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Alzheimer's Disease: Knowledge of Early Detection, Risk Factors, and Treatment

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ALZHEIMER'S DISEASE:

KNOWLEDGE OF EARLY DETECTION, RISK FACTORS,

AND TREATMENT

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ABSTRACT

Alzheimer's disease causes a progressive and irreversible decline in cognitive functioning. There are many people living with this disease, and the prevalence is expected to triple between 2010 and 2050. Many members of society are affected through either a personal diagnosis or the diagnosis of a family member. There have been numerous studies outlining risk factors, signs and symptoms, and treatments for this disease, but it is unknown if this has translated to greater public awareness. This study aims to assess the general adult population's knowledge of Alzheimer's disease. The participants are 35 to 70 years old and live in the Minneapolis and St. Paul metropolitan area. A survey was sent via email to participants, and assessed the knowledge they had regarding Alzheimer's disease. This initial survey was followed by a brief educational piece outlining information on the disease. A second survey was then completed by the participants to determine the effectiveness of the educational component. The data was aggregated and analyzed using Microsoft Excel. No statistical significance was found, likely due to a small population size. However, the study did give insight into aspects of the disease that require more public education, which includes warning signs and nonpharmacological treatments. Increasing public awareness of Alzheimer's disease will allow for earlier diagnosis. Timely recognition is imperative to the initiation of prompt and accurate treatment. It is recommended that further research be conducted with a larger population in an expanded geographical area.

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Chapter One: Introduction

Background

Alzheimer's disease is characterized by a progressive and irreversible decline in cognitive functioning (Alzheimer's Disease Facts and Figures, 2007). Currently, over 5 million people are living with the disease, and that number is expected to rise at an alarming rate (DeFina, Moser, Glenn, Lichtenstein, & Fellus, 2013). The incidence of Alzheimer's disease will triple between 2010 and 2050 (Herbert, Weuve, Scherr, & Evans, 2013). Many risk factors have been identified that may contribute to the development of the disease, however, some risk factors are more predictive than others. The available treatment options aim to lessen and slow progression of symptoms associated with Alzheimer's disease (Alzheimer's Disease Facts and Figures, 2007). With no cure available, early detection of the disease is crucial.

The greatest known risk factor in the development of Alzheimer's disease is increasing age (Alzheimer's Disease, n.d.). Diagnosis typically occurs after the age of 65, with early onset Alzheimer's disease occurring as early as the 40s (Alzheimer's Disease, n.d.). Family history is also a strong predictive factor for the disease (Alzheimer's Disease, n.d.). Other variables potentially affecting the development of Alzheimer's disease include diabetes mellitus, depression, and smoking (Williams JW, Plassman BL, Burke J, Holsinger T, Benjamin S., 2010).

At this time, two types of drugs are approved by the United States Food and Drug Administration (FDA) to reduce the cognitive symptoms of Alzheimer's disease. Other medications are also available to help counteract the behavioral changes that occur alongside the disease, which include anxiety, depression, agitation, and aggression.

Alternatives to medication have also been explored and have shown promising benefits in the improvement in cognitive ability (Bredesen, 2014). As with most medical conditions, starting medication early yields improved results. Effects of early medication initiation is described by Doraiswamy, et al (2002). Assessment of rivastigmine, a cholinesterase inhibitor, was performed by giving patients the drug at different time intervals. Patients that were treated immediately experienced greater benefit compared to those who began treatment after six months (Doraiswamy, et al., 2002). This demonstrates just how critical it is to begin drug treatments as close to onset of diagnosis as possible.

The key to early detection of this devastating disease is recognition of the presenting symptoms. Unfortunately, a considerable delay still exists between the initial appearance of symptoms of cognitive and memory decline and the formal disease diagnosis (Werner, 2003). Many people presume that the presenting cognitive decline is part of the normal aging process. Patient knowledge of early Alzheimer's disease symptoms is important and may prompt them to seek medical help earlier.

Problem Statement

Studies have shown that early detection and treatment of Alzheimer's disease can delay the onset of more severe symptoms associated with the disease. Often times, early warning signs are ignored or dismissed as being part of the normal aging process. Many people are not aware of the warning signs, risk factors, and what can potentially be done to treat the symptoms of the disease.

Purpose

The purpose of this study is to assess the general adult (age 35 to 70) population's current knowledge of early detection, risk factors, and treatment options of Alzheimer's disease. This research also aims to determine if an Alzheimer's disease fact sheet is sufficient in increasing the public's awareness of the disease.

Research Questions

The following research questions will be addressed with this study:

1. Does the general population have an understanding of foundational information regarding Alzheimer's disease?
2. Is the general population aware of early warning signs and symptoms of Alzheimer's disease?
3. What risk factors are the general population familiar with?
4. Is the general population aware of all the treatment options that are available for Alzheimer's patients, both pharmacological and nonpharmacological?
5. Is an Alzheimer's fact sheet effective in raising awareness of the disease?

Significance of the Study

A diagnosis of Alzheimer's disease is overwhelming for both the patient and the family because of the poor prognosis. Every 67 seconds, someone in the United States is diagnosed, adding to the 5.2 million Americans already diagnosed (Alzheimer's Disease Facts and Figures, 2007). Unfortunately, that number is expected to rise at an alarming rate with the aging baby boomer generation. By 2050, prevalence of Alzheimer's disease may reach 16 million (Alzheimer's Disease Facts and Figures, 2007). Currently, there are 500,000 deaths per year that are attributed to Alzheimer's disease and it is the sixth

leading cause of death in the United States (Alzheimer's Disease Facts and Figures, 2007). Out of the top 10 leading causes of death in the United States, Alzheimer's is the only disease that cannot be prevented or cured. Not only is the disease becoming increasingly prevalent among the American population, the financial toll also continues to climb. It is estimated that the total cost to the United States is 214 billion dollars per year and that could escalate to 1.2 trillion dollars per year by 2050 (Alzheimer's Disease Facts and Figures, 2007). The impact of Alzheimer's disease on society can also occur directly when a loved one is diagnosed, in addition to indirectly through the economic repercussions.

Recently, a study of 10 individuals diagnosed with Alzheimer's disease were treated through lifestyle alterations such as diet modification, vitamins, optimizing sleep, and reducing stress (Bredesen, 2014). Nine out of ten patients slowed the progression of symptoms or improved their memory function. The patient that did not improve was further along in the progression of the disease at the start of the study (Bredesen, 2014). This study suggests that it may be important to diagnose and begin treatment for Alzheimer's disease early. This was a small scale study and was only based on anecdotal information, therefore, it does not definitively prove that early detection is critical in the treatment and outcome of the disease. Many other studies have also associated early diagnosis and treatment with an improvement of symptoms. With that being said, this current survey will uncover the adult (age 35 to 70) population's knowledge about early detection, risk factors, and treatment options. The information gathered will allow practitioners to better target where patient education needs to be improved and will allow the researchers to determine if an Alzheimer's fact sheet is sufficient to increase the

general population's knowledge of the disease. Increasing patient education may help with earlier recognition of symptoms resulting in an earlier diagnosis.

Limitations of the Study

Limitations to this study include the number of participants that will respond to the survey, appropriate completion of the survey by participants, and the ability to quantify participant responses into statistically significant data.

The study is dependent on the research that is already available regarding Alzheimer's disease. While this survey will be focusing on the data and statistics that are currently available, this data is continuously changing. More research still needs to be conducted on Alzheimer's disease, and this survey may need to be reproduced as more information becomes available.

A delimitation of this study is that the survey will only gather information from a certain population. For a thorough understanding on the general population's knowledge of Alzheimer's disease, additional surveys would have to be distributed to people in multiple locations across the country. A nationwide study would provide a well rounded understanding of the topic because knowledge on the disease can vary depending on advertisements, public health education, and many other factors that are location and culturally dependent.

Definitions

Dementia - a decline in brain function that markedly impacts a person's ability to perform activities of daily living. Alzheimer's is the most common type of dementia, but the category also includes Huntington's Disease, traumatic brain injury, vascular dementia, and many more.

Alzheimer's disease - A subset of dementia that negatively impacts a person's memory, thinking, and behavior and occurs through degeneration of the brain.

Early onset Alzheimer's disease - 5% of diagnoses are considered early onset, or occurring before the age of 65. People can be affected as early as 40 to 50 years old and is generally a result of genetic predisposition.

Apolipoprotein E – A protein in the body that is partially responsible for the metabolism of cholesterol and fats in the bloodstream. Apolipoprotein E can be abbreviated as ApoE.

Cognitive or cognition - Relating to mental processing, acquiring knowledge, and the understanding of information.

Summary

Alzheimer's disease affects millions of people, and the numbers are expected to rise. Not only is the disease prevalence rising, it is the only disease in the top 10 causes of death that is neither preventable nor curable. Memory loss and cognitive decline are often dismissed as part of the normal aging process in the middle aged and elderly. These changes may be caused by Alzheimer's disease, which is progressive and incurable. Many risk factors have been identified including age, genetics, diabetes mellitus, depression, and smoking. Current drugs are available to lessen the cognitive and behavioral changes experienced by those with Alzheimer's disease. Alternative methods can also be tried, and may offer an improvement in symptoms. Recent research has proven the importance of detecting the disease early so that treatment can be initiated promptly and the progression of disease symptoms can potentially be slowed. The central issue in early detection and diagnosis is patient education and recognition of Alzheimer's disease symptoms. A survey of adults will provide information on the

general population's current knowledge of early detection, risk factors, and treatment options. An Alzheimer's fact sheet will then be administered followed by a short survey on its effectiveness. This will allow the researchers to assess if this form of brief education is sufficient to help patients recognize the disease earlier and therefore seek treatment more readily.

Chapter 2: Literature Review

Introduction

Dementia is a broad term for a variety of disorders that cause irreversible cognitive decline (Alzheimer's Disease Facts and Figures, 2007). In order to be diagnosed with dementia, an individual must have a decline in two of the following areas: memory, ability to speak coherently, ability to plan and do complex tasks, and ability to process visual information (Alzheimer's Disease Facts and Figures, 2007). Many different types of dementia are classified based on the pattern of symptoms that the individual displays and their brain abnormalities (Alzheimer's Disease Facts and Figures, 2007). Alzheimer's disease is the most common type of dementia, accounting for 50 to 70 percent of those diagnosed with dementia, but other forms include vascular dementia, Parkinson's disease, frontotemporal dementia, and mild cognitive impairment (Alzheimer's Disease Facts and Figures, 2007).

Alzheimer's disease causes nerve cells in the cortex and hippocampus of the brain to deteriorate and die at an increasing rate. The exact cause of Alzheimer's disease is still unknown but the current theory is called the "amyloid hypothesis" (Alzheimer's Disease Facts and Figures, 2007). This hypothesis suggests that beta amyloid protein is overproduced and the brain is unable to get rid of the excess, resulting in plaques. The

extra beta amyloid blocks the neuronal pathways and results in cell death (Alzheimer's Disease Facts and Figures, 2007). Furthermore, tau proteins begin to twist abnormally in the dying neurons and tangles are formed. Additional damage to the brain is caused by inflammation and oxidative stress (Alzheimer's Disease Facts and Figures, 2007). These abnormal changes in the body result in cognitive impairment and the symptoms that are associated with Alzheimer's disease.

Risk Factors

Alzheimer's disease has been widely studied in an attempt to discover the cause of the disease and how to prevent or treat it. There have only been a few risk factors identified that are supported by data which result in an increased prevalence of the disease. Age, the apolipoprotein E gene, diabetes mellitus, depression, and smoking all have considerable data supporting that they put an individual at an increased risk for developing Alzheimer's disease (Williams JW, Plassman BL, Burke J, Holsinger T, Benjamin S., 2010).

The greatest predictor of Alzheimer's disease is age. Typical onset occurs after the age of 65 and the likelihood of developing the disease increases as the person ages (Alzheimer's Disease Facts and Figures, 2007). In a study conducted in 2007, Alzheimer's disease was diagnosed in two percent of people age 65 to 74, 19 percent of people ages 75 to 84, and 42 percent of people greater than 85 years old (Alzheimer's Disease Facts and Figures, 2007). In addition, women are at an even greater risk. Women, at age 65, have a 1 in 6 chance of developing Alzheimer's disease at some point in their lifetime (Women and Alzheimer's Disease, 2014). Men on the other hand, have only a 1 in 11 chance of developing the disease (Women and Alzheimer's Disease, 2014).

Family history of Alzheimer's disease is the second strongest risk factor for Alzheimer's disease behind age (Williams JW, et al., 2010). Four known genetic risk factors associated with Alzheimer's disease include the amyloid precursor protein (APP), the presenilin 1 gene (PS 1), the presenilin 2 gene (PS 2), and the apolipoprotein E (ApoE) gene (Hsiung, G. Y., Sadovnick, A. D., & Feldman, H, 2004). The apolipoprotein E ε4 allele increases the risk of developing the disease while the APP, PS 1, and PS 2 are associated more with early onset Alzheimer's disease (Hsiung, G. Y., et al., 2004). More specifically, the ApoE gene ε4 allele increases the risk of Alzheimer's disease while an ε2 allele actually reduces one's risk (Hsiung, G. Y., et al., 2004). The ApoE ε4 allele works in a dose dependent fashion; with one ε4 allele, a person is three times as likely to get the disease, whereas a person with two ε4 alleles is nine times more likely to get the disease, compared to someone with no ε4 alleles (Hsiung, G. Y., et al., 2004). When the ApoE gene is combined with other risk factors, it can act synergistically and increase a person's chances even more. For example, when a person has the ApoE gene as well as diabetes mellitus, that individual is at a higher risk for developing Alzheimer's disease compared to having either the ApoE gene or diabetes mellitus alone (Irie, F. et al., 2008).

Diabetes mellitus has effects on the vascular system which can amplify a person's chances of developing Alzheimer's disease. Hyperglycemia can increase oxidative stress within a person's body, which harms neurons. Diabetes mellitus also decreases the amount of acetylcholine in the brain (Irie, F. et al., 2008). All of these vascular changes may result in degeneration of neurons. In a study done by Xu et al., those who had undiagnosed diabetes mellitus were 3.29 times more likely to have Alzheimer's disease

than those who were nondiabetic (2009). Participants with controlled diabetes were still at an increased risk for Alzheimer's disease, although their chance for actually developing the disease was only slightly elevated (Xu, W. L., von Strauss, E., Qiu, C. X., Winblad, B., & Fratiglioni, L., 2009). In summary, this study showed that unregulated glucose can be neurodegenerative while controlling one's diabetes can minimize the dementia related complications of the disease.

Depression can also put a person at a higher risk for Alzheimer's disease. The connection between the two diseases is not entirely known, but there are a few hypotheses. One hypothesis states that both depression and Alzheimer's disease have similar risk factors such as vascular disease (Ownby, R. L., Crocco, E., Acevedo, A., John, V., & Loewenstein, D., 2006). Also, inflammatory cytokines (such as tumor necrosis factor) are seen in people with depression and those same cytokines are linked to Alzheimer's disease (Ownby, R. L, et al., 2006). Even if the exact link between the two diseases is unknown, people who have experienced depression are about two times as likely to suffer from Alzheimer's disease later in life (Ownby, R. L, et al., 2006).

Damage to the vascular system is another risk factor for Alzheimer's disease. For example, smoking has detrimental effects on the cardiovascular and vascular system, and is linked to Alzheimer's disease (Anstey, K. J., von Sanden, C., Salim, A., & O'Kearney, R., 2007). Historically, it has been believed that smoking and nicotine decreases one's chance of Alzheimer's disease because it improves short term memory (Elrod, K., Buccafusco, J. J., & Jackson, W. J., 1988) and hinders amyloid formation (Salomon, A. R., Marcinowski, K. J., Friedland, R. P., & Zagorski, M. G., 1996). A meta analysis looked at the connection between smoking and Alzheimer's disease and found that

current smokers have a 1.79 times risk of developing Alzheimer's disease compared to nonsmokers. People who have smoked at some time in their life and have since quit, are not at an increased risk (Anstey, K. J., von Sanden, C., Salim, A., & O'Kearney, R., 2007). Another study looked at how much a person smoked in midlife and found that those who smoked more than 2 packs per day were twice as likely to get Alzheimer's disease than someone who has never smoked. People who have smoked 0.5 to 2 packs per day are only 1.4 times more likely to develop the disease (Rusanen, M., Kivipelto, M., Quesenberry, C. P.,Jr, Zhou, J., & Whitmer, R. A., 2011). These studies have disproved the thought that smoking protects against Alzheimer's disease, and that the habit actually increases the chance of developing the disease.

There are many additional factors that have been researched but are not conclusively linked to Alzheimer's disease. Studies looking at the association between hypertension, obesity, metabolic syndrome, certain occupations, alcohol, and toxic environmental exposures to Alzheimer's diseases don't have consistent data to confirm they are potential risk factors (Williams JW, et al., 2010). Furthermore, there is not enough evidence to link socioeconomic status, marital status, social network, and traumatic brain injuries to Alzheimer's disease (Williams JW, et al., 2010).

Although more emphasis is placed on identifying risk factors, there are also factors that have been shown to decrease a person's chance of developing Alzheimer's disease. It is likely that physical activity later in adulthood, cognitive engagement, more education, and folic acid may decrease a person's risk for Alzheimer's disease (Williams JW, et al., 2010).

The two strongest risk factors that lead to Alzheimer's disease are age and the apolipoprotein E ε4 allele. Diabetes mellitus, depression, and smoking all have considerable data showing they increase a person's risk for Alzheimer's disease. On the other hand, many other factors are thought to increase a person's risk, but there is currently not enough statistical evidence to make that claim. While countless studies look at what increases the chance of developing Alzheimer's disease, there are no studies that document public knowledge about these risk factors.

Early Symptoms of Alzheimer's Disease

Usually, symptoms of Alzheimer's disease are present during the early stages of the condition, even before formal diagnosis. Memory loss affecting daily life, problem solving challenges, inability to complete familiar tasks, time/place confusion, trouble understanding spatial relationships, verbal and writing problems, misplacing of objects, poor judgment, withdrawal from social situations, and changes in personality are the most common first symptoms of Alzheimer's disease highlighted by the Alzheimer's Association (Memory Loss & 10 Early Signs of Alzheimer's, 2009).

Early diagnosis of Alzheimer's disease is important, but is often difficult because presenting symptoms can vary between individuals. Symptoms of the disease may be dismissed or ignored for a time before medical help is sought (Werner, 2003). Clinically measurable symptoms of Alzheimer's disease have been found to exist 12 years prior to a dementia diagnosis (Amieva, H., et al., 2008). A 14 year study of elderly subjects found the first measurable decline in cognitive function can be picked up on the Isaacs Set Test (IST), which is a special test looking at semantic and long term memory. (Amieva, H., et al., 2008). Approximately two years later, decline in verbal concept formation occurred

and was shown through the Wechsler Similarities test (Amieva, H., et al., 2008). The data obtained from the IST and Wechsler test results correlate to the neuroanatomic distribution of histopathological abnormalities expected in mild stages of the disease (Amieva, H., et al., 2008). Predemented participants began to report declines in personal cognitive performance and they also had depressive symptoms (Amieva, H., et al., 2008). Results show that the depressive condition accompanies the progression of cognitive decline (Amieva, H., et al., 2008).

Depression is a common neuropsychiatric comorbidity of Alzheimer's disease (Lee H., & Lyketsos, C., 2003). A study performed in the Netherlands found that depression, or a severely depressed mood, may be an early finding in patients with Alzheimer's disease (Geerlings, et al., 2000). The data obtained by Geerlings, et al. (2000) support the hypothesis that depression in the elderly is an early symptom of the neuropathological processes that occur in the early stages of the disease. However, the depressive state experienced by the elderly can have varying etiologies and cannot exclusively be linked to the development of Alzheimer's disease. If an individual is in the early stages of Alzheimer's disease, they could be experiencing an emotional reaction to the cognitive deficits that are occurring (Lee, H. et al., 2003). Vascular diseases that are often associated with Alzheimer's disease may also contribute to the depression (Lee H., et al., 2003). Symptoms seen in the elderly may simply be recurrences of a long standing depressive disorder and are not linked to Alzheimer's disease at all (Lee H., et al., 2003). Or rather, the cognitive processes of Alzheimer's disease may actually be causing the symptoms mimicking depression (Lee H., et al., 2003).

There have been great amounts of speculation on the early warning signs of Alzheimer's disease. While detection of these symptoms may provide a method of early diagnosis, they are often nonspecific and do not always mean that Alzheimer's disease is present. Effectively educating the public on these warning signs can aid in the diagnosis of the disease and early initiation of treatment.

Pharmacological Treatment

Although Alzheimer's disease is incurable, there are medications that can be taken to lessen the severity of the symptoms (Latest Medication for Memory Loss, n.d.). Cholinesterase inhibitors and memantine have been approved by the United States FDA to combat the cognitive effects of the disease (Latest Medication for Memory Loss, n.d.). Vitamin E can also be prescribed to patients with Alzheimer's disease because it is thought to be neuroprotective (Latest Medication for Memory Loss, n.d.).

Many healthcare providers consider cholinesterase inhibitors (donepezil, galantamine, and rivastigmine) first line pharmacotherapy in the treatment of Alzheimer's disease symptoms (Birks, J, 2012). This drug class increases the transmission of acetylcholine by inhibiting the enzyme responsible for its degradation (Lee, P., Hsiung, G., Seitz, D., Gill, S., & Rochon, P., 2011). Acetylcholine itself is a key neurotransmitter in the brain that is associated with memory processes (Birks, J, 2012). A Cochrane review on cholinesterase inhibitors concluded that the medication class was most effective in patients who had mild to moderate Alzheimer's disease (Birks, J, 2012). The same Cochrane study also determined that the three available drugs in the cholinesterase inhibitor class were all of equal efficacy (Birks, J, 2012). A meta analysis performed by K.L. Lanctôt, et al. (2003) aimed to quantify trial results that

looked at the efficacy and safety of cholinesterase inhibitors. A modest, but significant, improvement in cognitive functioning was found in the patients that received the cholinesterase inhibitor compared to those receiving a placebo (Lanctôt, K.L., et al., 2003). During treatment, the number of patients that experienced adverse effects with cholinesterase inhibitors was 8% higher than the patients receiving a placebo, showing that this class of medications is well tolerated overall (Lanctôt, KL, et al., 2003).

While cholinesterase inhibitors are typically prescribed for patients diagnosed with mild to moderate Alzheimer's disease, memantine is prescribed for the treatment of moderate to severe stages of the disease (Latest Medication for Memory Loss, n.d.). Memory improvements are seen in Alzheimer's disease patients taking memantine, however, the full mechanism of action of the drug is not completely known (Johnson, J., & Kotermanski, S., 2006). Memantine is an antagonist of the N methyl D aspartate (NMDA) receptor in the central nervous system, and binding to the receptor is thought to block current flow through the NMDA channel resulting in positive cognitive effects (Johnson, J., et al., 2006). A Cochrane review gathered data from trials assessing the efficacy of memantine for patients diagnosed with Alzheimer's disease (McShane R., Sastre, AA., & Minakaran, N., 2009). The review concluded that memantine produced a small beneficial effect in patients with moderate to severe Alzheimer's disease over a six month period (McShane R., et al., 2009). Memantine use in people with mild to moderate stages of the disease over six months also showed an improvement in symptoms, but this benefit was minimally detectable in the clinical setting (McShane R., et al., 2009). In addition, another symptom associated with Alzheimer's disease, agitation, was found to be decreased in those taking memantine (McShane R., et al.,

2009). The beneficial effects of memantine may be enhanced when taken concomitantly with donepezil (McShane R., et al., 2009). Patients with moderate to severe Alzheimer's disease currently taking donepezil were given doses of memantine over one year in a randomized controlled trial conducted by McShane et al (2009). When compared to placebo and donepezil use, a combination of memantine and donepezil produced significant beneficial outcomes in the areas of cognition, activities of daily living, and behavior (McShane R., et al., 2009).

The use of cholinesterase inhibitors and memantine in the treatment of Alzheimer's disease are well known and accepted. Alternatively, Vitamin E prescription and use for the disease seems to be more debated and controversial. The U.S. Department of Health & Human Services National Guideline Clearinghouse notes that the use of vitamin E to treat cognitive decline in Alzheimer's disease was considered, but not recommended due to inconsistent evidence (EFNS guidelines for the diagnosis and management of Alzheimer's disease, 2007). Caution is also expressed by the Alzheimer's Association. Vitamin E is listed as a treatment of Alzheimer's disease by this organization, but it comes with warnings. The Alzheimer's Association outlines that no one should take vitamin E for Alzheimer's disease unless they are under the supervision of a physician because the vitamin can negatively interact with other antioxidants and medications (Latest Medication for Memory Loss, n.d.). A recent randomized trial studied the effect of vitamin E and memantine on the cognitive impairments experienced with Alzheimer's disease (Dysken, M., et al., 2014). Over a period of 6 months to 4 years, 613 participants with mild to moderate Alzheimer's disease were given either vitamin E, memantine, a combination of both, or a placebo

(Dysken, M., et al., 2014). Primary outcomes of the trial exhibited slower cognitive decline in participants receiving vitamin E compared to those receiving the placebo (Dysken, M., et al., 2014). The authors of the study concluded that a benefit may be seen by taking vitamin E to combat decline associated with mild to moderate stage Alzheimer's disease (Dysken, M., et al., 2014). While this new information is encouraging, the study has some faults, and vitamin E use will need further investigation. An article in *Science Based Medicine* discusses a few drawbacks of the large study on vitamin E use (Hall, 2014). First, the decreased effect of a combination of vitamin E and memantine could not be explained by the authors, which emphasized the need for further trials (Hall, 2014). The study by Dysken, M., et al. (2014) was performed primarily on men at Veterans Affairs hospitals. Women and minority groups with Alzheimer's disease were largely underrepresented in the trial (Hall, 2014). Additional research on vitamin E effects on cognitive decline will be necessary before a conclusion can be reached.

Nonpharmacological Treatment

Aside from pharmacological treatment for Alzheimer's disease there are also other therapies available that can help a person decrease adverse effects of the disease or help them cope with the diagnosis. Some of the interventions that have evidence proving their effectiveness include exercise, occupational therapy, cognitive training, adhering to the Mediterranean diet, music therapy, and counseling.

Exercise is known to be beneficial for a person's physical health, but unfortunately, it does not have much effect on the cognitive status of a person with Alzheimer's disease (McDonnell, M. N., Smith, A. E., & Mackintosh, S. F., 2011). Even

though a meta analysis shows that there is no effect on the mind, there are other health benefits. Exercise is recommended for older adults because it reduces the risk of diabetes mellitus, hypertension, obesity, and coronary artery disease (McDonnell, et al., 2011). One study noted that Alzheimer's patients experienced improvement in hand function and lower extremity strength with regular exercise, although they also noted higher depression rates and a lower quality of life (Steinberg, M., Leoutsakos, J.-M. S., Podewils, L. J. and Lyketsos, C. G., 2009). Evidence concerning the effect of exercise on Alzheimer's patients shows both risks and benefits. The decision to incorporate this into a care plan should be made on a case by case basis.

Occupational therapy is a promising option for people with Alzheimer's disease to improve their activities of daily living and to reduce the stress on the caregiver (Graff et al., 2006). In the study conducted by Graff et al. (2006), 135 patients with Alzheimer's disease went to 10 sessions of occupational therapy over the course of 5 weeks. The occupational therapist looked at modifying the patient's home, compensatory strategies (adapting activities so the patient is still able to complete them), and environmental strategies (adapting the environment to fit the patient's ability). The caregivers were trained on how to help the Alzheimer's patient maintain autonomy. This study showed a significant improvement in activities of daily living for the Alzheimer's patients and an increase in sense of competence in the caregivers (Graff et al., 2006).

Stimulating the brain of a person with Alzheimer's disease can have positive effects on many aspects of life (Woods B, Aguirre E, Spector AE, Orrell M, 2012). A Cochrane review of 15 randomized controlled trials showed consistent benefits that resulted from cognitive stimulation. The benefits seen were in cognitive functioning,

quality of life, communication, and social interaction (Woods B, et al., 2012). This intervention, only shows effects for mild to moderate forms and not for severe dementia. Some activities that were used to stimulate the patient's brain included discussion of current events, talking about topics of interest and history, the use of clocks, calendars, and puzzles, and activities like gardening and baking (Woods B, et al., 2012). This therapy is so effective that it is thought to benefit the Alzheimer's patient more than medications (Woods B, et al., 2012).

The Mediterranean diet has been shown to decrease the mortality rate among those diagnosed with Alzheimer's disease (Scarmeas, N., Luchsinger, J. A., Mayeux, R., & Stern, Y., 2007). The Mediterranean diet consists of high amounts of legumes, fruits, vegetables, cereals, and unsaturated fatty acids like olive oil. Dairy products and fish are consumed moderately and red meat is rarely eaten. Wine is optional, and can be consumed at a low to moderate amount (Scarmeas, N., et al., 2007). Higher adherence to the Mediterranean diet is correlated with lower mortality rates as noted by Scarmeas et al. (2007). People with Alzheimer's disease that adhered to the diet the least experienced a 29 to 35 percent reduction in mortality while those who adhered to the diet the most showed a 67 to 73 percent reduction (Scarmeas, N., et al., 2007). This study shows that the more a person with Alzheimer's disease adheres to the Mediterranean diet, the greater the benefit that person will receive.

Music therapy can help a person with Alzheimer's disease overcome challenging behaviors associated with the disease instead of having to resort to pharmacological intervention (Vasionytė, I. and Madison, G., 2013). A review of literature of 21 articles concluded that music has the ability to reduce aggression, agitation, wandering, repetitive

vocalizations, and irritability (Vasionytė, I., et al., 2013). The mechanism for how music helps someone with Alzheimer's disease relax is unclear. This study duplicated the results that were found in a meta analysis that was conducted in 1999 that also showed music can help maintain or improve behavioral problems, social skills, and cognitive functioning (Koger, S. M., Chapin, K., & Brotons, M., 1999).

Providing counseling for people with Alzheimer's disease also shows some benefit. In a Cochrane review of six randomized controlled studies, it was concluded that providing counseling was able to reduce depression in people with Alzheimer's disease (Orgeta V, Qazi A, Spector AE, Orrell M, 2014). Clinician rated anxiety decreased, although there was no improvement with self-rated anxiety. There is limited research on the effect of counseling on those with Alzheimer's disease so the effect on quality of life, cognition, and activities of daily living is still unknown (Orgeta V, et al., 2014). Research still needs to be done on this subject, but counseling is a valid treatment option for those with Alzheimer's disease and depression.

There are many options for a person diagnosed with Alzheimer's disease. Although Alzheimer’s disease is not curable, there are steps a person can take to prolong their life and improve the quality of their life. There is an abundance of data about different treatment options, pharmacological and nonpharmacological, but none of these studies touched on what treatment options the public is aware of.

Summary

Alzheimer's disease is a highly researched condition due to its progressive and incurable effects on the central nervous system. Data suggests the etiology, risk factors, and best treatment options for the disease. The data available is not as beneficial if the

public is unaware of the facts. Assessing public knowledge and educating individuals on this subject area is the next step in combating Alzheimer's disease. Increasing public knowledge about Alzheimer's disease would help with early diagnosis and treatment. This would then offer more treatment options and more effective symptom relief for those diagnosed.

Chapter 3: Methodology

Introduction

The purpose of this study was to determine the general population's knowledge of Alzheimer's disease. This survey examined five separate areas of the disease to assess the knowledge of the participants.

1. Does the general population have an understanding of foundational information regarding Alzheimer's disease?
2. Is the general population aware of early warning signs and symptoms of Alzheimer's disease?
3. What risk factors are the general population familiar with?
4. Is the general population aware of all the treatment options that are available for Alzheimer's patients, both pharmacological and nonpharmalogical?
5. Is an Alzheimer's fact sheet effective in raising awareness of the disease?

This chapter covers the study design, the population that was surveyed, methods, validity and reliability, data analysis, limitations, and delimitations.

Study design

This research study was a preexperimental one group, pretest, postsurvey assessment. The project was a cross sectional analysis conducted through a survey sent

out electronically with a hyperlink via email. The study participants answered questions regarding general knowledge, early detection of signs and symptoms, risk factors, and treatment options for Alzheimer's disease. Next, the participants were presented with an Alzheimer's fact sheet, which was followed by questions on whether or not the education increased their knowledge of Alzheimer's disease risk factors, warning signs, and treatment options. Question types included were a combination of the following: select all that apply, multiple choice, yes or no, and Likert scales. Each answer was assigned a numerical value allowing for quantitative analysis (see appendix D for survey grading). There was no specified hypothesis for this research project, as this is a pilot study.

Subjects and Population

This survey was delivered electronically via email to the general population, ages 35 to 70, in the Minneapolis and St. Paul metropolitan area in Minnesota. The participants received an email containing an explanation of the study, a consent form, and a hyperlink to the Bethel Qualtrics questionnaire. Local church groups were contacted to distribute the survey to group members. All members were sent the survey and the researchers discarded the surveys that did not fit within the target population. Names were not asked for in order to protect the confidentiality of the participants. The goal was to receive 50 completed surveys. The following church groups agreed to participate in the study, a Wednesday night small group at Hosanna Church (Shakopee, MN), the small group leaders of Rebuilders at Hosanna (Lakeville, MN), and WifeLine at Grace church (Eden Prairie, MN). All churches are located in the Minneapolis and St. Paul metropolitan area in Minnesota.

Methods

The research study was centered around a two part survey and an educational component. An electronic survey was made and consisted of a consent form, survey, Alzheimer's disease information sheet, and a questionnaire about the effectiveness of the information sheet. The survey questions for this research study were compiled by the researchers and reviewed by Bethel University faculty members. The study itself and all of the survey components were submitted and reviewed by the Bethel University Institutional Review Board.

The first survey was comprised of three subsections. The first subsection included demographic questions such as age, city and state of residence, education level, and occupation. A second subsection involved questions regarding the subjects' previous experience with Alzheimer's disease. The third subsection aimed to assess participant knowledge of Alzheimer's disease warning signs, risk factors, and treatment options. This was then followed by an educational piece and a final education assessment survey. See appendix B for the full survey. Participants had two weeks to complete the survey.

Participation in the survey was optional, and participants were required to electronically sign a consent form before continuing on with the survey questions.

Validity and Reliability

The survey questions were created by the researchers of this study and assessed the participants' current knowledge of Alzheimer's disease. After the initial survey, a brief educational component was presented to the participants. The educational information included in the survey was gathered from trusted Alzheimer's disease

sources. Since the survey distributed is outlined in this paper, reproduction of the study results can be repeated if the same survey and educational piece are used.

Care was taken to ensure that the survey questions adequately answered the research questions at hand. The questions were primarily focused on assessing the level of knowledge of the participants. Additionally, after the initial survey, an educational piece was presented to the participants followed by a survey about the efficacy of the Alzheimer's education. This allowed the researchers to evaluate if a short educational handout containing information on Alzheimer's disease facts is adequate enough to increase participant knowledge of the disease.

Data Analysis

Survey responses were collected by the online survey generating site and sent back to the researchers for data analysis. The data was entered into Microsoft Excel spreadsheet for statistical analysis. Based on the results, the surveys were scored according to the guidelines outlined in Appendix D. The data was quantitative and categorical. The categorical analysis allowed for identification of which populations should be targeted for further education on Alzheimer's disease. At the conclusion of the study, all data was transferred onto a CD and stored with the Research Coordinator of the Bethel University Physician Assistant Program.

Limitations and Delimitations

One limitation for this study was the distribution of the survey itself. Due to the timeline of the research project, the survey was only distributed among organizations that had email databases in place. This placed constriction on the study population that was not necessarily intended by the researchers. The amount of respondents who completed

the survey was another limitation that the researchers were not able to control. This limitation was avoided by sending out a larger number of surveys. A delimitation was placed on study participants by excluding those that do not fit the selected age range of 35 to 70 years old.

Chapter Four: Results

Demographics:

This study was based on the responses from three small groups, a Wednesday night small group at Hosanna Church, the small group leaders of Rebuilders at Hosanna, and WifeLine at Grace church. All churches are located in the Minneapolis and St. Paul metropolitan area in Minnesota. The majority of the respondents were between 46 and 60 years of age, had a Bachelor's degree or higher (58.93%), and were Caucasian (100%). Most respondents were married (83.93%) and the remaining 16.07% were divorced.

Figure 1: Demographic Information – Age

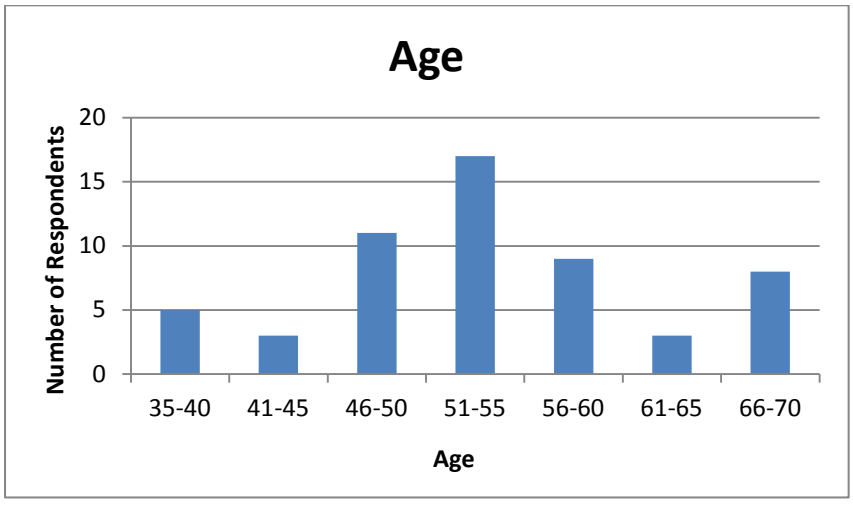
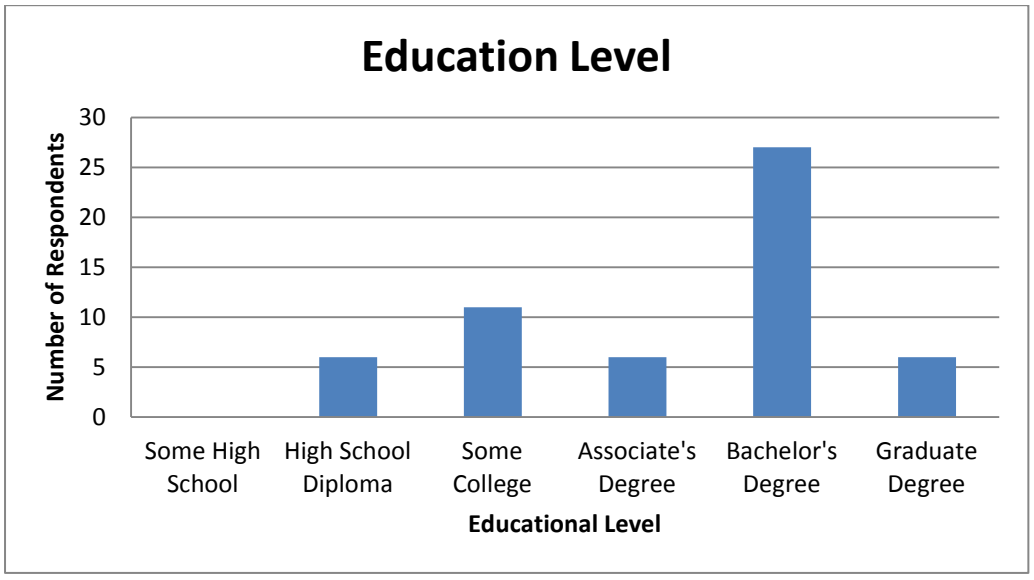


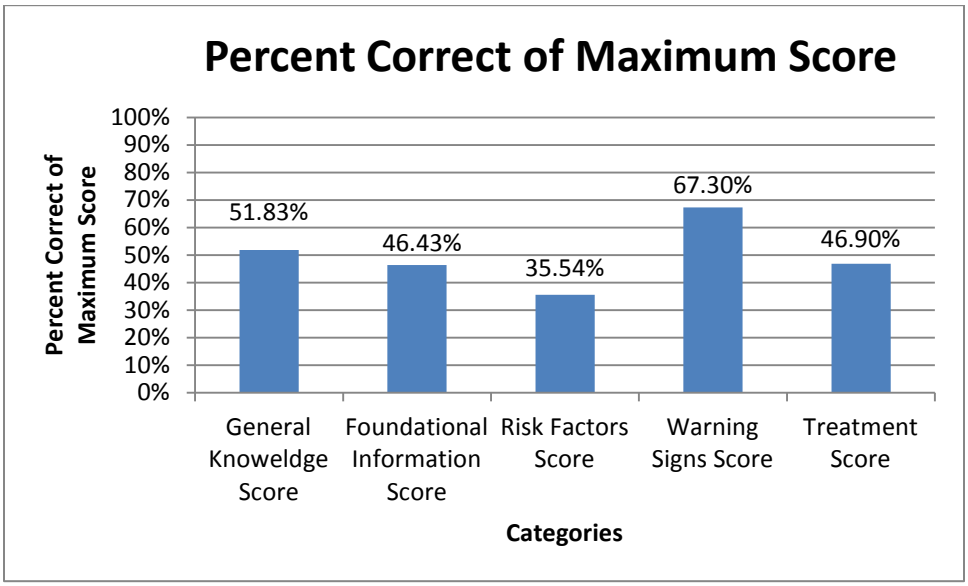
Figure 2: Demographic Information – Educational Level



Overall Scores:

Grading of the survey is outlined in Appendix D. The average percent correct is based on the maximum possible score (all answers correct and no incorrect answers). Respondents scored highest in the warning signs category (max score of 16 with an average score of 10.77 ± 4.09) and lowest in the risk factors category (max score of 10 with an average score of 3.55 ± 1.98). The average score of the general knowledge category (the score of all categories combined) was 22.29 ± 6.65 with the maximum score being 43 (average of 51.83% correct).

Figure 3: Average Percent Correct of Maximum Scores



Scores Based on Age:

The respondents ages 35 to 40 years of age had the highest general knowledge score of 25.4 ± 6.69 with a maximum possible score of 43. Note that this is the raw score and not the percent correct as shown in figure 3. The lowest score was achieved by those 51 to 55 years of age with an average of 21.18 ± 7.69. No statistical significance was found between the average score of any age group using ANOVA analysis, because the p value was greater than 0.05.

Figure 4: Average General Knowledge Score Based on Age

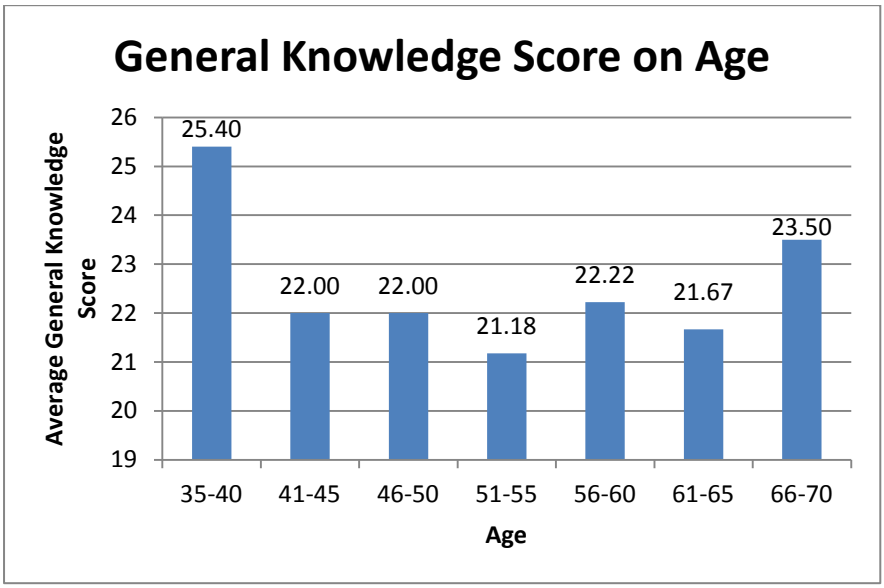


Table 1: ANOVA Based on Age

Source of Variation	*SS*	*df*	*MS*	*F*	*P value*	*F crit*
Between Groups	83.53576	6	13.92262683	0.290314823	0.938748	2.290432
Within Groups	2349.893	49	47.95699613			
Total	2433.429	55				

Scores Based on Educational Level:

Those with a graduate degree and a high school diploma had the highest average scores of 24.33 ± 4.13 and 24.0 ± 10.22, respectively. Based on the ANOVA analysis, there was no statistical significance between the various educational levels since the p value was greater than 0.05.

Figure 5: Average General Knowledge Score Based on Educational Level

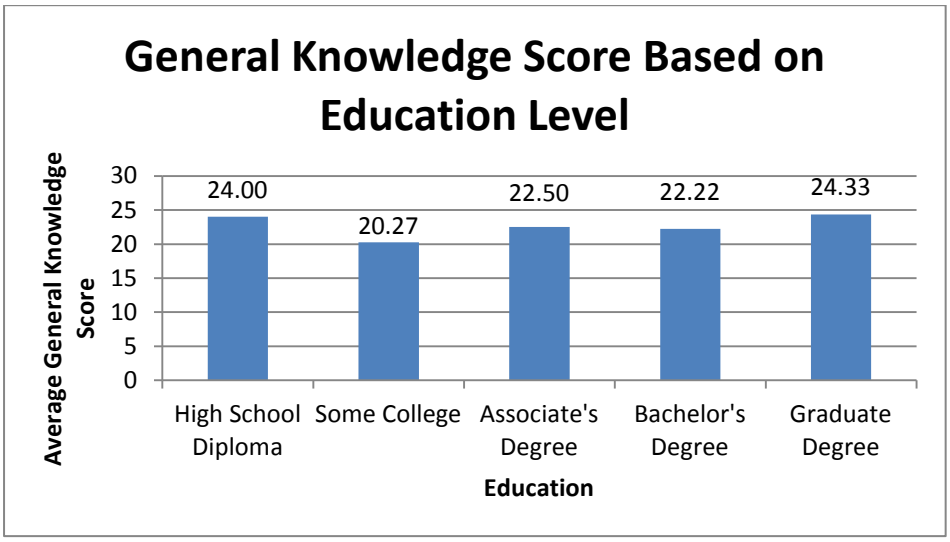


Table 2: ANOVA Based on Educational Level

Source of Variation	*SS*	*df*	*MS*	*F*	*P value*	*F crit*
Between Groups	87.7467	4	21.9366	0.476949	0.752447	2.55339
Within Groups	2345.68	51	45.9937			
Total	2433.42	55				

Scores Based on Past Experience with Alzheimer's Disease:

The highest general knowledge score was achieved by those with an immediate family member affected by Alzheimer's disease (24.64 ± 7.75) and those who have been a primary caregiver for someone with Alzheimer's disease had the lowest score (18.0 ± 9.90). Once again, because the p-value was less than 0.05, there was no statistical significance between the groups.

Figure 6: Average General Knowledge Score Based on Past Experience with Alzheimer's Disease

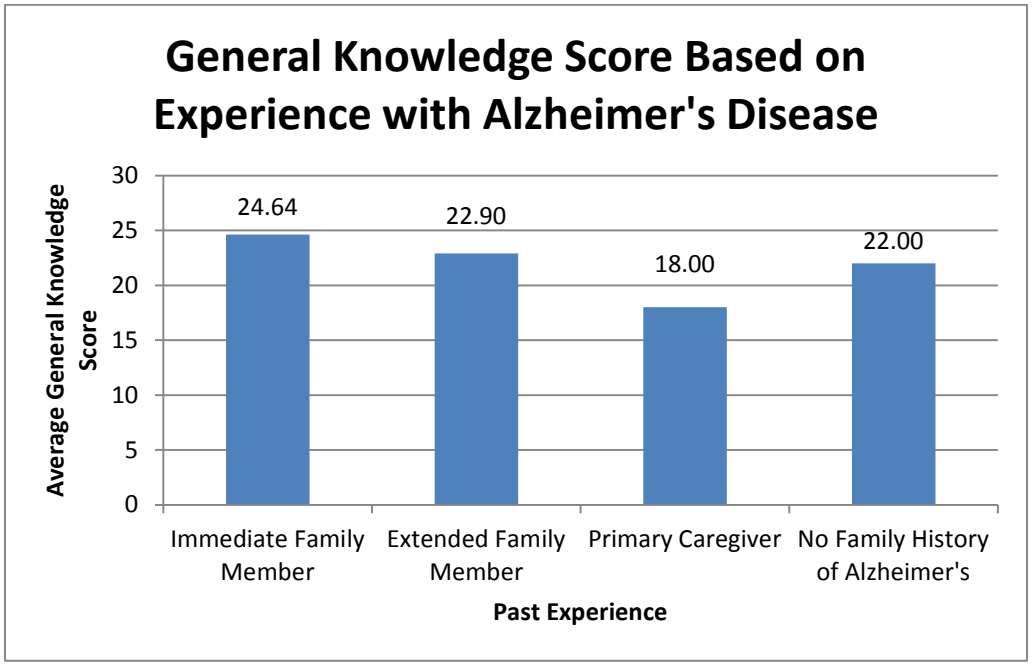


Table 3: ANOVA Based on Past Experience with Alzheimer's disease

Source of Variation	*SS*	*df*	*MS*	*F*	*P value*	*F crit*
Between Groups	100.88892	3	33.62964	0.735249422	0.535098	2.758078
Within Groups	2744.34545	60	45.73909			
Total	2845.23438	63				

Percent Correct of Individual Questions:

When the respondents were asked, "How are Alzheimer's disease and dementia related," only 49.09% knew that Alzheimer's disease is a subset of dementia. In addition, only 44.64% of participants knew that the cause of Alzheimer's disease is nerve cells dying due to amyloid plaque buildup in the brain. Most (98.21%) knew that Alzheimer's disease is not curable and 88.93% knew that Alzheimer's is not preventable. The general

population is aware of the risk factors of genetics (88.33%) and age (75.0%) for Alzheimer's disease according to this survey, but smoking (16.67%), diabetes mellitus (11.67%), and depression (18.33%) are not as well known (see Table 4). Most warning signs were known by more than 60% of the respondents except for withdrawal from social situations (55.36%) and poor judgment (42.86%) (see Table 5). Sixty-six percent knew that cholinesterase inhibitors are the mainstay pharmacological treatment but non-pharmacological treatments were not as well known. Occupational therapy, the Mediterranean diet, music, and counseling were the treatment options that most respondents were not aware of (see Table 6).

Table 4: Risk Factors for Alzheimer's Disease

Which of the following are risk factors for Alzheimer's Disease? Select all that apply.			
Answer	**Correct (X)**	**Number of Responses**	**Percent**
High Cholesterol		13	21.67%
Age	X	41	75.00%
Aluminum		6	11.67%
Aspartame		6	10.00%
Male gender		2	6.67%
Education level		2	3.33%
Genetics	X	49	88.33%
Flu shots		1	1.67%
Diabetes Mellitus	X	7	11.67%
Silver dental fillings		3	5.00%
Depression	X	11	18.33%
Lower socioeconomic status		3	5.00%
Smoking	X	10	16.67%
Coal mining		1	1.67%

Table 5: Warning Signs of Alzheimer's Disease

Which of the following are warning signs of Alzheimer's Disease? Select all that apply.			
Answer	**Correct (X)**	**Number of Responses**	**Percent**
Loss of appetite		9	16.07%
Headache		3	5.36%
Memory loss that affects daily activity	X	55	98.21%
Difficulty with problem solving	X	42	75.00%
Confusion	X	50	89.29%
Vision changes		5	8.93%
Difficulty with speaking or writing	X	35	62.50%
Misplacing objects	X	40	71.43%
Loss of balance		12	21.43%
Poor judgment	X	24	42.86%
Withdrawal from social situations	X	31	55.36%
Personality changes	X	39	69.64%

Table 6: Nonpharmacological Treatment for Alzheimer's Disease

What are nonpharmacological treatments that can be used for Alzheimer's disease? Select all that apply.			
Answer	**Correct (X)**	**Number of Responses**	**Percent**
Exercise	X	40	75.47%
Coconut Oil		6	11.32%
Occupational Therapy	X	22	41.51%
Chiropractic adjustments		2	3.77%
Cognitive training	X	44	83.02%
CoQ10		7	13.21%
Mediterranean diet	X	14	26.42%
Ginkgo biloba		13	24.53%
Music	X	20	37.74%
Counseling	X	9	16.98%
Acupuncture		5	9.43%
Essential Oils		8	15.09%

Post Survey Data:

After the initial survey was given, the participants were given an Alzheimer's disease fact sheet (see Appendix C) that addressed the questions that were asked in the primary survey. They were then surveyed on the degree to which the fact sheet expanded their knowledge on Alzheimer's disease. Ninety-six percent agreed that the fact sheet expanded their knowledge. The extent to which the fact sheet expanded the participants' knowledge is outlined in Figure 7. Furthermore, 61.4% agreed or strongly agreed that they are more likely to recognize the symptoms of Alzheimer's disease in someone and 63.16% agreed they have a better understanding of the treatment options available for Alzheimer's disease after reading the educational information. The participants were given an opportunity to comment on additional information that they wished was included in the fact sheet and their comments are summarized in Table 4.

Figure 7: To What Extent Did the Alzheimer's Disease Fact Sheet Expand your Knowledge?

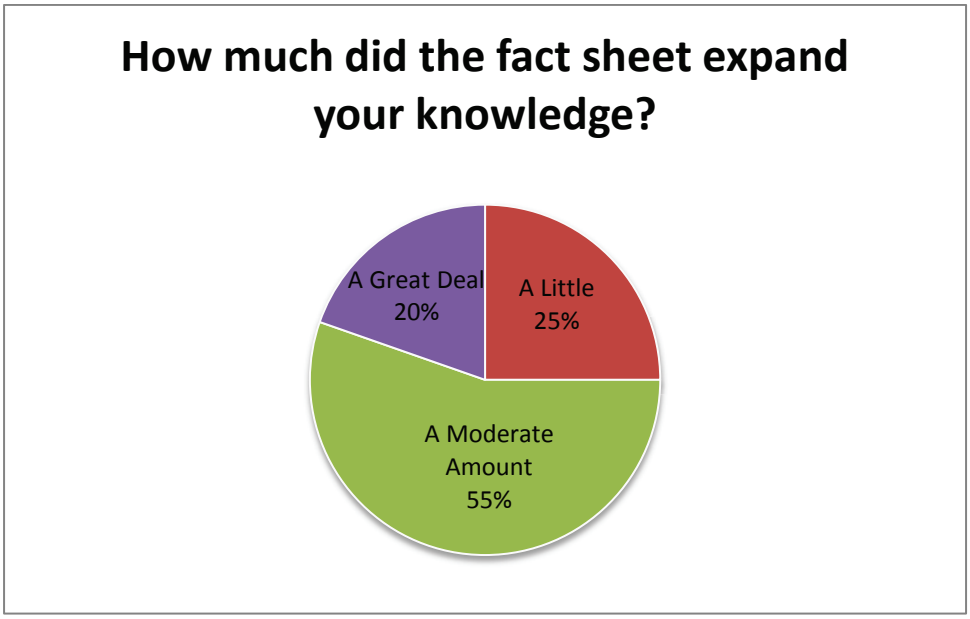


Table 7: Summary of Suggestions for Fact Sheet

Comment:	Number of Comments:
Difference between Alzheimer's disease and normal aging.	3
What can be done to prevent Alzheimer's disease.	3
More information on treatment options.	2
Percentage of improvement with various treatment options.	1
More information on how to identify Alzheimer's disease.	1
How insurance companies cover Alzheimer's disease.	1
It was not mentioned that if your parent has early onset, then you have 50% chance of having a gene.	1

Results Discussion:

Although there is no statistical significance between groups based on age, educational level, and past experience with Alzheimer's disease, there is evidence exhibited through this survey that further education needs to be done. From the responses to the post-survey regarding the Alzheimer's disease fact sheet, a similar fact sheet would be beneficial to the general population to raise awareness of this prevalent disease.

Chapter 5: Discussion and Conclusion

Summary of the Study

Although there was no stated hypothesis for this pilot study, multiple research questions were outlined exploring the public awareness of Alzheimer's disease. The categories of warning signs, risk factors, and treatment options were chosen and included in the study survey because of their importance in the recognition and clinical management of the disease. A short fact sheet was also included to assess the adequacy of this form of educational piece in increasing the subjects' knowledge. Data gathered from the survey responses gives insight on potentially weak areas of knowledge for the general public and which demographic groups should be targeted for further education

Awareness of warning signs was the highest among the study subjects, while the subjects as a whole scored the lowest on risk factors of Alzheimer's disease. It was found that individuals aged 51 to 55 years of age scored the lowest on all categories combined. Conversely, participants ages 35-40 scored the highest. High scores were also found among those with a graduate degree and experience with Alzheimer's disease in an immediate family member. While low scores were compiled by subjects with some college experience and those who have been a primary caregiver for someone with the disease.

Areas of weakness include correct risk factor identification such as the link between smoking, diabetes mellitus, and depression to Alzheimer's disease. Warning signs were fairly well known, as were the pharmacological treatment options available. Knowledge of nonpharmacological options however, is an area that needs great improvement.

The results of this pilot study were not statistically significant, which may be due to the small number of participants.

Limitations

There were a few limitations to this pilot study that should be recognized. First, there was a small number of study participants. Since the survey was distributed via email, databases of email addresses was a requirement for the study. Several large entities were originally contacted and declined to release the email addresses of members. Smaller groups were then contacted and agreed to participate in the research study. The groups that agreed to be a part of the research were all from churches in the Minneapolis

and St. Paul metropolitan area in Minnesota. This in itself leads to limitation of the subject population.

The restricted number of willing participants led to a low number of responses. No statistical significance can be drawn from the data, which is another limitation of this study. In the future, it may be possible to gain statistically significant results while using a larger sample size.

A final limitation is that the survey was completed by the participants in private settings. While all responses were recorded, the researchers cannot be sure that outside sources were not consulted by the subjects while completing the survey.

Recommendations for Further Research

Research methods of this study were outlined in detail, with the hopes that it may be duplicated in the future with more participants. As noted above, statistical significance may be attained with a larger population. More research subjects will also allow for reliable trends in the data to be seen.

Future research could also focus on expanding the geographical distribution of the surveys. This pilot study was released in one metropolitan area of Minnesota only. Therefore, research subject demographics were not diverse. Applying this study to individuals in other parts of the United States, would offer insight into the influences of varying cultures, medical care, and experiences. For example, different ethnic groups may score differently on the survey based on their cultural teachings and views on illnesses. Expansion of the survey would aid in the appropriate methods and subject areas of public education on Alzheimer's disease.

With a more comprehensive and nationwide study, the data on public awareness of Alzheimer's disease can be taken a step further. After analyzing the data and recognizing the weak areas of public knowledge on the disease, it would be beneficial to follow up the study with community outreach. This could be in the form of pamphlets handed out at the clinic, open public education meetings, or TV and newspaper advertisements. Doing so would take an identified area in need of education and help to build public awareness of Alzheimer's disease.

Discrepancy

While writing this paper, there was a noted discrepancy between information found during the literature review and the facts used for the educational piece of the survey distributed to participants. The literature review listed that high cholesterol, obesity, hypertension, education status, and traumatic brain injury were not found to have conclusive evidence supporting an increased risk of Alzheimer's disease. Conversely, the Alzheimer's disease fact sheet given to the research subjects listed that the above mentioned factors do increase the risk for the disease. Two different sources were used for the review and the educational component, which led to the inconsistency. The inaccurate information in the survey did not affect the data collected since the quiz was taken by participants before they read the educational piece. The post education survey was very brief and asked the participants subjective questions. Data was obtained from the post survey, but it was not directly linked to the details presented in the educational piece.

Conclusion

There are currently 5.2 million Americans diagnosed with Alzheimer's disease, and that number is only expected to rise (Alzheimer's Disease Facts and Figures, 2007). With no method of prevention or cure available, it is imperative to offer other methods to combat this disease. Studies have shown that early diagnosis and treatment initiation offer a delay in symptom severity associated with Alzheimer's disease (Doraiswamy, et al., 2002). The goal of this research project was to assess the general public's knowledge of Alzheimer's disease warning signs, risk factors, and treatment options, as well as to determine in what areas public knowledge was lacking. Additionally, the study examined the effectiveness of a simple Alzheimer's fact sheet on public knowledge. The following research questions were explored throughout the study:

1. Does the general population have an understanding of foundational information regarding Alzheimer's disease?
2. Is the general population aware of early warning signs and symptoms of Alzheimer's disease?
3. What risk factors are the general population familiar with?
4. Is the general population aware of all the treatment options that are available for Alzheimer's patients, both pharmacologically and nonpharmacologically?
5. Is an Alzheimer's fact sheet effective in raising awareness of the disease?

The survey questions presented to participants explored the research questions. Research subject responses were compiled to show areas of needed improvement. An Alzheimer's disease fact sheet was also included in the survey and was followed by a post survey to evaluate its effectiveness on raising participant awareness. It was found

that individuals ages 51 to 55 would benefit the most from public education on the disease. The risk factors of Alzheimer's disease are not as well known as the warning signs that can be present, and nonpharmacological treatment options should be emphasized more to the public to increase familiarity. Data analysis revealed p values of greater than 0.05, so there was no statistical significance of this study. Expansion of this study, both in subject number and distributive area, may yield more significant and reliable data in the future. The majority (96%) of study participants agreed that an Alzheimer's fact sheet expanded their knowledge of the disease, and may be a viable method of public education.

Data from this study can be used to offer public education on Alzheimer's disease that is specific to areas of insufficiency. Multiple methods such as pamphlets, public education forums, and advertisements can be employed to increase public awareness and recognition of this disease. Furthermore, medical providers can use this data to increase patient education during office visits, while clinics and hospitals may choose to display posters or hold informational meetings on Alzheimer's disease. For now, raising awareness about this devastating disease is the only way to combat its effects until methods of prevention or a cure can be found.

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Appendix A

Study Participant Consent Form

The purpose of this research project is to assess the general public's knowledge of Alzheimer's disease, as well as examine the adequacy of a short educational Alzheimer's disease fact sheet. This research project is being conducted by students in the Physician Assistant program at Bethel University. This survey is being distributed with the help of Bethel Qualtrics. You are being included in this study because you are a member of a chosen organization in the Twin Cities area.

Your participation in this study is strictly voluntary, and you may choose not to participate. If you choose to participate in the survey, you may withdraw at any point. If you withdraw or choose not to participate, there will be no penalties. We do not expect this survey to cause emotional harm or distress, however, should you need counseling services due to emotional distress caused by this survey, such services will be provided at Bethel University Counseling Services (phone: 651-635-8540).

This study involves a short primary survey, an educational Alzheimer's disease fact sheet, and a secondary survey about the educational piece. The total time to complete all components is approximately 15 to 20 minutes. Your responses will be kept anonymous and confidential. No identifying information will be collected.

The primary survey will collect demographic information and ask about previous experience with Alzheimer's disease. Multiple choice questions regarding Alzheimer's disease information will also be included. The fact sheet will present important information on the disease and will only need to be read through. The secondary survey will ask questions about the educational piece.

If you have any questions about this research study or the survey, please see the contact information at the bottom of this page. This research study has been reviewed and approved by the Bethel University Institutional Review Board.

Electronic Consent: Please select your choice below.

Selecting "Agree" below indicates that:

a) You have read the above information.

b) You voluntarily agree to participate.

c) You are at least 18 years of age.

If you do not wish to participate in the research study, please decline participation by choosing the "disagree" button.

- o Agree
- o Disagree

<u>Contact Information:</u>

Anna Smith ahf53643@bethel.edu

Katie Spadino kas69934@bethel.edu

This consent form was adapted from Survey Monkey.

Consent Form. (n.d.). Retrieved February 26, 2015, from https://www.surveymonkey.com/r/?sm=7uzSOKkoj3RdITQOr/I3GpZglaFqTSy6NjlA

Appendix B:

Survey Questions, Exclusion Criteria, and Answer Key

Section One - Demographics

1. Age (fill in the blank)
2. City and state of residence (fill in the blank)
3. Marital Status
    a. Single, never married
    b. Married or domestic partnership
    c. Widowed
    d. Divorced
    e. Other
4. Education level
    a. Some high school
    b. High school diploma
    c. Some College
    d. Associate's degree
    e. Bachelor's degree
    f. Graduate Degree
5. Occupation (fill in the blank)
6. Employment Status
    a. Employed
    b. Unemployed
    c. Student

   d. Military
   e. Retired
   f. Unable to work

7. Ethnicity
   a. White
   b. Hispanic or Latino
   c. Black or African American
   d. Asian/Pacific Islander
   e. Other

Section 2 - Previous experience with Alzheimer's disease

1. Have you or an immediate family member (parent, spouse, children) ever been diagnosed with Alzheimer's disease?
   a. Yes
   b. No
2. Have you had an extended family member (grandparent, aunt, uncle, cousin) or friend been diagnosed with Alzheimer's disease.
   a. Yes
   b. No
3. If you answered yes to question number one or two, what was your relation to that person that was diagnosed with Alzheimer's disease? (fill in the blank)
4. Have you ever been the primary caregiver for a person with Alzheimer's disease?
   a. Yes
   b. No

5. Has anyone in your family (immediate or extended) or a friend been diagnosed with any form of dementia?
    a. Yes
    b. No

Section three – Knowledge of Alzheimer's disease

1. How are dementia and Alzheimer's disease related?
    a. Dementia is a subset of Alzheimer's disease
    b. Alzheimer's is a subset of dementia
    c. They are the same thing
2. What causes Alzheimer's disease?
    a. Nerve cells die due to amyloid plaque buildup in the brain
    b. Nerve cells die due to an autoimmune disease
    c. The cause is unknown
    d. The brain dies due to toxin exposure throughout a person's life
3. Which of the following is a risk factor for Alzheimer's disease? Select all that apply.
    a. High Cholesterol
    b. Age
    c. Aluminum
    d. Aspartame
    e. Males
    f. Education level
    g. Genetics

h. Flu shots

i. Diabetes Mellitus

j. Silver dental fillings

k. Depression

l. Lower socioeconomic status

m. Smoking

n. Coal mining

4. Which of the following are warning signs of Alzheimer's disease? Select all that apply.

    a. Loss of appetite

    b. Headache

    c. Memory loss that affects daily activities

    d. Difficulty with problem solving

    e. Confusion

    f. Vision changes

    g. Difficulty with speaking or writing

    h. Misplacing Objects

    i. Loss of balance

    j. Poor judgment

    k. Withdraw from social situations

    l. Personality changes

5. Is Alzheimer's disease curable?

    a. Yes

b. No

6. Is Alzheimer's disease preventable?
    a. Yes
    b. No
7. What is the mainstay of pharmacological treatment for Alzheimer's disease?
    a. Tylenol and aspirin
    b. Beta blockers
    c. Statins
    d. Cholinesterase inhibitors
8. What are nonpharmacological treatments that can be used for Alzheimer's disease? Select all that apply
    a. Exercise
    b. Coconut oil
    c. Occupational therapy
    d. Chiropractic adjustments
    e. Cognitive training
    f. CoQ10
    g. Mediterranean diet
    h. Ginkgo biloba
    i. Music
    j. Counseling
    k. Acupuncture
    l. Essential oils

Section four – Education (see Appendix C)

Section five – Post-education survey

1. The fact sheet expanded my knowledge of Alzheimer's disease.
    a. Yes
    b. No
2. If you answered yes to question one, to what degree did the fact sheet expand your knowledge?

Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1	2	3	4	5

3. Do you think the fact sheet gives you sufficient information to recognize Alzheimer's disease in a family member or friend?
    a. Yes
    b. No
    c. Somewhat
4. Do you feel you are now more likely to recognize Alzheimer's disease in yourself or someone close to you?

Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1	2	3	4	5

5. Do you feel you better understand the treatment options that are available for someone diagnosed with Alzheimer's disease?

Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1	2	3	4	5

6. Is there any other information you would have liked to learn about? (fill in the blank)

Criteria for exclusion based on answers in section one and two:

- Section one; question one: age. Those that do not fall into the targeted age range (35 to 70 years old) will be excluded.

Answer Key to section three – Knowledge of Alzheimer's disease

1. B - Alzheimer's is a subset of dementia
2. A - Nerve cells die due to amyloid plaque buildup in the brain
3. B (age), G (genetics), I (diabetes mellitus), K (depression), M (smoking)
4. C (memory loss that affects daily activities), D (difficulty with problem solving), E (confusion), G (difficulty with speaking and writing), H (misplacing objects), J (poor judgment), K (withdraw from social situations), L (personality changes)
5. B – No
6. B – No
7. D – Cholinesterase inhibitors
8. A (exercise), C (occupational therapy), E (cognitive training), G (Mediterranean diet), I (music), J (counseling)

Appendix C:

Alzheimer's Disease Fact Sheet

- Dementia is a broad term that encompasses many diseases and conditions characterized by a decline in memory or other thinking skills that affects the ability of a person to complete activities of daily living. Alzheimer's disease is a subtype of dementia, with its own defining characteristics. Alzheimer's disease and the other dementias cannot be cured with current treatment regimens, nor can they be prevented, slowed, or stopped.
- The cause of Alzheimer's disease can be attributed to progressive accumulations of beta amyloid plaques around the outsides of the neurons and tau protein tangles inside the neurons. The plaques and tangles eventually cause damage to and kill the neurons.
- Risk factors for Alzheimer's disease include:
    - Age: this is the greatest risk factor. Most people are diagnosed at age 65 or older. Diagnosis at a younger age can occur, but is rare.
    - Family history: A person with a direct relative diagnosed with Alzheimer's disease is more likely to be diagnosed as well. Having more than one direct relative with the disease increases the risk further. This genetic connection may be related to the inheritance of the apolipoprotein E ε4 (ApoE) gene.
    - Poor Cardiovascular Health: Evidence suggests that the health of the brain is closely related to the health of the heart. Smoking, obesity, diabetes,

cholesterol, and high blood pressure all increase the risk of Alzheimer's disease.

  - Education level: People with few years of formal education are at an increased risk for Alzheimer's disease and other dementias. This could be related to a "cognitive reserve" that people of higher education have to compensate for the deleterious effects of Alzheimer's disease. Another theory relates this risk factor to the increased risk for diseases in general that is related to a lower socioeconomic status.
  - Traumatic brain injury: These injuries disrupt normal brain function. Moderate to severe brain injuries, defined by a loss of consciousness or amnesia ranging from 30 minutes to 24 hours, increase the risk of Alzheimer's or dementia significantly.

- Early symptoms include apathy, depression, and memory loss affecting daily living. Further progression of the disease leads to trouble communicating (speaking and writing), disorientation, misplacing objects, confusion, lack of judgment, trouble with problem solving, withdrawal from social activities, and behavior changes.
- The medications and therapies for Alzheimer's disease are designed to slow or stop the malfunction and destruction of neurons. These treatments improve the symptoms of the disease, however efficacy varies from person to person. The mainstay drug for Alzheimer's disease are cholinesterase inhibitors.

- Non medicinal therapies to aid in symptom relief include cognitive training and stimulation, occupational therapy, the Mediterranean diet, music therapy, and counseling.

This fact sheet was compiled using information from the following sources:

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Appendix D:

Grading of Survey Questions

1. Multiple choice questions will receive one point for a correct answer and zero points for an incorrect answer.
2. In questions where the participant has to select all that are correct, they will receive two points for each correct answer and negative one points for each incorrect answer.
3. Each survey will receive a general knowledge score that will be the sum of the total survey.
4. Each survey will receive a foundational information score which will be the sum of their score of questions one and two from section three.
5. Each survey will receive a risk factors score which will be their score based on question three from section three.
6. Each survey will receive a warning signs score which will be their score from question four from section three.
7. Each survey will receive a treatment score which will be the sum of questions five, six, seven, and eight from section three.

Appendix E:

Population's Permission to Access

The following small groups have agreed to disperse the survey to the members of the designated groups:

1. Wednesday night small group at Hosanna Church (Shakopee, MN)
2. Small group Leaders of Rebuilders at Hosanna Church (Lakeville, MN)
3. WifeLine at Grace Church (Eden Prairie, MN)