APPROACHING ALZHEIMER’S DISEASE THROUGH NON-PHARMACOLOGICAL INTERVENTIONS

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Approaching Alzheimer’s Disease through Non-Pharmacological Interventions

Introduction

Never before has such a large portion of the American population consisted of people 65 years of age and older (Population Division, 2016). The aging population continues to grow, and, with this increase, new problems are arising. One of the most significant struggles the aging population faces is that of Alzheimer’s disease. Alzheimer’s disease is closely related to age in that the older a person becomes, the greater their risk for developing the disease (Alzheimer’s Association, 2016; Alzheimer’s Foundation of America, 2016; Hayajneh & Shehadeh, 2014; Pearlin, Harrington, Lawton, Montgomery & Zarit, 2001). Dementia symptoms appear in a few serious illnesses, but Alzheimer’s disease is the most common illness to present with dementia symptoms. Alzheimer’s disease accounts for 60-70% of all dementia cases (Alzheimer’s Association, 2016; D’Onofrio et al., 2014; Hayajneh & Shehadeh, 2014). Alzheimer’s disease is defined as the death of nerve cells in the brain. The National Institute on Aging and the Alzheimer’s Association classify Alzheimer’s disease as an irreversible and permanent brain disorder that worsens over time and that slowly destroys memory and thinking skills, causes changes in personalities and behavioral patterns, and eventually results in a loss of independence and death (Alzheimer’s Association, 2016; García-Alberca et al., 2013; National Institute on Aging, 2016). More than five million people in the United States live with Alzheimer’s disease and of that
five million almost two-thirds are women (Alzheimer’s Association, 2016; Alzheimer’s Foundation of America, 2016; National Institute on Aging, 2016). Alzheimer’s is the sixth leading cause of death in the United States and one in three seniors dies with the disease or some other form of dementia (Alzheimer’s Association, 2016; National Institute on Aging, 2016; Wang, Pai, Hsiao & Wang, 2015).

**Project Objectives**

This critical review addresses four goals. First, this review will define Alzheimer's disease, including its prevalence and symptoms. Second, this review will distinguish between formal and informal caregivers and describe research on caregiver burden and outcomes. Third, this critical review will describe both pharmacological and non-pharmacological interventions and argue that non-pharmacological interventions are the most beneficial. Lastly, this review suggests more education and resources be made available to informal caregivers in order to better support informal caregivers’ ability to understand and utilize non-pharmacological interventions.

**Definition and Prevalence of Dementia and Alzheimer’s Disease**

*Defining dementia.* Alzheimer’s disease falls under the umbrella of dementia. The word dementia refers to a neurodegenerative set of symptoms or a set of symptoms that result in the decomposition of neurons in the brain that affects a person’s cognitive and functional abilities (Clarke & Wolverson, 2016; Hayajneh & Shehadeh, 2014). Dementia is not a disease but a set of symptoms that apply to certain illnesses. These symptoms are most commonly identified as a severe decline in memory or cognitive ability that hinder a person in normal, daily life (Alzheimer’s Association,
2016; García-Alberca et al., 2013; National Institute on Aging, 2016). Daily life includes a person’s ability to pay bills, eat regular meals, bathe and dress, or drive a vehicle, among other tasks. A diagnosis of dementia is often frightening and debilitating for those in the early stages (Clarke & Wolverson, 2016; Mast, 2013). Illnesses associated with dementia are negatively stigmatized and described as a “living death” (Clarke & Wolverson, 2016; Edvardsson, Winblad & Sandman, 2008), because while a person’s body may still be healthy and intact, their brain tissue is slowly dying. With the death of this brain tissue and nerve cells, a person may be physically alive but cognitively absent (Falcão, Teodoro & Bucher-Maluschke, 2016). Unlike other diseases such as cancer, which an individual could fight and defeat, dementia is a losing battle to which its sufferers become helpless victims (Clarke & Wolverson, 2016). Viewing dementia in this way gives no hope and is inaccurate. A person with dementia is a valuable person who still has life to live.

Such a negative stigma may hinder people from noticing dementia signs and instead, mistaking the signs as a normal part of aging. The beginnings of diseases associated with dementia may appear to be simple confusion or be mistaken as a natural part of the aging process (Alzheimer’s Foundation of America, 2016; National Institute on Aging, 2016). The Alzheimer’s Association has gone to great lengths to inform the population that dementia and Alzheimer’s disease are not a natural part of aging. In addition to negative stigma, the progressive symptoms of dementia are often difficult to identify as they appear slowly and over time (García-Alberca et al., 2013; National Institute on Aging, 2016). At first, people may not obviously exhibit dementia
symptoms. Symptoms usually appear slowly, but as time goes on, they become more apparent and advanced (Alzheimer’s Association, 2016). When experiencing dementia symptoms, an individual may go through many stages that eventually lead to loss of function and end-of-life (Clarke & Wolverson, 2016; National Institute on Aging, 2016). These severe outcomes and the serious decline in mental capacity that are caused by dementia support that dementia related illnesses such as Alzheimer’s are not part of the natural aging process.

_Prevalence of Alzheimer’s._ Many people are unaware that Alzheimer’s disease even exists and may be surprised to see its appearance in the top ten leading causes of death in the nation (Alzheimer’s Association, 2017; The Centers for Disease Control and Prevention, 2015; National Institute on Aging, 2016). Education of Alzheimer’s disease is important for those who are unaffected at this time because Alzheimer’s disease is an age related illness. Lifestyle changes in recent decades are causing Americans to live longer than ever before (Cichy & Leslie, 2017; The Centers for Disease Control and Prevention, 2015; Pearlin et al., 2001). The US Census Bureau reported in 2005 that the population 65 years of age and older is expected to double in size within the next 25 years (National Institute on Aging, 2016; US Census Bureau, 2005), and the 85 years of age and older have the fastest growth rate of any age division (Cichy & Leslie, 2017; National Institute on Aging, 2016; US Census Bureau, 2005). With increased longevity comes an increase in one’s odds of developing Alzheimer’s (The Centers for Disease Control and Prevention, 2015; Pearlin et al., 2001). While only one in eight people over the age of 65 suffer with Alzheimer’s disease (Alzheimer’s Association, 2016; Wang et
al., 2015), one out of three seniors over the age of 85 develops the disease (Alzheimer’s Association, 2016). The growing prevalence of people living with Alzheimer’s disease should be striking enough to raise the red flag that this disease is an issue that requires national, if not global attention (Clément, Tonini, Khatir, Schiaratura & Samson, 2012; D’Onofrio et al., 2014; Guétin et al., 2009; Wang et al., 2015). If the prevalence is not enough, one should consider that the disease affects not only those who live with it, but also those who love and care for people with Alzheimer’s. Considering the sheer number of people who are in some way affected by Alzheimer’s, the aim of this critical analysis is to demonstrate how it is increasingly important to provide caregivers with knowledge of the effects of the disease and of appropriate care for persons with Alzheimer's disease.

**Behavioral and Psychological Symptoms Related to Alzheimer’s disease**

With decline in cognition come changes to an Alzheimer’s patient’s behaviors and personality. These changes often uncontrollable and may worsen as the disease progresses. Many of the changes to behavior and personality can be difficult to manage, turning caregiving a burdensome task (García-Alberca et al., 2013; Jeste et al., 2008; Wang et al., 2015). Behavioral outbursts usually accompany personality changes as Alzheimer’s patients find themselves unable to communicate their needs and desires. Unable to communicate, patients attempt to physically represent their needs, often in unwanted and sometimes harmful ways (Sung & Chang, 2005; Wang et al., 2015). These representations are known as behavioral and psychological symptoms.

Behavioral and psychological symptoms most often occur due to Alzheimer’s patients’ needs or desires going unmet (García-Alberca et al., 2013; Wang et al., 2015).
These needs and desires touch on several different aspects of life for Alzheimer’s patients. Some of these aspects include physical needs and desires related to safety, prevention of pain, fatigue and hunger (Edvardsson et al., 2008), as well as psychological needs and desires such as security, comfort and a sense of belonging (Edvardsson et al., 2008; Wang et al., 2015). Unable to conventionally convey needs or desires, Alzheimer’s patients may become frustrated. Further, patients are suffering from cognitive decline, and may be unsure of what they’re actually seeking (Edvardsson et al., 2008; Wang et al., 2015). This makes the deciphering of actual needs and desires difficult for caregivers. When needs or desires go unmet, Alzheimer’s patients, who are unable to appropriately communicate their feelings, engage in disruptive behaviors (Ehresman, 2014; Wang et al., 2015). These disruptive behaviors occur due to apathy, anxiety, depression, delusions, or aggression, among other emotions (García-Alberca et al., 2013; Jeste et al., 2008; Wang et al., 2015). These symptoms may also cause patient distress. Behavioral and psychological symptoms can interfere with patients’ autonomy and impair their ability to complete activities of everyday living (García-Alberca et al., 2013; Wang et al., 2015). Impairment of daily activities negatively affects the psychological well-being of patients. The effects and outcomes of behavioral and psychological symptoms act in a circular cause and effect manner. This circular cause and effect manifests in behavioral and psychological symptoms that cause impairment to daily activities resulting in agitation, frustration, anxiety or depression which are then classified as further behavioral and psychological symptoms.
Due to the encompassing effect of behavioral and psychological symptoms, caregivers may feel burden and sometimes distress when attempting to manage these behaviors while caring for a patient. Behavioral and psychological symptoms are a consistent indicator for high levels of caregiver burden, which may lead to early institutionalization of Alzheimer’s patients (D’Onofrio et al., 2014; García-Alberca et al., 2013; Jeste et al., 2008; Wang et al., 2015). Caregiver burden can be decreased when caregivers have the proper education and resources to care for patients. In many situations, where it is not the case that caregivers have been appropriately equipped for caregiving, both the individual with Alzheimer’s disease and the caregiver have a poorer quality of life (García-Alberca et al., 2013; Jeste et al., 2008; Wang et al., 2015). Caregivers must be trained to manage behavioral and psychological symptoms of Alzheimer’s patients, because they have a great impact on the quality of life an Alzheimer’s patient leads.

**Formal and Informal Caregiving**

Caregivers are an essential component in the quality of life that a person lives after being diagnosed with Alzheimer’s disease. The relationship that is established between the caregiver and the patient has a large impact on improvements or declines in the quality of life for both parties (Edvardsson et al., 2008; Roberto & Jarrott, 2008; Wang et al., 2015). For this reason, in this critical analysis, the importance of the role of the caregiver is emphasized and discussed.

*Formal caregivers.* Caregivers exist in many different capacities, but can be broken down into the two categories of formal and informal caregivers. As either a
formal or informal caregiver, having the proper education to care for a patient with Alzheimer’s disease is of the upmost importance. Formal caregivers are defined as anyone with a certification or a formal education in any health-care related specialty (Alzheimer’s Association, 2016; Hayajneh & Shehadeh, 2014). Formal caregivers include a broad scope of healthcare professionals. Of these healthcare professionals, nurses tend to be the main line of caregiving staff. Currently, there is a well-known shortage of nursing staff across the nation especially of geriatric facilities which often are severely understaffed (Alzheimer’s Association, 2016; Eldercare Workforce Alliance, 2012). Alzheimer’s patients placed in institutions face the risk of low quality care due to the shortage of staff and the accompanying high patient to nursing staff ratios. On the physician side, many are unenthusiastic to contribute to Alzheimer’s care as they do not wish to treat a disease that has no cure (Pearlin et al., 2001). Due to these factors, society depends upon informal caregivers, such as friends and family, to provide support, as the healthcare industry neither has the time nor the financial resources to support the aging population at this time (Alzheimer’s Association, 2016; Pearlin et al., 2001). For this reason, the nation must reshape its government policy to best provide its citizens with the tools to care for those with Alzheimer’s disease.

Informal caregivers. While many Alzheimer’s patients live in long-term care facilities and receive professional care, a great number are cared for by informal caregivers. This critical review aims to analyze best-care practices that are typically implemented in formal settings and demonstrate the effectiveness they would have if implemented in informal settings (i.e., the home). Informal caregivers need to be aware
and educated on methods that they can implement when caring for a person with Alzheimer’s as older adults typically turn to family and friends to care for them (Cichy & Leslie, 2017; Mittelman, 2002; Pearlin et al., 2001; Roberto & Jarrot, 2008). In addition to Alzheimer’s patients looking to friends and family, often friends and family wish to take on the responsibility of caring for their loved one (Mittelman, 2002; Roberto & Jarrot, 2008) which is seen in the fact that on average one in four family members care for an individual with Alzheimer’s disease (Alzheimer’s Foundation of America, 2016; Roberto & Jarrot, 2008). These friends and family are referred to as informal caregivers as they are typically people with no medical background. In 2015, the Alzheimer’s Association found that almost 16 million caregivers of Alzheimer’s patients were family and friends. Of these 16 million, the majority are female caregivers, usually wives or daughters (Alzheimer’s Association, 2016; D’Onofrio et al., 2014; Falcão, Teodoro & Bucher-Maluschke, 2016; Mittelman, 2002; Roberto & Jarrot, 2008). These 16 million caregivers experience caregiving for their loved one at extreme personal cost. Personal cost is commonly known as caregiver burden. Research studies have been conducted to record caregiver burden related to Alzheimer’s disease and have found that caregiver burden can be broken down in terms of physical, economic, and psychological strain (Alzheimer’s Association, 2016; D’Onofrio et al., 2014; Falcão et al., 2016; Hayajneh & Shehadeh, 2014). As these overwhelming burdens are not uncommon among informal caregivers, these caregivers have begun to be referenced as ‘hidden patients’ (Hayajneh & Shehadeh, 2014). Once aware of the burdens associated with caregiving, a caregiver may find that he/she needs to put more time into his/her own personal care. Caring for a
person with Alzheimer’s disease is only possible if a caregiver cares for himself or herself first.

Caregivers report declines in personal health, loss of personal income, or feelings of depression due to the added stress of caring for a loved one with Alzheimer’s disease (Alzheimer’s Association, 2016; D’Onofrio et al., 2014; Hayajneh & Shehadeh, 2014; Mittelman, 2002). Personal health, loss of personal income, and feelings of depression all correspond to the previously mentioned types of burden (physical, economic, and psychological) and are often closely linked. Mental and physical burdens contribute to declines in ability to perform a job. Declining job performance can lead to lost income. Experiencing loss of income often contributes to mental and physical burden. The Alzheimer’s Association found that on average more than $15,000 worth of personal income was lost by informal caregivers in order to be able to have the time and resources to care for an individual with Alzheimer’s disease (Alzheimer’s Foundation of America, 2016). This means cutting back on hours spent at work, or even leaving jobs to be full time caregivers (Alzheimer’s Association, 2016; Roberto & Jarrott, 2008). Mental or psychological strain occurs most often when a patient has mental or psychological symptoms. Caregivers in the presence of patients with depressive symptoms are more likely to have depressive symptoms themselves (D’Onofrio et al., 2014; Roberto & Jarrott, 2008; Wang et al., 2015). With financial and psychological strain, caregivers will begin to reach caregiving capacity. Due to limited caregiving capacity, caregivers often sacrifice their own health needs to tend to those of Alzheimer’s patients (Alzheimer’s Association, 2016; Falcão et al., 2016; Mittelman, 2002; Roberto & Jarrott, 2008). If all
three factors of caregiver burden—physical, economic and psychological—build to a critical point for caregivers, then informal caregivers will turn to formal settings. The increases in these strains often lead to early institutionalization for Alzheimer’s patient (D’Onofrio et al., 2014; Wang et al., 2015). With early institutionalization, the government must allocate more budgeted dollars to the healthcare industry as care provided in informal settings currently saves the government billions of dollars (Alzheimer’s Association, 2016; The Centers for Disease Control and Prevention, 2016).

*Government savings due to informal caregiving.* The hours spent by almost 16 million informal caregivers caring for individuals with Alzheimer’s disease in 2016 totaled 18.1 billion unpaid hours. Those 18.1 billion hours amounted to 221.3 billion dollars of unpaid care (Alzheimer’s Association, 2016; The Centers for Disease Control and Prevention, 2016). Without those 16 million informal caregivers, these patients would have found their way into the Medicaid or Medicare system, or died without care; therefore, the hours of care provided by these caregivers amounts to a 221.3 billion dollar savings for the US government. Tax dollars put towards Medicare and Medicaid in 2016 covered 160 billion dollars’ worth of healthcare costs for individuals with Alzheimer’s and other dementias (Alzheimer’s Association, 2016; The Centers for Disease Control and Prevention, 2016), and in 2017, that number is expected to rise to 175 billion dollars (Alzheimer’s Association, 2017). The U.S. Department of Health and Human Services reported that in 2015 the population of 65 years of age and above made up 13 percent of the total US population, but accounted for 31% of all healthcare spending. As Alzheimer’s disease is estimated to reach an even larger population in the coming years,
it is important that the healthcare system and government funding of the healthcare system be ready to accommodate the growing population. Therefore, healthcare systems that offer not only interventions for Alzheimer’s disease, but which also teach proper informal caregiver interventions will be most effective and helpful to the future affected population (Hayajneh & Shehadeh, 2014; Pearlin et al., 2001). In the future, government money put towards educational programs promoting proper caregiving for Alzheimer’s patients may result in a decrease in healthcare spending on the Alzheimer’s population, and, in the long run, a government savings.

**Pharmacological Interventions**

People with Alzheimer’s disease can often be misunderstood as their cognitive function decreases and they lose the ability to communicate through conventional methods. These losses can lead to Alzheimer’s patients manifesting their uncommunicated needs and desires in unwanted behaviors (Macfarlane & O’ Connor, 2016). In many cases, instead of analyzing the situation and finding the root cause of behaviors, health care professionals immediately turn to pharmacological interventions in order to treat unwanted behaviors (Macfarlane & O’ Connor, 2016; Hawaleshka, 2005). The pharmaceuticals used are often unsuccessful in changing behavior, and can be detrimental to the well-being of the patient (Hawaleshka, 2005). This critical analysis aims to discourage the use of pharmaceuticals in treatment of behavioral and psychological symptoms of Alzheimer’s disease, but does not intend to discourage the use of medications such as Aricept, Exelon, Namenda, among others, that are often used
to slow progression of the disease (National Institute on Health, 2016; Alzheimer’s Association, 2016).

In all care settings, Alzheimer’s patients experience behavioral and psychological symptoms as the disease progresses. These symptoms can be problematic and make the act of caregiving difficult. Several pharmaceuticals are currently on the market, from sedatives to anti-psychotics (Jeste et al., 2008; Macfarlane & O’Connor, 2016; National Institute on Health, 2016). These medications, meant to alter behavioral and psychological symptoms, are rarely effective. With a reduced ability to communicate and declining cognitive function, Alzheimer’s patients are unable to communicate the effects or results of medications and other confounding variables that are involved in regular Alzheimer’s care; therefore, health care professionals cannot be sure that medications are improving psychological health in Alzheimer’s patients (Jeste et al., 2008; Zarit & Zarit, 2011). Finding the correct dosage is also exceedingly difficult. These medications often have only a small therapeutic window, so the benefit will only be felt if the exact amount is given consistently (Zarit & Zarit, 2011). The passing of medication presents another problem, as Alzheimer’s patients lose or forget where medications are, or forget to take a dose. Caregivers themselves, being overwhelmed with caregiver responsibilities, may forget about medications (Alzheimer’s Association, 2017; Macfarlane & O’Connor, 2016; National Institute on Aging, 2017). Without consistently correct dosage, pharmaceuticals will not work effectively and benefit is unlikely to be seen.

Some pharmaceuticals have been effective in managing behavioral problems, but even this is short lived. Many medications appear to end in effectiveness between six to
twelve months (Zarit & Zarit, 2011). These benefits seen in behavioral health come with great risk of adverse effects. As the bodies of Alzheimer’s patients are experiencing old age, liver and kidney damage are among the serious consequences that may occur due to the body’s inability to process medications (Zarit & Zarit, 2011). Other serious side effects have included excessive sedation, constipation or low bowel control, tremors, jerking facial muscles which inhibit regular speech, hospitalization and even death (Gill et al., 2007; Jeste et al., 2008; National Institute on Health, 2016). This is not to say that in serious cases, use of medication is not necessary. In circumstance where the only options are restraint or sedation as a patient is a threat to caregivers or to themselves, the use of medication is the better option. In circumstances other than threat of harm or slowing the progression of Alzheimer’s, caregivers should look to non-pharmacological interventions in order to avoid unnecessary adverse effects or negative consequences.

The adverse effects and negative consequences that come from medicating Alzheimer’s patients to control for behavioral and psychological symptoms come at a serious cost. Pharmaceuticals should only be used as a last resort, after all behavioral interventions have been exhausted to treat behavioral and psychological symptoms in Alzheimer’s patients (Gill et al., 2007; Macfarlane & O’ Connor, 2016; National Institute on Aging, 2017). Patients are better suited to be cared for by those who are willing to find the root cause of their behaviors and find solutions to the initial problem than to be cared for by those who immediately turn to pharmaceuticals that have more negative consequences than positive outcomes.

**Effective Communication between Caregivers and Alzheimer's Patients**
When caring for any person, it’s important that communication take place between a caregiver and the patient. Effective communication is necessary to achieve positive outcomes for the patient and the caregiver. Caring for a person with Alzheimer’s disease is often more difficult than giving care to a person with another disease, because conventional methods of communication deteriorate along with cognitive function in Alzheimer’s patients (Edvardson et al., 2008, Wilson, Rochon, Mihailidies & Leonard, 2012). Due to this deterioration, caregivers must learn to adapt their outlook on communication in order to provide quality care to Alzheimer’s patients.

**Communication deficits.** Providing caregivers with knowledge on how Alzheimer’s disease will affect a patient’s ability to communicate is essential. Caregivers struggle to communicate with Alzheimer’s patients as Alzheimer’s disease disrupts a patient’s cognitive and language functions, which contribute to the disruption of regular speech patterns and the expression of emotion (Alzheimer’s Association, 2016; Clément et al., 2012; Gentry & Fisher, 2007). As Alzheimer’s disease progresses, patients will often find that they have difficulty remembering the words to convey a specific idea, concept, or need, and they may also regularly forget what it is that they want to communicate (Gentry & Fisher, 2007; Gopal Jee, 2017; National Institute on Aging, 2012; Savundranayagam & Orange, 2014). As the disease reaches severity, patients will forget how to speak and will not be able to form words (Alzheimer’s Association, 2016; Gentry & Fisher, 2007; National Institute on Aging, 2016; Savundranayagam & Orange, 2014; Wray, 2011). This decline in ability can be frustrating, depressing, and frightening for patients (Wilson et al., 2012), but patients must learn to adapt with a limited and
declining set of communication skills. As verbal communication becomes more difficult, patients may begin to physically represent their concerns, needs and feelings (Wang et al., 2015; Todd, 2002). These physical behaviors are often misinterpreted and categorized as behavioral problems, which leads to poor caregiving practices.

Methods for effective communication. In order to provide best-care practices to all Alzheimer’s patients, caregivers must be educated on methods to foster effective communication. Comprehension from both patients and caregivers is necessary for effective communication, although, this can be difficult as cognitive skills decline. The individual may begin to experience a shortened attention span, skipping from topic to topic in a conversation and leaving thoughts incomplete (Gentry & Fisher, 2007; Gopal Jee, 2017; National Institute on Aging, 2012; Wray, 2011). The fragmentation in conversation happens because of an Alzheimer’s patient’s decline in cognitive function. Decline in cognitive function presents through communication as Alzheimer’s patients form empty phrases, are repetitive, and use improper word substitution and disruptive topic shifts (Bohling, 1991; Gentry & Fisher, 2007; Savundranayagam & Orange, 2014; Wray, 2011). These losses in ability to verbally communicate, comprehend and pay attention can lead to frustration, not only for a patient, but also for a caregiver. Loss of communication is linked to greater levels of caregiver burden (Gentry & Fisher, 2007; Savundranayagam & Orange, 2014; Wilson et al., 2012). In situations of frustration, it is important that a caregiver remain calm when caring for and communicating with a patient (Alzheimer’s Association, 2016; National Institute on Aging, 2012; Todd, 2002; Wilson et al., 2012). Another problem that Alzheimer’s
patients may experience is trouble blocking out environmental factors (Edvardsson, 2008; National Institute on Aging, 2012). Overly stimulating environments can distract a patient from a conversation, in which case, comprehension will be even more difficult. To combat these problems and to properly care for an individual with Alzheimer’s disease, caregivers must change their communication practices to meet the ability of the patient. This means changing the way a caregiver views communication.

When communicating with Alzheimer’s patients, no matter the severity of their condition, there are common practices that enhance understanding, and reduce frustration and confusion. First, it is important that a caregiver has the attention of the patient. While this is a normal step in communicating with any person, it is especially important when interacting with an Alzheimer’s patient as gaining attention can be more difficult due to a limited attention span (Gentry & Fisher, 2007; Gopal Jee, 2017). To gain the attention of a patient, a caregiver should approach the individual from the front, address them by name and make eye contact (Alzheimer’s Association, 2016; National Institute on Aging, 2012; Wilson et al., 2012). This is critical as it indicates attention, but also gives an individual a sense of respect. In order to provide a patient with a sense of self-value and importance, a caregiver should always acknowledge the patient. An Alzheimer’s patient should never be spoken to as if he/she is too incompetent to understand his/her own care, or be spoken about as if he/she is not present. Patients who are treated as valuable and autonomous respond more positively to interventions than those who are treated as passive objects (Edvardsson et al., 2008; Pearlin et al., 2001). When patients have questions or concerns they should be responded to and addressed
(Alzheimer’s Association, 2016; Hayajneh & Shehadeh, 2014). Acting in this way when communicating with a patient will help to build a trusting and respectful relationship that will lead to a higher standard of care.

After a caregiver has the attention of the patient, effective communication can begin. Research demonstrates that to help a patient understand and feel comfortable, a caregiver should use simple themes, concepts, and directions (Todd, 2002). Simple words and short phrases, along with simple questions with yes or no answers, reduce chances for confusion (Alzheimer’s Association, 2016; Todd, 2002; Wilson et al., 2012). When simplifying ideas for Alzheimer’s patients, a caregiver must remember to remain respectful and create a sense of value for the patient. Not only does verbal communication have an impact on patients, but body language must be kept in mind as well. Caregivers should be aware of the messages they send through body language as body language tends to be universally understood. Non-verbal communication is one of the most effective channels when interacting with an Alzheimer’s patient (Bohling, 1991; National Institute on Health, 2012; Savundranayagam & Orange, 2014). As speech loss progresses, Alzheimer’s patients may still be able to interpret physical signs and body language while they cannot understand speech. Nonverbal expressions of emotion and need are often still intact as the disease reaches more extreme severity (Clément et al., 2012). Positive body language is usually well received, and allows for a patient to feel connected. Gentle touch or physical contact can be used to guide a patient, or gain attention (Wilson et al., 2012). Whether engaging a patient with body language, physical
contact, or regular speech to communicate, a caregiver should remain positive, calm and respectful.

Effective communication is often linked to positive feelings; therefore, in order to avoid ineffective communication, a caregiver should refrain from negative or confrontational behavior with patients. Arguing and correcting the thoughts of individuals with Alzheimer’s is usually ill received. It is best for caregivers to agree with patients or redirect patients’ attention, instead of engaging in confrontational behavior that may cause distress to patients (Alzheimer’s Association, 2016; Todd, 2002). A patient’s thought process and judgment is often compromised as the disease progresses, and an individual’s view of reality can be distorted. Due to this decline in thought and judgment, a patient may make claims or statements that a caregiver knows to be false (Alzheimer’s Association, 2016). A patient may refuse to eat dinner until his/her spouse arrives. Even though a caregiver knows the spouse to be deceased, informing a patient of this would only cause unneeded distress. A patient could become uncontrollably angry, deeply depressed, or extremely confused with this information (Alzheimer’s Association, 2016; Bohling, 1991). Instead of trying to reorient a patient to reality, a caregiver should become part of the patient’s reality (Bohling, 1991; Edvardsson et al., 2008). This consists of redirecting the patient’s attention, possibly asking questions about the spouse to calm the patient, or telling the patient that the spouse will be arriving shortly, but had said to start the meal without him/her. When these practices are used with patients, communication seems to be more effective. Effective communication tends to allow individuals to feel more independent and comfortable and less agitated (Bohling, 1991;
Todd, 2002). These feelings allow for a positive experience for Alzheimer’s patients; which increases their desire to communicate. Non-receptive Alzheimer’s patients also seem to have more of a desire to communicate when these methods are put into practice (Todd, 2002). While effective communication is a key component to successful caregiving, other interventions must take place as well in order for an Alzheimer’s patient to remain as well as possible.

**Therapies to Help Improve Quality of Life**

Some of the most common and well received interventions for Alzheimer’s disease are therapies. In the section below, music and art therapy are discussed. These two therapies are relatively low in cost and easy to implement (Chang & Sung, 2005; Guétin et al., 2009), while also seeming to affect outcomes in promoting positive mood and behaviors (Chang & Sung, 2005; Clément et al., 2012; Dessel & Farkas, 2014). While therapies are most often used in professional settings and facilitated by skilled therapists, it is possible that informal caregivers can employ the discussed therapies as well.

*Music therapy.* Music therapy is a common method used in the treatment of many different illnesses. The effect of music therapy is far reaching, and research supports the therapy’s effectiveness in many different dementia cases, including those specifically documented as Alzheimer’s cases (Chang & Sung, 2005; Clément et al., 2012; Guétin et al., 2009). By definition, music therapy is “controlled use of music and its influence on the human being to aid in physiologic, psychologic, and emotional integration of an individual during treatment of an illness or disability” (Chang & Sung, 2005, p. 1134),
and it is a fairly low in cost and an easy method of therapy to implement (Guétin et al., 2009; Chang & Sung, 2005). As an Alzheimer’s patient’s ability to identify facial expressions and participate in verbal communication declines, studies demonstrate that a patient’s ability to associate emotions with music remains intact (Clément et al., 2012; Chang & Sung, 2005). A patient’s ability to associate emotions with music allows for music therapy to be a useful tool when working with Alzheimer’s patients. Several studies have shown that music therapy is effective in regulating behavior and emotion in Alzheimer’s patients, as well as positively impacting mood and sleep quality (Clément et al., 2012; Chang & Sung, 2005; Dessel & Farkas, 2014). Music therapy seems to have an almost immediate effect and a long-term positive influence on mood (Clément et al., 2012). With these findings, different types of music therapies have begun to emerge and the therapy best suited for the patient is being used by caregivers.

There are two different categories of music therapy. Receptive music therapy is when a patient is solely listening to music, whereas active music therapy involves a patient in making music or playing an instrument (Chang & Sung, 2005; Guétin et al., 2009). Choosing which method of music therapy to enact is based upon the ability of the patient and what the patient is most responsive to. The outcome that a caregiver hopes to achieve through music therapy while working with an Alzheimer’s patient also influences which type of music therapy a caregiver will implement. This is because music therapy can have different effects, either relaxing or soothing a patient, or encouraging expression and development of thought (Guétin et al., 2009). Typically, listening to music will
affect a patient’s mood, whereas playing or creating music will encourage a patient to express emotions throughout the process (Guétin et al., 2009).

When using music therapy to influence the mood, feelings, or behaviors of a patient, a caregiver should take the patient’s preferences into consideration. Musical selections that are based on individual preferences have been shown to be more effective (Chang & Sung, 2005; Clément et al., 2012). When musical selections are based on patients’ personal preferences or experiences, then there is a greater chance of stimulating a patient’s memory and helping them recall past experiences (Chang & Sung, 2005; Guétin et al., 2009). In addition to music therapy stimulating the memory, this therapy has also been effective in controlling behavior. Music chosen by a patient or music that is culturally relevant to a patient typically has a greater and more positive impact (Clément et al., 2012). Allowing a patient to listen to a genre of music that they enjoy can put them into a more positive mood, which will lead to more positive behaviors. Listening to an individual’s preferred genre of music is suggested to help manage behavioral problems in dementia patients (Chang & Sung, 2005; Guétin et al., 2009). Music therapy does not only have a positive impact upon Alzheimer’s patients, but also upon Alzheimer’s caregivers. Increased positive moods are seen in patients and caregivers during music therapy, and the burden felt by caregivers seems to decrease (Clément et al., 2012; Guétin et al., 2009). This is because patients with positive moods are easier to care for, making the job of a caregiver less stressful, and even enjoyable. These reports support that music therapy therefore has an indirect positive impact on the health and well-being of caregivers (Clément et al., 2012). Finding
therapies that are effective in not only helping Alzheimer’s patients, but also their
caregivers is exceedingly important as caregiver burden seems to be associated with the
mood of Alzheimer’s patients (D’Onofrio et al., 2014).

Art therapy. Art therapy is another commonly practiced therapy when working
with Alzheimer’s patients and is defined by the American Art Therapy Association as
“the use of art media, the creative process, and the resulting artwork to explore [patient’s] feelings, reconcile emotional conflicts, foster self-awareness, manage behavior … develop social skills, improve reality orientation, reduce anxiety, and increase self-esteem” (Dessel & Farkas, 2014, p. 21). Many of these results are similar to music
therapy and the implementation of art therapy matches music therapy in several
aspects. Art therapy may be practiced with individuals or in groups of people with
Alzheimer’s disease. Both the individual and group settings seem to improve behavioral
problems and quality of life (Ehresman, 2014; Dessel & Farkas, 2014). Similar to music
therapy, improving mood and quality of life for Alzheimer’s patients tends to, in turn,
lessen caregiver burden. Mood and quality of life seem to improve as art therapy
provides patients with an outlet for expression and acts as a form of
communication. Through art therapy, an Alzheimer’s patient is able to express thoughts
and emotions that may otherwise not be communicated due to barriers in conventional
communication (Ehresman, 2014). This method of communication may be found as a
patient completes a work of art, or communication will more likely to take place
throughout the creation process. When implemented among a group, patients are given
the opportunity not only to express themselves creatively and autonomously, but are also
placed within a social situation that encourages communication, expression, and sharing (Dessel & Farkas, 2014; Hertz, 2016). During the creation process, it is likely that patients will engage the therapist, instructor, caregiver, or other participants in verbal or nonverbal communication (Dessel & Farkas, 2014). This is the main reason why art therapy or any creative therapy in general can improve communication and expression as well as positive social behaviors.

Art therapy appears to have several positive impacts aside from encouraging communication. Art therapies provide sensory stimulation and opportunities for creativity (Dessel & Farkas, 2014; Ehresman, 2014). Taking part in art therapy tends to be empowering to Alzheimer’s patients as well. The creative process gives patients the ability to make decisions and choices when they are working on a project (Ehresman, 2014; Hertz, 2016). The ability to make these decisions and choices is empowering as in many other aspects of life, individuals with Alzheimer’s disease are losing control over the decisions and choices pertaining to their lives. In addition to empowering patients, art therapy has also been reported to give a patient a sense of their identity. As the disease progresses, Alzheimer’s individuals are losing their sense-of-self, but, through art therapy, self-expression is promoted (Ehresman, 2014; Hertz, 2016). Self-expression allows patients to grasp a concept of self and possibly remind them of parts of their identity. Overall, the process of participating in art therapy is often more important than the final outcome or artwork that is created (Ehresman, 2014). The many benefits that come from the therapy are the focus.

**The Person-Centered Care Model**
There are countless approaches to the care that is provided to Alzheimer’s patients. These methods to care can all be successful when implemented in the proper way, but to achieve the highest quality of care, caregivers should look to incorporating several care-practices into an integrated care plan. The integrated approach discussed in the final portion of this critical analysis is the Person-Centered Care Model. The Person-Centered Care Model is an encompassing method of care currently practiced in formal care settings that should be considered as a method taught to informal caregivers.

The purpose of the Person-Centered Care Model is to integrate all aspects of care to meet the needs of the specific individual. Care providers define the term differently, but broadly understand Person-Centered Care to be care that is designed to fit the needs, desires and preferences of each individual, while seeing the individual as a person and not as their disease (Edvardsson et al., 2008; Hayajneh & Shehadeh, 2014). As stated at the beginning of this review, dementia and dementia related illnesses, such as Alzheimer’s disease, are negatively stigmatized (Clarke & Wolverson, 2016). When interacting with an Alzheimer’s individual, there is a tendency to treat them as nothing more than their disease. Society has labeled Alzheimer’s disease to be so debilitating that human value is lost (Edvardsson et al., 2008; Mast, 2013). Society’s view on Alzheimer’s disease has negatively impacted the perspective of caregivers. Caregivers who see patients as valueless and ‘empty-shelled’ do not take the time to create meaningful relationships and may see their caretaking responsibilities as meaningless (Edvardsson et al., 2008; Hayajneh & Shehadeh, 2014; Penrod et al., 2007). When a caregiver feels that their responsibilities are meaningless and they do not create a positive
relationship with an Alzheimer’s patient, the quality of care a patient receives is
negatively affected which in turn negatively affects a patient’s quality of life. In order to
provide high quality care, caregivers must look past these negative stigmas and see a
patient as more than the disease.

The Person-Centered Care Model aims to do just that by considering the concept
of personhood. The concept of personhood was formed by Tom Kitwood in his person-
centered care for people with dementia theory, and is the quality or condition of being a
person in relation to who one is and who one could be (Edvardsson et al., 2008; Penrod et
al., 2007). When considering personhood, a caregiver should take into account the
individuality, rights, values and beliefs of the individual. These are different for
everyone and can include personal history, religious preferences, emotions and previous
dispositions, and hopes and fears for the future (Edvardsson et al., 2008; Mast, 2013;
Pearlin et al., 2001). Doing so leads to a deeper understanding of the individual for the
caregiver and the creation of a positive relationship. A positive relationship will lead to
the creation of a positive psychological environment.

Positive psychological environments are critical to the well-being of Alzheimer’s
patients. There is a tendency, due to the previously discussed stigma, to see a patient as
nothing more than a mere passive object to be acted upon (Edvardsson et al., 2008;
Pearlin et al., 2001). This perspective, once again, leads to poor quality in care and
overall life for Alzheimer’s patients. Caregivers exposed to this perspective approach
caregiving in a purely biomedical fashion, and ignore patients’ dignity and worth
(Edvardsson et al., 2008; Hayajneh & Shehadeh, 2014; Penrod et al., 2007). Caregivers
who approach patients as such run the risk of ignoring the psychological needs of a patient. Their work becomes task based, which is objectifying, degrading, and depersonalizing to individuals with Alzheimer’s (Edvardsson et al., 2008; Penrod et al., 2007). Patients who are treated in such ways tend to exhibit more behavioral problems as their needs are unmet. Alzheimer’s patients, while in cognitive decline, are often still acutely aware of the interactions taking place around them, and may feel strong emotions regarding the way they are treated and communicated with (McEvoy & Plant, 2014; Pearlin et al., 2001). The Person-Centered Care Model is a solution to this problem as well.

When interacting with an Alzheimer’s patient, personhood should always be taken into account. To stop objectifying care practices, caregivers must see that even while in cognitive decline, Alzheimer’s patients still have human value or personhood; personhood is never lost, it is merely in a state of constant change (Edvardsson et al., 2008; Mast, 2013). Caregivers that remember a patient’s value and individuality at all times are acting within the Person-Centered Care Model. These caregivers will seek to provide care that meets not only the physical needs of patients, but also the psychological needs as well (Edvardsson et al., 2008; Hayajneh & Shehadeh, 2014; Mast, 2013). The model achieves this behavior in caregivers by promoting practices and methods of communication that reach patients on an individual level and address needs that are specific to that one person. These methods involved the perspective of the caregiver to change so that feelings of empathy and acceptance could be achieved when working with Alzheimer’s patients (D’Onofrio, 2014; Hayajneh & Shehadeh, 2014). All methods can
be effective if implemented correctly. These methods all require a different approach and perspective on patient-caregiver interaction. In order to create empathy, caregivers must be willing to see from the patient’s view, and understand their feelings as if they were the patient (Hayajneh & Shehadeh, 2014; McEvoy & Plant, 2014). Having the ability to do this allows caregivers to only give care that they would be pleased to receive thus controlling the quality of care they give. The validation piece of Alzheimer’s care involves meeting a person in his/her own reality and not attempting to reorient him/her back to the current reality (Hayajneh & Shehadeh, 2014). By practicing this method, Alzheimer’s patients feel that the reality they are experiencing is valid and do not have to face the frustration or fear that comes from knowing their experiences are not true.

Choice also plays a large role in the Person-Centered Care Model. This model promotes that Alzheimer’s patients be given as much autonomy as is appropriate to make choices (Edvardsson et al., 2008; Hayajneh & Shehadeh, 2014; Mast, 2013). The only times that caregivers should distinguish a personal reality from actual reality, or interfere with a patient’s autonomy, is when a patient is going to make a choice that would result in harm to his/herself due to that personal reality or autonomy. In that instance, caregivers must intervene and use negotiations while still interacting with respect to ensure the safest outcome possible outcome (Hayajneh & Shehadeh, 2014).

Caregivers who practice Person-Centered Care often have more positive outcomes with Alzheimer’s patients. When practicing this care model, caregivers are more prone to hear, see, and acknowledge Alzheimer’s patients once they have taken the patient’s personhood into account (Hayajneh & Shehadeh, 2014). There is individualized
meaning to the care that is being provided to each patient. As a result of a caregiver’s heightened awareness to the needs and desires of a patient, a patient tends to exhibit more positive behavior and emotions (Edvardsson et al., 2008; Hayajneh & Shehadeh, 2014). Due to this result, the Person-Centered Care Model is beneficial not only to the patient, but to the caregiver themselves. Care falling in line with the method laid out in the Person-Centered Care Model seems to result in outcomes that reduce caregiver burden (Edvardsson et al., 2008; Hayajneh & Shehadeh, 2014). Overall, correct implementation and practice of the Person-Centered Care Model leads to positive outcomes in all aspects of Alzheimer’s patient care. The method mostly includes changing the perspective of the caregiver to see past negative stigmas, viewing the patient as a person and not their disease. In the long run, this model should be implemented as an encompassing approach to care for formal as well as informal caregivers.

**Conclusion**

The epidemic that is Alzheimer’s disease will not be disappearing anytime soon. This disease is only predicted to grow in far reaching effect (Alzheimer’s Association, 2017; Alzheimer’s Foundation of America, 2016; Guétin et al., 2009; Wang et al., 2015). While health care professionals, including physicians and researchers, are searching for treatment options and a cure, they are too far off to rely upon and will not fix the current problems that society faces with regard to the disease. As a society, hope and an optimistic outlook on the procurement of a cure should not be lost, but all hope most certainly should not be hinged upon a cure (Pearlin et al., 2001). Therefore, society must look towards improving awareness, education, and resources to properly provide for the
population that is affected by Alzheimer’s disease right now (Alzheimer’s Association, 2016).

Change must take place. Current programs are not meeting the needs of those affected. Caregivers are unaware that programs and resources exist, and of those who are aware, many are unwilling to take advantage of programs and resources as they are too busy with care tasks to seek help (Roberto & Jarrott, 2008). In these instances, caregivers seem to only access programs and resources once they have hit a critical point and are extremely over-burdened (Pearlin et al., 2001; Roberto & Jarrott, 2008). While searching for a cure, resources are most well spent on educating caregivers. Education on how to implement non-pharmacological interventions, as well as the benefits of such interventions, is a valuable investment when considering the growing Alzheimer’s population and the care they will require. By educating caregivers, caregivers are able to access help before the critical point is reached, and provide better quality care (D’Onofrio et al., 2014; Mittelman, 2002). Educational programs and materials are beneficial and necessary for achieving positive outcomes for not only the patient, but also the caregiver.

This critical review highlighted the importance of informal caregivers and their increasing role in Alzheimer’s care. Knowing the figures that relate to unpaid hours of care provided by informal caregivers in the above section, there is no dispute in the value and worth of informal caregivers. Providing the government savings of over $220 billion (Alzheimer’s Association, 2016; The Centers for Disease Control and Prevention, 2016), the government should be willing to put even a small percentage of that savings into providing proper education on effective caregiving practices to those people who are
serving a growing population. Those who take on the immense task of caring for an individual with Alzheimer’s disease should be equipped with the proper knowledge to do so. This knowledge includes the harm and dangers caused by pharmacological interventions, and, more importantly, safer and more effective non-pharmacological care practices to improve quality of life for both the patient and the caregiver. The above mentioned non-pharmacological interventions are not implemented enough in informal care settings, but would all serve as effective methods to achieve higher quality care and life and are not too difficult or costly to implement.

Therefore, the problem stands that the ill consequences of pharmacological interventions and the benefits of non-pharmacological interventions are not well understood as the population remains uneducated on Alzheimer’s disease. Education is the answer when seeking improvement in quality of care for Alzheimer’s patients. This care, mainly non-pharmacological care practices, need to be taught to those outside of formal settings, as informal caregivers make up a large portion of the caregiver population. These informal caregivers will only continue to increase government savings as they incur all of the cost- financial, psychological and physical- of caring for the Alzheimer’s population (Alzheimer’s Association, 2016; G. D’Onofrio et al., 2014; Falcão et al., 2016; Hayajneh & Shehadeh, 2014). The American government can be sure of this; the immense savings attributed to informal caregivers will not only remain, but escalate as people have a desire to care for their loved ones.
References


