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ALZHEIMER'S DISEASE AND OTHER DEMENTIAS CAREGIVER WORKSHOP

FACILITATOR MANUAL FOR THE BEAVER DAM COMMUNITY HOSPITAL

A Chapter Style Project Report Submitted in Partial Fulfillment of the Requirements for the Degree of Master of Public Health in Community Health Education

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We recommend acceptance of this project report in partial fulfillment of the candidate's requirements for the degree of Master of Public Health in Community Health Education.

The candidate has met all of the project completion requirements.

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ABSTRACT

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The population in the United States is aging and with the aging population is an increase in the prevalence of Alzheimer's disease and other dementias. Alzheimer's disease and other dementias put a great demand on the healthcare system. One approach to addressing the demand on the healthcare system is to address the knowledge and abilities of caregivers of people with Alzheimer's disease and other dementias. The literature reveals that caregivers have insufficient knowledge and training in regards to caring for people with dementia. The *Alzheimer's Disease & Other Dementias Caregiver Workshop Facilitator Manual* is a tool developed to facilitate and support the ongoing education of professional caregivers at the Beaver Dam Community Hospital in Beaver Dam, Wisconsin. It includes an overview of Alzheimer's disease and other dementias, an adaptation of the Virtual Dementia Tour®, and caregiver techniques while encouraging dialogue about the challenges, experiences, and perspectives of professional caregivers at the Beaver Dam Community Hospital. The objectives of the manual are to: (a) increase the caregivers' knowledge about the conditions, (b) increase the caregivers' empathy for individuals with the conditions, (c) improve the caregivers' techniques, and (d) reduce stigma related to Alzheimer's disease and other dementias.

TABLE OF CONTENTS

PAGE

CHAPTER I: INTRODUCTION 1
Statement of the Problem 1
Issue 1
Affected Population 1
Scope of the Issue 3
Significance of the Problem 4
Purpose of the Study 5
LITERATURE REVIEW 6
Dementia 6
Types of Dementia 6
Alzheimer's Disease 7
Prevalence 8
Diagnosis 9
Treatment 10
Risk Factors 11
Symptoms 14
Stages of Alzheimer's Disease 16
Early stage. 16
Middle stage. 17
Final stage. 17
Early-Onset Alzheimer's 18

Cost 19
Stigma 20
Caregivers 22
Caregiver Challenges 23
Support Strategies for Caregivers 25
Proper Caregiving Techniques 26
Bathing. 26
Dressing and grooming 28
Eating. 29
Toileting. 30
Communication. 30
Coping with Agitation and Aggression. 32
CHAPTER II: METHODOLOGY 34
Pilot Educational Experience 34
Participants 35
Setting 36
Part I: Overview of Alzheimer's Disease & Other Dementias 36
Part II: Virtual Dementia Tour® 37
Part III: Caregiving Techniques & Debriefing 40
Surveys 42
CHAPTER III: FINDINGS 44
Surveys 44
Demographics 44

Likert Scale Questions 45
Table 1. Participant Responses to 5-Point Likert Scale Questions on Program Surveys 46
Open-Ended Questions 48
Discussion Feedback 49
CHAPTER IV: CONCLUSIONS & RECOMMENDATIONS 51
Conclusions 51
Recommendations 52
REFERENCES 56
APPENDICES 59

LIST OF APPENDICES

APPENDIX PAGE

A. Flyer Notification for Pilot Educational Workshop..……...……..……..59

B. PowerPoint……...…61

C. Pilot Educational Workshop Handouts……...…71

D. Pre- And Post-Program Surveys……..…79

E. Facilitator Manual……..……...….84

CHAPTER I

INTRODUCTION

Statement of the Problem

Issue

The baby boomer generation is advancing into their elderly years resulting in an aging population. With the aging of the population, comes an increase in Alzheimer's disease and other dementias. Increases in the aging population and the prevalence of Alzheimer's disease put a great demand on the healthcare system. One approach to addressing the demand on the healthcare system is to address the knowledge and abilities of caregivers of people with Alzheimer's disease and other dementias. The literature reveals that caregivers have insufficient knowledge and training in regards to caring for people with dementia. Caregivers need to be aware of the details of Alzheimer's disease and other dementias, their abilities in caring for individuals with the conditions, the need for empathy for individuals with the conditions, and support strategies for themselves. Inadequate knowledge and training may lead to adverse complications for both the individual with the disease and the caregiver.

Affected Population

There are several populations in need of further education about Alzheimer's disease and other dementias. The *Alzheimer's Disease & Other Dementias Caregiver Workshop Facilitator Manual* focuses on educating and creating experiences for professional caregivers at the Beaver Dam Community Hospital in Beaver Dam,

Wisconsin. The literature, the author's experiences in the hospital setting, and key informant interviews revealed that professional caregivers need additional education, training, and exposure to Alzheimer's disease and other dementias in order to provide the highest-quality of care. The increase in the aging population comes with an increase in the prevalence of Alzheimer's disease and other dementias. These escalations put a greater demand on the healthcare system. Many times, individuals with Alzheimer's disease and other dementias face physical and mental impacts that can lead to hospitalizations, especially in cases where professional or unpaid caregivers have insufficient training (Alzheimer's Association, 2012). The growth in hospitalizations puts an increased demand on healthcare workers. Professional caregivers often are working in demanding environments with insufficient knowledge. These factors can lead to negative health impacts on the caregiver and those for whom they are caring. In addition, a lack of training and knowledge can lead to job dissatisfaction and high turnover rates of employees (Stone & Wiener, 2001).

Professional caregivers are the targeted population for the *Alzheimer's Disease & Other Dementias Caregiver Workshop Facilitator Manual*, but other populations are greatly affected by the conditions. Unpaid, family caregivers are affected by the issue because with a lack of knowledge about various facets of Alzheimer's disease and other dementias, the physical and emotional health of the caregiver can be affected. In addition, they may not be able to care for the individuals with Alzheimer's disease in the most effective and caring way.

Another population affected by the issue is the individuals living with Alzheimer's disease and other dementias. The individuals with the conditions may not

receive adequate care if their caregiver is not educated to an optimal level. They may experience negative events such as safety issues, inadequate nutrition, or communication barriers (Coogle, Head, Parham, & Zeman, 2004; Wray, 2011). It is essential to implement more education, training, and experiences for professional caregivers in order to increase their knowledge, caregiver techniques, and empathy for individuals living with Alzheimer's disease and other dementias.

Scope of the Issue

The issue of adequate education and training for professional caregivers is an ongoing problem that is exacerbated by the increasing prevalence of Alzheimer's disease. Unfortunately, there is no cure for the disease; there only are drugs to slow the advancement of the symptoms (Alzheimer's Disease Education and Referral Center, n.d.). Since there is no cure for the disease, quality care for individuals with Alzheimer's disease and other dementias is essential. Professional caregivers provide a substantial amount of care to individuals with the disease and they will continue to provide a large portion of care. In addition, research and knowledge about the disease will continue to evolve, and professional caregivers continually will need to have adequate knowledge of Alzheimer's disease in order to most effectively care for the individuals. The issue will persist until it is routine practice for professional caregivers to pursue education and training that are proven to be effective and beneficial in the goals of improving knowledge, abilities, and empathy of caregivers, and reducing stigma related to Alzheimer's disease and other dementias.

Significance of the Problem

The United States' *National Plan to Address Alzheimer's Disease: 2013 Update* conveys the importance of creating continued awareness and resources to support individuals with dementia and those subsequently impacted by the condition. The plan discusses the importance of implementing a multi-tiered approach to provide individuals with Alzheimer's disease the highest-quality care efficiently. The availability of high-quality care depends on having an adequate supply of competent and skilled professionals. All professionals including direct-care workers, social workers, physicians, community health workers, and all others involved in the quality of life of individuals with Alzheimer's disease need to be competent. Competency and the quality of care provided by these professionals need to be continuously assessed and improved (U.S. Department of Health and Human Services, 2013).

According to the *National Plan to Address Alzheimer's Disease: 2013 Update,* the Obama Administration has demonstrated its awareness of the need for more resources in relation to the need for educating health care providers on ways to better identify and treat the disease. The government has made a six million dollar investment over two years for provider education and outreach. Training professionals who work with individuals with Alzheimer's disease will be essential in providing quality care for the growing number of people with the disease. Training and information for all providers for individuals with Alzheimer's disease needs to include "benefits of early diagnosis, how to address the physical, cognitive, emotional, and behavioral symptoms of the disease, and how to assist caregivers as they cope with the physical and emotional aspects of their caregiving responsibilities" (U.S. Department of Health and Human Services, 2013, p.

15). Caregivers and other impacted professionals need information on how to connect individuals with Alzheimer's disease and their families to services in their communities. Person-centered care also is an important element to include in caregiver training in order to promote the highest-quality of care (U.S. Department of Health and Human Services, 2013).

Purpose of the Study

The purpose of the *Alzheimer's Disease & Other Dementias Workshop Facilitator Manual* is to have an accessible tool for health educators to educate caregivers at the Beaver Dam Community Hospital in Wisconsin about Alzheimer's Disease and other dementias. Specifically, the tool was developed to: (a) increase the caregivers' knowledge about the conditions, (b) increase the caregivers' empathy for individuals with the conditions, (c) improve the caregivers' caregiving techniques, and (d) reduce stigma related to Alzheimer's disease and other dementias.

LITERATURE REVIEW

Dementia

Dementia is a set of symptoms that results in the loss of cognitive functioning. Specifically, dementia affects thinking, remembering, and reasoning, and leads to disturbances in behavioral abilities that are severe enough to interfere with an individual's daily life (Alzheimer's Association, 2013a; Alzheimer's Disease Education and Referral Center, n.d.). The set of symptoms can vary greatly in severity and from person to person. Symptoms can include impaired memory, struggles with communication and language, an inability to focus and pay attention, compromised reasoning and judgment, and problems with visual perception (Alzheimer's Association, 2013a).

Types of Dementia

There are several types of dementia and numerous conditions and diseases that cause it. The types of dementia include vascular dementia, Lewy body dementia, frontotemporal disorders, and Alzheimer's disease. In addition to these types, there are upwards of ninety other conditions that can cause dementia including Huntington's disease, Creutzfeldt-Jakob disease, Parkinson's disease, head injury, and HIV (U.S. Department of Health and Human Services, n.d.).

Vascular dementia results from injuries to the vessels that supply blood to the brain. It often occurs after an individual experiences a stroke or series of strokes. The risk factors for this type of dementia include irregular and rapid heart rate, hypertension,

diabetes, and high cholesterol. Vascular dementia is the second most common type of dementia behind Alzheimer's disease. The symptoms of vascular dementia can be similar to the symptoms of Alzheimer's, but vascular dementia can begin suddenly and worsen or improve over time while Alzheimer's disease develops gradually and cannot improve over time. There are many individuals who are afflicted with mixed dementia, a combination of several types of dementia most often involving Alzheimer's disease and vascular dementia (U.S. Department of Health and Human Services, n.d.).

Another type of dementia is Lewy body. Lewy body dementia is a brain disorder caused by abnormal protein deposits, and is common in older people. Alpha-synuclein, a protein found in the brain, can cause problems with thinking, movement, behavior, and mood. Symptoms of this type of dementia include changes in alertness and attention, hallucinations, tremors, muscle stiffness, sleep problems, and memory loss (U.S. Department of Health and Human Services, n.d.).

Frontotemporal disorders are another cause of dementia that results from damage to neurons (nerve cells) in the frontal and temporal lobes of the brain. The neurons die, resulting in atrophy to the frontal and temporal lobes. The damage to these regions of the brain results in symptoms such as behavior changes, emotional problems, communication issues, difficulty walking, and trouble with other basic movements (U.S. Department of Health and Human Services, n.d.).

Alzheimer's Disease

Alzheimer's disease is the most common cause of dementia accounting for 60 to 80 percent of cases (Alzheimer's Association, 2013b), and is the sixth leading cause of death in the United States (U.S. Department of Health and Human Services, 2012).

Alzheimer's is a progressive disease that affects the brain irreversibly. The disease slowly destroys the memory and thinking skills of an individual, eventually preventing them from performing daily living tasks independently (National Institute on Aging, 2012b).

In the preclinical stage of Alzheimer's disease, there are no obvious outer signs or symptoms, but there are changes happening in the brain. Scientifically, Alzheimer's disease presents two main features in the brain--plaques and tangles. "Plaques are deposits of a protein fragment called beta-amyloid that build up in the spaces between nerve cells" and "tangles are twisted fibers of another protein called tau that build up inside cells" (Alzheimer's Association, 2014b, The role of plaques and tangles, para. 1-2). Scientists do not know the exact role plaques and tangles play in the development of Alzheimer's disease, but most agree they play a critical role in the loss of connections between nerve cells (neurons) in the brain. Changes to the brain occur when abnormal deposits of proteins start to form amyloid plaques and tau tangles. These deposits eventually cause previously healthy neurons to work less efficiently. Specifically, the neurons lose their ability to communicate with each other and die. As the disease progresses, more structures of the brain are damaged and more neurons die. Eventually, the damage is widespread and the brain shrinks significantly by the final stages of the disease (Alzheimer's Association, 2014b).

Prevalence

Approximately one in nine people age 65 and older has Alzheimer's disease and about one-third of people age 85 and older have the disease (Hebert, Weuve, Scherr, & Evans, 2013). According to the Alzheimer's Association (2013b), an estimated 5.2 million Americans were living with Alzheimer's disease in 2013. Of these 5.2 million

individuals, 5 million were age 65 and older and the remaining 200,000 had younger-onset Alzheimer's. A further breakdown of these numbers revealed that four percent of the individuals with the disease were under the age of 65.

More women than men develop Alzheimer's disease. Of the 5 million people age 65 and older with Alzheimer's in America, 3.2 million are women and 1.8 million are men (Hebert, Weuve, Scherr, & Evans, 2013). In addition, 16 percent of women 71 and older have Alzheimer's disease or other dementias (Plassman et al., 2007). The larger prevalence of women with Alzheimer's disease primarily is due to the fact that, on average, women live longer than men and the disease usually develops later in life (Alzheimer's Association, 2013b).

With the baby boomer generation growing older, the prevalence of Alzheimer's disease is projected to increase. It is projected that by 2025, the number of people age 65 and older with Alzheimer's disease will increase by 40 percent. The number of individuals with the disease is estimated to rise from 5.2 million in 2013 to 7.1 million in 2025. If no discoveries or advancements for the prevention or treatment of Alzheimer's disease materialize, it is projected that by 2050, 13.8 million individuals 65 years of age and older will have the disease (Alzheimer's Association, 2013b). These projections demonstrate the great need to make Alzheimer's disease and other dementias a priority. Education of caregivers is an essential facet in promoting the highest quality of care for the substantial amount of individuals projected to be living with Alzheimer's disease.

Diagnosis

Detecting and diagnosing Alzheimer's disease early are essential in helping individuals maintain as much independence as possible and allowing them time to make

decisions about their future care while they are still able. No single test is used to diagnose Alzheimer's disease. Diagnosis involves an extensive number of exams and tests including an assessment of the individual's medical history, a physical exam, cognitive and neuropsychological tests, neurological evaluations, brain scans, laboratory tests, and psychiatric evaluations (Mayo Clinic Staff, 2011).

Treatment

There is no cure for Alzheimer's disease although much effort is being made to find one. While there is no cure, there are drug and non-drug options that subdue or slow symptoms of the disease. The United States Food and Drug Administration has approved four medications to treat Alzheimer's disease. Donepezil, rivastigmine, and galantamine are used for individuals with mild-to-moderate Alzheimer's and Memantine is used to treat moderate-to-severe symptoms. These medications can help by regulating neurotransmitters and maintaining thinking skills, memory, speaking skills, and behavioral skills. It is important to note that although the drugs can subdue symptoms, they do not change the underlying disease process. In addition, there is no guarantee that the drugs will help an individual with Alzheimer's because the drugs are effective for some, but not all, persons with the disease. In addition, the drugs may only work for a limited period of time (National Institute on Aging, 2012b).

In addition to drugs, there are non-drug options to help individuals with Alzheimer's disease manage their symptoms. Individuals with the disease often have behavioral issues such as aggressive and agitated behavior. There are reasons behind these behaviors and if the underlying reasons are discovered, the behaviors may change. One non-drug option for managing behavior is to explore the underlying antecedents

(Alzheimer's Association, 2014b). For example, an individual with the disease may be agitated because they have to use the bathroom, but because of the disease symptoms, they are not able to connect the urge to go to the bathroom with the need to find a toilet. Assisting the individual to the bathroom and encouraging the use of the toilet every two to three hours may help with behavioral issues that are related to these urges. If caregivers search to find these underlying antecedents, the behaviors may be better managed without medication.

While there is no cure for Alzheimer's disease, researchers are looking beyond treating symptoms. Specifically, they are addressing the underlying disease processes through ongoing clinical trials. These trials are looking at preventive measures related to immunization therapy, cognitive training, physical activity, antioxidants, and the effects of cardiovascular and diabetes treatments (National Institute on Aging, 2012b).

Risk Factors

There is no known cause of Alzheimer's, but there are several risk factors linked to the disease. These risk factors include age, family history, genetics, mild cognitive impairment, past head trauma, lifestyle behaviors, heart health, and cognitive and social engagement. Age is the most significant risk factor associated with Alzheimer's disease. An individual's risk of the disease increases significantly after the age of 65 and almost half of all individuals over the age of 85 have Alzheimer's disease (Mayo Clinic Staff, 2013).

Family history is another risk factor associated with Alzheimer's disease. Individuals have an increased likelihood of developing the disease if they have a parent or sibling with Alzheimer's compared to those that do not have a first-degree relative

with the disease. The risk increases if an individual has more than one first-degree relative with the disease. The association between Alzheimer's and family history of the disease can be linked to genetics, shared environmental factors, and lifestyle choices (Mayo Clinic Staff, 2013).

Another risk factor for Alzheimer's is genetics. Rare mutations in three genes are a strong, if not guaranteed, predictor of Alzheimer's disease. The genes coding three proteins include amyloid precursor protein (APP), presenilin-1 (PS-1), and presenilin-2 (Ps-2). Although these genetic mutations almost guarantee a person who inherits them to have the disease, they only account for less than 5 percent of Alzheimer's cases (Mayo Clinic Staff, 2013; Alzheimer's Association, 2014b).

Mild cognitive impairment (MCI) "is a condition in which an individual has mild but measurable changes in thinking abilities that are noticeable to the person affected and to family members and friends, but that do not affect the individual's ability to carry out everyday activities" (Alzheimer's Association, 2013b, p. 11). MCI is another risk factor for Alzheimer's disease. Individuals with MCI are more likely to develop the disease than people without MCI. Although MCI is a risk factor for Alzheimer's, it does not always lead to Alzheimer's and other dementias. Some individuals experience the changes in thinking and memory abilities, but then revert back to normal cognition and remain stable (Alzheimer's Association, 2013b).

Another risk factor for Alzheimer's and other dementias is traumatic brain injury (TBI). TBI occurs when "sudden trauma causes damage to the brain. TBI can result when the head suddenly and violently hits an object, or when an object pierces the skull and enters brain tissue. Symptoms of a TBI can be mild, moderate, or severe, depending on

the extent of the damage to the brain. A person with a mild TBI may remain conscious or may experience a loss of consciousness for a few seconds or minutes. Other symptoms of mild TBI include headache, confusion, lightheadedness, dizziness, blurred vision or tired eyes, ringing in the ears, a bad taste in the mouth, fatigue or lethargy, a change in sleep patterns, behavioral or mood changes, and trouble with memory, concentration, attention, or thinking. A person with a moderate or severe TBI may show these same symptoms, but may also have a headache that gets worse or does not go away, repeated vomiting or nausea, convulsions or seizures, an inability to awaken from sleep, dilation of one or both pupils, slurred speech, weakness or numbness in the extremities, loss of coordination, and increased confusion, restlessness, or agitation" (National Institute of Neurological Disorders and Stroke, 2013, What is Traumatic Brain Injury?, para. 1). Individuals that have experienced moderate or severe TBI have a greater risk of developing Alzheimer's disease and other dementias than those who have not experienced moderate or severe TBI (Alzheimer's Association, 2013b).

Recent research has revealed that factors related to heart health and lifestyle choices can influence an individual's risk of developing Alzheimer's disease. Lack of exercise, smoking, high blood pressure, high blood cholesterol, poorly managed diabetes, and a poor diet lacking fruits and vegetables are factors that may increase an individual's risk of developing Alzheimer's (Mayo Clinic Staff, 2013).

Some studies also suggest that continued cognitive and social engagement can reduce an individual's likelihood of developing Alzheimer's disease. More research is needed on this issue, but factors that may reduce an individual's risk of Alzheimer's

include continued education, a stimulating career, mentally stimulating leisure activities, and frequent social engagements (Mayo Clinic Staff, 2013).

Symptoms

Alzheimer's affects each individual with the disease differently. The symptoms begin at various ages and progress at different rates. The disease often starts with a gradual progressive inability to remember new information. Other common symptoms that occur with the inability to remember new information include "memory loss that disrupts daily life, challenges in planning or solving problems, difficulty completing familiar tasks, confusion with time or place, trouble understanding visual images and spatial relationships, new problems with words in speaking or writing, misplacing things and losing the ability to retrace steps, decreased or poor judgment, withdrawal from work or social activities, and changes in mood and personality" (Alzheimer's Association, 2013b, p. 5).

On average, individuals with Alzheimer's disease live four to eight years after diagnosis, but they can live 20 years or more (Worthington, 2012). As the disease progresses, the individuals become unable to perform daily living tasks such as bathing, dressing, and eating. They also can become incontinent, start to wander or get lost, experience changes in their personality and behavior, have trouble walking, and have difficulty swallowing (Worthington, 2012). They also can display poor judgment, communication problems, hallucinations, and impulsive behavior. In the final stages, the individual with Alzheimer's disease becomes unable to communicate, may not be able to recognize friends and family, and becomes bed-bound (Alzheimer's Association, 2013b).

These symptoms convey the need for caregivers to support and enhance the quality of life for the individual with Alzheimer's disease.

The Alzheimer's Foundation (2014) divides the symptoms of Alzheimer's disease into the categories of cognitive and psychiatric. This distinction is important because many times, behavioral issues occur because of a loss of cognitive functioning, not because of a psychiatric reason; therefore, anti-psychotic medications should not be used in these situations. Instead, the underlying reasons for the behavior should be investigated by the caregiver. Cognitive symptoms include amnesia, aphasia, apraxia, and agnosia. Amnesia is the loss of memory, or the inability to recall events or facts. Individuals with Alzheimer's disease have issues with their short-term memory before experiencing issues with their long-term memory. Aphasia is the inability to communicate effectively including difficulties with speaking, writing, reading, and understanding the spoken word. Individuals experiencing aphasia still can have the ability to understand non-verbal behavior such as a smile or the tone of a caregiver's voice. Apraxia is the difficulty and inability to preform motor skills and daily living tasks (Alzheimer's Foundation, 2014). Individuals with Alzheimer's disease eventually become completely dependent on caregivers to help them with daily living tasks such as eating, bathing, and grooming. The final cognitive symptom is agnosia, which is an individual's inability to interpret signals from their five senses. An example of agnosia includes an individual's inability to sense a full bladder (Alzheimer's Foundation, 2014).

The Alzheimer's Foundation also divides the symptoms of Alzheimer's disease into a category of psychiatric symptoms which include changes in personality, depression, hallucinations, and delusions. Irritability, apathy, and isolation are several

common personality changes that occur in individuals with the disease. Individuals with Alzheimer's disease can experience both visual and auditory hallucinations that can cause agitation, paranoia, fear, and aggression. The use of psychiatric drugs may be appropriate in situations with psychotic symptoms, but a collaboration among physicians, neurologists, and psychiatrists can result in better treatment and care for individuals with the disease (Alzheimer's Foundation, 2014).

Stages of Alzheimer's Disease

There are three main stages in the progression of Alzheimer's disease. The first stage is the early stage before apparent symptoms and clinical diagnosis. The disease then progresses at different rates to a middle stage with mild-to-moderate cognitive impairment. Lastly, an individual with Alzheimer's disease enters a final stage with severe symptoms (U.S. Department of Health and Human Services, n.d.)

Early stage. The early stage of Alzheimer's disease includes a preclinical period. Scientists have determined that the disease starts in the area of the brain known as the entorhinal cortex where healthy neurons begin to work less efficiently, lose their ability to communicate, and die. The hippocampus, the area of the brain that plays a significant role in learning and turning short-term memories into long-term memories, also is eventually impacted with the death of neurons. Atrophy, or shrinking, eventually begins in these affected regions of the brain. Scientists believe that these impacts on the brain can begin ten to twenty years before Alzheimer's disease has clinically detectable signs and symptoms. Eventually, the damages to the brain result in detectable signs and symptoms. Memory problems and forgetfulness typically are the first signs of the disease.

Thinking problems such as trouble finding the right words or poor judgment also are frequent during this stage (U.S. Department of Health and Human Services, n.d.)

Middle stage. The middle stage of Alzheimer's disease ranges from mild-to-moderate symptoms. Diagnosis of the disease often occurs at this stage in which mild symptoms are apparent. Symptoms include a worsening of memory loss and mild cognitive impairment. Specific signs and behaviors include getting lost, trouble handling money and paying bills, repeating questions, taking longer to complete daily tasks, poor judgment, losing things or misplacing them in odd places, and mood and personality changes (U.S. Department of Health and Human Services, n.d.).

The middle stage can include moderate Alzheimer's disease which is the progression of more severe symptoms. Language, reasoning, sensory processing, and conscious thoughts are affected negatively because of damage to the brain. Moderate symptoms of the disease can include increased memory loss and confusion, problems recognizing family and friends, an inability to learn new things, difficulty carrying out tasks that involve multiple steps (such as getting dressed), problems coping with new situations, hallucinations, delusions, paranoia, and impulsive behavior (U.S. Department of Health and Human Services, n.d.)

Final stage. When Alzheimer's affects an individual in the final stage of the disease, the individual is known to progress from moderate-to-severe symptoms. Some of the frequent symptoms at this stage include an inability to communicate, weight loss, seizures, skin infections, and difficulty swallowing. As the individual with Alzheimer's progresses into the final stage of the disease, they often become bed bound most or all of the time and rely on others for nearly all, if not all, of their care. The disease eventually

progresses to cause the death of the individual (U.S. Department of Health and Human Services, n.d.). Death of individuals with Alzheimer's commonly results because of cardiac arrest, infection, pneumonia, or aspiration (National Institute on Aging, 2012c).

Early-Onset Alzheimer's

Although Alzheimer's mainly is a disease that affects the elderly population, some individuals under the age of 65 can develop the disease. The development of the disease under the age of 65 is referred to as early-onset or younger-onset Alzheimer's disease. In the United States, there are 5.2 million individuals with Alzheimer's disease and it is estimated that more than 200,000, or four percent, of those affected have early-onset. Symptoms of early-onset Alzheimer's disease start developing when the individuals are in their 40s and 50s, but there are very rare cases where the symptoms start developing when the individuals are in their 30s. Scientists do not know why Alzheimer's disease develops in younger individuals, but they have discovered several rare genes associated with early-onset Alzheimer's (Alzheimer's Association, 2014c).

Since Alzheimer's disease generally affects individuals over the age of 65, those with early-onset have a difficult time being accurately diagnosed. Many times, symptoms of the disease are attributed to other causes (Alzheimer's Association, 2014c). Individuals with early-onset often are very busy in their lives with families, careers, and leisure activities so it is important for an accurate diagnosis to occur early. Early diagnosis allows for individuals to be a part of the decision-making process before they are no longer able to fully communicate their wishes.

Cost

In 2013, the direct cost of caring for individuals with Alzheimer's disease in the United States was about $203 billion (Alzheimer's Association, 2013b). Individuals with the disease use amenities such as adult day services, assisted living, healthcare, long-term care, and hospice. On average, adult day services cost $70 per day, assisted living costs $42,600 per year, and long-term care such as nursing home care costs $81,030 to $90,520 per year (MetLife Mature Market Institute, 2012).

Medicare and Medicaid covered about 70 percent, or $142 billion, of the cost of care for individuals with Alzheimer's disease in 2013. The services that individuals with Alzheimer's disease and other dementias often need are expensive so many individuals use their excess income and assets on medical expenses so they can qualify for Medicaid. Individuals with Alzheimer's disease and other dementias often need to move to long-term care nursing homes in the late stage of the disease and Medicaid is the only public program that covers these stays (Alzheimer's Association, 2013b).

According to the Alzheimer's Association (2012), people with Alzheimer's disease and other dementias have more than three times as many hospital stays as other older adults. These increased hospitalizations add to the cost of the disease. Prevention measures taken by caregivers and awareness of conditions can help reduce these hospitalizations.

The cost of Alzheimer's disease is projected to increase substantially with the current treatment practices. It is projected that in 2050, the cost of Alzheimer's disease for the American society will increase exponentially to $1.2 trillion. This cost includes a

500 percent increase in the spending of Medicare and Medicaid (Alzheimer's Association, 2013b).

Stigma

The stigma associated with Alzheimer's disease and other dementias can impact early diagnosis, the public's perspective, and care quality. Stigma is defined as something that causes an individual to be stereotyped by others in an undesirable way and thus, socially rejected (Batsch & Mittelman, 2012). Education, awareness, and understanding of Alzheimer's disease and other dementias are important in addressing the stigma associated with the conditions. There is more general awareness of dementia, but many people do not know that dementia and its symptoms are caused by medical disorders and physical damage to the brain. In addition, there is a lack of social acceptance of individuals that are impacted by dementia. The stigma associated with dementia leads to decreased independence and depersonalization of individuals with Alzheimer's disease and other dementias. An increased understanding of the stage-specific symptoms of dementia will promote more independence and use of adaptive techniques among individuals with the condition. At each stage of Alzheimer's disease and other dementias, it is beneficial to focus on the individuals' remaining strengths and abilities rather than their impairments in order to promote independence and a positive quality of life (Batsch & Mittelman, 2012).

An increase in education, awareness, and understanding can reduce negative attitudes, create empathy, and decrease fear, thus reducing stigma. Both unpaid family caregivers and healthcare institution caregivers are affected by the stigma associated with Alzheimer's disease and other dementias. Unpaid family caregivers do not use

community services and avoid seeking help because of guilt and stigma. Healthcare facilities and professional caregivers reinforce the negative implications of Alzheimer's and other dementias, which can inhibit unpaid caregivers from seeking further assistance. In addition, isolation of the individuals with Alzheimer's disease and other dementias can result from the stigma that caregivers feel. If independence among individuals with Alzheimer's and other dementias is not promoted, their companionship with friends and family may be reduced. Isolation and decreased stimulation can cause additional problems that are not directly caused by the conditions (Batsch & Mittelman, 2012).

Ageism is another factor that leads to the stigma associated with Alzheimer's disease and other dementias. Alzheimer's disease and other dementias largely are conditions that affect older individuals. Older age is stigmatized by misconceptions about increased dependence and vulnerability associated with driving, maintaining employment, and consenting to medical procedures (Zebrowitz & Montepare, 2000). It also is a false expectation that as individuals age, they will experience cognitive decline. This expectation can decrease an individual's urgency in seeking a medical evaluation to determine the cause of the cognitive decline. Many individuals do not want to find out if they have dementia; therefore, they avoid having discussions with their physicians until symptoms have progressed to an advanced stage (Batsch & Mittelman, 2012).

The stigma associated with Alzheimer's disease and other dementias along with the lack of understanding can impede physicians and health care workers from addressing the conditions appropriately. Physicians who have an attitude that nothing can be done may not discuss the symptoms of dementia with their patients (Batsch & Mittelman, 2012). Thus, stigma can prevent early diagnosis of Alzheimer's disease and other

dementias because of an individual's apprehension to seek cognitive evaluation and a physician's reluctance to evaluate individuals with cognitive issues. The lack of early diagnosis prevents individuals with Alzheimer's disease and other dementias from having the ability to take part in making decisions about their care and circumstances before they are no longer able. A decrease in independence can lead to a decrease in dignity, self-esteem, quality of life, and income, and an increase in isolation (Batsch & Mittelman, 2012). Advocacy and awareness, developing and implementing programs and policies, strengthening healthcare systems, supporting caregivers and research are all important actions to decrease stigma and improve the quality of life of individuals with Alzheimer's disease and other dementias (World Health Organization, 2012).

Caregivers

As the symptoms of Alzheimer's disease and other dementias progress, individuals with the conditions continue to lose their ability to perform daily living tasks and their ability to live independently. As such, they have an increased reliance on caregivers. There are two types of caregivers--paid and unpaid. Paid caregivers include direct-care workers and professionals (Alzheimer's Association, 2012). The majority of caregivers for older adults in the formal health care delivery system are direct-care workers, such as nursing assistants, home health aides, and personal- and home-care aides. Physicians, physician assistants, nurses, social workers, pharmacists, case workers, dentists, community health workers and others may receive special training in caring for older adults. Professional direct-care workers are underpaid and, many times, do not receive adequate training for their responsibilities. Recruitment and retention of these workers remains a constant challenge. The other type of caregiver is unpaid caregivers

who usually are immediate family members, but in some cases, they may be other relatives or friends (Alzheimer's Association, 2012). “In 2011, these people provided an estimated 17.4 billion hours of unpaid care, a contribution to the nation valued at over $210 billion” (Alzheimer's Association, 2012, p. 27). Family caregivers provide eighty percent of home care (Alzheimer's Association, 2012).

As Alzheimer’s disease progresses, both paid and unpaid caregivers may become responsible for providing personal care such as bathing, dressing, grooming, and toileting (Alzheimer’s Association, 2012). It also is important that the caregivers assist in maintaining safety by helping the person take medications correctly, aiding in mobility needs, and supervising the person so he/she avoids unsafe activities such as getting lost when he/she wanders (Alzheimer’s Association, 2012). If a family member is the main caregiver, there are additional responsibilities to consider. In most instances, family caregivers are involved in making financial, medical, and personal decisions (Alzheimer’s Association, 2012). For both paid and unpaid caregivers, communication is a key responsibility. Communicating effectively with the individual with Alzheimer’s disease, his/her family, and other caregivers is essential to providing optimal quality of care and creating the most effective support network (Alzheimer’s Association, 2013a).

Caregiver Challenges

There are numerous challenges that impede both paid and unpaid caregivers from providing individuals with Alzheimer’s disease with the highest quality of care. Challenges include insufficient caregiver training and the emotional status of the caregiver. These challenges support the need to establish successful support strategies.

As revealed by Coogle, Head, Parham, and Zeman (2004), there is insufficient training of staff which can lead to an increased risk for falls, elopement, poor medication management, and an increased risk of the individual with Alzheimer's disease being dehumanized. According to Stone and Wiener (2001), direct care employees often do not receive training on how to perform specific demands of their job, which can lead to a decrease in job satisfaction and ultimately, a higher turnover rate. In addition, the policies in the United States do not require certified nursing assistants to receive training in dementia care communication, which alludes to a hidden policy of neglect (Davis & Pope, 2009). The inadequate dementia training among hands-on care providers, in conjunction with the demanding environments under which care is provided, lead to significant communication problems (Wray, 2011). The institutionalization of care can contribute to caregivers talking over, talking across, and silencing individuals with Alzheimer's disease (Davis & Pope, 2009). The busy environment in which care is provided also leads to communication barriers. Caregivers can become task-oriented instead of having meaningful interpersonal interactions with the individual with Alzheimer's disease (Davis & Pope, 2009). Subsequently, there becomes a conflict between meeting the physical needs of the individual and socializing with the individual (Wray, 2011).

Additional challenges are connected to the symptoms of Alzheimer's disease and the impacts on the emotional well-being of the care provider. Stress, burden, depression, and grief are emotional feelings that most professional and family caregivers of individuals with Alzheimer's disease experience (Sanders, Ott, Kelber, & Noonan, 2007). A qualitative study about grief asked caregivers questions related to yearning for the past,

regret and guilt, isolation, restricted freedom, life stressors, systemic issues (e.g., difficulties communicating with social services and health care delivery systems), and coping strategies. All of these categories were common experiences among the 44 caregivers (of a sample of 201) that experienced grief (Sanders, Ott, Kelber, & Noonan, 2007). Many of the caregivers' responses in the study alluded to wanting normalcy, experiencing guilt from admitting their loved one to a long-term care facility, and experiencing frustration about professional care providers having limited knowledge on how to provide quality care for their loved one (Sanders, Ott, Kelber, & Noonan, 2007).

Support Strategies for Caregivers

The literature conveys the many challenges related to providing high quality care for individuals with Alzheimer's disease. In order to preserve the independence, dignity, and quality of life of individuals with the disease, it is essential to have support strategies for caregivers because they become the main support for these individuals as the disease progresses. There are several support strategies and interventions to help caregivers cope with the stress involved with caring for someone with Alzheimer's disease. These strategies and interventions include psychoeducation, support systems, psychotherapy, and multicomponent programs (Alzheimer's Association, 2012). Psychoeducational interventions include educational programs that provide information about the disease, resources, and means by which the caregiver can gain more skills to respond to symptoms of the disease (Alzheimer's Association, 2012). Support systems allow caregivers to bond and gain support from other caregivers by sharing their feelings, struggles, and strategies (Alzheimer's Association, 2012). Another intervention for caregivers includes psychotherapy. Many times, psychotherapy is a strategy for family

caregivers, but the ideas and support also can apply to paid caregivers. Psychotherapy is an intervention in which a therapist teaches caregiver skills such as self-monitoring, problem-solving abilities, time management, and management of emotions (Alzheimer's Association, 2012). Any combination of psychoeducation, support systems, and psychotherapy also can be effective for caregivers (Alzheimer's Association, 2012).

Proper Caregiving Techniques

Caring for individuals with Alzheimer's disease and other dementias can be challenging because of the symptoms of the disease. Every individual with the disease will have different needs at different stages of symptom development. Caregiving techniques that work effectively for individuals with the disease will change from moment to moment. In the early stage of Alzheimer's, the individual with the disease may only need small reminders, redirection, or assistance, but as the disease progresses, the individual eventually will be completely dependent on caregivers. Individuals with the disease will need assistance with tasks such as bathing, dressing and grooming, eating, and toileting. Other skills that are important for caregivers to master are communication and coping with mood and behavior changes such as agitation and aggression (Alzheimer's Research Association, 2011; National Institute on Aging, 2012a; National Institute on Aging, 2012b; National Institute on Aging, 2012d; National Institute on Aging, 2012e; National Institute on Aging, 2012f).

Bathing. Bathing an individual with Alzheimer's disease and other dementias usually is the most difficult personal care experience for the caregivers because the intimate nature of the care can be uncomfortable and threatening to the individual with the disease. The individual with dementia may exhibit specific behaviors such as

resistance because of the difficulty associated with the loss of privacy and independence. It is important for the caregiver to prepare for the bath ahead of time, create a safe environment, and help promote a feeling of control for the individual with the disease. In order to prepare the room, the caregiver should gather all of the necessary supplies and put them in reach for when the individual is in the bath. In addition, the caregiver should make the room comfortable by using a padded shower seat and adjusting the temperature in the room to a comfortable level. It also is essential to make the bathroom safe by installing grab bars, using non-skid mats, and keeping all sharp objects such as razors out of reach. Another safety concern for individuals with Alzheimer's disease and other dementias is that they may not sense when the water is dangerously hot; therefore, the caregiver needs to check the water temperature to ensure it is at a safe level (National Institute on Aging, 2012d).

When caring for an individual with Alzheimer's disease and other dementias, it is important to assist them with remaining as independent and in control as possible. There are several techniques a caregiver can try to use to help instill independence for the individual when bathing. The caregiver can give the individual choices such as whether they want to take a bath now or in ten minutes. The caregiver also can give the individual certain tasks such as holding on to the washcloth. There are several strategies caregivers can use to help keep the individual with dementia comfortable. These strategies include having a familiar person of the same sex assist with the process, removing or covering mirrors (often an individual with Alzheimer's does not recognize their own reflection so they will see the person in the mirror and may think there is a stranger in the room), always covering the person with a bath towel to preserve privacy, and being flexible with

what the individual wants. After the bath, it important for the caregiver to assess the individual's skin for sores and rashes, dry the skin gently, and use cornstarch or talcum powder in any folds and creases in the skin (National Institute on Aging, 2012d).

Dressing and grooming. In order to help promote self-esteem, independence, and dignity, caregivers can assist in the dressing and grooming of individuals with Alzheimer's disease and other dementias to varying levels depending on the progression of the conditions. Techniques that can be effective when a caregiver is assisting in dressing include simplifying choices, organizing the process, picking comfortable and simple clothing, and being flexible. One specific suggestion is for caregivers to hand the individual one item of clothing at a time while giving simple and direct instructions such as "put on your shirt" or "put your arm in this sleeve." Another tip for caregivers is that if the individual with dementia always wants to wear the same outfit, the caregiver could get duplicate outfits (National Institute on Aging, 2012f).

Assisting individuals with dementia with dressing and grooming tasks to help them with their appearances is important in promoting their self-esteem and dignity. As the disease progresses, individuals may forget how to dress themselves, use a comb, or trim their nails. They may forget the purpose of grooming items such as a comb or razor. Caregivers should assist individuals with dementia by coordinating and maintaining their previous grooming routines such as continuing to assist them in going to get their hair done at the salon or helping them continue to use their preferred toiletries such as makeup, deodorant, or toothpaste. The imitation technique is a method caregivers can use to help individuals do their grooming independently. An example of the imitation technique is when a caregiver combs his/her hair alongside the individual with dementia

and encourages the individual to imitate the caregiver's motions. Safety always is a concern when it comes to the care of individuals with Alzheimer's disease and other dementias. In order for individuals to safely groom themselves, it is helpful to use safer and simpler tools such as cardboard nail files and electric shavers instead of clippers and razors (National Institute on Aging, 2012f).

Eating. Individuals with dementia often struggle to get enough nutrition because of the challenges associated with eating. They may be overwhelmed by too many food choices, forget to eat, think they already ate, or have difficulty knowing how to use the utensils. Caregivers can be instrumental in making this process easier for the individual with dementia. To help facilitate more successful mealtimes, a caregiver can limit distractions by serving meals in quiet spaces and having a simple table setting. Since the individual's visual and spatial abilities may be affected, caregivers should use white plates and bowls that contrast with the table and the food so the individual can distinguish each item from the other. It also may be necessary for the caregiver to give ample time for meals and to continue to remind the individual with dementia to chew and swallow. In addition, the caregiver can implement the imitation technique by showing the person how to eat. Using adaptive equipment, such as spoons with large handles or non-skid surfaces to place plates and bowls on, can help with promoting independence (Alzheimer's Research Association, 2011).

As the disease progresses, the individual with Alzheimer's can have difficulty swallowing. Caregivers can provide foods that are easy to swallow such as pudding or scrambled eggs. In addition, the caregiver should be aware of choking hazards. The individual with dementia should be encouraged to sit up straight with his/her head

slightly forward in order to prevent choking. The caregiver also should check the individual's mouth after he/she is done eating to ensure the food was swallowed (Alzheimer's Research Association, 2011).

Toileting. As Alzheimer's disease and other dementias progress into the later stages, many individuals become unable to control their bladder or bowels, and experience incontinence. Incontinence in individuals with dementia can be caused by several factors including an inability to recognize urges to use the bathroom, forgetting where the bathroom is located, medications, stress, specific physical conditions (e.g., urinary tract infections, enlarged prostate gland, and untreated diabetes), and clothing that is difficult to remove. If incontinence is a new issue for the individual, it is important for the caregiver to inform the doctor to determine possible medical causes such as a urinary tract infection or diabetes. The caregiver's role in toileting is to be supportive, provide reminders, and be proactive. The caregiver should reduce the individual's embarrassment and preserve his/her dignity. Incontinence can be reduced by encouraging the individual to use the bathroom regularly. In addition, the caregiver may learn trigger words or phrases that the individual uses when he/she needs to go to the bathroom. For example, "I cannot find my glasses" may mean they have to use the bathroom. Another important element related to toileting is for caregivers to make a clear and visible path to the toilet (National Institute on Aging, 2012e).

Communication. The communication techniques that caregivers use when working with individuals with Alzheimer's disease and other dementias are essential in the quality of care the individual receives. Individuals with dementia gradually will begin to struggle with their ability to communicate and they may find it difficult to express their

thoughts and emotions as well as struggle to understand others. The early symptoms related to communication may not seem very different from normal behavior, but they may begin to repeat stories or struggle to find the right words. As the disease progresses, other communication changes may occur with the individual such as repeatedly using a familiar word, inventing new words, easily losing his/her train of thought, having difficulty organizing words logically, and limiting how often he/she speaks. Caregivers play a vital role in helping people with dementia communicate. Caregivers need to be patient and reassuring, not criticizing and correcting. If the individual with dementia says something incorrect, the caregiver should not tell the person he or she is incorrect. The caregiver needs to listen and try to find the meaning of what the individual is saying. Arguing and distracting need to be avoided by caregivers in order to promote calm and effective communication. It also is advantageous for the caregiver to focus on the feelings behind what the individual is saying, not necessarily the words that are being said (National Institute on Aging, 2012a).

Continued communication is essential between the caregiver and the individual with Alzheimer's disease no matter what level of ability the individual has to respond. An appropriate technique for caregiver communication with the individual involves the caregiver identifying himself/herself and calling the person with Alzheimer's by name. The caregiver should also use short, simple words and sentences while speaking slowly and clearly. Patience and nonverbal communication also are important for caregivers. Caregivers need to use positive and friendly nonverbal communication and tones in their voice. Another strategy for effectively communicating with individuals with dementia is to use visual cues such as pointing to items or beginning a task such as starting to brush

the individual's hair and then helping the person take over after they visually see what the caregiver is suggesting (National Institute on Aging, 2012a). It is essential for caregivers to treat the individuals with Alzheimer's disease and other dementias with dignity by talking to them and providing person-centered care rather than talking about them or over them.

Coping with Agitation and Aggression. Individuals living with Alzheimer's disease and other dementias may experience mood and personality changes. Some individuals may exhibit agitation and aggression because of the disease. Pacing, sleeplessness, or aggression can result from agitation. Most of the time, when an individual with Alzheimer's disease is agitated or aggressive, there is a reason behind his/her behavior. Many times, an individual is unable to communicate so he/she communicates through his/her behavior. There are many reasons why an individual with the disease may be agitated or aggressive to include: pain, depression, stress, too little sleep, constipation, incontinence, a sudden change in routine, well-known place, or person, a feeling of loss, too much noise or action around him/her, feeling lonely, and an interaction of medicines (National Institute on Aging, 2012b). Caregivers need to try to discover these underlying causes for the behaviors in order to address the individual's needs and issues. Many times, when the underlying causes for the behaviors are discovered and addressed, the behavior will stop.

There are several techniques to promote effective coping strategies for caregivers when individuals with Alzheimer's disease and other dementias are agitated or aggressive. Caregivers need to reassure and listen to the individual while remaining calm. Allowing the individual to keep as much control as possible in his/her life and keep

cherished photographs and keepsakes around may help address agitation and aggression. In addition, creating and maintaining routines is a strategy that can help an individual with Alzheimer's disease and other dementias. Other strategies to help the individual cope with agitation and aggression include using soothing music, reading, and reducing noise and clutter around the person (National Institute on Aging, 2012b). Individualizing care is important in addressing the specific needs, personalities, and support for those living with Alzheimer's disease and other dementias.

CHAPTER II

METHODOLOGY

Pilot Educational Experience

A Master of Public Health in Community Health Education candidate created an educational program for professional caregivers responsible for caring for individuals with Alzheimer's disease and other dementias. The *Alzheimer's Disease & Other Dementias Caregiver Workshop* was used as a pilot educational experience to refine the *Facilitator Manual* for future health education professionals to utilize for educating caregivers. The *Facilitator Manual* was evaluated through the feedback from co-facilitators, observations, and surveys that occurred in conjunction with the pilot educational experience.

Participants in the pilot educational program were professional caregivers at the Beaver Dam Community Hospital in Beaver Dam, Wisconsin. The caregivers underwent the educational program pertaining to caring for individuals with Alzheimer's disease and other dementias. *The Alzheimer's Disease & Other Dementias Caregiver Workshop* was broken down into three sessions that spanned a total of an hour and a half on a single day. The first session covered general information about Alzheimer's disease and other dementias including information on the prevalence, symptoms, warning signs, stages, diagnosis, and treatment. The second session included the Virtual Dementia Tour® (Beville, 2011). The tour is a simulation experience that is aimed at giving participants perspective on what it is like to have Alzheimer's disease and other dementias. The third

session included caregiving techniques and a debriefing section to discuss the Virtual Dementia Tour®. Topics covered in this session were communication techniques, coping with agitation and aggression along with specific techniques in assisting with bathing, eating, toileting, dressing, and grooming.

Participants

Workers in healthcare settings are affected by the increase in the aging population and the increase in the prevalence of Alzheimer's disease and other dementias. These increases put a greater demand on the healthcare system. Individuals with Alzheimer's disease and other dementias often have increased hospitalizations due to the physical and mental impacts of the conditions (Alzheimer's Association, 2013b). The increase in hospitalizations puts an increased demand on healthcare workers. In addition, there are many individuals with Alzheimer's disease and other dementias who live in nursing homes and assisted living and depend on the care of professionals. Professional caregivers need to gain a greater awareness about Alzheimer's disease, have perspective on what it is like to live with the disease, and be educated on proper caregiving techniques in order to provide the highest quality of care for individuals with the disease.

An assessment of the Beaver Dam Community Hospital through key informant interviews concluded a need for additional educational opportunities in regards to Alzheimer's disease and other dementias. There were eight participants in the pilot educational experience held at the Beaver Dam Community Hospital. The participants included a certified nursing assistant, two nurses, an occupational therapist, and two managers of various facets of the organization. There were two other individuals that participated in Parts I and III of the pilot educational program, but assisted in the

facilitation of Part II: The Virtual Dementia Tour®. Participating caregivers were notified of the opportunity to participate in the educational experience through the hospital's "Meeting Signups" section of the organization's intranet. They also were informed of the experience through an e-mail flyer notification sent to all caregivers at the organization (see Appendix A). The signup for the experience was limited to eight people because of resources and the time it takes to complete the Virtual Dementia Tour®. In order to attract participants, the Public Health Student coordinated with the Nurse Educator so the pilot educational program could be counted for WISHET CEUs. WISHET CEUs are continuing education units that some caregivers, including nursing assistants, can count toward their yearly requirement for professional development.

Setting

The *Alzheimer's Disease & Other Dementias Caregiver Workshop* was held at the Beaver Dam Community Hospital in Beaver Dam, Wisconsin. The hospital was the facility for the educational experience because of the resources available and the willingness of the employees to participate. The facility had a room available for Part I of the workshop, Learning Center A & B, with proper seating and computer equipment that allowed for the use of PowerPoint. The hospital also had two patient rooms available for Part II of the workshop, which requires rooms to set up the Virtual Dementia Tour®. Part III of the educational experience was held in the same Learning Center room as Part I because of the need for computer equipment and an area for discussion.

Part I: Overview of Alzheimer's Disease & Other Dementias

Part I of the pilot educational experience included a twenty-minute introduction and an overview of Alzheimer's disease and other dementias. Part I began with an

introduction of the facilitator and the participants in order to gain an idea of the roles and responsibilities of those involved in the experience. Other information presented in this section included an overview of the definition of dementia, types of dementia, and an in-depth focus on Alzheimer's disease. The information on Alzheimer's disease included a definition, prevalence, symptoms and warning signs, diagnosis, treatment, and stages of the disease. The overview of Alzheimer's disease and other dementias was facilitated through the use of a PowerPoint presentation, discussion questions, and handouts (see Appendices B and C). The handout included information regarding warning signs of Alzheimer's disease in order to help the caregivers have a better understanding of the disease.

The resources used for Part I of the pilot educational experience included a conference room with appropriate seating for discussion and education, equipment with PowerPoint capabilities, and handouts related to symptoms and warning signs of Alzheimer's disease. A facilitator who is skilled in educating and promoting discussion also was required for Part I of the experience.

Part II: Virtual Dementia Tour®

Part II of the pilot educational experience was the Virtual Dementia Tour®. This session took forty-five minutes to complete. However, the amount of time required to complete the experience depends on the number of participants. The Virtual Dementia Tour (VDT®) is an experience developed by Beville (2011), in connection with Second Wind Dreams©, a national non-profit organization with a mission to change the perception of aging. The Master of Public Health student who organized the pilot educational experience connected with the manager of the Remembrance Home, a facility

that is part of the Beaver Dam Community Hospital. The Remembrance Home is a home for individuals diagnosed with dementia. The manager shared the VDT® material with the student, which previously was purchased by the Remembrance Home in connection with the Beaver Dam Community Hospital. Key informants at the hospital educated the student the success of past use of VDT®, and shared that the lack of resources and time of current employees to facilitate the experience interfered with its continued implementation.

The Virtual Dementia Tour® is aimed at sensitizing participants to the needs of elders in order to improve the care that people with Alzheimer's disease and other dementias receive. The VDT® was developed in response to two studies indicating participants' perception of the need for such experiences. The educational experience was designed to simulate the known effects of dementia on a person and examine the cognitive and physical impacts that occur with aging. It is a tool used to create experiences for caregivers, families, communities, and agencies. The participants have several items placed on them, including goggles, headphones, and gloves, to simulate dementia. Participants then are placed in a VDT® "experience room" that is set up beforehand by the facilitator. The "experience room" is a space that is set up as a normal living space where the participants have to complete daily living tasks such as folding towels or setting a table. The participant is asked to perform five simple tasks in the ten minutes they are in the "experience room." Another facilitator sits in the room and observes the behaviors and reactions of the participants. Lastly, the participants complete their time in the "experience room" and have time to discuss the experience (Beville, 2011).

There are several resource needs in regards to this section of the pilot experience. VDT® supplies a toolkit that includes a binder with information about the Virtual Dementia Tour® studies, supplies needed for the experience, how to set up the "experience room," tour guide training, behavioral observation insights, the wrap-up session, and helpful forms. The participants have to put on several garb items before they go into the "experience room." The supplies used to simulate dementia include goggles, gloves, shoe inserts, and confusion audio. Before participants go in to complete their tasks, inserts with uncomfortable bumps are placed in their shoes to simulate foot pain that can be associated with poor circulation, neuropathy, and arthritis. The participants then put on a pair of rubber gloves that have a tablespoon of popcorn kernels in them and another pair of cloth gloves over to simulate arthritis and a loss of sensory and fine motor skills. Next, a pair of goggles with yellow tinted lenses and a black dot in the center is placed on the participants. Elders can have a yellowish haze in their sight because of the aging of the eye. This condition can create problems with having enough illumination to see things clearly. The black dot on the goggles represents macular degeneration which is common in the aging process. The goggles also serve as a way to simulate the loss of peripheral vision which can be common for individuals with middle and late stage dementia. Lastly, headphones that have audio with various muffled sounds are placed on the participants. This exercise simulates hearing loss and the difficulty individuals with dementia have with auditory stimulation (Beville, 2011).

According to the VDT® instructions, one room needs to be set up as the Virtual Dementia Tour® "experience room." This suggestion was adapted because of the timeframe and layout of the pilot educational experience. Two patient rooms at the

Beaver Dam Community Hospital were used as the "experience rooms" in order to get all of the participants through the experience in an efficient timeframe. The rooms were used because they had a bed, closet, bedside table, and desk area. The rooms were dim, but not dark. The beds were made, but there were towels, a sheet, washcloths, pillowcases, neck ties, and eight pairs of assorted colored socks randomly scattered on each of the beds. The facilitator also prepared the rooms by putting paper, pens, and envelopes on the desks. Paper plates, cups, silverware, and napkins were placed in each of the rooms. White extra-large t-shits, pants, and belts were placed in the closets. Finally, cups for water were placed next to the sink in the room. The setup of the experience rooms is based on the tasks that the participants will be asked to complete (Beville, 2011).

Facilitators of the VDT® experience are essential in the implementation of the exercise. During the pilot educational experience, two facilitators worked together and were responsible for garbing the participants, keeping track of the time, reading the task instructions to the participants, and de-garbing participants when they were done with the experience. Two other facilitators were responsible for observing and documenting the participants' behavior while they were in the "experience room" using the Behavioral Observation Form provided by VDT®. The behaviors observed in the "experience rooms" are important in the discussion that takes place in Part III of the workshop.

Part III: Caregiving Techniques & Debriefing

Part III of the *Alzheimer's Disease & Other Dementias Caregiver Workshop* pilot educational experience included a debriefing period for participants to share their thoughts and perspectives on their experience with the Virtual Dementia Tour® from Part II. Part III also included information on caregiver techniques for individuals with

Alzheimer's disease and other dementias to include communication, agitation and aggression, bathing, grooming, dressing, eating, and toileting. Thirty minutes were allocated for the facilitation and discussion of the debriefing and caregiver techniques for Part III.

The participants were encouraged to share their reactions and insights on their experience with the Virtual Dementia Tour®. Participants were eager to contribute to the dialogue because of the nature of the experience. The debriefing accounted for ten to fifteen minutes of Part III of the pilot workshop.

After the discussion of the Virtual Dementia Tour®, the pilot educational experience addressed caregiver techniques. A PowerPoint presentation was used along with handouts about various tips and techniques (see Appendices B and C). The handouts included Communication, Coping with Aggression & Agitation, Bathing, Daily Living Tasks, and Caregiver Resources & Support. The PowerPoint and handouts were used to explain the challenges individuals with Alzheimer's disease and other dementias have with each issue. Strategies for professional caregivers to care for and facilitate successful interactions with individuals with Alzheimer's were emphasized during this session.

The pilot educational experience ended by going through a handout with resources and support strategies for Alzheimer's caregivers (see Appendix C). In addition, the facilitator ended with a take home message that concluded with the following quote from Elie Wiesel: "We must not see any person as an abstraction. Instead, we must see in every person a universe with its own secrets, with its own treasures, with its own sources of anguish, and with some measure of triumph."

Surveys

A preliminary *Alzheimer's Disease & Other Dementias Caregiver Workshop Facilitator Manual* was used to conduct the pilot educational program. The intent of the pilot educational program was to evaluate the effectiveness of the facilitator manual and determine any changes that needed to be made. Pre-program and post-program surveys were disseminated during the pilot educational workshop to evaluate the program (see Appendix D). In part, the surveys were developed through the use of the evaluations provided in the Virtual Dementia Tour® manual (Beville, 2011). The questions adapted from the Virtual Dementia Tour® include those related to the justification of behaviors exhibited by individuals with dementia and the participants' capabilities during the simulation experience. The surveys also were developed by directly aligning the objectives of the manual with the questions asked. Empathy, improved knowledge, and an increased awareness of caregiver techniques were directly addressed in the questions in the surveys referring to an understanding of emotional needs, sufficient knowledge about dementia, confidence in caregiver techniques, and overall feelings towards individuals with the conditions. The post-program survey includes additional qualitative questions to address the overall benefits of the workshop and areas that need improvement.

Participants provided a unique, respondent ID (the last two digits of their phone number followed by the two digits of their birthday month and their middle initial) on the pre- and post-surveys so the evaluations could be matched anonymously. The project and the surveys were approved and exempt from further examination by the Institutional

Review Board (IRB) at the University of Wisconsin-La Crosse. Informed consent forms were created and distributed before the pilot educational experience began.

The pre-program survey was administered at the beginning of the pilot educational workshop immediately following introductions of the facilitator and participants. It inquired about demographic information related to the participants' role as caregivers, how many years they had been caregiving, and how often they worked with individuals living with Alzheimer's disease and other dementias. The majority of the remaining questions on the survey included 5-point Likert scales used to discover the participants' opinion on their understanding of the emotional needs of individuals with dementia, their general knowledge about the condition, their confidence in caregiver techniques, and other general feelings they had about individuals with Alzheimer's disease and other dementias.

The post-program surveys were distributed after the entire pilot educational program was completed in order to compare changes from the pre-program surveys and evaluate the overall program. The post-survey included several of the same questions as the pre-survey such as inquiring about the participants' opinion on their understanding of the emotional needs of individuals with dementia, their general knowledge about the condition, their confidence in caregiver techniques, and other general feelings they had about individuals with Alzheimer's disease and other dementias. The post-survey also included open-ended questions asking about how the experience affected the participants, what had the greatest impact on them, examples of what they would do differently because of the experience, the most beneficial aspects of the program, and aspects of the workshop that needed improvement.

CHAPTER III

FINDINGS

Surveys

Pre-program and post-program surveys were disseminated before and after the *Alzheimer's Disease & Other Dementias Caregiver Workshop* pilot educational experience to evaluate the effectiveness of the program and facilitator manual. The pilot educational program included eight individuals, but only six pre- and post-surveys were completed. Two of the participants of the program helped with the facilitation of the Virtual Dementia Tour®, so they did not complete surveys. The use of the unique, respondent ID identifiers that were placed on the corresponding pre- and post-surveys allowed for matching of the surveys in order to evaluate the impact of the workshop for each individual.

Demographics

The pre-program surveys revealed demographic data about the participants in the pilot educational workshop. The participants had a variety of different roles at the Beaver Dam Community Hospital and included a certified nursing assistant, two registered nurses, two managers of different facets of the organization, and an occupational therapist. All but one of the participants had twenty or more years of experience. The outlier had six years of experience. In addition, all six of the participants had at least a moderate level of experience with individuals with Alzheimer's disease and other dementias. They all had worked with ten or more individuals with the conditions. The

demographic data from the pilot educational experience and the discussions that took place during the experience revealed the widespread interest in Alzheimer's disease and other dementias among professional caregivers at the Beaver Dam Community Hospital. It also was revealed that caregivers at the hospital are seeking additional information and experiences even if they have a substantial number of years of experience. The demographic data and discussions during the pilot educational experience indicated the benefits of having participation from individuals with a variety of caregiver roles and experiences. Each individual had different experiences, strategies, insights, and perspectives that brought value to discussions during the educational experience.

Likert Scale Questions

The pre- and post-program surveys included several questions with 5-point Likert scales. The Likert scale responses varied for each question; see Appendix D for a copy of the surveys. Numerous findings resulted from these questions. One finding indicated that all six of the participants improved or remained strongly aware in their understanding of the emotional needs of elders with dementia after participating in the pilot educational experience. In regards to the question, "Do you feel your general knowledge about Alzheimer's disease and other dementias is sufficient for the care you provide?," five of the six participants improved or remained the same from the pre-program survey to the post-program survey, but one participant responded "agree" on the pre-survey and "neutral" on the post-survey. This participant, "Participant 3" in Table 1, also went from "agree" on the pre-survey to "neutral" on the post-survey in response to their confidence in their knowledge of techniques for providing care to individuals with Alzheimer's

disease and other dementias. The remaining five participants improved or remained at "strongly agree" or "agree" in response to this question.

Table 1 depicts each of the six participants' responses to the 5-point Likert scale questions on the pre-program and post-program surveys.

Table 1. Participant Responses to 5-Point Likert Scale Questions on Program Surveys

	Participant 1		Participant 2		Participant 3		Participant 4		Participant 5		Participant 6	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Do you feel you understand the emotional needs of our elders with dementia?	Neutral	Agree	Disagree	Strongly Agree	Neutral	Agree	Strongly Agree	Strongly Agree	Strongly Agree	Strongly Agree	Agree	Strongly Agree
Do you feel your general knowledge about Alzheimer's disease and other dementias is sufficient for the care you provide?	Neutral	Neutral	Neutral	Agree	Agree	Neutral	Neutral	Strongly agree	Strongly Agree	Strongly Agree	Neutral	Agree
Are you confident in your knowledge of technique for providing care to individuals with Alzheimer's disease and other dementias?	Neutral	Agree	Disagree	Agree	Agree	Neutral	Agree	Strongly Agree	Strongly Agree	Strongly Agree	Agree	Agree
From a physical standpoint, how capable did you feel carrying out simple tasks during the VDT®?	Somewhat Capable		Capable		Somewhat Capable		Not Capable		Neutral		Not Capable	
How justified are people with dementia when they exhibit inappropriate behaviors?	Very Justified	Very Justified	Very Justified	Very Justified	Somewhat iustified	Somewhat Justified	Very Justified	Very Justified	Very Justified	Very Justified	Somewhat Justified	Very Justified

In conclusion, the responses to the Likert Scale questions (quantitative data) in conjunction with the open-ended questions (qualitative data) show that the pilot educational workshop was effective. The responses in the post-program surveys indicate that the participants' realization of the emotional needs of elderly with dementia

improved or remained at a high capacity with all of the responses to the Likert Scale question being “agree” and “strongly agree.”

The responses to the question “Do you feel your general knowledge about Alzheimer’s disease and other dementias is sufficient for the care you provide?” resulted in a variety of responses, but when examined in connection with the qualitative findings, responses indicate that individuals gained a foundation of information related to Alzheimer’s disease and other dementias. Four of the participants improved or remained satisfactory in regards to having sufficient knowledge about dementia with responses to the Likert Scale question being “agree” and “strongly agree”. One of the participants remained neutral. Participant 3 responded “agree” in the pre-program survey and “neutral” in the post-program survey. Examining the qualitative data related to this participant, their “neutral” response in the post-survey may be due to the fact that they are now aware that they need additional education about dementia.

The participants’ knowledge of their caregiver techniques for individuals with dementia also improved or remained satisfactory. Five of the participants responded “agree” or “strongly agree” to the Likert Scale question “Are you confident in your knowledge of techniques for providing care to individuals with Alzheimer’s disease and other dementias?” Participant 3 responded “agree” in the pre-program survey and “neutral” in the post-program survey. As previously explained, examining the qualitative data related to this participant, their “neutral” response in the post-survey may be due to the fact that they are now aware that they need to improve their caregiver techniques.

Open-Ended Questions

The open-ended questions on the post-program surveys revealed qualitative feedback regarding the *Facilitator Manual*. The question, "Explain how this experience affected you; what will stay with you and what had the most impact on you," resulted in several insightful responses including "The virtual dementia tour had the most impact," "I feel all people caring for people with any dementia should also go through this experience," "The disease is just saddening to me; that stays with me," "How frustrating their life is and how difficult simple tasks can be," and "The sensory loss and how it affects our life physically and emotionally." These responses show the impact that the pilot educational experience had on the participants and the perspective that more individuals need to participate in the experience.

The question "Give examples of something you will do differently because of the experience" resulted in many responses related to slowing down interaction with individuals with Alzheimer's disease and other dementias and giving them more time to complete tasks. The responses included "Take more time with patients, give simple instructions," "Explain myself better when working with patients with dementia. Speak slowly, calmly, and limit to one task until completed and then move on," "Slow down my conversation with residents," "Go slower with instructions," and "Be more patient with my patients." Each of the participants learned from the discussion and caregiver techniques aspect of the experience.

In response to the question on the survey related to the most beneficial aspect of the educational program, the participants unanimously stated that the Virtual Dementia

Tour® was effective. It also was conveyed that all of the aspects of the program were helpful and beneficial.

The question "How could the program be improved?" resulted in two recommendations. One participant's response indicated the benefit of providing the educational experience to all staff. Another participant stated that the program could be improved through facilitating more discussion questions and sharing.

Discussion Feedback

During Part III, the debriefing and caregiver techniques section of the *Alzheimer's Disease & Other Dementias Caregiver Workshop* pilot program, the focus was on group discussion with the participants. The group discussion and feedback resulted in several findings that are important in the development of educational programs for professional caregivers. One important finding was that professional caregivers sometimes are assisting and caring for family members who have Alzheimer's disease or other dementias. This finding conveyed the additional demands that these professional caregivers face in their professional and personal lives when caring for individuals with dementia.

During and after the completion of the pilot educational workshop, observation and oral feedback from the co-facilitators were essential in the assessment of the *Facilitator Manual*. The co-facilitators included two nurse educators, a librarian, and a manager of a home for individuals living with dementia in Beaver Dam. One of the most important findings from the observation and feedback from the co-facilitators was the need for more extensive clarification in the roles of the assisting facilitators. It was found that the responsibilities of the co-facilitators during the Virtual Dementia Tour® needed

further explanation. In addition, more time allocated for questions and clarification for the co-facilitators before the workshop was needed. These findings resulted in the final *Facilitator Manual* further outlining the responsibilities of the co-facilitators. The manual contains specific responsibilities with tools and checklists for the co-facilitators to utilize. In addition, the manual includes suggestions and time allocation for the lead facilitator to meet with the assisting facilitators.

Through observation and feedback from the co-facilitators, continued enthusiasm about the workshop was indicated. The co-facilitators discussed the need and potential for future workshops. One of the co-facilitators, who is a nurse educator, also has helped coordinate future workshops within the Beaver Dam Community Hospital.

CHAPTER IV

CONCLUSIONS & RECOMMENDATIONS

Conclusions

Through a review of the literature and implementation of the pilot educational experience, the need for further education, experiences, and awareness about Alzheimer's disease and other dementias is apparent. The prevalence of Alzheimer's disease already is putting a great demand on our society and the number of people living with Alzheimer's is continuing to increase substantially with the current treatment practices. These trends are putting a great demand on society from a financial, healthcare, and personal perspective. The literature reveals that professional caregivers have insufficient training and knowledge about caring for individuals with Alzheimer's disease and other dementias, which leads to many negative health and quality of life implications for both the caregivers and the individuals with the conditions. In order to address this lack of education, the *Alzheimer's Disease & Other Dementias Caregiver Facilitator Manual* was developed for health education professionals to use as a tool to create training programs for professional caregivers. The facilitator manual is an effective tool in increasing caregivers' awareness and knowledge about Alzheimer's disease and other dementias, increasing caregivers' empathy for individuals with the conditions, improving caregivers' techniques, and reducing stigma associated with the conditions. The manual is intended to provide the procedures, equipment, and information needed to conduct educational experiences for professional caregivers. It includes an overview of

Alzheimer's disease and other dementias, an adapted version of the Virtual Dementia Tour®, and a debriefing section that addresses caregiver techniques.

Recommendations

After reviewing the literature, developing the *Alzheimer's Disease & Other Dementias Caregiver Workshop Facilitator Manual*, and implementing a pilot educational experience using the manual, several recommendations surfaced. First, the facilitator manual focuses on educational experiences for professional caregivers, but it would be beneficial to adapt the manual in order to provide educational experiences for unpaid, family caregivers and general community members. Unpaid, family caregivers experience challenges, strategies, and situations that differ from professional caregivers. Adapting the manual to address these varying experiences would include information related to financial strategies, additional emotional support, and coping with changes in loved ones. In addition, an adaptation of the manual to create educational experiences for general community members would be beneficial in increasing awareness, discussion, and knowledge about Alzheimer's disease and other dementias to help decrease the stigma related to the conditions.

The *Alzheimer's Disease & Other Dementias Caregiver Workshop Facilitator Manual* was created for use among professional caregivers at the Beaver Dam Community Hospital, a smaller hospital setting. In general, smaller hospitals have a more limited capacity in regards to resources and the number of available facilitators than larger facilities. Because of the limited capacity, the target number of participants is eight to ten. Adapting the manual to focus on educating more individuals at once or finding solutions to the limited capacities of smaller organizations would be beneficial in

addressing the issue of educating caregivers about Alzheimer's disease and other dementias. The limited capacities of smaller organizations can be addressed by developing and maintaining connections with students and volunteers who are interested in educating individuals about Alzheimer's disease and other dementias. Preceptorship possibilities for students could be developed with the use and adaptation of the *Facilitator Manual* as a focus. It is important to note that there are substantial benefits in facilitating educational experiences with a smaller number of participants. A smaller number of participants encourages more discussion and, in some cases, more intimate discussion related to the caregivers' experiences related to Alzheimer's disease and other dementias.

The *Alzheimer's Disease and Other Dementias Caregiver Training Facilitator Manual* is a sustainable product because educators can use the manual to facilitate future educational programs. The Beaver Dam Community Hospital and the Remembrance Home are committed to using the training manual to educate professional caregivers about Alzheimer's disease and other dementias. A recommendation is that the manual be used during the hospital's new employee orientation education. Discussion with the nurse educators has taken place and they are able to incorporate the dementia caregiver training into the orientation education timeframe. The facilitator manual can be used by the educators to organize and facilitate the experience.

In addition to the Beaver Dam Community Hospital using the manual during the new employee orientation, the manual also can be used during staff meetings. The various departments and facets of the hospital can use the manual to train their staff. The managers of the departments can use the manual to organize the experience, coordinate

staff meeting dates that are appropriate for the training, and facilitate the experience. The Remembrance Home is one entity of the organization that would specifically benefit from periodic dementia training since professionals at the home work exclusively with individuals living with the conditions.

Another recommendation is that the Beaver Dam Community Hospital continues to make connections with students who are interested in educating and raising awareness about Alzheimer's disease and other dementias. The student connection would entail a relationship between the hospital and the University of Wisconsin-La Crosse (and other similar Universities). The hospital can continue to be a Preceptorship site for students in the Master of Public Health Program at the University of Wisconsin-La Crosse. Interested master's students could use the *Facilitator Manual* to implement the training for general staff and caregivers at the hospital. In addition, they could use the manual to conduct training for the community.

The continued implementation of the caregiver workshop will result in additional findings with the use of the pre-program and post-program surveys. It is recommended that quantitative data from the surveys be complied so statistical analyses can be conducted. It also is recommended that qualitative data from the surveys be analyzed. The compilation of data from multiple workshops could be used to provide evidence and support for the experience as well as indicate areas for improvement for the educational workshop and manual. In order to ensure the surveys are measuring what they are intended to measure, it is recommended that appropriate measures be taken such as having an expert panel review the pre- and post-program surveys to ensure content validity of the instrument.

The prevalence of Alzheimer's disease is projected to increase substantially over the next decades; therefore, it is a growing problem that needs continuing attention and innovation. Educational programs will continue to be important to implement. It is essential that educational experiences advance and adapt in order to meet the needs of individuals living with Alzheimer's disease and other dementias, their families, professional caregivers, the healthcare system, and society.

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APPENDIX A

FLYER NOTIFICATION FOR PILOT EDUCATIONAL WORKSHOP

Beaver Dam Community Hospitals, Inc.
Beaver Dam, WI 53916

Alzheimer's Disease & Other Dementias Caregiver Workshop

(Overview of Alzheimer's Disease, Virtual Dementia Tour, & Caregiving Techniques)

Whitney R. Thompson,
Master of Public Health Student

Learning Center A&B

March 6, 2014--1330-1500

Objectives: Increase knowledge about the disease, increase empathy for individuals with the disease, improve caregiving techniques, & reduce stigma

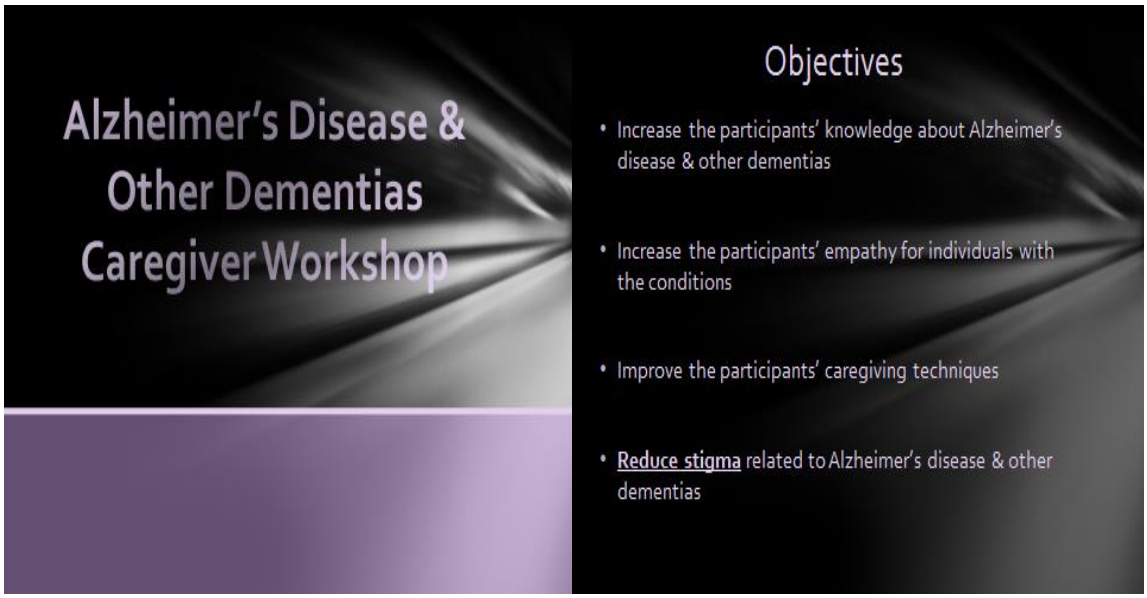
WISHET CEUs Available

Please sign up for the class in
Scheduler in the BDCH Intranet page.
Class size is limited.

Intended Audience: All Caregivers (Nurses, Certified Nursing Assistants, Physical Therapists, Occupational Therapists, Respiratory Therapists, etc.)

APPENDIX B

POWERPOINT


Alzheimer's Disease & Other Dementias Caregiver Workshop
Objectives
• Increase the participants' knowledge about Alzheimer's disease & other dementias
• Increase the participants' empathy for individuals with the conditions
• Improve the participants' caregiving techniques
• Reduce stigma related to Alzheimer's disease & other dementias

Agenda
• Part I: Overview of Alzheimer's disease and other dementias
• Part II: Virtual Dementia Tour®
• Part III: Caregiving Techniques & Debriefing
PART 1:
Overview
http://alzheimers.gov/#panel1-1

Dementia

Loss of the cognitive functions of thinking, remembering, and reasoning along with disturbances in behavioral abilities that are severe enough to interfere with an individual's daily life

- Set of symptoms, not a disease

Dementia Symptoms

- Symptoms can vary greatly in severity
- Impaired memory
- Struggles with communication & language
- An inability to focus & pay attention
- Compromised reasoning & judgment
- Problems with visual perception

Types of Dementia

- Alzheimer's Disease
- Vascular Dementia
  - Results from injuries to vessels that supply blood to the brain
  - Often occurs after strokes; can begin suddenly and worsen or improve over time
  - Risk Factors: irregular/rapid heart rate, hypertension, diabetes, high cholesterol
- Lewy Body Dementia
  - Caused by abnormal deposits of protein
  - Problems with thinking, movement, behavior, & mood
  - Symptoms: changes in alertness & attention, hallucinations, tremors, muscle stiffness, sleep problems, & memory loss

Types of Dementia

- Frontotemporal Disorders
  - Results from damage to neurons in the frontal and temporal lobes (atrophy of these lobes)
  - Symptoms: behavior changes, emotional problems, communication issues, difficulty walking, and trouble with other basic movements
- Mixed Dementias
  - Often Alzheimer's & Vascular
- Huntington's disease, Parkinson's, Creutzfeldt-Jakob disease, head injuries, and HIV

Alzheimer's Disease

- Most common cause of dementia (60-80% of cases)
- Progressive disease that affects the brain irreversibly
- The disease slowly destroys the memory and thinking skills of an individual, eventually preventing them from performing daily living tasks independently
- 6th leading cause of death in the U.S.

Prevalence

- 2013: 5.2 million in the U.S. living with AD
  - 5 million: Age 65+
  - 200,000: younger-onset*
- More women than men:
  - 3.2 million are women; 1.8 million are men (women live longer)
- Future Projections:
  - 2025: 7.1 million 65+ with AD (increase by 40 %)
  - 2050: 13.8 million individuals 65+ will have the disease

Diagnosis

- Early detection is essential→ allows the individual to be involved in planning
- No single test is used to diagnose
- Involves an extensive number of exams and tests:
  - Assessment of the individual's medical history, a physical exam, cognitive and neuropsychological tests, neurological evaluations, brain scans, laboratory tests, and psychiatric evaluations

Treatment

- Early diagnosis is an essential element to treatment & care
- No cure for the disease
- Drugs to slow the advancement of the symptoms
  - Regulate neurotransmitters-help maintain thinking, memory, speaking, and behavioral abilities, but do not change underlying disease process
- Palliative Care & Hospice

Risk Factors

- No known cause
- Risk Factors:
  - Age
  - Family History
  - Genetics
  - Mild Cognitive Impairment
  - Past Head Trauma
  - Lifestyle and heart health
  - Cognitive & Social Engagement

Warning Signs (Handout)

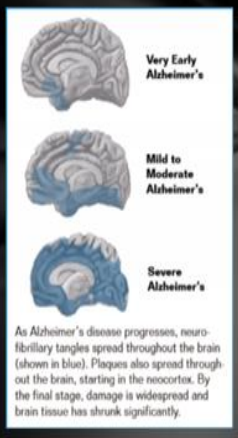
1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood and personality

Symptoms

- Have difficulty and eventually are unable to perform daily living tasks (bathing, dressing, eating, etc.)
- Incontinence
- Wander or get lost
- Experience changes in their personality and behavior
- Trouble walking
- Problems swallowing
- Communication problems
- Hallucinations
- Not able to recognize friends and family
- *Other Symptoms?*

Stages

- Plaques & tangles in the brain are two of the main features of AD
- The loss of connections between nerve cells (neurons) in the brain is another
- Abnormal deposits of proteins form amyloid plaques & tau tangles throughout the brain→ once-healthy neurons begin to work less efficiently
- Neurons eventually lose their ability to function & communicate with each other & die



As Alzheimer's disease progresses, neurofibrillary tangles spread throughout the brain (shown in blue). Plaques also spread throughout the brain, starting in the neocortex. By the final stage, damage is widespread and brain tissue has shrunk significantly.

Stages

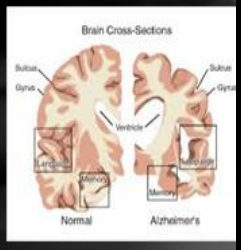
- Early Stage
  - Before known symptoms & clinical diagnosis
  - Symptoms may begin 10-20 years before clinically detectable
  - Memory problems & forgetfulness are typical first signs

Stages

- Middle Stage (Mild to Moderate)
  - Diagnosis
  - Mild symptoms: getting lost, trouble handling money, repeating questions, taking longer to complete normal daily tasks, poor judgment, losing things or misplacing them in odd places, personality changes
  - Moderate symptoms: increased memory loss & confusion, problems recognizing family & friends, inability to learn new things, difficulty carrying out tasks that involve multiple steps, problems coping with new situations, hallucinations, delusions, paranoia, & impulsive behavior

Stages

- Final Stage (Severe)
  - Symptoms: inability to communicate, weight loss, seizures, skin infections, and difficulty swallowing
  - Final stages: often become bed bound & rely almost entirely on caregivers
  - Death of the individual
    - Aspiration, pneumonia, infection, cardiac arrest



Part 2:

Virtual Dementia Tour®

Part 3:

Caregiving Techniques: Debriefing

Debriefing

Thoughts & Reactions to the Virtual Dementia Tour®

Caregiving

- Individuals with AD & other dementias depend on caregivers
- Essential to promote dignity & independence
- Promote the highest-quality of life

"Patience and perseverance have a magical effect before which difficulties disappear and obstacles vanish."
John Quincy Adams

Caregiving Challenges

- **What are challenges?**
- Insufficient Training→ increase risk for falls, elopement, poor medication management, & an increased risk of dehumanization of individual with AD
- Insufficient training & Demanding environments→ Communication problems; Task-oriented
- Institutionalization of care→ caregivers talking over & talking across individuals with AD
- Not knowing why challenging behaviors are occurring
- Impact on emotional well-being of caregiver: Stress, burden, burnout, depression, & grief

Caregiving Techniques

- Communication
- Coping with Agitation & Aggression
- Bathing
- Dressing & Grooming
- Eating
- Toileting

Communication!!!

- Difficulties?
  - Finding the right word, understanding what a word means, remembering steps to common activities
- Strategies?
  - Pay close attention to your non-verbal body language: smile, comforting/calm tone, hold their hand…
  - Simple, straight forward instructions
  - Use visual cues
  - DO NOT TALK AS IF THEY ARE NOT THERE!
  - Be patient & give them time
  - Family & friends of the individual may be able to give you insights

Coping with Agitation & Aggression

Underlying Causes?

- Pain, depression, or stress
- Too little rest or sleep
- Constipation
- Incontinence
- Sudden change in a well-known place, routine, or person
- A feeling of loss
- Too much noise or confusion
- Being pushed by others to do something
- Feeling lonely and not having enough contact with other people
- Interaction of medicines

Strategies?

- Be calm, listen, establish routines, create a calm environment, & care for yourself

Bathing

- Difficult because it is a private activity; can be viewed as threatening & uncomfortable

- Create a safe environment
- Prepare for the bath
- Promote independence, privacy, & dignity

Dressing & Grooming

- **Helps increase self-esteem**
- **Promote Independence**
- **Oral Care:**
  - Show the person how; step-by-step
- **Dressing:**
  - Need more time
  - Hand them one thing at a time & give step-by-step instructions
- **Other Grooming:**
  - Encourage women to do things they use to such as wearing makeup; men promote shaving, etc.

Eating

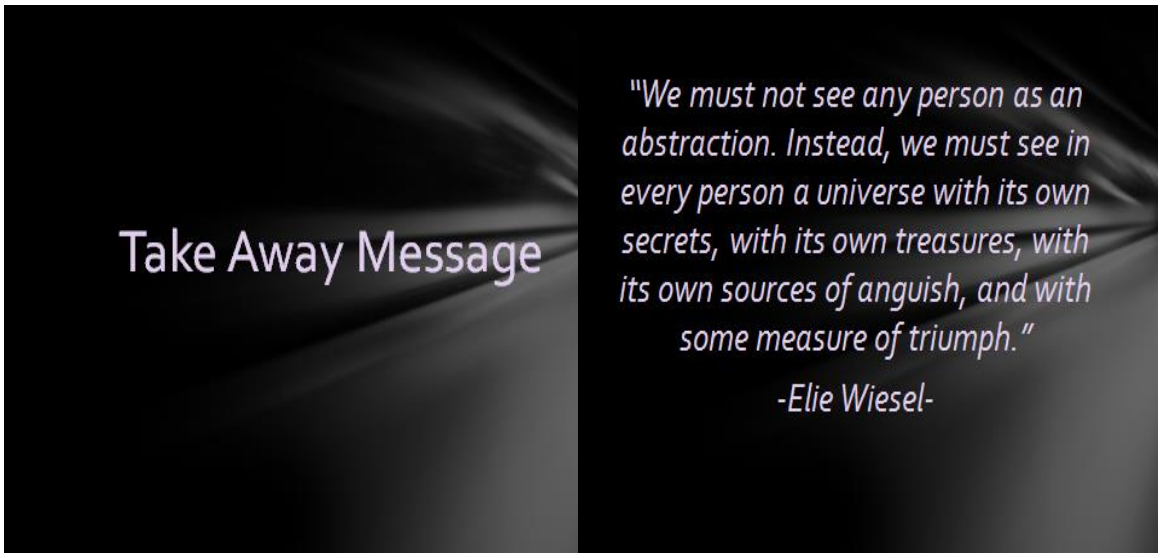
- Struggle getting enough nutrition
- Tips:
  - Quiet space; simple table settings
  - Contrasting colors of food, plates, & table
  - Adaptive utensils
  - Imitation Technique
  - Give them time

Toileting

- Remind the person to go to the bathroom every 2 to 3 hours
- Show the person the way to the bathroom
- Watch for signs that the person may have to go to the bathroom
- Loose clothes
- Using a colorful toilet seat may help the person identify the toilet

Caregiving Support

- http://www.alzwisc.org/index.html
- Caregiver Center: http://www.alz.org/care/overview.asp
- E-Learning Courses: http://www.alz.org/care/alzheimers-dementia-care-training-certification.asp
- Online Learning Courses: http://elearning.alz.org/home.aspx
- Caregiver Tips Sheets: http://www.nia.nih.gov/alzheimers/topics/caregiving
- Video Resources & Tip Sheets: http://caregiveraction.org/resources/alzheimer-videos/
- Overall Help Guide : http://www.helpguide.org/elder/alzheimers_disease_dementia_support_caregiver.htm
- Alz.org (Document with information about Alzheimer's disease: http://www.alz.org/downloads/facts_figures_2012.pdf
- Support Strategies/Stress Management: http://www.alz.org/care/alzheimers-dementia-caregiver-stress-burnout.asp
- Book: *Still Alice* (Lisa Genova); perspective of individual with early-onset Alzheimer's disease


Take Away Message
"We must not see any person as an abstraction. Instead, we must see in every person a universe with its own secrets, with its own treasures, with its own sources of anguish, and with some measure of triumph."
-Elie Wiesel-

APPENDIX C

PILOT EDUCATION WORKSHOP HANDOUTS

Alzheimer's Disease:

10 Warning Signs

(Examples of warning sign behavior of someone with possible symptoms of AD vs. examples of typical behavior of someone who does not have AD)

1. **Memory loss that disrupts daily life.**
   - Examples: Forgetting recently learned information, forgetting important dates or events, asking for the same information over and over, relying on memory aides
   - Typical: Sometimes forgetting names or appointments, but remembering them later

2. **Challenges in planning or solving problems.**
   - Examples: Changes in ability to develop and follow a plan or work with numbers, trouble following a familiar recipe, difficulty keeping track of monthly bills, problems concentrating, taking much longer to do things than they did before
   - Typical: Making occasional errors when balancing a checkbook

3. **Difficulty completing familiar tasks at home, at work or at leisure.**
   - Examples: Difficulty in completing daily tasks, trouble driving to a familiar location, difficulty managing a budget, struggle remembering the rules of a favorite game
   - Typical: Occasionally needing help to use the settings on a microwave

4. **Confusion with time or place.**
   - Examples: Lose track of dates, seasons, and the passage of time; the individual may forget where they are or how they got there
   - Typical: Getting confused about the day of the week but figuring it out later

5. **Trouble understanding visual images and spatial relationships.**
   - Examples: Difficulty reading, judging distances, determining color or contrast; their perception may change resulting in walking by a mirror and thinking someone else is in the room, not recognizing their own reflection
   - Typical: Vision changes related to cataracts

6. **New problems with words in speaking or writing.**
   - Examples: Trouble following or joining a conversation, stopping in the middle of a conversation and having no idea how to continue, repeating themselves; struggle with vocabulary, trouble finding the right word or calling things by the wrong name
   - Typical: Sometimes having trouble finding the right word

7. **Misplacing things and losing the ability to retrace steps.**
   - Examples: Putting things in unusual places, may accuse others of stealing
   - Typical: Misplacing things from time to time

8. **Decreased or poor judgment.**
    - Examples: Poor judgment when dealing with money, giving large amounts to telemarketers, paying less attention to grooming
    - Typical: Making a bad decision once in a while

9. **Withdrawal from work or social activities.**
    - Examples: Remove themselves from hobbies, social activities, work projects, or sports; trouble remembering how to complete a favorite hobby; avoiding social activities because of the changes they are experiencing
    - Typical: Sometimes feeling weary of work, family, and social obligations

10. **Changes in mood and personality.**
    - Examples: Become confused, suspicious, depressed, fearful, or anxious; may become easily upset
    - Typical: Developing very specific ways of doing things and becoming irritable when routine is disrupted

Alzheimer's Association. (2009). Know the 10 Signs. In *alz.org*. Retrieved February 19, 2014, from http://www.alz.org/alzheimers_disease_know_the_10_signs.asp

Communication: Alzheimer's Caregiving Tips

Individuals with Alzheimer's disease & other dementias may struggle with the following communication issues:

- Finding the right word or losing his or her train of thought
- Understanding what words mean
- Paying attention during long conversations
- Remembering the steps in common activities, such as getting dressed
- Blocking out background noises
- Frustration in communication struggles

Communication Tips:

- Understand that the disease causes changes in communication skills
- Make eye contact & call the person by name
- Be aware of your tone, how loud your voice is, how you look at the person, & your body language
- Encourage a two-way conversation for as long as possible
- Use other methods besides speaking, such as gentle touching
- Try distracting the person if communication creates problems

To encourage the person to communicate with you:

- Be warm & loving
- Hold the person's hand while you talk
- Be open to the person's concerns, even if he or she is hard to understand
- Let him or her make some decisions & stay involved
- Be patient with angry outbursts

To speak effectively with a person who has Alzheimer's:

- Offer simple, step-by-step instructions
- Repeat instructions & allow more time for a response
- Don't talk about the person as if he or she isn't there
- Use visual cues such as pointing to a commode when you are getting them up to go to the bathroom
- Family & friends of the individual may have helpful insights

Examples of what you can say:

- "Let's try this way," instead of pointing out mistakes.
- "Please do this," instead of "Don't do this."
- "Thanks for helping," even if the results aren't perfect.
- Limit the number of choices. For example, you could say, "Would you like fish or chicken for dinner?" instead of "What would you like for dinner?"
- Try not to say, "Don't you remember?" or "I told you."

If you become frustrated, take a moment for yourself.

Adapted from the Alzheimer's Disease Education and Referral Center's
Family Caregiver Tips
http://www.nia.nih.gov

Coping with Agitation & Aggression: Alzheimer's Caregiving Tips

Individuals with Alzheimer's disease may be agitated or aggressive. Agitation may cause pacing, sleeplessness, or aggression (lashing out verbally or physically).

Causes of Agitation and Aggression:

Most of the time there is a reason behind the agitated & aggressive behavior & if the caregiver can find the cause, the behavior may stop.

- Pain, depression, or stress
- Too little rest or sleep
- Constipation
- Soiled underwear or brief
- Sudden change in a well-known place, routine, or person
- A feeling of loss
- Too much noise or confusion or too many people in the room
- Being pushed by others to do something
- Feeling lonely & not having enough contact with other people
- Interaction of medicines

Coping Tips:

- Reassure the person & speak calmly
- Listen to his or her concerns & frustrations
- Try to show that you understand if the person is angry or fearful
- Allow the person to keep as much control in his or her life as possible
- Try to keep a routine (bathing, dressing, & eating at the same time each day)

Coping Tips Continued…:

- Build quiet times & times for activity into the routine
- Keep well-loved objects & photographs around
- Try gentle touching, soothing music, reading, or walks
- Reduce noise, clutter, or the number of people in the room
- Try to distract the person with a favorite snack, object, or activity

Caring for Yourself:

- Slow down & give yourself moments if you need them
- Take a break if possible
- Keep yourself safe while trying to keep others safe---You may need to back away from the individual at times
- Be patient

Adapted from the Alzheimer's Disease Education and Referral Center's
Family Caregiver Tips
http://www.nia.nih.gov

Bathing: Alzheimer's Caregiving Tips

Difficulties associated with bathing:

- Individuals with the disease will need help at some point
- It is a private activity which can make it feel uncomfortable & threatening
- Individual may be angry they cannot do it themselves
- It can be one of the hardest caregiving responsibilities

Safety Tips:

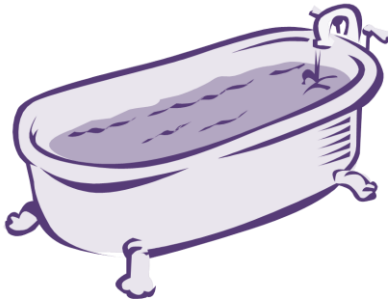
- Never leave the individual with Alzheimer's alone while bathing
- Always check the water temperature before he or she gets in the tub or shower
- Use a hand-held showerhead
- Use a rubber bath mat, safety bars, & a shower chair
- Keep sharp objects such as razors out of reach

Prepare for the bath:

- Know the individuals preferences & bathing habits
- Have all the necessary supplies (soap, washcloths, towels, shampoo) ready & organized
- Adjust the temperature in the room & perhaps play soft music so the individual will be comfortable & relaxed while bathing
- Be matter-of-fact about bathing. Say, "It's time for a bath now." Don't argue about the need for a bath or shower. Be gentle and respectful. It may help to give them a choice by saying, "Do you want to bathe now or in 5 minutes?"

While Bathing:

- Promote independence by encouraging the individual to do as much as possible
- Preserve their privacy & dignity by covering the individual's shoulders or lap with a bath towel
- Give them a washcloth to hold in order to distract them & promote independence
- Talk through the bath step-by-step, with simple directions so the individual can know what to expect



After Bathing:

- Be sure to protect the individuals skin by completely drying it, examining the skin for rashes or infections, & using protective ointment if needed
- Take note of effective bathing routines & strategies for each individual

<u>Be patient, allow yourself time, & be aware of your communication</u>

Adapted from the Alzheimer's Disease Education and Referral Center's
Family Caregiver Tips
http://www.nia.nih.gov

Daily Living Tasks: Alzheimer's Caregiving Tips

As Alzheimer's disease & other dementias progress, individuals with the diseases have an increased need for assistance from caregivers to complete daily living tasks such as eating, dressing, grooming, and toileting. Caregivers need to encourage **independence, dignity, & increased self-esteem.**

Eating:

Individuals with Alzheimer's disease often struggle to get enough nutrition because of such things as being overwhelmed by too many food choices, forgetting to eat, thinking they already have, or have difficulty knowing how the use the utensils

Tips:

- Limit distractions: eat in quiet spaces; use simple table settings
- Use contrasting colors of food, plates, & table because of visual issues
- Promote independence with the use of adaptive utensils such as spoons with larger handles when helpful
- Implement the imitation technique by showing the individual how to eat
- Give them enough time

Dressing:

Individuals with Alzheimer's & other dementias may need more time to dress because they might struggle choosing clothes, matching clothes for the season, or remembering how to put the clothes on

Tips:

- Hand them one thing at a time & give clear step-by-step instructions
- Use Velcro® or large zipper pulls for clothing instead of shoelaces, buttons, or buckles

Grooming:

- Can increase self-esteem
- Encourage women to do things they use to such as wearing makeup; encourage & assist men in shaving
- Promote oral care: Show the person how; step-by-step

Toileting Tips:

- Remind the person to go to the bathroom every 2-3 hours
- Show the person the way to the bathroom
- Watch for signs that the person may have to go to the bathroom, such as restlessness or pulling at clothes
- Make sure that the person wears loose, comfortable clothing that is easy to remove
- Using a colorful/contrasting toilet seat may help the person identify the toilet
- Be understanding & patient; reassure the person if he or she is upset

Adapted from the Alzheimer's Disease Education and Referral Center's
Family Caregiver Tips
http://www.nia.nih.gov

Caregiver Resources & Support: Alzheimer's disease

1. Caregiver Center: http://www.alz.org/care/overview.asp
2. E-Learning Courses: http://www.alz.org/care/alzheimers-dementia-care-training-certification.asp
3. Online Learning Courses: http://elearning.alz.org/home.aspx
4. Caregiver Tips Sheets: http://www.nia.nih.gov/alzheimers/topics/caregiving
5. Video Resources & Tip Sheets: http://caregiveraction.org/resources/alzheimer-videos/
6. Overall Help Guide: http://www.helpguide.org/elder/alzheimers_disease_dementia_support_caregiver.htm
7. Alz.org (Document with information about Alzheimer's disease): http://www.alz.org/downloads/facts_figures_2013.pdf
8. Support Strategies/Stress Management: http://www.alz.org/care/alzheimers-dementia-caregiver-stress-burnout.asp
9. Book: *Still Alice* (Lisa Genova); perspective of an individual with early-onset Alzheimer's disease

Be aware of: support groups, resources, & educational opportunities

APPENDIX D

PRE- AND POST-PROGRAM SURVEYS

***** The instruments (pre- and post-program surveys) were revised based on feedback during the oral defense.

Pre-Program Survey:
Alzheimer's Disease & Other Dementias Caregiver Workshop

Respondent ID:_____
Please use the last 2 digits of your phone number followed by the two digits of your birthday (month) and your middle initial (5206r). This is to ensure your anonymity and allow the pre- and post-surveys to be matched.

Part I: *Demographics*

1. What is your caregiving role in relation to individuals with Alzheimer's disease & other dementias?

2. How many years have you been caregiving?
3. How many patients with Alzheimer's disease or other dementias have you cared for?

   a. 0 b. 1-10 c. 11-25 d. more than 25

Part II: *Please circle the response or check the box that best represents your opinion. In addition, there is space to add your optional comments.*

4. I understand the emotional needs of our elders with dementia.

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

   Comments:

5. My general knowledge about Alzheimer's disease and other dementias is sufficient for the care I provide.

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

   Comments:

6. I am confident in my knowledge of techniques for providing care to individuals with Alzheimer's disease and other dementias.

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

Comments:

7. People with dementia are justified when they exhibit inappropriate behaviors.

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

Comments:

8. I feel _____about individuals with Alzheimer's disease and other dementias. (Fill in the blank by checking <u>all</u> that apply)

- ☐ removed
- ☐ sad
- ☐ frustrated
- ☐ angry
- ☐ guilty
- ☐ embarrassed
- ☐ pleasant
- ☐ empathy
- ☐ other (please specify):_____

Post-Program Survey
Alzheimer's Disease & Other Dementias Caregiver Workshop

Respondent ID (same number used on previous survey):_____
Please use the last 2 digits of your phone number followed by the two digits of your birthday (month) and your middle initial (5206r). This is to ensure your anonymity and allow the pre- and post-surveys to be matched.

Directions: *Please circle the response or check the box that best represents your opinion. In addition, there is space to add your optional comments.*

1. I have a better understanding of the emotional needs of individuals with dementia as a result of this workshop.

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

Comments:

2. My general knowledge about Alzheimer's disease and other dementias is sufficient for the care I provide.

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

Comments:

3. I am confident in my knowledge of techniques for providing care to individuals with Alzheimer's disease and other dementias.

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

Comments:

4. From a physical standpoint, how capable did you feel carrying out simple tasks during the Virtual Dementia Tour®?

1	2	3	4	5
Very Capable	Capable	Neutral	Somewhat Capable	Not at all Capable

Comments:

5. People with dementia are justified when they exhibit inappropriate behaviors.

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

Comments:

6. I feel _____about individuals with Alzheimer's disease and other dementias. (Fill in the blank by checking <u>all</u> of the boxes that apply)
   - ☐ removed
   - ☐ sad
   - ☐ frustrated
   - ☐ angry
   - ☐ guilty
   - ☐ embarrassed
   - ☐ pleasant
   - ☐ empathy
   - ☐ other (please specify):_____

7. How did the workshop impact you personally?

8. How did the workshop impact you professionally?

9. What will you do differently because of the workshop?

10. What were the most beneficial aspects of the workshop?

11. What were the least beneficial aspects of the workshop?

12. How could the workshop be improved?

APPENDIX E

FACILITATOR MANUAL

Alzheimer's Disease & Other Dementias Caregiver Workshop Facilitator Manual

Beaver Dam Community Hospital

Whitney Thompson

Table of Contents

Mission Statement 2
Overview 2
Objectives 3
Workshop Coordination 4
Facilitator Requirements 4
Target Audience 4
Class Size 4
Setting 5
Promoting the Workshop 5
Equipment & Resource Needs 6
Workshop Course Outline 8
Part I: Overview of Alzheimer's Disease & Other Dementias 9
Beginning Part I: 9
The Focus of Part I: 9
Resources: 9
Part II: Virtual Dementia Tour® 11
Overview of the Virtual Dementia Tour® 11
Before Part II: 12
Beginning Part II: 14
After the Virtual Dementia Tour® 23
Part III: Caregiver Techniques & Debriefing 24
Beginning Part III: 24
Caregiver Techniques: 25
Wrapping Up: 26
Step-by-Step Preparation 27
Supply Checklist 28
Forms & Resources 29
Promotional Flyer 30
Pre- and Post-Program Surveys 32
Handouts 37
PowerPoint 45
Background Literature for PART I 55
References 66

Mission Statement

The mission of the *Alzheimer's Disease & Other Dementias Caregiver Workshop Facilitator Manual* is:

> "To guide educators and facilitators by providing an educational tool to promote the education, knowledge, techniques, and empathy of professional caregivers who care for individuals with Alzheimer's disease and other dementias."

Overview

The population is aging with the baby boomer generation coming into their elderly years. With the aging of the population, comes an increase in the number of people with Alzheimer's disease and other dementias. The increase in the aging population and the prevalence of Alzheimer's disease puts a great demand on families, caregivers, and the healthcare system. One approach to addressing these demands is to address the knowledge and abilities of caregivers of people with Alzheimer's disease and other dementias. Caregivers of individuals with Alzheimer's disease and other dementias are an essential facet in the quality of life of individuals suffering from the conditions, but many times, professional caregivers have insufficient training and knowledge. Caregivers need to be aware of the details of Alzheimer's disease, have empathy for the individuals they are caring for, and be mindful of their caregiving techniques in order to promote the highest-quality of life for individuals with dementia.

The *Alzheimer's Disease & Other Dementias Caregiver Workshop Facilitator Manual* is a tool developed to facilitate and support the ongoing education of professional caregivers at the Beaver Dam Community Hospital in Beaver Dam, Wisconsin. It includes an overview of Alzheimer's disease and other dementias, an adaptation of the Virtual Dementia Tour®, and caregiver techniques with debriefing information. The projected impact of the manual will be an

improvement in the knowledge, actions, and empathy of caregivers. The immediate impact will lead to a long-term improvement in the quality of life of individuals with Alzheimer's disease and other dementias and a decrease in stigma associated with the conditions.

Objectives

1. Increase the participants' knowledge about Alzheimer's disease and other dementias
2. Increase the participants' empathy for individuals with Alzheimer's disease and other dementias
3. Improve the participants' caregiving techniques when caring for individuals with Alzheimer's disease and other dementias
4. Reduce stigma related to Alzheimer's disease and other dementias

Workshop Coordination

Facilitator Requirements

Facilitators of the *Alzheimer's Disease & Other Dementias Caregiver Workshop* ideally should have past caregiving experience with individuals with dementia either as a professional caregiver or an unpaid, family caregiver. The past experience will allow the facilitator to contribute to discussions and questions from a first-hand perspective. In addition to previous experience, the facilitator should have a strong interest in Alzheimer's disease and other dementias and a desire to spread awareness and education.

Target Audience

The target audience of the *Alzheimer's Disease & Other Dementias Caregiver Workshop* is all professional caregivers at the Beaver Dam Community Hospital to include certified nursing assistants, registered nurses, occupational therapists, physical therapists, respiratory therapists, and other care providers. These professionals may work in the hospital directly or they may be part of other facets of the organization such as home care and long-term care. The target audience includes a wide range of professional caregivers because having individuals with a variety of caregiver roles and various experiences provides benefits. Each individual has different experiences, strategies, insights, and perspectives that bring value to discussions during the educational experience.

Class Size

It is recommended that the class size for the *Alzheimer's Disease & Other Dementias Caregiver Workshop* be limited to 8-10 participants at the Beaver Dam Community Hospital because of the nature of Part II of the workshop: The Virtual Dementia Tour®. The Virtual Dementia Tour® requires participants to go into an "experience room" for approximately 10

minutes to complete tasks. The hospital is equipped with two "experience rooms," each of which accommodates 4-5 participants.

Note: *In order to keep the workshop on an efficient timeframe and limit the amount of time participants are waiting while others are experiencing the Virtual Dementia Tour®, a maximum of five participants should be assigned to an "experience room." The class size can increase in increments of 4-5 if an additional "experience room" can be set up and an additional assistant facilitator can assist with the process. More information about the Virtual Dementia Tour® is included on page 11 of the Workshop Course Overview section to clarify what an "experience room" is and provide an in-depth overview of Part II of the workshop.*

Setting

The *Alzheimer's Disease & Other Dementias Caregiver Workshop* is held at the Beaver Dam Community Hospital. A portion of the workshop is held in a conference room setting and another portion is conducted in available patient rooms. Learning Center A & B on the second floor of the hospital is most conducive to delivery of Parts I and III of the workshop. This room has the proper computer equipment that allows for the use of PowerPoint. In addition, the arrangement and seating in the room is conducive for discussion. Learning Center A & B also is an ideal location because it is in close proximity to the area where the "experience rooms" are located to conduct Part II of the workshop. Part II, The Virtual Dementia Tour®, requires the availability of two patient rooms in the hospital. Patient Care Area 5 at the Beaver Dam Community Hospital is located near Learning Center A & B and is often unoccupied of patients, thus allowing for patient rooms to be set up as the "experience rooms."

Note*: More information about the Virtual Dementia Tour® is included on page 11 of the Workshop Course Overview section to clarify what an "experience room" is and provide an in-depth overview of Part II of the workshop.*

Promoting the Workshop

In order to promote the workshop at the Beaver Dam Community Hospital, the facilitator needs to work in coordination with the librarian to post the workshop on the hospital's "Meeting

Signups" section of the organization's intranet. The "Meeting Signups" should include the location of the workshop, a brief explanation, and a limit on the number of participants able to sign up for the experience (8-10 is the recommended limit).

The facilitator also should promote the workshop by sending a flyer via an e-mail notification to all of the professional caregivers at the Beaver Dam Community Hospital. A sample flyer is in the "Forms & Resources" section on page 31. In order to attract participants, the facilitator should include a brief overview of the workshop and specifically highlight the Virtual Dementia Tour® experience, which often attracts participants. In addition, the facilitator needs to coordinate with the Nurse Educators so the workshop can be counted for WISHET CEUs. WISHET CEUs are continuing education units that some caregivers, including nursing assistants, can count toward their yearly requirement for professional development. The availability of WISHET CEUs needs to be indicated on the flyer sent to the professional caregivers.

Note: *The "Meeting Signups" and the flyer should be distributed to the participants at least two weeks before the workshop is conducted.*

Equipment & Resource Needs

Part I: Overview of Alzheimer's Disease & Other Dementias

- Conference Room: Learning Center A & B with seating arranged for discussion
- Equipment with PowerPoint capabilities in Learning Center A & B
- Folder created for each participant with: Pre-Program Survey, Caregiver Tips (Communication, Coping with Agitation & Aggression, Bathing, Daily Living Tasks), and Resource & Support Handout (All of these material are in the "Forms & Resources" section starting on page 29)
- Pencils so participants can complete surveys and take notes

Part II: Virtual Dementia Tour®

- Two patient rooms to set up as "experience rooms"
- If available, another patient room located next to the "experience rooms" where participants can put on simulation equipment
- 3-4 assistant facilitators
- Simulation equipment

- Material to set up the "experience rooms"
- Behavioral Observation Forms on clip boards with pencils
- Sanitizing Material

Part III: Caregiver Techniques & Debriefing

- Conference Room: Learning Center A & B with seating arranged for discussion
- Equipment with PowerPoint capabilities working in Learning Center A & B
- The handouts provided in the folders created for each participant will be used
- Post-Program Surveys (The surveys are available in the "Forms & Resources" section starting on page 32)
- Pencils so participants can fill out surveys and take notes

Note: More detailed information about the equipment and resources needed for each part of the workshop is included in the corresponding sections of the Workshop Course Outline beginning on page 8.

Workshop Course Outline

The *Alzheimer's Disease & Other Dementias Caregiver Workshop Facilitator Manual* is an instructors tool to educate professional caregivers about Alzheimer's disease and other dementias, facilitate a Virtual Dementia Tour®, and assist in improving caregiver techniques while encouraging dialogue about the challenges, experiences, and perspectives of professional caregivers at the Beaver Dam Community Hospital. The *Facilitator Manual* is to be used to implement *Alzheimer's Disease & Other Dementias Caregiver Workshops.* The workshop is divided into three parts. Part I includes an introduction and overview of Alzheimer's disease and other dementias, Part II is the Virtual Dementia Tour®, and Part III includes caregiver techniques and a debriefing session about the experience. The following pages breakdown each of the three parts and outline how the facilitator can conduct the workshop.

Part I: Overview of Alzheimer's Disease & Other Dementias

Part I of the *Alzheimer's Disease & Other Dementias Caregiver Workshop* includes a twenty-minute introduction and overview of Alzheimer's disease and other dementias. This section mostly is facilitated through lecture, but feedback and insights from the participants always should be encouraged.

Beginning Part I:

To begin the workshop, the facilitator should introduce himself/herself , share his/her background education and work experiences, and his/her interest in Alzheimer's disease and other dementias. Since the workshop encourages participation and discussion from the caregivers, it also is important to have the participants share their caregiver roles, experiences, and interests related to the workshop. After the introductions, the participants need to be informed to fill out the pre-program survey (a sample survey is available in the "Forms & Resources" section found on page 32). Once they complete the surveys, the facilitator can proceed with the focus of Part I.

The Focus of Part I:

PowerPoint is recommended for Part I of the workshop, which addresses an overview of Alzheimer's disease & other dementias. Information presented in this section includes the definition of dementia and the types of dementia, with an in-depth focus on Alzheimer's disease. The information on Alzheimer's includes a definition, prevalence, diagnosis, treatment, risk factors, symptoms, warning signs, and stages of the disease.

Resources:

A handout that includes information regarding warning signs and symptoms of Alzheimer's disease is provided to help the caregivers have a better understanding of the disease.

The handout identifies the differences between warning signs of Alzheimer's disease and normal changes and challenges that come with everyday lifestyles. The handout and a sample PowerPoint presentation are provided in the "Forms & Resources" section that starts on page 29. A flash drive also is included in the facilitator manual. The flash drive has the PowerPoint and handouts available to download on the facilitator's computer for use throughout the workshop. In addition, background literature that supports the information provided in Part I of the workshop also is included in the "Forms & Resources" section starting on page 55.

Part II: Virtual Dementia Tour®

Part II of the *Alzheimer's Disease & Other Dementias Caregiver Workshop* is the Virtual Dementia Tour®. This simulation experience is an adaptation of the Virtual Dementia Tour®, which can be purchased at http://www.secondwind.org/virtual-dementia-tour/. The tour has been adapted to fit the needs of the Beaver Dam Community Hospital. The amount of time it takes to complete this session depends on the resources and number of participants available. If the workshop involves the recommended 8-10 participants and two "experience rooms," forty-five minutes should be allocated for completion of this section.

Overview of the Virtual Dementia Tour®

The Virtual Dementia Tour (VDT®) is an experience developed by Beville (2011), in connection with Second Wind Dreams©, a national non-profit organization with a mission to change the perception of aging. It is aimed at sensitizing participants to the needs of elders in order to improve the care that people with Alzheimer's disease and other dementias receive. The VDT® was developed in response to two studies that revealed participants' perception of the need for such an experience. The educational experience was designed to simulate the known effects of dementia on a person and examine the cognitive and physical impacts that occur with aging (Beville, 2011). The VDT® is a tool used to create experiences for caregivers, families, communities, and agencies.

Participants of the VDT® have several items, including goggles, headphones, and gloves, placed on them to simulate dementia. Participants are then placed in a "VDT® experience room" that the facilitator sets up beforehand, and are asked to perform five simple tasks during the ten minutes they are in the "experience room." Another facilitator sits in the room and observes the behaviors and reactions of the participants (Beville, 2011).

VDT® supplies a toolkit that includes a binder with information about the Virtual Dementia Tour® studies, supplies needed for the experience, how to set up the "experience room," tour guide training, behavioral observation insights, the wrap-up session, and helpful forms. The participants have to put on several garb items before they go into the "experience room." The supplies used to simulate dementia include goggles, gloves, shoe inserts, and confusion audio. Before the participants go in to complete their tasks, shoe inserts with uncomfortable bumps are placed in their shoes to simulate foot pain that can be associated with poor circulation, neuropathy, and arthritis. They then put on a pair of rubber gloves that have a tablespoon of popcorn kernels in them and another pair of cloth gloves to simulate arthritis and a loss of sensory and fine motor skills. Next, a pair of goggles with yellow tinted lenses and a black dot in the center is placed on the participants. Elders can have a yellowish haze in their site because of the aging of the eye. This can create problems with having enough illumination to see things clearly. The black dot on the goggles represents macular degeneration which is common in the aging process. The goggles also serve as a way to simulate the loss of peripheral vision which can be common for individuals with middle and late-stage dementia. Lastly, headphones with audio with various muffled sounds are placed on the participants. This exercise simulates hearing loss and the difficulty individuals with dementia have with auditory stimulation (Beville, 2011). Once the participants have this equipment on, they are read their instructions and placed in an "experience room" to complete their five tasks.

Before Part II:

The facilitator should review the Virtual Dementia Tour® manual purchased by the Beaver Dam Community Hospital at least two weeks in advance of the workshop to fully understand the logistics and set up of the simulation experience. While the facilitator uses the

Virtual Dementia Tour® manual, he/she should note that the *Alzheimer's Disease & Other Dementias Caregiver Workshop Facilitator Manual* involves an adapted version of the VDT® manual. The VDT® manual was adapted so the workshop would best meet the needs of professional caregivers at Beaver Dam Community Hospital.

In preparation for the Virtual Dementia Tour®, on the day of the workshop, two rooms need to be set up for the Virtual Dementia Tour® "experience rooms." The "experience rooms" are where the participants will complete the five tasks presented to them by one of the assistant facilitators. Two unoccupied patient rooms at the Beaver Dam Community Hospital can be used as the "experience rooms" because they have the needed space with a bed, closet, bedside table, and desk area.

Room Set Up (for each room):

- Draw the shades with dim (not dark) lighting
- Scatter 5 towels, 8 pairs of assorted socks, a sheet, washcloths, and a pillowcase on the bed
- Hang two neck ties, two white sweaters, and two belts in the closet (number of items depends on the number of participants and "experience rooms"-based on 8 participants and 2 rooms), and other random items of clothing
- Place two pairs of pants in the dresser
- Spread sheets of paper, pens, and envelopes on the desk or end table
- Post the Purple and Black Instructions in the room
- Put a table setting for four in the room (plates, cups, silverware, and napkins) on a desk or in a drawer
- Place a cup (need a cup for every participant that gets the Purple Instructions) next to a sink in the room
- Have a chair for the Behavioral Observer

An additional area or patient room located near the two "experience rooms" needs to be set up as an area where the participants put on the simulation equipment and return the equipment. The items that the facilitator needs to set up in this room include:

- Equipment: Shoe Inserts, Rubber Gloves, Popcorn Kernels, Cloth Gloves, Goggles, and MP3 Player with Earphones (downloaded noise provided by VDT ®)
- Non-alcohol baby wipes to clean goggles

- Anti-bacterial spray for shoe inserts
- Trash can to throw away rubber gloves after the experience

VDT® Facilitator & Assistant Facilitators. Facilitators of the VDT® experience are essential in the implementation of the experience. If the workshop involves the recommended 8-10 participants and two "experience rooms," the lead facilitator will need a total of four facilitators (during Part II of the workshop only):

1. Two facilitators are responsible for garbing the participants, keeping track of the time, reading the task instructions to the participants, and de-garbing participants when they are done with the experience.

2. Two facilitators are responsible for observing and documenting the participants' behavior while they are in the "experience rooms" using the Behavior Observation Form provided by VDT® (Sample form on page 22)

Note:

- *Using the facilitator manual, the lead facilitator can fill any of these four roles or he/she can oversee the Virtual Dementia Tour®, assisting the other facilitators where needed. Needs will vary depending on the resources and other individuals available to fill the assistant facilitator roles.*
- *If less than 6 caregiver participants attend the workshop, it is only necessary to have one "experience room" because fewer participants require a shorter amount of time for the VDT® section. If only one "experience room" is used, only one behavioral observer will be needed.*

The facilitator needs to schedule a time shortly before the Virtual Dementia Tour® to meet with all of the assistant facilitators. An overview of the experience should be provided to the assistant facilitators. In addition, all of the assistant facilitators should be aware of each other's responsibilities in order to encourage collaboration if needed. They also should be provided with an outline of their responsibilities (see outline of responsibilities on page 17). The facilitator needs to allow time for clarification with the assistant facilitators.

Beginning Part II:

At the beginning of Part II: The Virtual Dementia Tour®, the facilitator should direct the participants to the additional patient room, an area set up for the caregivers to put on the

simulation equipment. The facilitator should present the following information about the Virtual Dementia Tour® to all of the participants:

- The VDT® was developed by P.K. Beville, M.S., founder of Second Wind Dreams®, and is based on two studies.
- During the next few minutes, we will attempt to give you a sense of what dementia might be like.
- Your physical and sensory abilities will be altered. Please do not remove any of the equipment until instructed to do so.
- You will be asked to perform 5 simple tasks. You can find a list of these tasks in the room.
- You will be observed at all times during the tour.
- Please stay in the room until you are told that your time is up.
- The assistant facilitator will help you put on equipment that is used to simulate what it is like to have dementia. You will put inserts into your shoes, rubber and cloth gloves on your hands, goggles on your eyes, and headphones in your ears.
- You will be assisted into the "experience room" where you will complete the tasks. Once time is up, someone will assist you out of the room.
- When you leave the room you can remove the garb and we will sanitize it.
- You then can use time to reflect on the experience and we will meet back in the conference room at [insert time] after everyone has gone through the experience.
- Please do not share your experience with anyone until we all meet back together for the debriefing session.
- View the room as your own room.
- You will not receive any more information. Questions cannot be answered during the tour.
- Immerse yourself in the setting and be conscious of your feelings.

Adapted from: (Beville, 2011, p. 34)

After the general information is read to the participants, each assistant facilitator should begin his/her responsibilities. The following directions may seem complicated at first, but using the resources provided in both the *Alzheimer's Disease & Other Dementias Caregiver Workshop Facilitator Manual* and the Virtual Dementia Tour® manual will help clarify uncertainties. The Virtual Dementia Tour® manual contains a visual tool on a CD resource. In addition, after the facilitator gains experience and thoroughly comprehends the logistics of the Virtual Dementia Tour®, the responsibilities will become clear and straightforward.

An important note for the assistant facilitators is that the participants will be moving through the “experience rooms” in a synchronized manner and will be read one of the two sets of tasks which are referred to as Purple or Black Instructions. These instructions vary because two participants will be in an “experience room” at a time completing different tasks from one another.

A behavioral observer will be positioned with the Behavioral Observation Form in each of the “experience rooms”. The other two assistant facilitators will begin helping the first two participants put on the simulation equipment. After the assistant facilitators have gotten the equipment on the first two participants, they each will take one of the participants to a room and read the first set of instructions (Purple Instructions) to them. The first two participants will go into different rooms to begin completing their tasks. The behavioral observers will be in the rooms monitoring and recording the behaviors on the forms for later discussion.

The assistant facilitators will begin to help the next two participants put on the simulation equipment. Once they have the equipment on, the assistant facilitators will take them to the “experience rooms” and read them the second set of instructions (Black Instructions). These participants will go into separate “experience rooms”, but will join one of the first two participants who already are in the rooms. The behavioral observers will be in the rooms observing and documenting the behavior of the two participants as they complete different tasks.

The assistant facilitators then will help the next two participants put on the simulation equipment. After the first two participants (who were both read the Purple Instructions) are in the “experience rooms” for 8 to 10 minutes, the assistant facilitators help them out of the rooms. The behavioral observers then replace the equipment needed in the “experience rooms” because the third set of participants to enter the rooms will be trying to complete the same tasks as the first

set of participants. The third set of participants then is taken to the "experience rooms" and read the Purple Instructions before entering the rooms. These participants go into separate rooms, but join the second set of participants (who were read the Black Instructions) who are in the process of completing tasks in each of the rooms.

The fourth set of participants then is assisted with putting on the simulation equipment. The assistant facilitators also assist the second set of participants, each of whom has been in an "experience room" for 8 to 10 minutes, out of the rooms. The assistant facilitators give the behavioral observers a chance to replace the equipment needed in the "experience rooms" because the fourth set of participants to enter the rooms will be trying to complete the same tasks as the second set of participants. The fourth set of participants will be read the Black Instructions and then will be sent to the "experience rooms" to complete the tasks. They will go into separate rooms, but will join the third set of participants in their specific rooms.

All of the participants are assisted out of their respective "experience room" after they have had 8 to 10 minutes to complete their given tasks. If more than 8 participants come to the workshop, this pattern continues.

The roles of each of the facilitators, the Purple and Black Instructions, and additional insights about the Virtual Dementia Tour® are outlined on pages 18-22.

Assistant Facilitators: Simulation Equipment

There will be 4 pairs of participants that go through the "experience room:" 1s, 2s, 3s, and 4s (eight individuals total). 1s and 3s will be given the Purple Instructions; 2s and 4s will be given the Black Instructions. Purple and Black Instructions involve separate tasks to complete.

"1" Participants (two individuals) will start the experience:

- *Use the table on the next page to explain why the garb items are used*.
- Place shoe inserts in each shoe with the bumpy side up.
- Put on latex gloves with a tablespoon of popcorn kernels in them.
- Help them put on cloth gloves with the bumpy side on the inside.
- Assist them in putting on the goggles.
- Place the earphones on them with the MP3 player ready to push play.
- Take them to the appropriate experience rooms (1s both start simultaneously; each goes into a different "experience room").
- Play the MP3 players.
- In a normal voice, read them the Purple Instructions (do not repeat the instructions, just keep reading).
- Then put them in the rooms and walk out to help the next two participants.

"2" Participants (two individuals) will be next:

- Go back to the garbing area and get the "2" participants and garb them the same as the "1s."
- Take them to the experience rooms ("2s" both will start simultaneously, each going into one of the "experience rooms" the "1s" are in).
- Read the Black Instructions to them and place them in the rooms after the "1s" have been in for 4-5 minutes.

"3" Participants (two individuals) will be next:

- Go back to the garbing area and get the "3" participants and garb them the same as the previous participants.
- Take them to the experience rooms ("3s" will both start simultaneously, each going into the experience rooms the "2s" are in). **Assist the "1s" out of the rooms before the "3s" enter.**
- Read the Purple Instruction tasks to them and place them in the rooms after the "1s" have been in for 8-10 minutes ("2s" for 4-5 minutes).

"4" Participants (two individuals) will be last:

- Go back to the garbing area and get the "4" participants and garb them.
- Take them to the experience rooms ("4s" both will start simultaneously, each going into the experience rooms the "3s" are in). **Assist the "2s" out of the rooms before the "4s" enter.**
- Read the Black Instructions to them and place them in the rooms after the "2s" have been in for 8-10 minutes ("3s" for 4-5 minutes).

Garbing	Reasoning/Simulation
☐ Shoe Inserts	Arthritis, corns, bunions, and neuropathy
☐ Rubber Gloves with Popcorn Kernels	Arthritis, loss of fine motor skills, and tactile senses (common losses in aging)
☐ Cloth Gloves	Decreased sensitivity to touch, injury, and hot and cold because of decrease in sensory nerves
☐ Goggles	Macular degeneration, impaired peripheral vision, and illumination changes
☐ Headphones	Hearing loss and difficulty discriminating sounds
☐ Purple/Black Instructions	

Purple Instruction	Black Instructions
"1" Participants	"2" Participants
"3" Participants	"4" Participants
• Find the white sweater and put it on • Write a three-sentence note to your family and place it in an envelope • Set the table for four • Fold all of the towels • Fill the cup ½ full with water and drink it	• Put the belt through the belt loops on the pants • Match up six pairs of socks • Clear the dinner table • Draw a picture of your family and name them • Find the necktie and put it on

Time	Tasks
Pre-start	Garb 1s (approx. 5 min)
0-5	Garb 2s
5-11	Garb 3s
11-16	Garb 4s

Assistant Facilitators: Timing & Coordinating

- Each participant will be in the "experience room" for about 8-10 minutes (no longer).
- Start the timer when play is pushed on the MP3 Players.
- After the "1" participants have been in the "experience rooms" for 4-5 minutes, it is time for the "2" participants to enter the rooms.
- When the "1" participants have been in the rooms for 8-10 minutes, bring the "1" participants out, allow a few moments for the behavioral observer to fix the Purple tasks, and take the "3" participants in. Help the "1s" take off their garb and be there to make them comfortable in Learning Center A & B. **(the 1s' garbing items need to be brought back to the garb room for the 4s to use)**
- After the "2" participants have been in the room for 8-10 minutes, bring them out, allow a few moments for the behavioral observer to fix the Black tasks, and bring the "4" participants in. Help the "2s" take off their garb and be there to make them comfortable in Learning Center A & B.
- After the "3" participants have been in the room for 8-10 minutes, bring them out and help them take off their garb. Be there to make them comfortable in Learning Center A & B.
- Lastly, once the "4" participants have been in the room for 8-10 minutes, bring them out and help them take off their garb. Gather everyone back in Learning Center A & B to begin Part III of the workshop.

Time	Task
0	1s enter rooms
5	2s enter rooms
10	1s exit rooms
10-11	Fix color purple tasks
11	3s enter rooms
15	2s exit rooms
15-16	Fix color black tasks
16	4s enter rooms
21	3s exit rooms
26	4s exit rooms

Behavioral Observers

- Use the supplied Behavioral Observation Form
- Sit in "experience room" and observe the participants; watch and mark all of the tasks completed and behaviors observed on the form provided (Tally mark for each coinciding Instructions: Purple vs. Black)
- Participant only gets credit if entire task is completed (Example: if they do not fold ALL of the towels or match ALL of the socks, they do not get credit)
- Give reinforcement if the participant gives up; Say "You are doing find, you have X number of tasks, keep trying."
- Sometimes behaviors will fall into two categories (Example: an inappropriate behavior can be done in an agitated manner)
- **When the timer comes in and gets the first person who entered the room (Purple 1s), assess the situation and quickly fix the Purple Tasks (towels, table setting, etc.) to prepare for Purple 3s who will complete the same tasks**
- **When the timer comes in and gets the second person who entered the room (Black 2s), assess the situation and quickly fix the Black Tasks (socks, table setting) to prepare for Black 4s who will complete the same tasks**

Fixing Purple Tasks in between "1s" exiting and "3s" entering (approximately 9-11 minutes):

- Make sure the white t-shirt is in the closet
- Gather the envelope with sentences in it
- Scatter towels on the bed
- Fix table setting
- Replace the cup for drinking the water; make sure pitcher is full

Fixing Black Tasks in between "2s" exiting and "4s" entering (approximately 14-16 minutes):

- Make sure the pants are back in the drawer/closet and the belt is in the closet
- Scatter the socks on the bed
- Fix table setting
- Gather the picture of the participant's family
- Put the necktie back in the closet

Note: Behavioral Observation Form is on the following page (p. 22).

Behavioral Observation Form

Purple Instructions	**Black Instructions**
White Sweater	Find Pants and put Belt through loops
Note to Family	Match 6 pairs of socks
Set Table	Clear Table
Fold All Towels	Draw picture of family
Fill cup ½ full	Find and put on necktie
Reinforcement given (say they quit, sit, or stop)_____ # of tasks after reinforcement_____	Reinforcement given (say they quit, sit, or stop)_____ # of tasks after reinforcement_____
Left Room or Removed Garb_____	Left Room or Removed Garb_____
Negative Statements_____	Negative Statements_____
Sub Vocalizations_____	Sub Vocalizations_____
Requests for Help/Stop_____	Requests for Help/Stop_____
Interact with others_____	Interact with others_____
Inappropriate Behaviors_____	Inappropriate Behaviors_____
Agitation_____	Agitation_____
Shadowing_____	Shadowing_____
Doing other person's tasks_____	Doing other person's tasks_____
Wandering_____	Wandering_____
Hoarding_____	Hoarding_____

Notes About Observations:

Negative Statements: "I don't, I can't, I feel stupid, etc."
Sub-Vocalizations: talking, humming, singing, whispering to self
Requests for Help/to Stop: "I'm done, I don't know what to do, can you help me, etc."
Interact with others: positive or negative
Inappropriate or strange behaviors: running water in the bathtub, putting a towel around their waist, etc.
Agitation: Cussing, throwing things
Shadowing: following other person
Wandering: Purposeless pacing
Hoarding: carrying things around, putting everything together, gathering things

After the Virtual Dementia Tour®

After everyone has experienced the Virtual Dementia Tour®, the Lead Facilitator needs to gather the participants back in Learning Center A & B to facilitate a discussion about the experience.

Part III: Caregiver Techniques & Debriefing

Part III of the *Alzheimer's Disease & Other Dementias Caregiver Workshop* is approximately thirty minutes and includes a debriefing period for participants to share their thoughts and perspectives on their experience with the Virtual Dementia Tour®. Part III also includes information on caregiver techniques for individuals with Alzheimer's disease and other dementias to include communication, agitation and aggression, bathing, grooming, dressing, eating, and toileting.

Beginning Part III:

After participants have completed the Virtual Dementia Tour®, Part III allows for all of the participants to gather back together to share any thoughts or reactions they have to the simulation experience.

To encourage dialogue from the participants, the facilitator can:

- Simply ask the group about their reactions or feelings regarding the simulation experience.
- Share insights and feelings he/she may have about the experience.
- Read some of the sentences that the participants may have written during the simulation experience (in Part II, some of the participants are given the task to write three sentences to their family members during the simulation activity). These sentences may reveal stress or emotions the participants were feeling during the Virtual Dementia Tour®.
- Explain some of the behaviors observed by the behavioral observers during the Virtual Dementia Tour®. Many times, the behaviors reveal that healthy, young individuals display many of the same coping strategies as individuals living with Alzheimer's disease and other dementias.
- Ask direct questions such as: "What would be helpful to do when caring for individuals with dementia?," "What was frustrating about the experience?," "Will you change the way you care for individuals with dementia? If so, how?"

- It is important to note that the Virtual Dementia Tour® can create different reactions for different participants. Some participants may be too overwhelmed by the experience to share their thoughts and reactions. **Do not pressure any participant to contribute to the dialogue.**

The facilitator should allow 10-15 minutes for debriefing and discussion in the beginning of Part III so participants can fully share their reactions and perspectives about the Virtual Dementia Tour®. After discussion and dialogue has diminished, the facilitator should proceed to caregiver techniques. Many of the themes that come out during the debriefing and discussion will be reinforced during the segment on caregiver techniques.

Caregiver Techniques:

PowerPoint is recommended for facilitation of the information about caregiver techniques. A sample PowerPoint is provided in the "Forms & Resources" section. In addition, there are handouts for the participants which also are in the "Forms & Resources" section. These handouts are Communication: Alzheimer's Caregiver Tips, Coping with Aggression & Agitation: Alzheimer's Caregiver Tips, Bathing: Alzheimer's Caregiver Tips, Daily Living Tasks: Alzheimer's Caregiver Tips, and Caregiver Resources & Support. These materials also are available on the flash drive included in the facilitator manual if the educator prefers to download the resources to his/her computer.

Using the PowerPoint and Handouts as visual tools, the facilitator can progress through each topic-- communication, coping with agitation and aggression, bathing, and daily living tasks-- explaining the challenges individuals with Alzheimer's disease and other dementias have with each topic and strategies for professional caregivers to care for and facilitate successful interactions with the individuals.

The participants are professional caregivers, so the facilitator should encourage insights and feedback from them. During each topic the facilitator can ask participants to share:

- Challenges they have
- Successful strategies they have used
- Thoughts, reactions, or insights they have

Wrapping Up:

After facilitating a discussion about the Virtual Dementia Tour® and educating the participants about caregiver techniques and tips, the workshop is concluded by the facilitator:

1. Going through the final handout about resources and support for Alzheimer's caregivers (provided in the "Forms & Resources" section and on the flash drive provided in the manual).

2. Asking if there are any final questions, concerns, or insights.

3. Asking the participants what their take home message is (what will they remember from the workshop or what impacted them), having them write it down on a piece of paper to take with them, and having them share it with the group.

4. The facilitator concludes the workshop with his/her own take home message. Key points include:
    - Although Alzheimer's disease and other dementias are feared by many and the participants have gotten a glimpse of what it is like to have dementia, individuals with dementia still have a FULL life to live with laughter, frustration, joy, and sorrow (just like anyone else). Caregivers are essential in supporting, promoting independence, and providing the highest-quality of life for these individuals.
    - Recommended final statement: "We must not see any person as an abstraction. Instead, we must see in every person a universe with its own secrets, with its own treasures, with its own sources of anguish, and with some measure of triumph."
      -Elie Wiesel-

5. After the workshop is finished, the post-program surveys should be distributed to and completed by the participants so the facilitator can evaluate the experience and areas for improvement (a sample survey is on page 35 and on the flash drive provided in the manual).

Step-by-Step Preparation

1. Determine a date and time at least two weeks in advance to ensure the availability of Learning Center A & B as well as two patient rooms in Patient Area 5.
2. Post the workshop on the Beaver Dam Community Hospital Intranet under "Meeting Signup."
3. Send out a flyer to all professional caregivers at the hospital via e-mail.
4. Prepare for the presentation through using, modifying, or developing the PowerPoint provided on the flash drive in the forms section.
5. Prepare folders for the participants with the handouts in them. Suggested materials to include in the folders are found in the forms section and on the flash drive. These handouts include the pre-program survey, caregiver tips (communication, coping with agitation and aggression, bathing, and daily living tasks), and caregiver support and resources.
6. Review the Virtual Dementia Tour® information provided by the hospital (the hospital previously purchased the material).
7. Gather all of the equipment needed as outlined in the description for Part II. A checklist for all of the supplies needed for the workshop also is provided on page 28.
8. Print off the papers needed for Part II including, assistant facilitator instructions, behavioral observation forms, and task instructions.
9. Communicate with the Nurse Educators about WISHET CEUs being available for the workshop and gather the WISHET CEU Certificates from the Nurse Educators.
10. On the day of the workshop:
    - **a.** Make sure the equipment for the PowerPoint presentation is working in Learning Center A & B.
    - **b.** Make sure the seating is arranged appropriately for discussion and communication in Learning Center A & B.
    - **c.** Set up the "experience rooms" as described in the Part II description on page 13.
    - **d.** Communicate with your assistant facilitators so they are clear on their responsibilities during the Virtual Dementia Tour®. This is important because the roles can be confusing and difficult to understand. Make sure they know their roles.
    - **e.** Set out the folders and pencils for the participants in Learning Center A & B.
11. **Facilitate the workshop!**
12. After the workshop, be prepared to spend time gathering and cleaning the equipment used during the experience.
13. Review the evaluations of the workshop. Determine the successes of the workshop and improvements that are needed.

Supply Checklist

- ☐ Conference Room: Learning Center A & B with seating arranged for discussion
- ☐ Equipment with PowerPoint capabilities in Learning Center A & B
- ☐ 8 folders created for each participant with: Pre-Program Survey, Caregiver Tips (Communication, Coping with Agitation & Aggression, Bathing, Daily Living Tasks), and Resource & Support Handout
- ☐ Pencils
- ☐ Two patient rooms to set up as "experience rooms"
- ☐ If available, another patient room located next to the "experience rooms" where participants can put on simulation equipment
- ☐ 3-4 assistant facilitators
- ☐ Simulation equipment:
    - 6 pairs of shoe inserts
    - 6 pairs of goggles
    - 6 pairs of rubber gloves
    - Popcorn kernels
    - 6 pairs of cloth gloves
    - 6 MP3 Players with headphones (downloaded noise provided by VDT ®)
- ☐ Material to set up the "experience rooms"
    - 10 towels
    - 16 pairs of assorted socks
    - 2 bed sheets
    - 4 washcloths
    - 2 pillowcases
    - 4 neck ties
    - 4 white sweaters/shirts
    - 4 belts
    - Approximately 16 pieces of other random clothing
    - 4 pairs of pants with belt loops
    - Paper
    - Pens
    - Envelopes
    - Purple and Black Instructions
    - 4 plastic table settings for four (16 plates, 16 cups, 16 forks, 16 spoons, 16 knives and 16 napkins)
    - 8 plastic cups
    - For each Behavioral Observer: a chair in the "experience room" and a Behavioral Observation Form on a clip board with a pencil
- ☐ Sanitizing Material
    - Non-alcohol baby wipes to clean goggles
    - Anti-bacterial spray for shoe inserts
- ☐ Trash can to throw away rubber gloves after experience
- ☐ Post-Program Surveys

Forms & Resources

Promotional Flyer

Beaver Dam Community Hospitals, Inc.
Beaver Dam, WI 53916

Alzheimer's Disease & Other Dementias Caregiver Workshop

(Overview of Alzheimer's Disease, Virtual Dementia Tour, & Caregiving Techniques)

Whitney R. Thompson,
Master of Public Health Student

Learning Center A&B

March 6, 2014--1330-1500

Objectives: Increase knowledge about the disease, increase empathy for individuals with the disease, improve caregiving techniques, & reduce stigma

WISHET CEUs Available

Please sign up for the class in
Scheduler in the BDCH Intranet page.
Class size is limited.

Intended Audience: All Caregivers (Nurses, Certified Nursing Assistants, Physical Therapists, Occupational Therapists, Respiratory Therapists, etc.)

Pre- and Post-Program Surveys

Pre-Program Survey:
Alzheimer's Disease & Other Dementias Caregiver Workshop

Respondent ID:_____
Please use the last 2 digits of your phone number followed by the two digits of your birthday (month) and your middle initial (5206r). This is to ensure your anonymity and allow the pre- and post-surveys to be matched.

Part I: *Demographics*

1. What is your caregiving role in relation to individuals with Alzheimer's disease & other dementias?

2. How many years have you been caregiving?
3. How many patients with Alzheimer's disease or other dementias have you cared for?
   a. 0 b. 1-10 c. 11-25 d. more than 25

Part II: *Please circle the response or check the box that best represents your opinion. In addition, there is space to add your optional comments.*

4. I understand the emotional needs of our elders with dementia.

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

   Comments:

5. My general knowledge about Alzheimer's disease and other dementias is sufficient for the care I provide.

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

   Comments:

6. I am confident in my knowledge of techniques for providing care to individuals with Alzheimer's disease and other dementias.

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

   Comments:

7. It is necessary for me to sensitize myself to our elders to provide good care.

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

Comments:

8. People with dementia are justified when they exhibit inappropriate behaviors.

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

Comments:

9. In general, people with dementia receive the care they need.

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

Comments:

10. I feel _____about individuals with Alzheimer's disease and other dementias. (Fill in the blank by checking <u>all</u> that apply)

- ☐ removed
- ☐ sad
- ☐ frustrated
- ☐ angry
- ☐ guilty
- ☐ embarrassed
- ☐ pleasant
- ☐ empathy
- ☐ other (please specify):_____

Post-Program Survey
Alzheimer's Disease & Other Dementias Caregiver Workshop

Respondent ID (same number used on previous survey):_____
Please use the last 2 digits of your phone number followed by the two digits of your birthday (month) and your middle initial (5206r). This is to ensure your anonymity and allow the pre- and post-surveys to be matched.

Directions: *Please circle the response or check the box that best represents your opinion. In addition, there is space to add your optional comments.*

1. I have a better understanding of the emotional needs of individuals with dementia as a result of this workshop?

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

Comments:

2. My general knowledge about Alzheimer's disease and other dementias is sufficient for the care I provide.

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

Comments:

3. I am confident in my knowledge of techniques for providing care to individuals with Alzheimer's disease and other dementias.

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

Comments:

4. From a physical standpoint, how capable did you feel carrying out simple tasks during the Virtual Dementia Tour®?

1	2	3	4	5
Very Capable	Capable	Neutral	Somewhat Capable	Not at All Capable

Comments:

5. It is necessary to sensitize myself to our elders to provide good care.

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

Comments:

6. People with dementia are justified when they exhibit inappropriate behaviors.

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

Comments:

7. In general, people with dementia receive the care they need.

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

Comments:

8. I feel _____about individuals with Alzheimer's disease and other dementias. (Fill in the blank by checking <u>all</u> of the boxes that apply)
   - ☐ removed
   - ☐ sad
   - ☐ frustrated
   - ☐ angry
   - ☐ guilty
   - ☐ embarrassed
   - ☐ pleasant
   - ☐ empathy
   - ☐ other (please specify):_____

9. How did the workshop impact you personally?

10. How did the workshop impact you professionally?

11. What will you do differently because of the workshop?

12. What were the most beneficial aspects of the workshop?

13. What were the least beneficial aspects of the workshop?

14. How could the workshop be improved?

Handouts

Alzheimer's Disease:

10 Warning Signs

(Examples of warning sign behavior of someone with possible symptoms of AD vs. examples of typical behavior of someone who does not have AD)

1. **Memory loss that disrupts daily life.**
   - Examples: Forgetting recently learned information, forgetting important dates or events, asking for the same information over and over, relying on memory aides
   - Typical: Sometimes forgetting names or appointments, but remembering them later

2. **Challenges in planning or solving problems.**
   - Examples: Changes in ability to develop and follow a plan or work with numbers, trouble following a familiar recipe, difficulty keeping track of monthly bills, problems concentrating, taking much longer to do things than they did before
   - Typical: Making occasional errors when balancing a checkbook

3. **Difficulty completing familiar tasks at home, at work or at leisure.**
   - Examples: Difficulty in completing daily tasks, trouble driving to a familiar location, difficulty managing a budget, struggle remembering the rules of a favorite game
   - Typical: Occasionally needing help to use the settings on a microwave

4. **Confusion with time or place.**
   - Examples: Lose track of dates, seasons, and the passage of time; the individual may forget where they are or how they got there
   - Typical: Getting confused about the day of the week but figuring it out later

5. **Trouble understanding visual images and spatial relationships.**
   - Examples: Difficulty reading, judging distances, determining color or contrast; their perception may change resulting in walking by a mirror and thinking someone else is in the room, not recognizing their own reflection
   - Typical: Vision changes related to cataracts

6. **New problems with words in speaking or writing.**
   - Examples: Trouble following or joining a conversation, stopping in the middle of a conversation and having no idea how to continue, repeating themselves; struggle with vocabulary, trouble finding the right word or calling things by the wrong name
   - Typical: Sometimes having trouble finding the right word

7. **Misplacing things and losing the ability to retrace steps.**
   - Examples: Putting things in unusual places, may accuse others of stealing
   - Typical: Misplacing things from time to time

Alzheimer's Association. (2009). Know the 10 Signs. In *alz.org*. Retrieved February 19, 2014, from

8. **Decreased or poor judgment.**
    - Examples: Poor judgment when dealing with money, giving large amounts to telemarketers, paying less attention to grooming
    - Typical: Making a bad decision once in a while

9. **Withdrawal from work or social activities.**
    - Examples: Remove themselves from hobbies, social activities, work projects, or sports; trouble remembering how to complete a favorite hobby; avoiding social activities because of the changes they are experiencing
    - Typical: Sometimes feeling weary of work, family, and social obligations

10. **Changes in mood and personality.**
    - Examples: Become confused, suspicious, depressed, fearful, or anxious; may become easily upset
    - Typical: Developing very specific ways of doing things and becoming irritable when routine is disrupted

Alzheimer's Association. (2009). Know the 10 Signs. In *alz.org*. Retrieved February 19, 2014, from

Communication: Alzheimer's Caregiving Tips

Individuals with Alzheimer's disease & other dementias may struggle with the following communication issues:

- Finding the right word or losing his or her train of thought
- Understanding what words mean
- Paying attention during long conversations
- Remembering the steps in common activities, such as getting dressed
- Blocking out background noises
- Frustration in communication struggles

Communication Tips:

- Understand that the disease causes changes in communication skills
- Make eye contact & call the person by name
- Be aware of your tone, how loud your voice is, how you look at the person, & your body language
- Encourage a two-way conversation for as long as possible
- Use other methods besides speaking, such as gentle touching
- Try distracting the person if communication creates problems

To encourage the person to communicate with you:

- Be warm & loving
- Hold the person's hand while you talk
- Be open to the person's concerns, even if he or she is hard to understand
- Let him or her make some decisions & stay involved
- Be patient with angry outbursts

To speak effectively with a person who has Alzheimer's:

- Offer simple, step-by-step instructions
- Repeat instructions & allow more time for a response
- Don't talk about the person as if he or she isn't there
- Use visual cues such as pointing to a commode when you are getting them up to go to the bathroom
- Family & friends of the individual may have helpful insights

Examples of what you can say:

- "Let's try this way," instead of pointing out mistakes.
- "Please do this," instead of "Don't do this."
- "Thanks for helping," even if the results aren't perfect.
- Limit the number of choices. For example, you could say, "Would you like fish or chicken for dinner?" instead of "What would you like for dinner?"
- Try not to say, "Don't you remember?" or "I told you."

If you become frustrated, take a moment for yourself.

Adapted from the Alzheimer's Disease Education and Referral Center's Family Caregiver Tips
http://www.nia.nih.gov

Coping with Agitation & Aggression: Alzheimer's Caregiving Tips

Individuals with Alzheimer's disease may be agitated or aggressive. Agitation may cause pacing, sleeplessness, or aggression (lashing out verbally or physically).

Causes of Agitation and Aggression:

Most of the time there is a reason behind the agitated & aggressive behavior & if the caregiver can find the cause, the behavior may stop.

- Pain, depression, or stress
- Too little rest or sleep
- Constipation
- Soiled underwear or brief
- Sudden change in a well-known place, routine, or person
- A feeling of loss
- Too much noise or confusion or too many people in the room
- Being pushed by others to do something
- Feeling lonely & not having enough contact with other people
- Interaction of medicines

Coping Tips:

- Reassure the person & speak calmly
- Listen to his or her concerns & frustrations
- Try to show that you understand if the person is angry or fearful
- Allow the person to keep as much control in his or her life as possible
- Try to keep a routine (bathing, dressing, & eating at the same time each day)

Coping Tips Continued…:

- Build quiet times & times for activity into the routine
- Keep well-loved objects & photographs around
- Try gentle touching, soothing music, reading, or walks
- Reduce noise, clutter, or the number of people in the room
- Try to distract the person with a favorite snack, object, or activity

Caring for Yourself:

- Slow down & give yourself moments if you need them
- Take a break if possible
- Keep yourself safe while trying to keep others safe---You may need to back away from the individual at times
- Be patient

Adapted from the Alzheimer's Disease Education and Referral Center's Family Caregiver Tips
http://www.nia.nih.gov

Bathing: Alzheimer's Caregiving Tips

Difficulties associated with bathing:

- Individuals with the disease will need help at some point
- It is a private activity which can make it feel uncomfortable & threatening
- Individual may be angry they cannot do it themselves
- It can be one of the hardest caregiving responsibilities

Safety Tips:

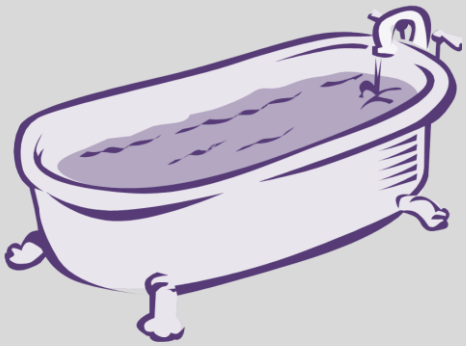
- Never leave the individual with Alzheimer's alone while bathing
- Always check the water temperature before he or she gets in the tub or shower
- Use a hand-held showerhead
- Use a rubber bath mat, safety bars, & a shower chair
- Keep sharp objects such as razors out of reach

Prepare for the bath:

- Know the individuals preferences & bathing habits
- Have all the necessary supplies (soap, washcloths, towels, shampoo) ready & organized
- Adjust the temperature in the room & perhaps play soft music so the individual will be comfortable & relaxed while bathing
- Be matter-of-fact about bathing. Say, "It's time for a bath now." Don't argue about the need for a bath or shower. Be gentle and respectful. It may help to give them a choice by saying, "Do you want to bathe now or in 5 minutes?"

While Bathing:

- Promote independence by encouraging the individual to do as much as possible
- Preserve their privacy & dignity by covering the individual's shoulders or lap with a bath towel
- Give them a washcloth to hold in order to distract them & promote independence
- Talk through the bath step-by-step, with simple directions so the individual can know what to expect



After Bathing:

- Be sure to protect the individuals skin by completely drying it, examining the skin for rashes or infections, & using protective ointment if needed
- Take note of effective bathing routines & strategies for each individual

<u>Be patient, allow yourself time, & be aware of your communication</u>

Adapted from the Alzheimer's Disease Education and Referral Center's Family Caregiver Tips
http://www.nia.nih.gov

Daily Living Tasks: Alzheimer's Caregiving Tips

As Alzheimer's disease & other dementias progress, individuals with the diseases have an increased need for assistance from caregivers to complete daily living tasks such as eating, dressing, grooming, and toileting. Caregivers need to encourage **independence, dignity, & increased self-esteem.**

Eating:

Individuals with Alzheimer's disease often struggle to get enough nutrition because of such things as being overwhelmed by too many food choices, forgetting to eat, thinking they already have, or have difficulty knowing how the use the utensils

Tips:

- Limit distractions: eat in quiet spaces; use simple table settings
- Use contrasting colors of food, plates, & table because of visual issues
- Promote independence with the use of adaptive utensils such as spoons with larger handles when helpful
- Implement the imitation technique by showing the individual how to eat
- Give them enough time

Dressing:

Individuals with Alzheimer's & other dementias may need more time to dress because they might struggle choosing clothes, matching clothes for the season, or remembering how to put the clothes on

Tips:

- Hand them one thing at a time & give clear step-by-step instructions
- Use Velcro® or large zipper pulls for clothing instead of shoelaces, buttons, or buckles

Grooming:

- Can increase self-esteem
- Encourage women to do things they use to such as wearing makeup; encourage & assist men in shaving
- Promote oral care: Show the person how; step-by-step

Toileting Tips:

- Remind the person to go to the bathroom every 2-3 hours
- Show the person the way to the bathroom
- Watch for signs that the person may have to go to the bathroom, such as restlessness or pulling at clothes
- Make sure that the person wears loose, comfortable clothing that is easy to remove
- Using a colorful/contrasting toilet seat may help the person identify the toilet
- Be understanding & patient; reassure the person if he or she is upset

Adapted from the Alzheimer's Disease Education and Referral Center's Family Caregiver Tips http://www.nia.nih.gov

Caregiver Resources & Support: Alzheimer's disease

1. Caregiver Center: http://www.alz.org/care/overview.asp
2. E-Learning Courses: http://www.alz.org/care/alzheimers-dementia-care-training-certification.asp
3. Online Learning Courses: http://elearning.alz.org/home.aspx
4. Caregiver Tips Sheets: http://www.nia.nih.gov/alzheimers/topics/caregiving
5. Video Resources & Tip Sheets: http://caregiveraction.org/resources/alzheimer-videos/
6. Overall Help Guide: http://www.helpguide.org/elder/alzheimers_disease_dementia_support_caregiver.htm
7. Alz.org (Document with information about Alzheimer's disease): http://www.alz.org/downloads/facts_figures_2013.pdf
8. Support Strategies/Stress Management: http://www.alz.org/care/alzheimers-dementia-caregiver-stress-burnout.asp
9. Book: *Still Alice* (Lisa Genova); perspective of an individual with early-onset Alzheimer's disease

Be aware of: support groups, resources, & educational opportunities

PowerPoint Presentation

Alzheimer's Disease & Other Dementias Caregiver Workshop

Objectives

- Increase the participants' knowledge about Alzheimer's disease & other dementias
- Increase the participants' empathy for individuals with the conditions
- Improve the participants' caregiving techniques
- **Reduce stigma** related to Alzheimer's disease & other dementias

Agenda

- Part I: Overview of Alzheimer's disease and other dementias
- Part II: Virtual Dementia Tour®
- Part III: Caregiving Techniques & Debriefing

PART 1:

Overview

http://alzheimers.gov/#panel1-1

Dementia

Loss of the cognitive functions of thinking, remembering, and reasoning along with disturbances in behavioral abilities that are severe enough to interfere with an individual's daily life

- Set of symptoms, not a disease

Dementia Symptoms

- Symptoms can vary greatly in severity
- Impaired memory
- Struggles with communication & language
- An inability to focus & pay attention
- Compromised reasoning & judgment
- Problems with visual perception

Types of Dementia

- Alzheimer's Disease
- Vascular Dementia
  - Results from injuries to vessels that supply blood to the brain
  - Often occurs after strokes; can begin suddenly and worsen or improve over time
  - Risk Factors: irregular/rapid heart rate, hypertension, diabetes, high cholesterol
- Lewy Body Dementia
  - Caused by abnormal deposits of protein
  - Problems with thinking, movement, behavior, & mood
  - Symptoms: changes in alertness & attention, hallucinations, tremors, muscle stiffness, sleep problems, & memory loss

Types of Dementia

- Frontotemporal Disorders
  - Results from damage to neurons in the frontal and temporal lobes (atrophy of these lobes)
  - Symptoms: behavior changes, emotional problems, communication issues, difficulty walking, and trouble with other basic movements
- Mixed Dementias
  - Often Alzheimer's & Vascular
- Huntington's disease, Parkinson's, Creutzfeldt-Jakob disease, head injuries, and HIV

Alzheimer's Disease

- Most common cause of dementia (60-80% of cases)
- Progressive disease that affects the brain irreversibly
- The disease slowly destroys the memory and thinking skills of an individual, eventually preventing them from performing daily living tasks independently
- 6th leading cause of death in the U.S.

Prevalence

- 2013: 5.2 million in the U.S. living with AD
  - 5 million: Age 65+
  - 200,000: younger-onset*
- More women than men:
  - 3.2 million are women; 1.8 million are men (women live longer)
- Future Projections:
  - 2025: 7.1 million 65+ with AD (increase by 40 %)
  - 2050: 13.8 million individuals 65+ will have the disease

Diagnosis

- Early detection is essential→ allows the individual to be involved in planning
- No single test is used to diagnose
- Involves an extensive number of exams and tests:
  - Assessment of the individual's medical history, a physical exam, cognitive and neuropsychological tests, neurological evaluations, brain scans, laboratory tests, and psychiatric evaluations

Treatment

- Early diagnosis is an essential element to treatment & care
- No cure for the disease
- Drugs to slow the advancement of the symptoms
  - Regulate neurotransmitters-help maintain thinking, memory, speaking, and behavioral abilities, but do not change underlying disease process
- Palliative Care & Hospice

Risk Factors

- No known cause
- Risk Factors:
  - Age
  - Family History
  - Genetics
  - Mild Cognitive Impairment
  - Past Head Trauma
  - Lifestyle and heart health
  - Cognitive & Social Engagement

Warning Signs (Handout)

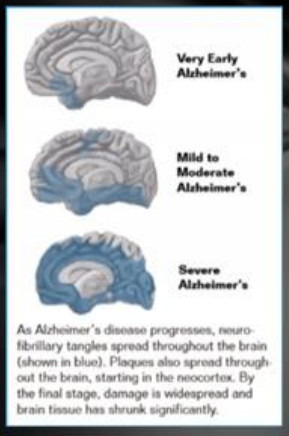
1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood and personality

Symptoms

- Have difficulty and eventually are unable to perform daily living tasks (bathing, dressing, eating, etc.)
- Incontinence
- Wander or get lost
- Experience changes in their personality and behavior
- Trouble walking
- Problems swallowing
- Communication problems
- Hallucinations
- Not able to recognize friends and family
- *Other Symptoms?*

Stages

- Plaques & tangles in the brain are two of the main features of AD
- The loss of connections between nerve cells (neurons) in the brain is another
- Abnormal deposits of proteins form amyloid plaques & tau tangles throughout the brain→ once-healthy neurons begin to work less efficiently
- Neurons eventually lose their ability to function & communicate with each other & die



As Alzheimer's disease progresses, neurofibrillary tangles spread throughout the brain (shown in blue). Plaques also spread throughout the brain, starting in the neocortex. By the final stage, damage is widespread and brain tissue has shrunk significantly.

Stages

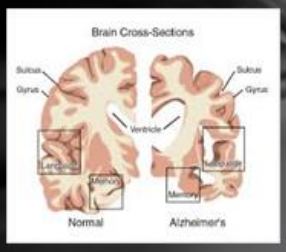
- Early Stage
  - Before known symptoms & clinical diagnosis
  - Symptoms may begin 10-20 years before clinically detectable
  - Memory problems & forgetfulness are typical first signs

Stages

- Middle Stage (Mild to Moderate)
  - Diagnosis
  - Mild symptoms: getting lost, trouble handling money, repeating questions, taking longer to complete normal daily tasks, poor judgment, losing things or misplacing them in odd places, personality changes
  - Moderate symptoms: increased memory loss & confusion, problems recognizing family & friends, inability to learn new things, difficulty carrying out tasks that involve multiple steps, problems coping with new situations, hallucinations, delusions, paranoia, & impulsive behavior

Stages

- Final Stage (Severe)
  - Symptoms: inability to communicate, weight loss, seizures, skin infections, and difficulty swallowing
  - Final stages: often become bed bound & rely almost entirely on caregivers
  - Death of the individual
    - Aspiration, pneumonia, infection, cardiac arrest



Part 2:

Virtual Dementia Tour®

Part 3:

Caregiving Techniques: Debriefing

Debriefing

Thoughts & Reactions to the Virtual Dementia Tour®

Caregiving

- Individuals with AD & other dementias depend on caregivers
- Essential to promote dignity & independence
- Promote the highest-quality of life

"Patience and perseverance have a magical effect before which difficulties disappear and obstacles vanish."
John Quincy Adams

Caregiving Challenges

- **What are challenges?**
  - Insufficient Training→ increase risk for falls, elopement, poor medication management, & an increased risk of dehumanization of individual with AD
  - Insufficient training & Demanding environments→ Communication problems; Task-oriented
  - Institutionalization of care→ caregivers talking over & talking across individuals with AD
  - Not knowing why challenging behaviors are occurring
  - Impact on emotional well-being of caregiver: Stress, burden, burnout, depression, & grief

Caregiving Techniques

- Communication
- Coping with Agitation & Aggression
- Bathing
- Dressing & Grooming
- Eating
- Toileting

Communication!!!

- Difficulties?
  - Finding the right word, understanding what a word means, remembering steps to common activities
- Strategies?
  - Pay close attention to your non-verbal body language: smile, comforting/calm tone, hold their hand…
  - Simple, straight forward instructions
  - Use visual cues
  - DO NOT TALK AS IF THEY ARE NOT THERE!
  - Be patient & give them time
  - Family & friends of the individual may be able to give you insights

Coping with Agitation & Aggression

Underlying Causes?

- Pain, depression, or stress
- Too little rest or sleep
- Constipation
- Incontinence
- Sudden change in a well-known place, routine, or person
- A feeling of loss
- Too much noise or confusion
- Being pushed by others to do something
- Feeling lonely and not having enough contact with other people
- Interaction of medicines

Strategies?

- Be calm, listen, establish routines, create a calm environment, & care for yourself

Bathing

- Difficult because it is a private activity; can be viewed as threatening & uncomfortable
- Create a safe environment
- Prepare for the bath
- Promote independence, privacy, & dignity

Dressing & Grooming

- **Helps increase self-esteem**
- **Promote Independence**
- **Oral Care:**
  - Show the person how; step-by-step
- **Dressing:**
  - Need more time
  - Hand them one thing at a time & give step-by-step instructions
- **Other Grooming:**
  - Encourage women to do things they use to such as wearing makeup; men promote shaving, etc.

Eating

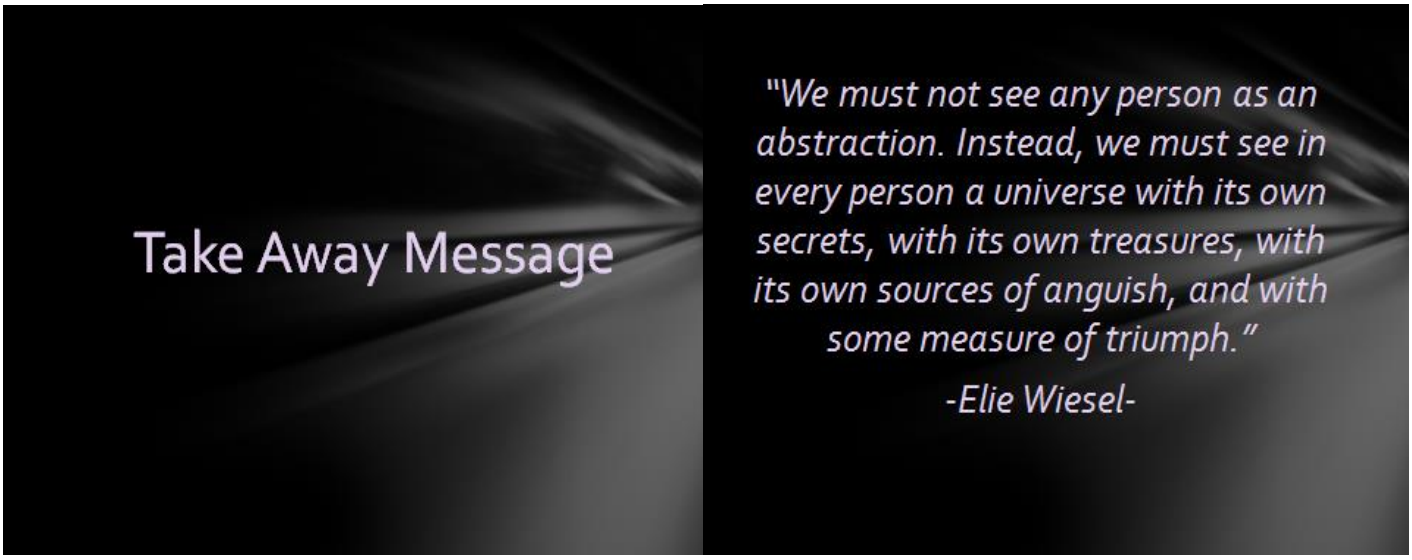
- Struggle getting enough nutrition
- Tips:
  - Quiet space; simple table settings
  - Contrasting colors of food, plates, & table
  - Adaptive utensils
  - Imitation Technique
  - Give them time

Toileting

- Remind the person to go to the bathroom every 2 to 3 hours
- Show the person the way to the bathroom
- Watch for signs that the person may have to go to the bathroom
- Loose clothes
- Using a colorful toilet seat may help the person identify the toilet

Caregiving Support

- http://www.alzwisc.org/index.html
- Caregiver Center: http://www.alz.org/care/overview.asp
- E-Learning Courses: http://www.alz.org/care/alzheimers-dementia-care-training-certification.asp
- Online Learning Courses: http://elearning.alz.org/home.aspx
- Caregiver Tips Sheets: http://www.nia.nih.gov/alzheimers/topics/caregiving
- Video Resources & Tip Sheets: http://careqiveraction.org/resources/alzheimer-videos/
- Overall Help Guide : http://www.helpguide.org/elder/alzheimers_disease_dementia_support_caregiver.htm
- Alz.org (Document with information about Alzheimer's disease: http://www.alz.org/downloads/facts_figures_2012.pdf
- Support Strategies/Stress Management: http://www.alz.org/care/alzheimers-dementia-caregiver-stress-burnout.asp
- Book: *Still Alice* (Lisa Genova); perspective of individual with early-onset Alzheimer's disease


Take Away Message
"We must not see any person as an abstraction. Instead, we must see in every person a universe with its own secrets, with its own treasures, with its own sources of anguish, and with some measure of triumph."
-Elie Wiesel-

Background Literature for PART I

LITERATURE REVIEW

Dementia

Dementia is a set of symptoms that results in the loss of the cognitive functioning. Specifically, dementia affects thinking, remembering, and reasoning, and leads to disturbances in behavioral abilities that are severe enough to interfere with an individual's daily life (Alzheimer's Disease Education and Referral Center, n.d; Alzheimer's Association, 2013a). The set of symptoms can vary greatly in severity and from person to person. Symptoms can include impaired memory, struggles with communication and language, an inability to focus and pay attention, compromised reasoning and judgment, and problems with visual perception (Alzheimer's Association, 2013a).

Types of Dementia

There are several types of dementia and numerous conditions and diseases that cause it. The types of dementia include vascular dementia, Lewy body dementia, frontotemporal disorders, and Alzheimer's disease. In addition to these types, there are upwards of ninety other conditions that can cause dementia including Huntington's disease, Creutzfeldt-Jakob disease, Parkinson's disease, head injury, and HIV (U.S. Department of Health and Human Services, n.d.).

Vascular dementia results from injuries to the vessels that supply blood to the brain. It often occurs after an individual experiences a stroke or series of strokes. The risk factors for this type of dementia include irregular and rapid heart rate, hypertension, diabetes, and high cholesterol. Vascular dementia is the second most common type of dementia behind Alzheimer's disease. The symptoms of vascular dementia can be similar to the symptoms of Alzheimer's, but vascular dementia can begin suddenly and worsen or improve over time while Alzheimer's disease develops gradually and cannot improve over time. There are many individuals who are afflicted with mixed dementia, a combination of several types of dementia most often involving Alzheimer's disease and vascular dementia (U.S. Department of Health and Human Services, n.d.).

Another type of dementia is Lewy body. Lewy body dementia is a brain disorder common in older people that is caused by abnormal protein deposits. Alpha-synuclein, a protein found in the brain, can cause problems with thinking, movement, behavior, and mood. Symptoms of this type of dementia include changes in alertness and attention, hallucinations,

tremors, muscle stiffness, sleep problems, and memory loss (U.S. Department of Health and Human Services, n.d.).

Frontotemporal disorders are another cause of dementia that results from damage to neurons (nerve cells) in the frontal and temporal lobes of the brain. The neurons die, resulting in atrophy to the frontal and temporal lobes. The damage to these regions of the brain results in symptoms such as behavior changes, emotional problems, communication issues, difficulty walking, and trouble with other basic movements (U.S. Department of Health and Human Services, n.d.).

Alzheimer's Disease

Alzheimer's disease is the most common cause of dementia accounting for 60 to 80 percent of cases (Alzheimer's Association, 2013b), and is the sixth leading cause of death in the United States (U.S. Department of Health and Human Services, 2012). Alzheimer's is a progressive disease that affects the brain irreversibly. The disease slowly destroys the memory and thinking skills of an individual, eventually preventing them from performing daily living tasks independently (National Institute on Aging, 2012b).

In the preclinical stage of Alzheimer's disease, there are no obvious outer signs or symptoms, but there are changes happening in the brain. Scientifically, Alzheimer's disease presents two main features in the brain, plaques and tangles. "Plaques are deposits of a protein fragment called beta-amyloid that build up in the spaces between nerve cells" and "tangles are twisted fibers of another protein called tau that build up inside cells" (Alzheimer's Association, 2014b). Scientists do not know the exact role plaques and tangles play in the development of Alzheimer's disease, but most agree they play a critical role in the loss of connections between nerve cells (neurons) in the brain. Changes to the brain occur when abnormal deposits of proteins start to form amyloid plaques and tau tangles. These deposits eventually cause previously healthy neurons to work less efficiently. Specifically, the neurons lose their ability to communicate with each other and die. As the disease progresses, more structures of the brain are damaged and more neurons die. Eventually, the damage is widespread and the brain shrinks significantly by the final stages of the disease (Alzheimer's Association, 2014b).

Prevalence

Approximately one in nine people age 65 and older has Alzheimer's disease and about one-third of people age 85 and older have the disease (Hebert, Weuve, Scherr, & Evans, 2013).

According to the Alzheimer's Association (2013b), an estimated 5.2 million Americans were living with Alzheimer's disease in 2013. Of these 5.2 million individuals, 5 million were age 65 and older and the remaining 200,000 had younger-onset Alzheimer's. A further breakdown of these numbers revealed that four percent of the individuals with the disease were under the age of 65.

More women than men develop Alzheimer's disease. Of the 5 million people age 65 and older with Alzheimer's in America, 3.2 million are women and 1.8 million are men (Hebert, Weuve, Scherr, & Evans, 2013). In addition, 16 percent of women 71 and older have Alzheimer's disease or other dementias (Plassman et al., 2007). The larger prevalence of women with Alzheimer's disease is primarily due to the fact that, on average, women live longer than men and the disease usually develops later in life (Alzheimer's Association, 2013b).

With the baby boomer generation growing older, the prevalence of Alzheimer's disease is projected to increase. It is projected that by 2025, the number of people age 65 and older with Alzheimer's disease will increase by 40 percent. The number of individuals with the disease is estimated to rise from 5.2 million in 2013 to 7.1 million in 2025. If no discoveries or advancements for the prevention or treatment of Alzheimer's disease materialize, it is projected that by 2050, 13.8 million individuals 65 years of age and older will have the disease (Alzheimer's Association, 2013b). These projections demonstrate the great need to make Alzheimer's disease and other dementias a priority. Education of caregivers is an essential facet in promoting the highest quality of care for the substantial amount of individuals projected to be living with Alzheimer's disease.

Diagnosis

Detecting and diagnosing Alzheimer's disease early are essential in helping individuals maintain as much independence as possible and allowing them time to make decisions about their future care while they are still able. No single test is used to diagnose Alzheimer's disease. Diagnosis involves an extensive number of exams and tests including an assessment of the individual's medical history, a physical exam, cognitive and neuropsychological tests, neurological evaluations, brain scans, laboratory tests, and psychiatric evaluations (Mayo Clinic Staff, 2011).

Treatment

There is no cure for Alzheimer's disease although much effort is being made to find one. While there is no cure, there are drug and non-drug options that subdue or slow symptoms of the disease. The United States Food and Drug Administration has approved four medications to treat Alzheimer's disease. Donepezil, rivastigmine, and galantamine are used for individuals with mild to moderate Alzheimer's and Memantine is used to treat moderate to severe symptoms. These medications can help by regulating neurotransmitters and maintaining thinking skills, memory, speaking skills, and behavioral skills. It is important to note that although the drugs can subdue symptoms, they do not change the underlying disease process. In addition, there is no guarantee that the drugs will help an individual with Alzheimer's because the drugs are effective for some, but not all, persons with the disease. In addition, they may only work for a limited period of time (National Institute on Aging, 2012b).

In addition to drugs, there are non-drug options to help individuals with Alzheimer's disease manage their symptoms. Individuals with the disease often have behavioral issues such as aggressive and agitated behavior. There are reasons behind these behaviors and if the underlying reasons are discovered, the behaviors may change. One non-drug option for managing behavior is to explore the underlying antecedents (Alzheimer's Association, 2014b). For example, an individual with the disease may be agitated because they have to use the bathroom, but because of the disease symptoms, they are not able to connect the urge to go to the bathroom with the need to find a toilet. Assisting the individual to the bathroom and encouraging the use of the toilet every two to three hours may help with behavioral issues that are related to these urges. If caregivers search to find these underlying antecedents, the behaviors may be better managed without medication.

While there is no cure for Alzheimer's disease, researchers are looking beyond treating symptoms. Specifically, they are addressing the underlying disease processes through ongoing clinical trials. These trials are looking at preventive measures related to immunization therapy, cognitive training, physical activity, antioxidants, and the effects of cardiovascular and diabetes treatments (National Institute on Aging, 2012b).

Risk Factors

There is no known cause of Alzheimer's, but there are several risk factors linked to the disease. These risk factors include age, family history, genetics, mild cognitive impairment, past

head trauma, lifestyle behaviors, heart health, and cognitive and social engagement. Age is the most significant risk factor associated with Alzheimer's disease. An individual's risk of the disease increases significantly after the age of 65 and almost half of all individuals over the age of 85 have Alzheimer's disease (Mayo Clinic Staff, 2013).

Family history is another risk factor associated with Alzheimer's disease. Individuals have an increased likelihood of developing the disease if they have a parent or sibling with Alzheimer's compared to those that do not have a first-degree relative with the disease. The risk increases if an individual has more than one first-degree relative with the disease. The association between Alzheimer's and family history of the disease can be linked to genetics, shared environmental factors, and lifestyle choices (Mayo Clinic Staff, 2013).

Another risk factor for Alzheimer's is genetics. Rare mutations in three genes are a strong, if not guaranteed, predictor of Alzheimer's disease. The genes coding three proteins include amyloid precursor protein (APP), presenilin-1 (PS-1), and presenilin-2 (Ps-2). Although these genetic mutations almost guarantee a person who inherits them to have the disease, they only account for less than 5 percent of Alzheimer's cases (Mayo Clinic Staff, 2013; Alzheimer's Association, 2014b).

Mild cognitive impairment (MCI) "is a condition in which an individual has mild but measurable changes in thinking abilities that are noticeable to the person affected and to family members and friends, but that do not affect the individual's ability to carry out everyday activities" (Alzheimer's Association, 2013b, p. 11). MCI is another risk factor for Alzheimer's disease. Individuals with MCI are more likely to develop the disease than people without MCI. Although MCI is a risk factor for Alzheimer's, it does not always lead to Alzheimer's and other dementias. Some individuals experience the changes in thinking and memory abilities, but then revert back to normal cognition and remain stable (Alzheimer's Association, 2013b).

Another risk factor for Alzheimer's and other dementias is traumatic brain injury (TBI). TBI occurs when "sudden trauma causes damage to the brain. TBI can result when the head suddenly and violently hits an object, or when an object pierces the skull and enters brain tissue. Symptoms of a TBI can be mild, moderate, or severe, depending on the extent of the damage to the brain. A person with a mild TBI may remain conscious or may experience a loss of consciousness for a few seconds or minutes. Other symptoms of mild TBI include headache, confusion, lightheadedness, dizziness, blurred vision or tired eyes, ringing in the ears, bad taste

in the mouth, fatigue or lethargy, a change in sleep patterns, behavioral or mood changes, and trouble with memory, concentration, attention, or thinking. A person with a moderate or severe TBI may show these same symptoms, but may also have a headache that gets worse or does not go away, repeated vomiting or nausea, convulsions or seizures, an inability to awaken from sleep, dilation of one or both pupils, slurred speech, weakness or numbness in the extremities, loss of coordination, and increased confusion, restlessness, or agitation" (National Institute of Neurological Disorders and Stroke, 2013). Individuals that have experienced moderate and severe TBI have a greater risk of developing Alzheimer's disease and other dementias than those who have not experienced moderate and severe TBI (Alzheimer's Association, 2013b).

Recent research has revealed that factors related to heart health and lifestyle choices can influence an individual's risk of developing Alzheimer's disease. Lack of exercise, smoking, high blood pressure, high blood cholesterol, poorly managed diabetes, and a poor diet lacking fruits and vegetables are factors that may increase an individual's risk of developing Alzheimer's (Mayo Clinic Staff, 2013).

Some studies also suggest that continued cognitive and social engagement can reduce an individual's likelihood of developing Alzheimer's disease. More research is needed on this issue, but factors that may reduce an individual's risk of Alzheimer's include continued education, a stimulating career, mentally stimulating leisure activities, and frequent social engagements (Mayo Clinic Staff, 2013).

Symptoms

Alzheimer's affects each individual with the disease differently. The symptoms begin at various ages and progress at different rates. The disease often starts with a gradual progressive inability to remember new information. Other common symptoms that occur with the inability to remember new information include "memory loss that disrupts daily life, challenges in planning or solving problems, difficulty completing familiar tasks, confusion with time or place, trouble understanding visual images and spatial relationships, new problems with words in speaking or writing, misplacing things and losing the ability to retrace steps, decreased or poor judgment, withdrawal from work or social activities, and changes in mood and personality" (Alzheimer's Association, 2013b, p. 5).

On average, individuals with Alzheimer's disease live four to eight years after diagnosis, but they can live 20 years or more (Worthington, 2012). As the disease progresses, the

individuals become unable to perform daily living tasks such as bathing, dressing, and eating. They also can become incontinent, start to wander or get lost, experience changes in their personality and behavior, have trouble walking, and have difficulty swallowing (Worthington, 2012). They also can display poor judgment, communication problems, hallucinations, and impulsive behavior. In the final stages, the individual with Alzheimer's disease becomes unable to communicate, may not be able to recognize friends and family, and becomes bed-bound (Alzheimer's Association, 2013b). These symptoms convey the need for caregivers to support and enhance the quality of life for the individual with Alzheimer's disease.

The Alzheimer's Foundation divides the symptoms of Alzheimer's disease into the categories of cognitive and psychiatric. This distinction is important because many times behavioral issues occur because of a loss of cognitive functioning, not because of a psychiatric reason; therefore, anti-psychotic medications should not be used in these situations (Alzheimer's Foundation, 2014). Instead, the underlying reasons for the behavior should be investigated by the caregiver. Cognitive symptoms include amnesia, aphasia, apraxia, and agnosia. Amnesia is the loss of memory, or the inability to recall events or facts. Individuals with Alzheimer's disease have issues with their short-term memory before experiencing issues with their long-term memory. Aphasia is the inability to communicate effectively including difficulties with speaking, writing, reading, and understanding the spoken word. Individuals experiencing aphasia can still have the ability to understand non-verbal behavior such as a smile or the tone of a caregiver's voice. Apraxia is the difficulty and inability to preform motor skills and daily living tasks (Alzheimer's Foundation, 2014). Individuals with Alzheimer's disease eventually become completely dependent on caregivers to help them with daily living tasks such as eating, bathing, and grooming. The final cognitive symptom is agnosia, which is an individual's inability to interpret signals from their five senses. An example of agnosia includes an individual's inability to sense a full bladder (Alzheimer's Foundation, 2014).

The Alzheimer's Foundation also divides the symptoms of Alzheimer's disease into a category of psychiatric symptoms which include changes in personality, depression, hallucinations, and delusions. Irritability, apathy, and isolation are several common personality changes that occur in individuals with the disease. Individuals with Alzheimer's disease can experience both visual and auditory hallucinations that can cause agitation, paranoia, fear, and aggression (Alzheimer's Foundation, 2014). The use of psychiatric drugs may be appropriate in

situations with psychotic symptoms, but a collaboration among physicians, neurologists, and psychiatrists can result in better treatment and care for individuals with the disease.

Stages of Alzheimer's Disease

There are three main stages in the progression of Alzheimer's disease. The first stage is the early stage before apparent symptoms and clinical diagnosis. The disease then progresses at different rates to a middle stage with mild to moderate cognitive impairment. Lastly, an individual with Alzheimer's disease enters a final stage with severe symptoms (U.S. Department of Health and Human Services, n.d.)

Early stage. The early stage of Alzheimer's disease includes a preclinical period. Scientists have determined that the disease starts in the area of the brain known as the entorhinal cortex where healthy neurons begin to work less efficiently, lose their ability to communicate, and die. The hippocampus, the area of the brain that plays a significant role in learning and turning short-term memories into long-term memories, also is eventually impacted with the death of neurons. Atrophy or shrinking eventually begins in these affected regions of the brain. Scientists believe that these impacts on the brain can begin ten to twenty years before Alzheimer's disease has clinically detectable signs and symptoms. Eventually, the damages to the brain result in detectable signs and symptoms. Memory problems and forgetfulness typically are the first signs of the disease. Thinking problems such as trouble finding the right words or poor judgment also are frequent during this stage (U.S. Department of Health and Human Services, n.d.)

Middle stage. The middle stage of Alzheimer's disease ranges from mild to moderate symptoms. Diagnosis of the disease often occurs at this stage in which mild symptoms are apparent. Symptoms include a worsening of memory loss and mild cognitive impairment. Specific signs and behaviors include getting lost, trouble handling money and paying bills, repeating questions, taking longer to complete daily tasks, poor judgment, losing things or misplacing them in odd places, and mood and personality changes (U.S. Department of Health and Human Services, n.d.).

The middle stage can include moderate Alzheimer's disease which is the progression of more severe symptoms. Language, reasoning, sensory processing, and conscious thoughts are affected negatively because of damage to the brain. Moderate symptoms of the disease can include increased memory loss and confusion, problems recognizing family and friends, an

inability to learn new things, difficulty carrying out tasks that involve multiple steps (such as getting dressed), problems coping with new situations, hallucinations, delusions, paranoia, and impulsive behavior (U.S. Department of Health and Human Services, n.d.)

Final stage. When Alzheimer's affects an individual in the final stage of the disease, the individual is known to progress from moderate to severe symptoms. Some of the frequent symptoms at this stage include an inability to communicate, weight loss, seizures, skin infections, and difficulty swallowing. As the individual with Alzheimer's progresses into the final stage of the disease, they often become bed bound most or all of the time and rely on others for nearly all, if not all, of their care. The disease eventually progresses to cause the death of the individual (U.S. Department of Health and Human Services, n.d.). Death of individuals with Alzheimer's commonly results because of cardiac arrest, infection, pneumonia, or aspiration (National Institute on Aging, 2012c).

Early-Onset Alzheimer's

Although Alzheimer's is mainly a disease that affects the elderly population, some individuals under the age of 65 can develop the disease. The development of the disease under the age of 65 is referred to as early-onset or younger-onset Alzheimer's disease. In the United States, there are 5.2 million individuals with Alzheimer's disease and it is estimated that more than 200,000, or four percent, of those affected have early-onset. Symptoms of early-onset Alzheimer's disease start developing when the individuals are in their 40s and 50s, but there are very rare cases where the symptoms start developing when the individuals are in their 30s. Scientists do not know why Alzheimer's disease develops in younger individuals, but they have discovered several rare genes associated with early-onset Alzheimer's (Alzheimer's Association, 2014c).

Since Alzheimer's disease generally affects individuals over the age of 65, those with early-onset have a difficult time being accurately diagnosed. Many times, symptoms of the disease are attributed to other causes (Alzheimer's Association, 2014c). Individuals with early-onset often are very busy in their lives with families, careers, and leisure activities so it is important for an accurate diagnosis to occur early. Early diagnosis allows for individuals to be a part of the decision making process before they are no longer able to fully communicate their wishes.

Cost

In 2013, the direct cost of caring for individuals with Alzheimer's disease in the United States was about $203 billion (Alzheimer's Association, 2013b). Individuals with the disease use amenities such as adult day services, assisted living, healthcare, long-term care, and hospice. On average, adult day services cost $70 per day, assisted living costs $42,600 per year, and long-term care such as nursing home care costs $81,030 to $90,520 per year (MetLife Mature Market Institute, 2012).

Medicare and Medicaid covered about 70 percent, or $142 billion, of the cost of care for individuals with Alzheimer's disease in 2013. The services that individuals with Alzheimer's disease and other dementias often need are expensive so many individuals use their excess income and assets on medical expenses so they can qualify for Medicaid. Individuals with Alzheimer's disease and other dementias often need to move to long-term care nursing homes in the late stage of the disease and Medicaid is the only public program that covers these stays (Alzheimer's Association, 2013b).

According to the Alzheimer's Association (2012), people with Alzheimer's disease and other dementias have more than three times as many hospital stays as other older adults. These increased hospitalizations add to the cost of the disease. Prevention measures taken by caregivers and awareness of conditions can help reduce these hospitalizations.

The cost of Alzheimer's disease is projected to increase substantially with the current treatment practices. It is projected that in 2050, the cost of Alzheimer's disease for the American society will increase exponentially to $1.2 trillion. This cost includes a 500 percent increase in the spending of Medicare and Medicaid (Alzheimer's Association, 2013b).

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