

SUPPORTING CAREGIVERS THROUGH EDUCATION
ON DEMENTIA

by

Kammiell Marie Smith

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Elizabeth Kinion, EdD, MSN, APN-BC, FAAN

Approved for the College of Nursing

Helen Melland, PhD, RN

Approved for The Graduate School

Dr. Carl A. Fox

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ABSTRACT

Dementia, a degenerative condition, is a progressive and debilitating disease evidenced by a decline in cognitive function affecting memory, communication, motor activity, and judgment. It is difficult for caregivers to cope with substantial changes in behavior, personality, and communication associated with this illness. Consequently, as the population ages the incidence of dementia will increase. It draws particular importance to the family caregiver role in maintaining the activities of daily care and managing unpredictable, progressive changes of the disease. Caregivers of persons with dementia take on a role that has considerable responsibility. Family caregivers also experience an added sense of duty that often leads to caregiver stress and burden.

The purpose of this project was to develop an educational program. The program included a comprehensive literature review, input gathered from two assistive living homes and one senior center, and a one-hour educational presentation. The one hour educational presentation was presented at two assisted living homes and one senior center.

Careful consideration was given to the aspects of stress and burden on family caregivers of individuals with dementia. Psychosocial interventions, caregiver self-care, community resources, and interventions to assist with activities of daily living were also discussed. Content for the educational presentation addressed the following topics: signs and symptoms of dementia; interventions to assist with communication, behavioral and environmental management; and community resources to help with caregiver burden.

Of the eight key lessons learned, two lessons are important to note. First, it is imperative to assess the emotional needs of the caregiver prior to the program development. Second, caregivers require an individualized approach to dealing with individuals with dementia.

Important roles for Family Psychiatric Mental Health Nurse Practitioners (FPMHNP) are to provide anticipatory guidance to family caregivers about managing the changes in behavior, personality, and communication associated with dementia. They should also develop individualized, appropriately tailored, psychosocial interventions for the management of dementia. The FPMHNP is instrumental in assisting family caregivers with self-care management and providing information on community resources.

CHAPTER 1

INTRODUCTION

Purpose of the Project

The purpose of this project was to develop an educational program. The program included a comprehensive literature review, input gathered from two assisted living homes and one senior center, and a one hour educational presentation, presented at the two assisted living homes and the senior center. The educational presentation for caregivers addressed the challenges of caring for individuals with dementia. The educational presentation was designed to increase caregiver's sense of efficacy, awareness of the capabilities of persons with dementia, and knowledge of caregiving strategies to reduce the challenges of stressful events. Each educational presentation focused on psychosocial interventions, caregiver self-care, community resources, and interventions to assist with activities of daily living.

Background and Significance of the Project

Dementia is an overall term used to describe a syndrome, a cluster of disorders that share common symptoms but exhibit different causes (Braun et al., 2009). Dementia, a degenerative condition, is evidenced by cognitive deficits including decline in memory, language, motor movement, and judgment (American Psychiatric Association, 2000). According to the American Psychiatric Association (2000), the

diagnosis of dementia must include memory impairment and one other cognitive deficit demonstrating a decline of baseline functioning adversely influencing occupational and social domains. The cause of dementia is not fully understood, but is believed to be a deterioration of cognitive and executive function caused by injury to the brain.

The term 'Alzheimer's' is mistakenly used by lay individuals to refer to memory impairment regardless of the type of dementia. The term 'dementia' is used to describe cognitive deficits including memory impairment, given that the different types of dementia share more in terms of common symptoms and psychosocial management techniques, than separates them. Common types of dementia are Alzheimer's disease, vascular dementia, dementia with Lewy Body, and frontotemporal dementia.

A steady increase in the dementia population draws particular importance to the family caregiver role in managing and maintaining activities of daily living in the community. Therefore, as the number of individuals with dementia increases, there will also be an increased need for education and information on enhancing caregiver skills, understanding the symptoms of dementia, and employing psychosocial interventions to minimize behavioral symptoms (Simpson & Carter, 2010).

"Both professionals and familial caregivers should be familiar with the treatment interventions that are most effective in reducing the disruptive behavioral and psychological symptoms of dementia" (Yuhás et al., 2006, p. 34). Dementia is a progressive and debilitating disease; therefore, caregivers must cope with substantial changes in behavior (Smith & Buckwalter, 2005; Smith, Gerdner, Hall, & Buckwalter, 2004), personality (Sherrod, Collins, Wynn, Gragg, 2010), emotions, activities of daily

living and physical health (Paun, Farran, Perraud, Loukissa, 2004) experienced by the individual with dementia. Progression of an individual's dementia can increase caregiver burden and stress (Bossen, 2010; Coon & Evans, 2009; Etters, Goodall, & Harrison, 2008; Hepburn et al., 2005). Spousal and family caregivers are vulnerable to stressors due to the pressures of caring for a person with dementia (Smith et al., 2004; Van Den Wijngaart, Vernooij-Dassen, & Felling, 2000).

In an effort to support caregivers who provide care for individuals with dementia, this author developed an educational program on caregiver management techniques to help them overcome challenges with caregiving. A comprehensive review of the literature, input gathered from two assisted living homes and the senior center, and information gathered from the National Institute on Aging and the Alzheimer's Association provided background information to support the one hour educational presentation.

Objectives of the Project

Two broad goals for the educational program were:

1. Increase caregivers' knowledge of symptoms of dementia and the psychosocial interventions to address communication, environment, and behavioral management.
2. Increase caregiver's awareness of the capabilities of a person with dementia.

Operational Definitions

For the purpose of this project, the following definitions were used:

1. Challenging behaviors—“Challenging behavior can be defined as any behaviour that is unpredictable, frequent and of long duration, and is distressing to the individual or a nuisance to others” (Ouldred, & Bryant, 2008, p. 243).
2. Agitation— "Inappropriate verbal, vocal, or motor activity that is not judged by an outside observer to result directly from the needs of confusion of the agitated individual” (Cohen-Mansfield, Marx, & Rosenthal, 1989, p. M77).
3. Dementia—“A progressive, irreversible decline in mental function, marked by memory impairment and, often, deficits in reasoning, judgment, abstract thought, registration, comprehension, learning, task execution, and use of language (Taber’s Cyclopedic Medical Dictionary, 2001, p. 529).

‘Dementia’ is a term used to describe a syndrome that may be caused by a number of illnesses in which there is progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities. (Banerjee, 2009, p. 10)
4. Family Caregiver—“ Family caregiver is broadly defined and refers to any relative, partner, friend, or neighbor who has a significant personal

relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care” (Family Caregiver Alliance, 2006, p. 5).

5. Psychosocial intervention—“Psychosocial intervention is defined as intervention techniques designed to utilize cognitive, behavioural or social mechanisms of action which focus on improving the caregiver’s psychological well-being and/or social well-being” (Andrén & Elmståhl, 2008, p. 100-101).

Principles of Adult Education

Development of the educational program was based on principles of adult education. Malcolm Knowles identified the concepts of adult learning and described that adult learners go through a process of self-directed curiosity. When defining adult education, Knowles (1980) stated, “In its broadest sense, the term describes a process—the process of adults learning. In this sense it encompasses practically all experiences of mature men and women by which they acquire new knowledge, understanding, skills, attitudes, interests, or values” (p. 25). During his research, Knowles (1980) developed six concepts, which are the theoretical framework supporting adult learning principles:

1. *Autonomous and self-directed*: Developmentally a mature person sheds dependency and moves toward developing and becoming independent and self-directed.

2. *Life experience and knowledge:* With age comes experience, as a person develops throughout life they acquire various experiences that become the foundation for self-directed learning.
3. *Readiness to learn:* Individuals have a willingness to learn when they experience an occasion for necessitating increased knowledge. Impetus to master new information and eagerness to learn are significant aspects in achieving learning by adults.
4. *Problem focused:* Adults are motivated to learn new knowledge, which will help them problem solve a current or future experience, or acquire skills that they actually are facing in the moment.
5. *Motivation:* Adult learners demonstrate internal motivation, which initiates desire to learn and apply their new knowledge to real life situations.
6. *Knowing:* It is beneficial for the adult learner to understand the importance of learning and what they can gain by learning new information.

Most adults participate in an educational program due to the necessity of gaining knowledge in a specific area affecting their current life situation. A fundamental reason why adults may participate in learning opportunities is to institute change in their level of knowledge, skills, behavior, and attitude.

Learning Styles

Many adult learners have adopted a learning style distinguished by specific preference patterns. An assessment of learners' style is a major step in the process of

educational planning. Many learning styles are used when synthesizing information. LeCroy (2009) and Russell (2006) report that three primary learning styles may be used: visual, auditory, and psychomotor methods. Some adult learners use a combination of these styles, further influencing an adult's ability to learn.

The visual learner prefers to visualize pictures, graphs, images to help comprehend the information, as compared to detailed explanations. The visual learner prefers written instruction, visual illustration, or reading notes (Russell, 2006).

The auditory learner favors listening to the information that is presented. The adult learner would rather listen to someone discuss and orally present instructional content, and would prefer auditory instruction rather than reading the information. Adult learners who prefer this style can remember verbal instruction and accept oral presentations.

The psychomotor learner desires to perform a task or skill that is being taught. They prefer the "hands on" type of instruction and the need to demonstrate newly acquired skills (Russell, 2006).

Adult learners are self-directed, have a wealth of experience, and are motivated and ready to learn. Adult learners usually come to an educational session with preconceived ideas, thoughts and concerns about the topic, they are problem-centered and want to expand their knowledge about practical information that pertains to them (LeCroy, 2009). Teachers, to be effective facilitators of learning, are encouraged to take learners' preferred learning styles and adult learning principles into consideration when planning and presenting educational programs.

CHAPTER 2

LITERATURE REVIEW

Review of Literature

The aim of the literature review was to identify and access research reports, which pertain to the subtypes of dementia, interventions that moderate communication, behavioral, and environmental challenges related to dementia symptoms, caregiver strategies for self-care, caregiving tips for activities of daily living, and psychoeducation. Three databases were used: CINAHL, PsycINFO, and the Cochrane Database. Search terms used to elicit literature included dementia, Alzheimer's, Lewy Body, vascular, frontotemporal, caregiving, strategies, interventions, stress, communication, adult learning, adult education, and psychoeducation. Articles were reviewed from nursing and psychological journals. Other dementia information was gathered from the Alzheimer's Association website. It is quite possible that the subject terms used in this literature review did not capture some publications that could be pertinent to this project. However, of the articles obtained, review of the reference lists provided further articles that pertain to this literature review. Peer reviewed and primary research studies were selected. The literature review will focus on Alzheimer's disease, vascular dementia, dementia with Lewy Body, frontotemporal dementia, and caregivers.

Dementia Sub-Types

Impaired memory and cognition are hallmarks of all dementia sub-types. However, the differences in the degree of cognitive, psychiatric, behavioral, and emotional disturbances an individual with dementia experiences will vary depending on the dementia sub-type, stage of the illness, and individual features. Each dementia sub-type has unique pathophysiology, progression, and signs and symptoms. Distinguishing between dementia sub-types such as Alzheimer's disease, vascular dementia, dementia with Lewy Body, and frontotemporal dementia is essential when developing intervention and management plans. In this project, the knowledge about dementia and caregivers contributed to the development of an appropriate education program for select groups of caregivers.

Alzheimer's Disease

Beatty (2006) investigated the historical perspective of Alzheimer's disease, and stated the disease was first discovered by a German psychiatrist and neurologist Dr. Alois Alzheimer in 1906. During that time it was a common occurrence that any patient with a psychological illness was institutionalized. What's more, little attempt or thought differentiated the cause or pathology of mental disorders (Beatty, 2006). However, Dr. Alzheimer noted that individuals living to senescence demonstrated a particular senility. "Dr. Alzheimer hypothesized that physical lesions in the brain caused the distinct dementia" (Beatty, 2006, p.33), though many in his field did not concur with his hypothesis.

Not until the latter part of the 20th century, with technological advances in research tools, equipment, and imaging did Dr. Alzheimer's hypothesis become realized. It was in the 1980s that researchers examined and implicated the role of toxic proteins, identified as plaques and tangles that destroyed nerve cells in the Alzheimer's diseased brain. These findings catapulted genetic research of Alzheimer's disease in the 1990s as well as pharmacological research treatments to halt the progression of the disease (Alzheimer Society of Canada, 2007). In reference to Alzheimer's disease treatment Stahl (2008) stated,

Fortunately, major progress is being made in understanding the cause of Alzheimer's disease and new treatments are being designed to interfere with the known pathological processes in an attempt to halt them, stop disease progression, and potentially to reverse the disease before neurons are irretrievably lost (p. 901).

The exact pathogenesis of Alzheimer's disease has not yet been determined; however, research has uncovered two hallmarks of Alzheimer's disease; amyloid plaques and neurofibrillary tangles (Gong, Grundke-Iqbal, & Iqbal, 2010; Iqbal et al., 2003; Marlow, Cain, Pappolla, & Sambamurti, 2003; Wang, Dickson & Malter, 2006). Formation of amyloid plaques and neurofibrillary tangles are implicated in the overall neuronal loss (Gong, Liu, Grundke-Iqbal, & Iqbal, 2006), brain atrophy and larger than normal cerebral ventricles (Sadock & Sadock, 2007) creating symptoms seen in Alzheimer's disease (American Psychiatric Association, 2000; Beatty, 2006).

Amyloid is a protein fragment normally produced by functions of the body. In healthy brain tissue toxic amyloid protein fragments are broken down and removed. In Alzheimer's disease, the amyloid plaques accumulate in the extracellular spaces of the

cerebral cortex (Launer, 2003), hippocampus (Boss & Wilkerson, 2006), and blood vessels (Boss & Wilkerson, 2006). It is thought that the formation of the toxic β -amyloid protein fragment is produced from abnormal processing of amyloid peptides from amyloid precursor protein (Boss & Wilkerson, 2006; Stahl, 2008; Tabira, 2004).

Furthermore, the accumulation of toxic amyloid plaques interrupts cholinergic neurons, particularly in the basal forebrain relatively early in the disease process, causing impaired memory (Stahl, 2008), thus interfering with the nerve impulse transmission. Theoretically, accumulation of the β -amyloid plaques throughout the brain destroys neurons. Alzheimer's disease is a problem with enhanced buildup of β -amyloid or lack of eliminating it (Stahl, 2008). Launer (2003) examined the use of nonsteroidal anti-inflammatory drug use in Alzheimer's disease:

Neuritic amyloid plaques contain deposits of fibrillar amyloid β ($A\beta$)₄₂ peptides surrounded by remnants of inflammatory reactions and other products of neuronal dysfunction and death. From genetic studies of the amyloid precursor protein and presenilin mutations, there is increasing evidence that the accumulation of $A\beta$ ₄₂ peptides and the formation of neuritic amyloid plaques is a primary feature of the disease... (p. 731).

Beatty (2006) and Stahl (2008) indicated the current thought is that the initial changes in Alzheimer's disease are from abnormal processing of amyloid precursor proteins fragments, with the most toxic fragment β -amyloid. As a result, the initial abnormal processing of amyloid leads to abnormal phosphorylation of tau proteins creating neurofibrillary tangles.

Tau proteins function to stimulate microtubule assembly (Gong et al., 2006) and stabilize the microtubular transport system in neurons (Boss & Wilkerson, 2006).

Microtubules are the neurons transport system allowing substances to be moved from one part of the neuron to another (Stahl, 2008). Neurofibrillary tangles are found inside neurons and are made of insoluble helical filaments from tau proteins that become detached from the microtubule (Boss & Wilkerson, 2006; Stege & Bosman, 1999). Normal phosphorylation is an aspect of tau's functioning; however, it is the hyperphosphorylation of tau that diminishes its functional integrity (Gong et al., 2006).

Fath, Eidenmüller, and Brandt (2002) studied the role of tau hyperphosphorylation in Alzheimer's disease. The study demonstrated that abnormal hyperphosphorylation causes tau to lose its normal stabilizing function, amassing tau collection in the microtubule, creating toxic activity, and accumulating into neurofibrillary tangles. Neurofibrillary tangles are not specific to Alzheimer's disease and are found in other dementia types as well (Tibira, 2004).

Development of abnormal structures such as amyloid plaques and neurofibrillary tangles accompanied by chronic inflammation in neuritic tissues leads to neurovascular dysfunction, resulting in the interference and destruction of cholinergic pathway functioning (Stahl, 2008). Deficiency in the neurotransmitter acetylcholine from cholinergic neurons is implicated in the pathogenesis of Alzheimer's disease (Salama, 2008). Stahl (2008) stated,

Evidence that cholinergic neuronal functioning is one of the earliest neurotransmitters to change in Alzheimer's disease and that it changes dramatically during the first year of symptoms comes from findings that the synthetic enzyme for acetylcholine, choline acetyl transferase, may already be decreased by 40 to 90 percent in cortex and hippocampus by the time of early diagnosis (p. 920).

Stages of Alzheimer's

Symptoms of Alzheimer's are grouped into three stages: early, moderate, and late stages. Distinct features of the three stages are described in this section.

Early Stage. Alzheimer's disease has an insidious onset with few symptoms during the early phase of the disease. Many persons with Alzheimer's disease present in the early stages with some memory problems, but compensate and hide their memory deficits with intact social skills (Smith & Buckwalter, 2005). They may have difficulty remembering recent events or names of people or objects.

Moderate Stage. Individuals at this stage show increased personality changes and continued decline in memory, cognitive ability, and function (Alzheimer's Association, 2010). They may have increasing difficulty doing tasks that were once very familiar to them. For example, they may not be able to do simple chores and are unable to organize, plan or follow directions. Individuals at this stage may need more assistance with personal hygiene, dressing and toileting. Loss of orientation to place and time is demonstrated at this stage. Increased behavioral symptoms such as paranoia, physical aggression, and agitation are demonstrated by screaming, hitting, cursing, and accusatory remarks (Alzheimer's Association, 2010).

Late Stage. Alzheimer's disease is a terminal disease and ends in the death of the individual. This stage often requires full time care of activities of daily living for the individual. Individuals at this stage often lose the ability to ambulate and are at increased

risk for falls and may become bed bound. They have increased difficulty with swallowing and refuse to eat. Moreover, this stage requires more physical and safety care.

The three stages of Alzheimer's dementia can serve as a guide for the dementia sub-types, to some degree. However, the pathogenesis of vascular dementia, dementia with Lewy Bodies, and frontotemporal dementia have distinct signs and symptoms and very diverse disease trajectories.

Vascular Dementia

Vascular dementia caused by cerebrovascular disease affects cerebral vessels from numerous infarcts. Multiple lesions resulting from infarcts commonly occur in the white matter of the brain, cortex and basal ganglia. Cortical infarcts from cardiac or cerebral emboli cause neurologic events that may instigate a specific cognitive impairment (Strub, 2003). Physical abnormalities such as long-standing and uncontrolled hypertension, cardiac disease, and hyperlipidemia contribute to decreased blood flow to the brain resulting in progressive cognitive damage (Nazarko, 2009).

Diagnostic neuroimaging studies typically reveal the presence of multiple vascular changes, strokes, and cerebrovascular disease (Smith & Buckwalter, 2005). Unlike Alzheimer's disease, multi-infarct dementia is attributed by a sudden onset, "...followed by a stepwise and fluctuating course that is characterized by rapid changes in functioning rather than slow progression" (American Psychiatric Association, 2000, p. 160). Rapid changes in functioning are demonstrated by ambulatory difficulties, extremity weakness, falls, drastic personality changes, and mood disturbances (Smith &

Buckwalter, 2005). Summarily, vascular dementia, also termed multi-infarct dementia is estimated to affect 20% of individuals' with dementia (Nazarko, 2009).

Dementia with Lewy Body Disease

Dementia with Lewy Body disease is the second most common cause of dementia after Alzheimer's disease, accounting for 15 to 25% of dementia cases. Lewy Bodies are characterized by small protein deposits found in nerve cells, which interfere with normal brain processes and disrupt chemical actions of acetylcholine and dopamine (Alzheimer's Association, 2011). Lewy Bodies are also found in the brains of people with Parkinson's disease, commonly known to affect motor movement (Alzheimer's Society, 2011).

Dementia with Lewy Bodies is difficult to diagnose because of the similar clinical features of Alzheimer's disease (Alzheimer's Association, 2011). Distinguishing characteristics of Lewy Body dementia from Alzheimer's disease is the variability in cognition, lack of memory impairment in the early stages, visual hallucinations (Yuhas et al., 2006), and motor movement difficulties. Another distinction of Lewy Body dementia is that short-term memory usually remains intact (Yuhas et al., 2006).

Summarily, Lewy Body dementia is a much more progressive disease compared to Alzheimer's disease. Moreover, it is important to correctly diagnose Lewy Body dementia, as it is common to have sensitivity to psychotropic medications used in treating psychotic symptoms (Nazarko, 2009b).

Frontotemporal Dementia

According to Sikkink, Rollinson, and Pickering-Brown, (2007), frontotemporal dementia (FTD), semantic dementia, progressive nonfluent aphasia and progressive ataxia contribute to a complex neurodegenerative syndrome called frontotemporal lobar degeneration. Frontotemporal lobar degeneration (FTLD), a clinically and pathologically degenerative disorder is characterized by progressive deterioration in personality, behavior, emotion, executive function and language (Rabinovici & Miller, 2010).

Tauopathy is one of the mechanisms thought to contribute to this disorder. Tauopathies are described as a set of neurodegenerative disorders caused by neurofibrillary degeneration of abnormally hyperphosphorylated tau protein in neurons. Tau positive pathology is implicated in about 40% of the familial cases of FTD (Baker, et al., 2006). Other FTD cases are associated with inheritance of a tau gene mutation, frontotemporal dementia with Parkinsonism linked to chromosome 17q21 (FTDP-17) (Baker, et al., 2006).

When investigating dysregulation of protein phosphorylation Gong et al., (2006) reported, “The discovery of tau mutations that cause hereditary frontotemporal dementia and Parkinsonism linked to chromosome 17 (FTDP-17) further indicates that tau abnormality alone is sufficient to produce dementia” (p. 1).

Unlike Alzheimer’s disease, frontotemporal dementia has relatively low β -amyloid pathology, making it less destructive to cholinergic pathways (Moretti et al., 2004). Individuals with frontotemporal dementia often exhibit changes in personality,

behavioral disinhibition, and impaired judgment in the early stages yet may demonstrate unimpaired memory and visual-perceptual skill (Merrilees, & Ketelle, 2010).

In summary, frontotemporal dementia is characterized by personality changes that can be difficult to manage. Additionally, frontotemporal dementia is a very progressive disease compared to Alzheimer's disease and has a shorter mean survival of 6 years.

Dementia Symptoms

A number of symptoms may be observed during the course of dementia, including symptoms that manifest from cognitive decline. Recognizing changes in behavior initially alerts families that something is “different” or “wrong” with their loved one (Farran, Loukissa, Perraud, & Paun, 2003).

In the early stages of dementia, behavioral changes are usually subtle and are often times regarded as the “normal aging process”. Behavioral changes associated with dementia are demonstrated by an increase in negative behavior or by a decrease in positive behaviors (Farran, et al., 2003). An example of negative behavior is the individual's paranoia that others are taking objects or stealing personal items. The lack of inhibition, social courtesies, or manners is an example of a decreased positive behavior.

Conclusively, a wide variety of non-cognitive behavioral symptoms pose difficult care management challenges for caregivers ranging from agitation, aggressiveness, wandering, hoarding, sun downing, anxiety, depression, disinhibition, paranoia,

delusions, and hallucinations. The manifestation of such symptoms is an inherent part of the syndrome of dementia (Banerjee, 2009).

Medication Management of Dementia

Psychopharmacologic management for Alzheimer's disease and other types of dementia is used to improve cognitive and functional changes, and behavioral and psychiatric symptoms (Slattum, Swerdlow, & Hill, 2008). The major classification of drug use therapy for maintaining and improving cognition and function are cognitive enhancers. The chemical classes of medication used for cognitive enhancers are cholinesterase inhibitors and N-methyl-D-aspartate (NMDA) receptor antagonists (Slattum et al., 2008). Cholinesterase inhibitor medications include donepezil (Aricept), rivastigmine (Exelon), and galantamine (Reminyl). Currently the only N-methyl-D-aspartate (NMDA) receptor antagonist is memantine (Namenda).

Interventions for behavioral and psychiatric symptoms should be managed first with psychosocial management using environmental modifications and behavioral strategies before psychotherapeutic agents are initiated (Dewing, 2010). Antipsychotic therapy is discouraged as a first line treatment in managing behavioral problems (National Institute for Health and Clinical Excellence, 2006).

Cognitive Enhancers

Currently, no medications exist to cure dementia; however, medications are available to slow or retard the progression of the disease. The only U. S. Food & Drug

Administration (FDA) approved medication, to slow progression of cognitive symptoms, is for Alzheimer's disease, with the exception of one drug also used in Parkinson's disease. A decreased level of acetylcholine (ACh) in Alzheimer's disease is reflected in cognitive and non-cognitive symptoms (Boss & Wilkerson, 2006). The destruction and dysfunction of neurons and synapses can render the cholinergic pathway ineffective. The most promising approach to improve cholinergic deficiency and improve memory impairment is to minimize the destructive forces that interfere with ACh (Stahl, 2008).

Cholinesterase inhibitors are the drug treatments used to inhibit the depletion of the neurotransmitter ACh, especially in the hippocampus and cerebral cortex (Brown, 2009). Acetylcholinesterase inhibitors (AChEI) increase the amount of acetylcholine levels in the brain, with the potential action of maintaining memory and cognitive function. It is common that AChEI are used off-label for mixed or other types of dementia (Ouldred & Bryant, 2008). In the United States, donepezil (Aricept), rivastigmine (Exelon), and galantamine (Reminyl) are the only approved AChE inhibitor medications for mild to moderated Alzheimer's disease (Alzheimer's Association, 2010; Brown, 2009).

Donepezil is a selective AChE inhibitor approved for severe Alzheimer's disease in 2006. Donepezil is metabolized by the CYP450 2D6 and CYP450 3A4 pathways, therefore other medication utilizing these metabolic pathways can induce or inhibit donepezil metabolism by either decreasing or increasing plasma levels respectively (Stahl, 2009). Donepezil interferes with the destruction of AChE in the synapse of cholinergic neurons throughout the body; consequently, temporary gastrointestinal side

effects may occur when taking this medication (Stahl, 2008). Donepezil may interact with anticholinergic medications decreasing the effectiveness of both medications. Donepezil should be cautiously used with individuals, who have cardiac conditions, as risk of bradycardia can occur when taken with beta-blockers (Stahl, 2009).

Rivastigmine was approved in 2000 for Alzheimer's and Parkinson's disease. Rivastigmine is a slow inhibitor of centrally acting AChE as well as an inhibitor of butyrylcholinesterase (BChEI) (Brown, 2009, Stahl, 2008). The properties of BChEI may contribute to the treatment of Alzheimer's disease by enhancing acetylcholine levels in the CNS (Stahl, 2008). Rivastigmine is not metabolized through the liver and does not utilize the CYP450 pathway for metabolism (Stahl, 2009). Nicotine use can increase clearance of rivastigmine. Rivastigmine inhibits peripheral AChE causing gastrointestinal side effects contributing to nausea, vomiting, and weight loss. This medication should be titrated slowly to avoid gastrointestinal upset. A recently developed rivastigmine transdermal patch may minimize peripheral effects that cause gastrointestinal side effects.

Galantamine, an AChEI, modulates ACh on neuronal nicotinic receptors. Stahl (2008) speculates that the inhibition of AChE may be potentiated by the action of galantamine on nicotinic receptors. Pharmacokinetics rely on the CYP450 2D6 and CYP450 3A4 metabolic pathways.

The recently developed class of cognitive enhancers is an N-methyl-D-aspartate (NMDA) receptor antagonist; memantine (Namenda) is prescribed for moderate to severe Alzheimer's disease. Memantine interferes with excessive excitotoxic effects of glutamate released from damaged brain cells associated with memory and cognition in

Alzheimer's disease (Stahl, 2009). The use of memantine is usually given in conjunction with AChEI to potentiate the cognitive enhancing effects for the person with Alzheimer's disease. Memantine is not metabolized by the liver and does not utilize the CYP450 metabolic pathway. There are no adverse interactions when given with AChEI. Memantine must be used cautiously with renal impairment and the dose may need to be reduced, however memantine should be avoided in severe renal disease.

A Cochrane Review (Birks, 2006) examined the results of 10 randomized, double-blind, placebo control studies and concluded that even though the three cholinesterase inhibitors have slightly different modes of action, no differences were reported to their efficacy for mild to moderate Alzheimer's disease.

In conclusion, McShane, Sastre, and Minakaran (2006) investigated the effects and safety of memantine for Alzheimer's disease. These investigators determined that there was an added benefit of administering memantine along with a cholinesterase inhibitor in moderate to severe Alzheimer's disease.

Antipsychotics in Dementia

Antipsychotic medications normally prescribed for psychotic symptoms such as hallucinations and delusions are commonly used to treat behavior challenges for individuals with dementia (Lindsey, 2009; Krishnan & Klaasen, 2009). There are two types of antipsychotics prescribed for psychosis: typical (conventional) and atypical (second generation) medications. Extrapyramidal side effects (EPS), such as drug induced Parkinsonism, dystonia (muscle rigidity, effecting neck, jaw and face), and

akathisia (pacing and restlessness) are more common side effects of typical antipsychotics; however, these side effects can also be seen with typical antipsychotics. When EPS side effects occur, it requires either discontinuing the medication or prescribing other medications to offset the side effects.

A common conventional antipsychotic, haloperidol, is often used for individuals with dementia experiencing behavioral and/or psychiatric symptoms. However, it has the potential to cause adverse symptoms as previously mentioned in addition to the metabolic disorders common with atypical antipsychotics. Haloperidol blocks dopamine 2 receptors decreasing positive symptoms of psychosis (Stahl, 2009). Moreover, haloperidol is not FDA approved for behavioral or psychotic symptoms related to dementia disease.

Atypical antipsychotics have fewer side effects compared with the typical antipsychotics, although newer generation drugs commonly cause weight gain and metabolic changes. The U.S. FDA have submitted “black box warnings” of prescribing these medications due to cerebrovascular, cardiac and mortality risks related to their treatment in individuals with dementia (American Association for Geriatric Psychiatry, 2006; Krishnan & Klaasen, 2009; Lindsey, 2009;). Sink, Holden, and Yaffe (2005) conducted a meta-analysis on psychotropic medication used for psychotic symptoms in dementia and concluded that atypical antipsychotic medications were only moderately effective for psychotic or agitation symptoms.

Schneider et al. (2006) conducted a double blind, placebo controlled- trial of individuals with Alzheimer’s disease who were experiencing psychosis, aggression and

agitation. The individuals with Alzheimer's disease experiencing these symptoms were randomized to receive olanzapine, quetiapine, risperidone, or placebo, for 36 weeks, results indicated that there was no significant difference in treatments. Schneider et al (2006) concluded, "Adverse effects offset advantages in the efficacy of atypical antipsychotics drugs for the treatment of psychosis, aggression or agitation in patients with Alzheimer's disease" (p. 1525).

In summary, when using antipsychotic medication for treatment of behavioral and psychiatric symptoms, caution must be heeded to balance the expected benefits with potential risks. In addition, there must be diligent monitoring for medication effectiveness and adverse effects. Psychosocial interventions are the primary means for managing challenging behaviors of individuals with dementia. Antipsychotics are recommended as a second-line treatment for challenging behaviors (Slattium et al., 2008).

Caregivers

Families will be the primary caregivers of more than 13 to 14 million individuals with dementia by the year 2050 (Hepburn et al., 2005; Simpson & Carter, 2010). Nearly 11 million Americans provide unpaid care to individuals with dementia (Alzheimer's Association, 2010). Informal caregivers provide the majority of the care for those individuals with dementia. Informal caregiving is not a role a person usually seeks; rather it transpires over time, as the individual with dementia requires increased care and

supervision. “Few family caregivers are prepared for the long-term demands of the deteriorating and disabling effects of dementia” (Ostwald, Hepburn, Burns, 2003, p. 37).

A number of reasons exist why some persons take on the role of caregiver for individuals with dementia. Examples are a sense of duty, financial restraints (Yaffe et al., 2002), cultural and familial obligation (Yaffe et al., 2002), fulfillment of a promise, sense of accomplishment (Carbonneau, Caron, & Desrosiers, 2010), and respect and satisfaction of caring for the person with dementia (Vikström, Josephsson, Stigsdotter-Neely, & Nygård, 2008). “When PWD [person with dementia] remain in community-based dyads, the primary informal CG [caregiver] play a principal role in managing the care environment and providing for the needs of the persons with dementia” (Campbell, 2009, p. 184).

Taking on the role of caregiver and providing for the needs of an individual with dementia can be a complex endeavor and may be fraught with feelings of loss and aloneness. Separation from activities outside of the caregiving role can contribute to a caregiver’s sense of loneliness and isolation (Vikström et al., 2008). These feelings compound a caregiver’s burden especially with the care recipients disease progression and ongoing decline necessitating around the clock care.

Caregivers experiencing increased responsibility with household chores, workload (Coon & Evans, 2009; Vikström et al., 2009), financial management (Michon, Weber, Rudhard-Thomazic, & Giannakopoulos, 2005), activities of daily living and personal care (Paun et al., 2004), and managing unwanted behaviors (Etters et al., 2008; Farran et al., 2003) may contribute to the burden of caregiving. Caregivers of individuals

with dementia must handle difficult situations and problem-solve numerous difficulties on a daily basis. For example, caregivers may have increasing difficulty interpreting communication from individuals with dementia (Small, Gutman, & Hillhouse, 2003) who demonstrate problems with perception, language (Sherrod et al., 2010), memory, and the ability to comprehend (Smith & Buckwalter, 2005). All of which pose potential barriers with verbal and nonverbal communication.

Communication difficulties can be a hallmark frustration, as caregivers try to understand and decipher communicative behaviors of the individual with dementia. In addition to communication difficulties, caregivers may experience the mounting challenges of day-to-day care, adding stress and burden to the demands of care, which threatens their sense of well-being and endurance (Yuhás et al., 2006). Caring for an individual with dementia is “uniquely challenging among caregiving situations with greater stress and more problems associated with duties” (Campbell, 2009, p.182). Mounting evidence indicates that spousal and family caregivers are vulnerable to stressors due to the pressures of caring for a person with dementia (Smith et al., 2004; Van Den Wijngaart, Vernooij-Dassen, & Felling, 2007).

Caregiver stress considered to be effected by the individual's with dementia behaviors may well influence the caregivers stress process, and likely determines the relationship quality and care environment. Farran et al., (2003), Hepburn et al., (2005), Hepburn et al., (2007), Michon et al., (2005), Ott, Kelber, & Blaylock, (2010), Smith & Buckwalter, (2005), and Yuhás et al., (2006) have focused on challenging behaviors associated with dementia, and how these behaviors influence caregiver stress and burden.

Hepburn et al. (2005) stated, “Managing day-to-day life and handling unpredictable behavior seem to be the most oppressive aspects of caregiving” (p. 54). The roller-coaster effect of dealing with unpredictable behaviors can be overwhelming for caregivers and threatens their perceived or actual management of stressful events (Ostwald et al., 2003).

Increased caregiver burden (Etters et al., 2008; Michon et al., 2005), unmanageable behavior and psychiatric symptoms (Connor et al., 2008; Farran et al., 2007; Yuhua et al., 2006), and the inability to “meet the complex needs of the care recipient with end-stage dementia” (Ott, Kelber, & Blaylock, 2010, p.90), are all major factors for seeking long-term care placement.

In their investigation of caregiver burden Papastavrou, Kalokerinou, Papacostas, Tsangari, and Sourtzi (2007), stated that the level of caregiver stress and burden was not alleviated when the individual with dementia was placed in a long-term home. Ott et al., (2010) reported, placing an individual with dementia in a long-term home triggered a sense of loss and increased caregiver grief. Therefore, the decision to place an individual with dementia in a long-term care home does not automatically provide relief from the burdens of caregiving (Campbell, 2009). Rather, the burden of day-to-day care at home is replaced with despair, worry, loneliness, and relinquished control of the primary caregiving role (Ott et al., 2010).

CHAPTER 3

METHODOLOGY

Project Design

The purpose of this project was to develop an educational program. The program included a comprehensive literature review, input gathered from two assisted living homes and one senior center, and a one hour educational presentation, presented at the two assisted living homes and the senior center. The target population was self-selected caregivers of individuals with dementia and interested individuals wanting to learn more about caring for family members or friends who were diagnosed with dementia.

Assessment

The author conducted an informal assessment of educational needs of family caregivers prior to planning and developing the one hour educational presentation. The assessment consisted of two parts, suggested content and location for the educational presentation. First, the author met with the support group coordinator of the first assisted living home, the activities director of the second assisted living home, and manager of the senior center to determine if a educational presentation would be appropriate for family caregivers. These individuals identified three primary topics to be discussed for the educational presentation: signs and symptoms of dementia; interventions to assist with communication, behavioral and environmental management; and community resources available to caregivers. Content for the educational presentation was based on a

comprehensive literature review, input gathered from the three facility contacts, and this author's experience as a professional nurse who worked in the palliative care department. Second, the author toured the assisted living homes and the senior center to identify an appropriate location for the educational presentations.

Setting

Two local assisted living homes and a local senior center agreed to host the educational presentations. Dates and times for each educational presentation were scheduled based on availability of facility meeting rooms and on scheduled times of regularly scheduled caregiver support groups. The author explained to the contact person at each of the three facilities, the support group coordinator and activities director of the assisted living homes, and manager of the senior center that there would be no identifying information given to the author regarding the participants. The assisted living homes advertised the educational presentation to members of their dementia support groups. The senior center advertised the educational presentation through the monthly newsletter and in the senior center section of the community newspaper.

Facility Descriptions

Assisted Living Home 1. The recently built assisted living home, opened for less than six months, caters to individuals who have a primary diagnosis of dementia. This 65-bed facility has a current resident census of 18. The foyer is bright and open with plenty of comfortable lounging chairs for residents to gather. The interior of the home is

elegantly furnished with a warm inviting décor of rich earth tone furnishings and carpet. Curio cabinets with memorabilia and artwork decorate the hallways.

Assisted Living Home 2. The well-established assisted living home is surrounded by landscaped gardens and patios and has been in the community for 6 years. There are several one bedroom and studio apartments, and larger suites for couples. The interior of the home has a warm décor with couches and a fireplace near the foyer. Residents eat nutritious home cooked meals in an elegant dining room. There are several sitting areas throughout the home, where residents can recreate and socialize.

Senior Center. The senior center is a large two-story community facility with several rooms on the main floor. A dining hall with the capacity to comfortably holding 250 people, a commercial kitchen, a sitting area with several couches and rocking chairs. The lower level houses the computer learning center and library, the second hand store, the wood workers shop, the foot and blood pressure clinic and the updated exercise room and fitness center. There are meeting rooms throughout the center and an intergenerational child-learning center located inside the center entrance. The senior center has over 1800 members age 50 and older. Many of the seniors participate in a variety of educational and learning activities offered through the senior center.

Institutional Review Board Approval

The Institutional Review Board for the Protection of Human Subjects at Montana State University approved the project. Participants attending the sessions would not be identified in any way.

Planning

The author selected evidence-based content suitable for this audience from the comprehensive literature review, and the National Institute on Aging, and the Alzheimer's Association. The author developed a 50-minute educational presentation covering the following topics: signs and symptoms of dementia; interventions to assist with communication, behavioral and environmental management; and community resources to help with caregiver burden. The content was divided into six sections: (a) an overview of definitions, diagnostic criteria, and risk factors; (b) communication, behavioral, and environmental strategies; (c) caregiver self-care; (d) support groups and community resources; (e) caregiving tips on activities of daily living and; (f) medications.

The participants' learning objectives for the educational presentation were to identify criteria for dementia diagnosis, identify communication techniques to convey a sense of caring and understanding, name behavior modifications to increase sense of well-being, name strategies for self-care, and identify interventions to ease caregiving. The objectives for the educational presentation were included in the Power Point presentation (Appendix B). The author allotted time for questions and discussion.

Implementation

At the beginning of each educational presentation, written copies of the Power Point, blank 3x5 cards, and the evaluation form (Appendix C) were distributed to the audience. The participants were instructed to write topic issues or concerns on the 3x5

cards and return them to the author without signing the cards. The application of Knowles (1980) self-directed learning principle was used to garner individual participants' questions about dementia or caregiving and to foster dialogue. Throughout the educational presentation the author read the note cards, discussion ensued.

The author showed respect and listened to the participants, allowing them to share their experiences about caregiving. At the end of the educational presentation, participants were instructed to complete and return the evaluation form without placing their name on the form. The author stayed after the educational presentation to meet with individuals who had personal issues with caregiving.

Assisted Living Home 1

The educational presentation was held in a spacious multipurpose room, allowing adequate seating for participants. The room was clean and open, comfortable temperature, with wood flooring and décor consistent with up-to-date furnishings in warm tones. The multipurpose room can serve as a dining area and or activities room. Located in one corner of the room is a small kitchen setup for cooking activities for the residents. Refreshments were available for participants.

Assisted Living Home 2

The educational presentation was held on the second floor in a small open area, adjacent to the elevator and two main hallways to resident apartments. This room was a smaller area than the meeting space at Assisted Living Home 1. Some participants sat in

chairs at tables and others sat in chairs without tables. There was some activity of residents and visitors using the elevator which distracted from the presentation. The acoustics did not seem to be a problem when there was discussion. The facility provided refreshments for participants.

Senior Center

The educational presentation at the senior center was located on the upper level. There was minimal natural light, the artificial lighting was adequate. The room was appropriate for the participants, but felt small because there were several chairs set up on one end of the room. At the other end of the room, there were four tables set up making a square with chairs around the tables. The author stood at one end of the table and participants sat around the tables making it easy to have discussion. There were no refreshments provided at this presentation.

CHAPTER 4

PROJECT OUTCOME

The purpose of this project was to develop an educational program. The program included a comprehensive literature review, input gathered from two assisted living homes and one senior center, and a one hour educational presentation, presented at the two assisted living homes and the senior center. There is a plethora of information about caring for individuals with dementia. However, it is difficult for caregivers to access accurate and appropriate information about meeting the individual needs of the person with dementia while also meeting their own needs.

The educational presentation at each of the three facilities was evaluated by the participants. The author provided emotional support and normalized participant's experiences throughout each of the three educational presentations. Additionally, some participants who requested further assistance concerning personal situations met with the author at the end of the educational presentation.

A total of twenty-nine individuals participated in the educational presentation. Of these 20 completed the evaluation form. The participants were engaged in discussion, asked questions and seemed interested in learning what they could to ease the burden of caregiving.

Unmet emotional needs, feelings of guilt, witnessing the progression of disease, increased symptom management, and grief and loss were five consistent themes raised by participants during the educational presentation at each of the three facilities.

It is important to note that participants who cared for their loved one at home had different emotional issues than participants who had their loved one cared for in an assisted living home. Each group of caregivers reported having unmet emotional needs; however, the nature of emotional support differed based on the progression of their loved one's disease. Although, the educational presentation offered solutions and ideas about easing caregiving, the majority of participants were concerned with the emotional component of witnessing the slow incremental losses and progression of disease of their loved one. During the educational presentation, participants raised questions that encouraged other participants to join the dialogue. The participants expressed a variety of caregiver concerns based on the level of care required and the level of increased dementia symptoms involved. For example, one participant reported her husband was in a facility for a one-month trial basis to give her respite. She reported feeling very guilty about not caring for her husband at home, and when she visits him, he becomes angry with her for leaving him at the facility. She also acknowledged feeling guilty because she knows her husband better than anyone else. The aides and nurses at the facility did not understand her husband's idiosyncrasies the way she understands them.

Many of the participants shared stories and experiences about caring for their loved one. One participant shared how difficult it was to have his wife in a facility. He shared his feelings about feeling guilty for doing so; he further explained that his wife becomes increasingly upset when he visits her.

One participant expressed an interest in learning more about the progression of dementia and wanted to know more about what to anticipate in terms of symptoms as the

disease progressed. Another participant, with a mother who was eating less and was bed bound, shared her concern about what she will need to do when her mother nears the dying stage. This participant wanted more information on the end-stage of dementia care, which was not covered in the dementia presentation.

Some participants engaged in dialogue concerning behavioral interventions. The participants expressed many concerns ranging from dealing with paranoia to managing stress of their loved one's repetitive questions. Several questions from participants requested specific intervention that they could implement. However, the author stressed that individuals with dementia may respond differently based on the intervention and to the emotional response of the individual implementing the intervention (Campbell, 2009).

The author also discussed various approaches for using behavioral techniques and strategies to implement; in addition, the author used case scenarios to discuss behavior techniques to improve positive aspects of caregiving (Carbonneau et al., 2010). The educational presentation was not designed to address each of the individual participants' needs. Some participants requested specific techniques and interventions for their family member. For example, one family member asked what could be done to help his mother who repeatedly asked the same question. Another family member asked what to do when his family member expressed paranoia about others taking her belongings. Some participants vocalized being more interested in learning about psychosocial strategies rather than discussing tips of activities of daily living. The author provided flexibility during each educational presentation, by following the participants lead.

Participants discussed the struggles of caregiving. One member shared her experience of placing her mother-in-law in an assisted living home, and how her mother-in-law complains about wanting to return home when she and her husband visit her. The participant also described how the paranoia of being home alone resulted in placing her mother-in-law in an assisted living home. Another participant indicated that she did not know how to respond to her mother's anxiety and repetitive paranoia. Another participant shared the difficulty she experienced when convincing other family members that her mother had dementia, as evidenced by forgetting day-to-day events. One participant shared a concern that she would not be able to care for her mother's personal needs when the dementia increased, consequently her mother would be admitted to an assisted living home.

Grief and loss were also commonly expressed by participants and these feelings were elaborated throughout the educational presentation. The group members discussed their feelings about caregiving and the burdens of caregiving. The author validated the difficulties of caregiving and normalized their experiences. The author also encouraged the participants to attend Alzheimer's support groups in the community to gain further support from others who have similar feelings and experiences (Coon & Evans, 2009).

After each educational presentation, some participants expressed appreciation for the educational presentation. Some participants also requested further suggestions for specific individual concerns. One participant indicated that she appreciated the reminder of avoiding the word "don't" with her mother-in-law who has Alzheimer's disease.

Evaluation

Evaluation and comments from each educational presentation were collected and summarized as group data. Nine participants did not submit an evaluation form. Twenty participants N=20 submitted the evaluation form. Two evaluation forms included written comments. The first comment was “Not a caregiver at this point. Informational, but I could read or study this. But interactive talk good”. The second comment was “Thank you!”

The evaluation form consisted of six questions. Each question could be rated strongly agree, agree, neutral, disagree, or strongly disagree. Responses to each of the six questions follows:

Question 1. *The information that was provided was important and useful to me and to my care of my family member.* Seventeen participants responded “strongly agree” and three participants responded “agree”.

Question 2. *The presentation provided helpful information and practical resources.* Sixteen participants responded “strongly agree” and four participants responded “agree”.

Question 3. *I understand how to implement coping strategies when overwhelmed with caring for family member.* Thirteen participants responded “strongly agree” and seven participants responded “agree”.

Question 4. *This presentation enables me to be a more effective caregiver.* Fifteen participants responded “strongly agree” and five participants responded “agree”.

Question 5. *I feel less stress in caring for my family member through the education, I learned today.* Eight participants responded “strongly agree”, nine participants responded “agree”, two participants responded “neutral” and one participant responded “disagree”.

Question 6. *I would recommend this educational presentation to my family and friends.* Seventeen participants responded “strongly agree” and three participants responded “agree”.

It is important for nurses to use teaching and learning principles when developing educational program objectives.

The two teaching objectives for the educational program were to:

1. Increase caregivers’ knowledge of symptoms of dementia and the psychosocial interventions to address communication, environment, and behavioral management.
2. Increase caregiver’s awareness of the capabilities of a person with dementia.

An evaluation of the educational program objectives revealed that objective one; Increase caregivers’ knowledge of symptoms of dementia and the psychosocial interventions to address communication, environment, and behavioral management, was attained. This was reflected by the responses “strongly agree” (n=17) and “agree” (n=3) to question one on the evaluation form, *I understand how to implement coping strategies when overwhelmed with caring for family member.*

Objective two of the educational program, Increase caregiver's awareness of the capabilities of a person with dementia, was partially attained. Although participant responses to question three, *I understand how to implement coping strategies when overwhelmed with caring for family member* "strongly agree" (n=13) and "agree" (n=7) and question four, *This presentation enables me to be a more effective caregiver* "strongly agree" (n=15) and "agree" (n=5) responses to question five, *"I feel less stress in caring for my family member through the education, I learned today"*, were varied, "strongly agree" (n=8), "agree" (n=9) "neutral" (n=2) and "disagree" (n=1). The possible reason that the responses to question five were varied was that participants' individual concerns were not addressed during the educational presentation.

CHAPTER 5

REFLECTIONS

Lessons Learned

The one hour educational presentation offered general information about dementia and caregiving. Topics discussed during the educational presentation were: signs and symptoms of dementia; interventions to assist with communication, behavioral and environmental management; and community resources to help with caregiver burden. The author noted that the educational presentation was not an appropriate venue for addressing the various individual emotional needs expressed by the participants. The most critical lesson learned by the author was, in order to support caregivers of individuals with dementia, it is imperative to address the emotional and psychological needs of the caregiver prior to providing information on interventions and strategies when caring for individuals with dementia.

The second key lesson learned by the author was that there is not a “one size fits all” approach to caregiving for individuals with dementia. Although, the educational presentation offered by the author provided general information, it did not address personal interventions and strategies for individuals with dementia.

The author’s awareness of the importance of providing individual follow-up was the third lesson learned. Although some participants expressed specific concerns

immediately following the educational presentation, the author was unable to follow up with the participant on a long term basis.

The fourth lesson learned by the author was that the educational presentation covered some information that was not pertinent to the participants. For example, the author addressed safe driving issues for persons with dementia. The majority of participants who had loved ones with dementia had already dealt with the issue of driving. The educational presentation was developed in response to the information gathered from the contact individuals from the two assisted living homes and the senior center. Conceivably, gathering information from the caregivers during a support group would have elicited greater information of their learning needs. The author could have developed a educational presentation based on an assessment of the caregivers' needs, rather than the assessment by the facility contacts.

The fifth lesson learned was that participants in each educational presentation expressed different concerns. The educational presentation was guided by the Power Point presentation; however, the author encouraged discussion and questions throughout the educational presentation.

The sixth lesson learned by the author was the importance of developing specific educational presentations that addressed psychosocial interventions or addressed caregiving for activities of daily living, thereby allowing more time for discussion. Another consideration would be to present a two or three part series of educational presentations on dementia and caregiving. A series of educational presentations would permit in-depth explanation and instruction of the subject matter. In addition, the

sessions would allow for a variety of learning strategies such as role playing and practicing new skills and behaviors.

The seventh lesson learned by the author is the importance of developing an evaluation tool that would indicate the learners' attainment of the educational presentation objectives. Another method of evaluating the learners' attainment of the objectives would be reviewing and discussing interventions and skills that would meet the educational presentation objectives.

The final reflection is the importance of recognizing that family caregivers are interested in specific interventions for their situation. For example, a participant in the educational presentation had a question about decreasing food and fluid intake because her mother was in end-stage dementia, yet another participant in the same session experienced the opposite problem with her loved one's new onset dementia and the behavioral symptom of hoarding food.

Dementia is a dynamic disease process characterized by a progressive declining trajectory, and caregivers struggle with the continuous changes in their family member's symptoms. An educational presentation addressing concerns of a family member with a newly diagnosed dementia is vastly different than a dialog session that addresses concerns associated with end-stage dementia.

Implications and Recommendations

A family psychiatric mental health nurse practitioner (FPMHNP) is a specialist expected to deliver primary mental health care services to individuals and families across

the life span. The FPMHNP provides comprehensive care, which includes assessment, diagnosis, treatment, and management of clients seeking mental health services. The role of FPMHNP also includes collaborating and consulting with clients primary health care providers to assist in the promotion of optimal mental health care. Caring for the mental health needs of individuals with dementia and their caregivers can be served by the role of the FPMHNP.

One implication for nursing practice is that dementia impacts personal, interpersonal, psychosocial, emotional, economic, and caregiving domains (Andrén & Elmståhl, 2009; Yuhas et al., 2006). During health care appointments with individuals with dementia, nurse practitioners should also assess the well-being of caregivers by assessing caregiver stress, family and social support systems, financial concerns, and individual emotional and physical needs. The author's recommendations would be to assess caregivers' care needs based on the literature (Vellone, Piras, Talucci, & Cohen, 2007). Questions for the caregiver should include questions about whether or not their needs are being met and whether he/she is caring for him/herself. Family conflict, decreased social support, and limited social interaction can be a consequence of caregiving for a family member with dementia (Etters et al., 2008).

Another implication for the FPMHNP is to provide anticipatory guidance for the caregiver about potential challenging behaviors demonstrated by individuals with dementia. It is also important for the FPMHNP to provide appropriately tailored psychosocial interventions to decrease unwanted behaviors that lead to stressful events (Andrén & Elmståhl, 2009; Etters et al., 2008; Farran et al., 2003). Providing additional

literature and information about local community caregiver and Alzheimer support groups, respite care facilities, and day programs for those with dementia can assist the caregivers with social support networks (Brown & Chen, 2008).

Finally, as a FPMHNP, it is important to assess caregiver burnout and the burden of caregiving. According to the Alzheimer's Association (2010) nearly 40% of the caregivers caring for individuals with dementia report high or very high emotional stress, about one-third describe that they suffer from depression. Family psychiatric mental health nurse practitioners are in a position to assess and evaluate the caregiver and individual with dementia dyad, and can offer individual strategies and interventions to improve the dyad's quality of life.

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APPENDICES

APPENDIX A

PERMISSION TO USE HUMAN SUBJECTS



INSTITUTIONAL REVIEW BOARD
For the Protection of Human Subjects
FWA 00000165

960 Technology Blvd. Room 127
c/o Veterinary Molecular Biology
Montana State University
Bozeman, MT 59718
Telephone: 406-994-6783
FAX: 406-994-4303
E-mail: cherylj@montana.edu

Chair: Mark Quinn
406-994-4707
mquinn@montana.edu
Administrator:
Cheryl Johnson
406-994-6783
cherylj@montana.edu

MEMORANDUM
.....

TO: Kammiell Smith
FROM: Mark Quinn, Ph.D. Chair *Mark Quinn Ch.*
Institutional Review Board for the Protection of Human Subjects
DATE: October 13, 2010
SUBJECT: *Supporting Caregivers Through Education on Dementia [KS101310-EX]*

The above research, described in your submission of October 13, 2010, is exempt from the requirement of review by the Institutional Review Board in accordance with the Code of Federal Regulations, Part 46, section 101. The specific paragraph which applies to your research is:

- (b)(1) Research conducted in established or commonly accepted educational settings, involving normal educational practices such as (i) research on regular and special education instructional strategies, or (ii) research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.
- (b)(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability, or be damaging to the subjects' financial standing, employability, or reputation.
- (b)(3) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior that is not exempt under paragraph (b)(2) of this section, if: (i) the human subjects are elected or appointed public officials or candidates for public office; or (ii) federal statute(s) without exception that the confidentiality of the personally identifiable information will be maintained throughout the research and thereafter.
- (b)(4) Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available, or if the information is recorded by the investigator in such a manner that the subjects cannot be identified, directly or through identifiers linked to the subjects.
- (b)(5) Research and demonstration projects, which are conducted by or subject to the approval of department or agency heads, and which are designed to study, evaluate, or otherwise examine: (i) public benefit or service programs; (ii) procedures for obtaining benefits or services under those programs; (iii) possible changes in or alternatives to those programs or procedures; or (iv) possible changes in methods or levels of payment for benefits or services under those programs.
- (b)(6) Taste and food quality evaluation and consumer acceptance studies, (i) if wholesome foods without additives are consumed, or (ii) if a food is consumed that contains a food ingredient at or below the level and for a use found to be safe, or agricultural chemical or environmental contaminant at or below the level found to be safe, by the FDA, or approved by the EPA, or the Food Safety and Inspection Service of the USDA.

Although review by the Institutional Review Board is not required for the above research, the Committee will be glad to review it. If you wish a review and committee approval, please submit 3 copies of the usual application form and it will be processed by expedited review.

APPENDIX B

POWERPOINT SLIDES

Overcoming Challenges of Caregiving for a Family Member with Dementia

Kamiell Smith BSN, RN
Montana State University
Family Psychiatric Mental Health Nurse
Practitioner Graduate Student

Learning Objectives

- Identify criteria for dementia diagnosis
- Identify 3 communication techniques to convey a sense of caring and understanding
- Name 3 behavioral modifications to increase sense of well-being
- Name 3 strategies for self-care
- List 4 interventions to ease caregiving

Overview

- Diagnostic criteria
- Review of risk factors
- Interventions
 - Communication techniques
 - Behavioral strategies
 - Environmental modifications
- Driving
- Caregiver self care
- Support groups/resources
- Caregiving Tips
 - Bathing Dressing
 - Eating/Nutrition
 - Toileting
 - Sleep
- Connect with nature
- Medications

Diagnostic Criteria

- Dementia of Alzheimer's Type
 - Decline in Memory and least one of the following cognitive deficits
 - Difficulty with language
 - Inability to identify objects
 - Inability to make appropriate judgments
 - Impaired movement
 - Lack of cognitive ability must impact activities of daily living

American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision. Washington, DC: American Psychiatric Association, 2000.

Risk Factors for Dementia

- The greatest risk factor for Alzheimer's disease is advancing age, but Alzheimer's is not a normal part of aging (Alzheimer's Association, 2010).
 - Aging
 - Parkinson's
 - Hypertension
 - Cardiovascular risks
 - Alcoholism



Psychosocial Interventions

- Communication techniques
 - Used to minimize and prevent behavioral symptoms
- Behavioral strategies
 - Used to decrease unwanted behavioral symptoms
- Environmental modification
 - Allows them to participate and be as independent as possible

Communication

- Choose simple phrases and words
- Be gentle and calm
- Make eye contact
- Give time to respond
- Be sensitive to tone of voice
- Be sensitive to body language
- Use distractions
 - Communication becomes a problem

Communication

- Refrain from criticizing
- Remember they can hear you
- Ask “yes” or “no” questions
- Use visual cues or pictures
- Avoid the word “Don’t”



Behavioral Modifications

- Focus on feelings and emotions
- Avoid reasoning
- Have a sense of humor
- Establish a consistent routine
 - be flexible as the need presents
- Creating a sense of familiarity
 - surroundings
 - familiar faces
 - knowing their habits and skills
 - promotes positive feelings
 - decreases anxiety



Responding to Agitation

- Early Dementia
 - provide a regular routine
 - consistent day-to-day activities
 - minimizes stress and agitation.
- Mid-late Dementia
 - knowledge of personal habits, practices and preferences
- Keep a log -pinpoint triggers.
 - Knowing triggers helps prevent future occurrences.

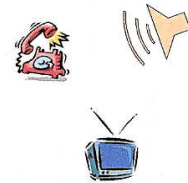
Environment

- Provide safety
- Display pictorial cues and signs
- Lighting
- Flooring
- Interior colors and decorations



Environment

- Background Noise
 - Television
 - Telephones
 - People talking
- Over stimulation
 - Too much activity
 - Busy public areas
- Under stimulation
 - Boredom
 - Lack of interaction



Driving

- Slow reaction time
- Day vs. Night
- Deny a problem
- Discuss concern with doctor
- Dents or scratches
- Gone for a long time



Caregiver Self Care

- It is okay to care for yourself
- Bozeman Senior Center offers Alzheimer Respite Program
- Day stay and Respite stay at Highgate and Spring Creek Inn
- Ask family and friends to stay with loved one so you can get out
- Schedule time for yourself
- Exercise
- It is normal to feel sad, frustrated, lonely, angry, and discouraged

Support Groups

- Senior Center: 406-586-2421
Meetings 1st Wednesday of month at 9:30 and 3rd Wednesday at 3:30
- Spring Creek Inn: 406-586-0074
Meetings 1st Tuesday of each month at 1:00 and 2nd Tuesday at 5:00
- Highgate: 406-587-5100
1st Wednesday of each month at 5:30

Resources

- Aging services Help Line 1-800-551-3191
- Bozeman Area IV Agency on Aging 1-800-356-6544
- Gallatin Valley Senior Source 2010 online
- Senior companionship program and the new Alzheimer's in-home care program 406-586-2421
- Alzheimer's Association Safe Return Home Program (www.alz.org)

Caregiving Interventions

- Bathing
- Dressing
- Eating and Nutrition
- Toileting
- Sleep
- Connecting with Nature
- Medications



Assistance with Bathing

- Establish a routine
- Have the bathroom warm
- Have supplies ready before bathing
- "It is time for a bath"
- Take time, don't rush




Assistance with Bathing

- Allow the person to do for themselves
 - Explain Step-by-step
 - Encourage them to help you
 - Use physical and verbal cues
 - Give them a wash clothe to use
 - Sponge bath in between baths


Assistance with Dressing

- Establish a routine
- Encourage them to assist you
- Limit choices to two
- Make it fun
- Arrange clothes in sequential order



Assistance with Dressing

- Easy to put on
- Elastic waistbands
- Velcro and zippers
- Clothing on backwards
 - zippers in back
 - Button in back





Eating and Nutrition

- Interventions to make eating simpler
 - Do not rush
 - Use colored plates
 - Cut food
 - Place one item at a time on plate
 - Provide finger foods
 - Provide liquid supplements
 - Provide high protein foods



Eating and Nutrition

- Caregivers should be alerted to chewing and swallowing risk
 - Grind food
 - Soft foods
 - Thick liquids vs. thin liquids
 - Do not use straws
 - Cold drinks vs. hot drinks

Toileting





- Establish a toileting schedule
- Automatic night light
- Paint bathroom wall behind toilet
- Reminders during day
- Eliminate fluids after supper
- Ignore accidents
- Avoid constipation

Sleep



- Establish a bedtime routine
- Have relaxing time prior to bedtime
- Maintain exercise, walks
- Limit caffeine
- Get outdoors
- Avoid napping in daytime

Connect with Nature

- Multimodal sensory stimulation
 - Walking outdoors
 - Gardening
 - Bird watching
 - Sitting outside looking at flowers
 - Listening to a fountain
 - Listening to bird calls



©Somn, A. (2010). The importance of getting back to nature for people with dementia. *Journal of Gerontological Nursing*, 35(2), 17-22.

Medications

- There is no medication to prevent or cure dementia
- Medication to slow progression
 - Aricept®
 - Exelon®
 - Namenda®
 - Razadyne®

Medications

- Aggression
- Agitation
- Inappropriate urination/defecation
- Wandering
- Hoarding
- Sexual disinhibition
- Screaming
- Cursing



Medications

- Medication risks/benefits.
- Focus on specific symptom
- Some medications used for agitation
 - Ativan
 - Klonopin
- Some medications used for aggression
 - Depakote®
 - Tegretol®
 - Trileptal®

Medications

- Behavioral Disturbances
 - Hallucinations/Paranoia
 - Delusions
 - Aggression
- Medications used for behavioral disturbance.
 - Risperdal®
 - Seroquel®
 - Zyprexa®

Questions

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APPENDIX C

CAREGIVER EVALUATION FORM

Caregiver Evaluation Form	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
The information that was provided was important and useful to me and to my care of my family member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The presentation provided helpful information and practical resources.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how to implement coping strategies when overwhelmed with caring for family member.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
This presentation enables me to be a more effective caregiver.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel less stress in caring for my family member through the education, I learned today.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would recommend this educational presentation to my family and friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>