 Survey (Control Group)

Participant ID: _____

Part I: Demographics

Please answer the following questions about yourself.

1.) Date of Birth: ____ /_____ /____

2.) Gender:

3.) Do you consider yourself Hispanic? Yes____ No_____

4.) Do you consider yourself primarily:

Black	
American Indian/Native American	
Asian	
White	
Other	

5.) Number of years working in nursing facilities: _____

6.) Number of years working in this specific facility: _____

7.) Number of years of formal educational training: _____

Part II: Alzheimer's Disease Knowledge Scale (ADKS)

Please answer each question by indicating whether the statement is true or false.

1. People with Alzheimer's disease are particularly prone to depression.
    a. True
    b. False
2. It has been scientifically proven that mental exercise can prevent a person from getting Alzheimer's disease.
    a. True
    b. False
3. After symptoms of Alzheimer's disease appear, the average life expectancy is 6 to 12 years.
    a. True
    b. False
4. When a person with Alzheimer's disease becomes agitated, a medical examination might reveal other health problems that caused the agitation.
    a. True
    b. False
5. People with Alzheimer's disease do best with simple instructions given one step at a time.
    a. True
    b. False
6. When people with Alzheimer's disease begin to have difficulty taking care of themselves, caregivers should take over right away.
    a. True
    b. False
7. If a person with Alzheimer's disease becomes alert and agitated at night, a good strategy is to try to make sure that the person gets plenty of physical activity during the day.
    a. True
    b. False
8. In rare cases, people have recovered from Alzheimer's disease.
    a. True
    b. False
9. People whose Alzheimer's disease is not yet severe can benefit from psychotherapy for depression and anxiety.
    a. True
    b. False
10. If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer's disease.
    a. True
    b. False

11. Most people with Alzheimer's disease live in nursing homes.
    a. True
    b. False
12. Poor nutrition can make the symptoms of Alzheimer's disease worse.
    a. True
    b. False
13. People in their 30's can have Alzheimer's disease.
    a. True
    b. False
14. A person with Alzheimer's disease becomes increasingly likely to fall down as the disease gets worse.
    a. True
    b. False
15. When people with Alzheimer's disease repeat the same question or story several times, it is helpful to remind them that they are repeating themselves.
    a. True
    b. False
16. Once people have Alzheimer's disease, they are no longer capable of making informed decisions about their own care.
    a. True
    b. False
17. Eventually, a person with Alzheimer's disease will need 24-hours supervision.
    a. True
    b. False
18. Having high cholesterol may increase a person's risk of developing Alzheimer's disease.
    a. True
    b. False
19. Tremor or shaking of the hands or arms is a common symptom in people with Alzheimer's disease.
    a. True
    b. False
20. Symptoms of severe depression can be mistaken for symptoms of Alzheimer's disease.
    a. True
    b. False
21. Alzheimer's disease is one type of dementia.
    a. True
    b. False
22. Trouble handling money or paying bills is a common early symptom of Alzheimer's disease.
    a. True
    b. False

23. One symptom that can occur with Alzheimer's disease is believing that other people are stealing one's things.
    a. True
    b. False
24. When a person has Alzheimer's disease, using reminder notes is a crutch that can contribute to decline.
    a. True
    b. False
25. Prescription drugs that prevent Alzheimer's disease are available.
    a. True
    b. False
26. Having high blood pressure may increase a person's risk of developing Alzheimer's disease.
    a. True
    b. False
27. Genes can only partially account for the development of Alzheimer's disease.
    a. True
    b. False
28. It is safe for people with Alzheimer's disease to drive, as long as they have a companion in the care at all times.
    a. True
    b. False
29. Alzheimer's disease cannot be cured.
    a. True
    b. False
30. Most people with Alzheimer's disease remember recent events better than things that happened in the past.
    a. True
    b. False

Part III: Self-Efficacy for Restorative Care Activities

These questions are about your confidence in your ability to provide restorative care at this present time. For each question, there is a scale from 1 to 10, with 1 representing no confidence and 10 representing total confidence. Please circle the number that best represents your feelings.

I feel confident that I can provide restorative care activities related to:

1= No confidence										*10= Total Confidence*
Having residents participate in bathing.	1	2	3	4	5	6	7	8	9	10
Having residents participate in dressing.	1	2	3	4	5	6	7	8	9	10
Having residents participate in eating.	1	2	3	4	5	6	7	8	9	10
Having residents participate in a walking program.	1	2	3	4	5	6	7	8	9	10
Having residents participate in a specific exercise program.	1	2	3	4	5	6	7	8	9	10
Having residents participate in toileting activities.	1	2	3	4	5	6	7	8	9	10
Episodes when the resident refuses to participate in specific activities.	1	2	3	4	5	6	7	8	9	10
Days when I am assigned more residents than usual because of staffing issues.	1	2	3	4	5	6	7	8	9	10
When the residents are anxious to get ready for an appointment or a visit from someone.	1	2	3	4	5	6	7	8	9	10
When the family wants me to provide total care.	1	2	3	4	5	6	7	8	9	10

Part IV: Caregiving Appraisal

These questions are about how you feel about the caregiving situation. Please indicate your amount of agreement with each statement.

	1 Not at all	**2 A little**	**3 Moderately**	**4 Quite a bit**	**5 A great deal**
Your health has suffered because of the care you must give to the nursing home residents with Alzheimer's disease.	1	2	3	4	5
You are isolated and alone as a result of your caring for the nursing home residents with Alzheimer's disease.	1	2	3	4	5
You will be unable to take care of the nursing home residents with Alzheimer's disease much longer.	1	2	3	4	5
You are very tired as a result of your caring for the nursing home residents with Alzheimer's disease.	1	2	3	4	5
Taking care of the nursing home residents with Alzheimer's disease gives you a trapped feeling.	1	2	3	4	5
Your social life has suffered because you care for nursing home residents with Alzheimer's disease.	1	2	3	4	5
Because of the time you spend with the nursing home residents with Alzheimer's disease, you don't have enough time for yourself.	1	2	3	4	5
You really enjoy being with the nursing home residents with Alzheimer's disease.	1	2	3	4	5
The nursing home residents with Alzheimer's disease pleasure over some little things gives you pleasure.	1	2	3	4	5
Helping the nursing home residents with Alzheimer's disease has made you feel closer to them.	1	2	3	4	5
Taking responsibility for the nursing home residents with Alzheimer's disease. Gives your self-esteem a boost.	1	2	3	4	5
You get a sense of satisfaction from caring for the nursing home residents with Alzheimer's disease.	1	2	3	4	5
Caring for the nursing home residents with Alzheimer's disease gives more meaning to your life.	1	2	3	4	5
You feel reassured about what to do about the nursing home residents with Alzheimer's disease.	1	2	3	4	5

	1 **Not at all**	**2** **A little**	**3** **Moderately**	**4** **Quite a bit**	**5** **A great deal**
You feel uncertain about what to do about the nursing home residents with Alzheimer's disease.	1	2	3	4	5
You feel that you should be doing more.	1	2	3	4	5
You feel that you could do a better job in caring for the nursing home residents with Alzheimer's disease.	1	2	3	4	5

Part V: Affiliate Stigma Scale

These questions are about how you feel about the working with persons with Alzheimer's disease. Please indicate your amount of agreement with each statement.

	1 **Not at all**	**2** **A little**	**3** **Moderately**	**4** **Quite a bit**
Other people would discriminate against me if I am with nursing home residents with Alzheimer's disease.	1	2	3	4
My reputation is damaged because I work with nursing home residents with Alzheimer's disease.	1	2	3	4
People's attitude towards me sour when I am with nursing home residents with Alzheimer's disease.	1	2	3	4
Working with nursing home residents with Alzheimer's disease negatively affects me.	1	2	3	4
Working with nursing home residents with Alzheimer's disease makes me think that I am incompetent compared to others.	1	2	3	4
Working with nursing home residents with Alzheimer's disease makes me think that I am lesser than others.	1	2	3	4
Working with nursing home residents with Alzheimer's disease makes me lose face.	1	2	3	4
I feel inferior because I work with individuals with Alzheimer's disease.	1	2	3	4
I feel emotionally disturbed because I work with individuals with Alzheimer's disease.	1	2	3	4
The behavior of residents with Alzheimer's disease makes me feel embarrassed.	1	2	3	4
I feel helpless because I work with nursing home residents with Alzheimer's disease.	1	2	3	4
I feel sad because I work with nursing home residents with Alzheimer's disease.	1	2	3	4
I worry if other would know that I work with nursing home residents with Alzheimer's disease.	1	2	3	4

	1 **Not at all**	**2** **A little**	**3** **Moderately**	**4** **Quite a bit**
I am under great stress as I work with nursing home residents with Alzheimer's disease.	1	2	3	4
I avoid communicating with nursing home residents with Alzheimer's disease.	1	2	3	4
I dare not tell others that I work with nursing home residents with Alzheimer's disease.	1	2	3	4
I have cut down on taking nursing home residents with Alzheimer's disease on outings.	1	2	3	4
Because of my work with nursing home residents with Alzheimer's disease, I have reduced my contacts with friends and relatives.	1	2	3	4
When I am with the residents with Alzheimer's disease, I keep an especially low profile.	1	2	3	4
I have reduced my contacts with the nursing home residents with Alzheimer's disease.	1	2	3	4
I dare not participate in activities related to Alzheimer's disease lest others suspect that I work with persons that have the disease.	1	2	3	4
Because of my work with nursing home residents with Alzheimer's disease, I have reduced my contacts with my neighbors.	1	2	3	4

APPENDIX C: RESIDENT WITH ALZHEIMER'S DISEASE ASSENT AND SURVEYS

SUBJECT ASSENT

I am invited to be in a research study being done Dr. Anna Faul, PhD, and Sam Cotton, MSSW, ABD. When a person is in a research study, they are called a "subject". I am invited because I have been diagnosed with Alzheimer's disease and I live in a nursing home.

This means that myself or my caregivers at the nursing home will be asked questions about me including questions about my demographics, my quality of life, and questions about when I get upset or agitated. As a subject in this study, I will have my salvia taken 3 times during the study so that the research team can look at my stress levels. There may be some risks with this study. These risks are having your saliva taken and answering questions which may cause discomfort. This study will last 8 months. The benefit to me for participating in this study is that the data we collect will be used to help inform your care and the care of others at the nursing home where you live.

My family, the researchers, and the workers at the nursing home I live at will know that I'm in the study. If anyone else is given information about me, they will not know my name. A number or initials will be used instead of my name.

I have been told about this study and know why it is being done and what I have to do. My family has agreed to let me be in the study. If I have any questions I can ask Dr. Faul or Sam Cotton. They will answer my questions. If I do not want to be in this study or I want to quit after I am already in this study, I can tell the researcher and they will discuss this with my family.

Printed Name of Subject Signature of Subject Date Signed

Printed Name of Legal Representative

Printed Name of Investigator Signature of Investigator Date Signed

Resident Survey Baseline, 6 weeks and 12 weeks

Participant ID: _____

Part I: Basic Demographics

Please answer the following questions about the resident.

1.) Date of Birth: ____ /_____ /____

2.) Gender:

3.) Do you consider yourself Hispanic? Yes____ No_____

4.) Do you consider yourself primarily:

Black	
American Indian/Native American	
Asian	
White	
Other	

Part II: Rapid Cognitive Screen (For Demographic purposes only)

1.) **Please remember these five objects. I will ask you what they are later.** [Read each object to patient using approximately 1 second intervals.]

Apple Pen Tie House Car

Please repeat the objects for me. [If patient does not repeat all 5 objects correctly, repeat until all objects are recalled correctly or up to a maximum of 2 times.]

2.) [Give patient pencil and blank sheet with clock face.]
This is a clock face. Please put in the hour markers and the time at ten minutes to eleven o'clock.

____/ 2 (points) Hour markers are okay

____/2 (points) Time correct

3.) **What were the five objects I asked you to remember?**

____/ 1 (point) Apple

____/ 1 (point) Pen

____/ 1 (point) Tie

____/ 1 (point) House

____/ 1 (point) Car

4.) I'm going to tell you a story. Please listen carefully because afterwards, I'm going to ask you about it.

Jill was a very successful stockbroker. She made a lot of money on the stock market. She then met Jack, a devastatingly handsome man. She married him and had three children. They lived in Chicago. She then stopped work and stayed at home to bring up her children. When they were teenagers, she went back to work. She and Jack lived happily ever after.

What state did she live in?

____/ 1 (point) Illinois

[Do not repeat the story but do make sure that the patient is listening the first time you read it to them. Do not prompt or give hints. The answer of "Chicago" as the state that she lives in gets no credit but you may prompt them once by repeating the question when "Chicago" is given as the answer.]

_____Total Score [0-10 points]

Scoring

8-10……Normal

6-7……Mild Cognitive Impairment

0-5……..Dementia

For RCS Clock Question

Part III: The Cohen-Mansfield Agitation Inventory

Please read each of the 29 agitated behaviors, and circle how often (from 1-7) each was manifested by the resident during the last 2 weeks:

	1 Never	2 Less than once a week	3 Once or twice a week	4 Several times a week	5 Once or twice a day	6 Several times a day	7 Several times an hour
Pace, aimlessly wandering	1	2	3	4	5	6	7
Inappropriate dress or disrobing	1	2	3	4	5	6	7
Spitting (including at meals)	1	2	3	4	5	6	7
Cursing or verbal aggression	1	2	3	4	5	6	7
Constant unwarranted request for attention or help	1	2	3	4	5	6	7
Repetitive sentences or questions	1	2	3	4	5	6	7
Hitting (including self)	1	2	3	4	5	6	7
Kicking	1	2	3	4	5	6	7
Grabbing onto people	1	2	3	4	5	6	7
Pushing	1	2	3	4	5	6	7
Throwing things	1	2	3	4	5	6	7
Strange noises (weird laughter or crying)	1	2	3	4	5	6	7
Screaming	1	2	3	4	5	6	7
Biting	1	2	3	4	5	6	7
Scratching	1	2	3	4	5	6	7
Trying to get to a different place (e.g., out of the room, building)	1	2	3	4	5	6	7
Intentional falling	1	2	3	4	5	6	7
Complaining	1	2	3	4	5	6	7

	1 Never	2 Less than once a week	3 Once or twice a week	4 Several times a week	5 Once or twice a day	6 Several times a day	7 Several times an hour
Negativism	1	2	3	4	5	6	7
Eating/drinking inappropriate substances	1	2	3	4	5	6	7
Hurt self or others (cigarette, hot water, etc.)	1	2	3	4	5	6	7
Handling things inappropriately	1	2	3	4	5	6	7
Hiding things	1	2	3	4	5	6	7
Hoarding things	1	2	3	4	5	6	7
Tearing things or destroying property	1	2	3	4	5	6	7
Performing repetitious mannerisms	1	2	3	4	5	6	7
Making verbal sexual advances	1	2	3	4	5	6	7
Making physical sexual advances	1	2	3	4	5	6	7
General restlessness	1	2	3	4	5	6	7

CURRICULUM VITAE

Samantha Gilbert Cotton, MSSW

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Education

Doctor of Philosophy in Social Work, University of Louisville, ABD, Dissertation: *Fostering Compassion for Individuals with Alzheimer's Disease in Nursing Home Settings*	2013-present
Masters of Science in Social Work, University of Louisville, Louisville, Kentucky.	2010-2012
P0st-Bacc Studies, Arabic Language and Culture, University of Louisville, Louisville, Kentucky.	2008-2010
Bachelor of Arts, Majors: Religion, International Relations, Centre College, Danville, Kentucky.	2004-2008

Employment History

Program Manager, Flourish Program, Funded through HRSA grant, Institute for Sustainable Health & Optimal Aging, University of Louisville, Louisville, Kentucky.	2017- Present
Alzheimer's Disease and Related Dementias (ADRD) Coordinator Funded through HRSA grant, Institute for Sustainable Health & Optimal Aging, University of Louisville, Louisville, Kentucky.	2016-present
Research Assistantship, Institute for Sustainable Health & Optimal Aging, University of Louisville, Louisville, Kentucky.	2015-2016

Adjunct Faculty Member, Kent School of Social Work, University of Louisville, Louisville, Kentucky.	2014-2017
Research Assistantship, Academic Affairs, Kent School of Social Work, University of Louisville, Louisville, Kentucky.	2013-2015
Program Director, Day Spring Foundation, Louisville, Kentucky.	2011-2013
Practicum Student, Baptist Hospital East, Crisis Management Unit, Louisville, Kentucky.	2011-2012
Data Collection and Intervention Support, First Steps to Success, University of Louisville, Kent School of Social Work, Louisville, Kentucky.	2011-2012
Practicum Student, Kentucky Refugee Ministries, Louisville, Kentucky.	2010-2012

Awards and Scholarships

Southeastern Association of Area Agencies on Aging Gerontology Student Scholarship Award	2016
Kentucky Association of Gerontology Student Scholarship Award	2016
The Gordon B. and Geraldine G. Davidson Study Abroad Award, Centre College, Danville, Kentucky.	2007
Performing Arts Scholarship (Drama), Centre College, Danville, Kentucky.	2004-2008
Centre Award Scholarship, Centre College, Danville, Kentucky.	2004-2008
Rogers Scholar, The Center for Rural Development, Centre College, Danville, Kentucky.	2004-2008

Teaching

Taught the following courses in the master's in science Program at the University of Louisville Kent School of Social Work:

Advanced Research Practice I (Fall 2014-Fall 2016)

Advanced Research Practice II (Spring 2015-Spring 2017)

Service

Proposal Reviewer, Council on Social Work Education for the 2017 Annual Program Meeting	2017
Associate Board Member, Coalition for the Homeless, Louisville, Kentucky.	2016-2017
Board Member, The DegondABA School for Persons with Autism, Louisville, Kentucky.	2015-Present
Grant Reviewer, Community Foundation of Louisville, Louisville, Kentucky.	2014-2015

Research

Grants

Co-Program Manager: September 2017 – Augustus 2021. Rural Geriatric Integrated Behavioral Health and Primary Care Training Network (RITN). Department of Health and Human Services. Human Resources and Services Administration. $1.92 million.

Project Staff: October 2017 – May 2018. Needs Assessment. Kentuckiana Regional Planning and Development Agency. Area Agency on Aging and Independent Living. $45,000.

Project Staff: July 2016 – May 2018. Engage in Art. Fund for the Arts & Jewish Heritage Foundations. $25,000.

Program Manager: July 2015 – June 2019. Kentucky Rural Underserved Geriatric Interdisciplinary Education Program. Department of Health and Human Services. Human Resources and Services Administration. $2.25 million.

Project Staff: November 2014 – October 2015. IHOP Dispensa de alimentos y hogar de assistencia medica preventive (The Food Pantry preventative medical home without walls). $75,000.

Research Projects

Fostering Compassionate Care for Individuals with Alzheimer's Disease in Nursing Home Settings	2016
Memory 360: Compassionate Care for Older Adults with Cognitive Decline and Their Caregivers	2016
Incorporating Mental Health Care into Primary Care Settings (Evaluator; Collaboration with Baptist Hospital)	2015
Veggie Rx: A Fresh Stop Prescription Food Program for Older Adults	2015
The John C. Wright Study on Optimal Aging	2015
Institute for Sustainable Health & Optimal Aging Participant Registry	2015
Community Foundation of Louisville: Organizational Capacity Building (Evaluator)	2014
Nutritional Needs of Older Adults (in collaboration with Kentuckiana Regional Planning & Development Agency)	2013

Scholarship

Peer Reviewed Articles

Furman, C.D., Wagner, L., Gomes, J., Gopalraj, R., Parker, B.F., Morton, L., Antimisiaris, D., Neamtu, D., Masroor, S., Martin-Galijatovic, R., Cotton, S., & Shaw, M.A. (2018.) Implementing Chief Resident Immersion Training (CRIT) in the Care of Older Adults: Overcoming Barriers and Promoting Facilitators. *Geriatrics, 3* (62), 1-15.

Faul, A.C., D'Ambrosio, J.G., Yankeelov, P.A., Cotton, S.G., Furman, C.D., Fall-Faul, M., Gordon, B. & Wright, B. (in press). Human Flourishing and Integrated Care Models: The Development of the Flourish Index. *The Gerontologist.*

D'Ambrosio, J.G., Faul, A.C., Fields, M. & Cotton, S.G. (in press). Baby-Boomer Longer Term Care Expectations. International Journal of Health, Wellness and Society.

Cotton, S., Faul, A.C. & D'Ambrosio, J.G. (2016). Veggie Rx: A "Fresh Stop" Food Prescription Program. *KY Academy of Family Physicians Journal*, 88.

Cotton, S., Faul, A.C., Yankeelov, P.A. (2016). Comparison of student characteristics and outcomes between an online and on-campus MSSW program. *Advances in Social Work,* 17 (1), 31-43.

Peer Reviewed Presentations

Faul, A.C., D'Ambrosio, J.G., Yankeelov, P.A. & Cotton, S. (2018). The Flourish Index: Outcomes of An Integrated Primary Care and Community Based Models of Care. CSWE 2018 Annual Meeting, Boston, MA, November 14-18, 2018.

Faul, A.C., D'Ambrosio, J.G., Yankeelov, P.A. & Cotton, S. (2018). Flourishing: Outcomes of An Integrated Primary Care and Community Based Models of Care. CSWE 2018 Annual Meeting, Orlando, FL, November 8-11, 2018.

Faul, A.C., D'Ambrosio, J.G., Dobson, M. & Cotton, S. (2018). EngAGE: Incorporating arts into healthcare settings using interprofessional approaches. CSWE 2018 Annual Meeting, Orlando, FL, November 8-11, 2018.

Faul, A.C., D'Ambrosio, J.G., Dobson, M., & Cotton, S. (2018). EngAGE: Incorporating arts into healthcare settings. SE4A 2018 Annual Meeting, Louisville, KY, September 30-October 3, 2018.

Faul, A.C., D'Ambrosio, J.G., Yankeelov, P.A., Cotton, S., & Furman, C.D. (2018). Development of the Flourish Index. SE4A 2018 Annual Meeting, Louisville, KY, September 30-October 3, 2018.

Faul, A.C., D'Ambrosio, J.G., Yankeelov, P.A., Furman, C.D., Cotton, S., Gordon, B., & Faul-Hall, M. (2018). Mobile Workshop: Interdisciplinary Case Management Experience . SE4A 2018 Annual Meeting, Louisville, KY, September 30-October 3, 2018.

Faul, A.C., D'Ambrosio, J.G., Yankeelov, P.A., Cotton, S. & Furman, C.D. (2018). Human Flourishing as an Outcome of Integrated Primary Care and Community Based Models of Care. AGS 2018 Annual Scientific Meeting, Orlando, May 3-5 2018.

Faul, A.C., Yankeelov, P.A., D'Ambrosio, J.G., Cotton, S. & Hall-Faul, M. (2018). Using Transdisciplinary Case Conceptualizations to Facilitate Coordinated Geriatric Care. 2019 Aging in America Conference, San Francisco, March 26-29 2018.

Cotton, S., Faul, A.C., Yankeelov, P. (2017) Developing Dementia Friendly Communities in Rural Counties. N4A 42nd Annual Conference & Tradeshow, Savannah, GA., July 29-August 2, 2017.

Faul, A.C., D'Ambrosio, J.G., Furman, C.D., Yankeelov, P.A., Cotton, S. & Gordon, B. (2017). The Flourish Care Model: A shared-Care Approach to Healthcare for Older Adults. 2nd Optimal Aging Conference, Louisville, KY., June 11-13, 2017.

Faul, A.C., D'Ambrosio, J.G., Furman, C., Yankeelov, P., Cotton, S. & Gordon, B. (2017). The Flourish Care Model: A shared-Care Approach to Healthcare for Older Adults. 2017 Aging in America Conference, Chicago, IL, March 20-24, 2017.

Cotton, S., Faul, A.C. & D'Ambrosio, J.G. (2016). Veggie Rx: A Fresh Stop Food Prescription Program. Gerontological Society of America's 69th Annual Scientific Meeting, New Orleans, LA, November 16-20 2016.

Faul, A.C., D'Ambrosio, J.G. & Cotton, S. (2016). Training Professional Learners Through a Geriatric Interprofessional Education Program. Gerontological Society of America's 69th Annual Scientific Meeting, New Orleans, LA, November 16-20 2016.

Cotton, S., Faul, A.C. & Yankeelov, P.A. & D'Ambrosio, J.G. (2016). Developing Dementia-Friendly Communities in Rural Counties. Council on Social Work Education Annual Program Meeting, Atlanta, GA., November 3-6, 2016.

Cotton, S., Faul, A.C., D'Ambrosio, J.G. & Yankeelov, P.A. Dementia Friendly Communities. Kentucky Association of Adult Day Centers Annual Conference. Louisville, KY., September 13, 2016.

Morgan, S., Cotton, S, Faul, A.C. & D'Ambrosio, J.G. (2016). Veggie Rx: A Prescription Food Program. 1st Optimal Aging Conference, Louisville, KY, June 12-14, 2016.

Cotton, S., Smith, L. & Faul, A.C. (2016). Serving Nutritional Needs of Older Adults. SSWR 20th Annual Conference, Washington DC, January 2016.

Cotton, S., Faul, A.C. & Yankeelov, P.A. (2015). Development of CSWE Competency Equivalency Between An On-campus and Online MSSW Program. 1st Social Work Distance Education Conference, Indianapolis, April, 20, 2015.

Invited Presentations

Cotton, S. (2018). Understanding Alzheimer's Disease: Simulation and Education Event. Buffalo Trace Area Agency on Aging Annual Caregiving Event, Maysville, KY, June 2018.

Cotton, S., Faul, A.C. & D'Ambrosio, J.G. (2018). Understanding Alzheimer's Disease: Simulation and Education Event. University of Louisville Brandeis School of Law Elder Law Event, Louisville, KY, March 2018.

Cotton, S. (2017). Understanding Alzheimer's Disease: Simulation and Education Event. Tri-County Community Action Agency, Lagrange, KY, June 2017.

Cotton, S., Faul, A.C. & D'Ambrosio, J.G. (2017). Caregiving for the Caregiver. University of Louisville School of Medicine SMART Staff Retreat, Louisville, KY, May 2017.

Cotton, S., Faul, A.C. & D'Ambrosio, J.G. (2016). Understanding Alzheimer's Disease: Simulation and Education Event. Kentucky Coalition for Healthy Communities, Shelbyville, KY, November 2016.

Cotton, S., Faul, A.C. & D'Ambrosio, J.G. (2016). Caregiving for the Caregiver. University of Louisville School of Medicine SMART Staff Retreat, Louisville, KY, May 2016.

Research Reports

Yankeelov, P.A., Faul, A.C. & Cotton, S. (2018). Non-Competing Continuation (NCC) Progress Report for the UofL GWEP HRSA grant. Louisville, KY: University of Louisville.

Yankeelov, P.A., Faul, A.C. & Cotton, S. (2017). Non-Competing Continuation (NCC) Progress Report for the UofL GWEP HRSA grant. Louisville, KY: University of Louisville.

Yankeelov, P.A., Faul, A.C. & Cotton, S. (2016). Non-Competing Continuation (NCC) Progress Report for the UofL GWEP HRSA grant. Louisville, KY: University of Louisville.

Cotton, S., Faul, A.C., D'Ambrosio, J., & Morgan, S. (2016). Veggie Rx Conclusion Report. Louisville, KY: University of Louisville.

Cotton, S., Faul, A.C., D'Ambrosio, J., & Morgan, S. (2016). Baptist Healthcare Behavioral Health Support Conclusion Report. Louisville, KY: University of Louisville.

Professional Memberships

Gerontological Society of America	Current
Council on Social Work Education	Current
American Society on Aging	Current