

Assessing Educational Needs of Unlicensed Assistive Personnel
in Assisted Living Facilities Caring for Dementia Patients

Randa Eury, APRN-BC

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Abstract

Background: The World Health Organization predicts the number of dementia cases worldwide to grow to 65.7 million by 2030 and 115.4 million by 2050. As this occurs, an increased number of older adults are expected to seek supportive services in residential care or assisted living facilities (ALF) to assist with increased care needs. In 2010, over 40% of ALF residents carried a diagnosis of Alzheimer's disease (AD) or another type of dementia. In the ALF setting, unlicensed assistive personnel (UAP) provide the majority of patient care, yet likely receive insufficient education and training on the disease process and how to deal with behavioral and psychological symptoms of dementia (BPSD).

Method: A quality improvement project with an educational program developed by the University of Iowa for UAP caring for dementia patients in the ALF setting. A needs assessment was performed via retrospective chart review to support the need for the program. A modified version of the Alzheimer's Disease Knowledge Scale (ADKS) was administered to establish a baseline understanding of dementia and familiarity with BPSD. This information supported the need for additional dementia specific education among the UAP at this facility. An educational intervention utilizing the Progressively Lowered Stress Threshold (PLST) model was provided to the UAP with the modified ADKS administered again following education.

Results: Analysis of the data showed the majority of residents carried a diagnosis of dementia and were being treated with a cholinesterase inhibitor. Benzodiazepines were used less frequently than antidepressants for these residents. A paired T-test analysis produced a significant improvement in ADKS scores between the pre and post-test.

Interpretation: Data analysis demonstrated the improved UAP knowledge of dementia and BPSD and UAP provided feedback on feeling better prepared to care for dementia patients.

Assessing Educational Needs of Unlicensed Assistive Personnel

In Assisted Living Facilities Caring for Dementia Patients

Dementia is a public health priority that will affect most people in their lifetime, either directly or indirectly. Projections are that dementia cases will nearly double every 20 years in the coming decades (World Health Organization [WHO], 2012). The World Health Organization (WHO, 2012) predicts the number of dementia cases worldwide to grow to 65.7 million by 2030 and 115.4 million by 2050. As this occurs, an increased number of older adults are expected to seek supportive services in residential care or assisted living facilities (ALF) to assist with increased care needs.

Adequate planning and preparation to ensure necessary care for these patients is imperative. Alzheimer's Dementia (AD) is the most common form of dementia with age being the greatest risk for development; over 40% of people over the age of 85 develop dementia (Casey, 2012). In the early and middle stages of the disease, symptoms vary from forgetfulness, difficulty with decision-making and mood changes, being unable to live alone safely and difficulty with comprehension of time and location. Later stages of the disease are often associated with behavioral and psychological symptoms of dementia (BPSD) that can make continued provision of care in the home setting difficult; BPSD can occur in up to 80% of people with dementia (Casey, 2012).

The development of BPSD, along with the significant assistance required with activities of daily living (ADL's) and near constant supervision, necessitate some families to seek alternative living arrangements where staff members are available to help meet caregiving needs. ADL's, as defined by the U.S. Department of Health and Human Services (USDHH), refers to basic activities of everyday life. These activities include bathing, dressing, toileting, eating,

ambulating, and transferring (Weiner, Hanley, Clark, & Van Nostrand, 1990). According to Mass & Buckwalter (2006)

In recent years, assisted living facilities have been the most recently expanding type of residential care settings for older persons in the United States, and the number of assisted living facilities (ALF) is expected to increase by approximately 40% during the next 20 years (p. 14).

Allen (2011) estimated that up to half of residents living in the ALF setting have some type of mild to moderate dementia. In 2010, over 40% of ALF residents carried a diagnosis of Alzheimer's disease (AD) or another type of dementia where unlicensed assistive personnel (UAP) provide the majority of patient care, yet likely receive insufficient education and training on the disease process and how to deal with BPSD (Caffrey, et al., 2012).

Project Purpose

In order to best support the UAP in the ALF setting in their efforts to deliver quality care to dementia patients and management of BPSD associated with the disease process, one must first evaluate the baseline level of understanding and knowledge of the individuals delivering that care. "Assisted living residences have assumed a prominent role in the long-term care of people with dementia" (Zimmerman et al., 2014, p. 664) and "adequate knowledge about dementia among health care staff is important to the quality of care delivered to this vulnerable population" (Smyth et al., 2013, p. 1). UAP are exposed to the least amount of formal knowledge regarding dementia in their training, but provide the majority of basic care for this population (Smyth et al., 2013). Care provided in the ALF setting is understudied as this option has only recently started to gain popularity. Creating a feeling of empowerment among front-line care staff members can facilitate coping and provision of quality care to dementia patients who reside in assisted living facilities (Gurnik & Hollis-Sawyer, 2003).

Assessing the UAP's level of knowledge prior to implementing any type of educational program is necessary to establish a baseline to gauge effectiveness of the intervention as well as identify knowledge gaps that need to be taken into consideration when implementing the program (Smyth et al., 2013). Educating UAP on the disease process of dementia will foster a better understanding of the BPSD that can occur in this population. "A good knowledge of dementia, including its progression and management, among staff and families of people living with dementia is essential for clear decision making and the provision of appropriate care. Yet there is limited information regarding relative levels of dementia knowledge" (Robinson et al., 2014, p. 158). The goal of this project is to provide insight and knowledge that will improve UAP abilities to recognize the clinical course of dementia and BPSD and support their capabilities to provide timely and appropriate care to residents in the ALF setting.

The clinical questions for this project are: 1. How knowledgeable are UAP's regarding Alzheimer's dementia and BPSD? 2. Will an educational intervention enable UAP's to feel better prepared in their role as caregivers?

AGS Beers Criteria

The American Geriatric Society Beers Criteria is a list of medications that should be used with caution or avoided in the older population due to side effects and other drug related problems that can be associated with these medications. Medications on this list include antipsychotics, benzodiazepines and some categories of antidepressants (American Geriatrics Society, 2012); medications that are sometimes used in the treatment of BPSD and can cause untoward side effects in the 65 and older population. Each year, one in three older adults experience adverse reactions to medication (American Geriatrics Society, 2012). Awareness of this issue will highlight the need for alternatives to treat BPSD aside from medication.

Dementia Typology

Tauopathies. Tau, an intracellular protein, abnormally clumps together inside cells, which causes them to stop functioning properly and die. Dementia disorders associated with accumulation of tau are referred to as tauopathies (National Institute on Aging [NIA], 2015). Tauopathies include AD, corticobasal degeneration (CBD), frontotemporal disorders (FTD), progressive supranuclear palsy (PSP) and argyrophilic grain disease.

Alzheimer's dementia. In AD, the tau protein twists and forms bundles called neurofibrillary tangles inside the neurons. Abnormal accumulation of the plaque protein amyloid occurs in the extracellular spaces. It is not clear if the plaques and tangles cause AD or if they result from another process that causes the neurons to die (National Institute on Aging [NIA], 2015). “The earliest and most common clinical manifestation of AD is impairment in episodic memory” (Karantzoulis & Galvin, 2011, p. 1581). This impairment is thought to be related to a diminished ability to encode new information into long-term memory (Karantzoulis & Galvin, 2011).

The clinical criteria for AD includes an insidious onset of months to years, rather than days to weeks, and a clear-cut history of progressive cognitive deterioration and decline in daily functioning, when consideration of other potential causes of the symptoms cannot be identified (Karantzoulis & Galvin, 2011). Problems with word finding, category fluency, word-picture naming and other areas related to semantic memory are associated with AD. In later disease stages, global aphasia is common and muteness may be present. Visual-spatial deficits are among the first symptoms noted in AD; examples of this include getting lost in familiar environments, misplacement of personal items and difficulty with driving or parking a car. Disease progression of AD involves problems with attention and executive functions. Decline in

the ability to apply abstract reasoning, concentration, calculations and sustained visual attention are the most common of these symptoms (Karantzoulis & Galvin, 2011). In later disease stages, inability to complete tasks and personality changes become pronounced. AD patients lack insight and awareness of their deficits; it is estimated that approximately 80% of patient's experience anosognosia (Karantzoulis & Galvin, 2011). In the final stages of AD, death usually results from sequela of an infection such as pneumonia (Brunnstrom & Englund, 2009).

In addition to the cognitive deficits with AD a spectrum of neuropsychiatric symptoms occurs throughout the course of the disease and represent a major source of morbidity. Mood disturbances, hallucinations, delusions, vegetative symptoms and aberrant motor disturbances are common (Karantzoulis & Galvin, 2011). Personality changes also occur with AD and can include neuroticism, decreased conscientiousness, egocentricity and coarsening of affect.

Corticobasal degeneration. CBD is a progressive neurological disorder characterized by neuron loss and atrophy of multiple areas of the brain, including the cerebral cortex and basal ganglia (National Institute of Neurological Disorders and Stroke [NINDS], 2015). CBD gradually progresses with symptoms similar to Parkinson's disease that first appear unilaterally, but eventually affect both sides of the body. These include poor coordination, akinesia, rigidity, impaired balance and dystonia, along with cognitive and visuospatial impairments, apraxia and halting speech, myoclonus and difficulty swallowing. Symptoms typically start around age 60 and progress to the point that ambulation becomes totally impaired (National Institute of Neurological Disorders and Stroke [NINDS], 2015). No curative treatment is available, symptoms are usually resistant to therapy and generally death occurs within 6 to 8 years from complications of severe disability.

Frontotemporal disorders. FTD is the second most common form of dementia in adults under the age of 65 (Reilly, Rodriguez, Lamy, & Neils-Strunjas, 2010). Some, but not all forms of FTD are considered tauopathies; genetic mutations also account for other cases with one form associated with an inherited type of amyotrophic lateral sclerosis (National Institute on Aging [NIA], 2015). Changes to the frontal lobe affect decision-making and the ability to reason, prioritize, act appropriately and control movement (National Institute on Aging [NIA], 2015). One of the variants associated with FTD features a behavioral component that affects behavior and personality while the memory may stay relatively intact. The other variant involves a primary progressive aphasia, which disrupts expression of speech and word finding. As the disease progresses, problems with memory, judgment and reasoning can develop along with a dementia. “Symptoms of FTD typically appear a decade earlier than AD, making age of onset a distinctive feature of the disease” (Reilly, et al., 2010, p. 440). Other types of FTD’s include Pick’s disease, characterized by Pick bodies that accumulate within nerve cells causing them to enlarge, and FTD with parkinsonism, a more rare condition thought to be inherited from one parent (National Institute on Aging [NIA], 2015). Early disease stages involve behavioral symptoms rather than memory loss.

Progressive supranuclear palsy. PSP is a rare brain disorder that involves damage to the upper brain stem impacting eye movements and balance and causing a general body stiffness, apathy and depression (National Institute on Aging [NIA], 2015). Pseudobulbar affect is a hallmark characteristic of PSP causing affected persons to suddenly laugh or cry. As the disease progresses, speech becomes slurred and swallowing becomes impaired.

Argyrophilic grain disease. This degenerative disease is distinguished by tau deposits, called argyrophilic grains, in brain regions involved with memory and emotion (National

Institute on Aging [NIA], 2015). The signs and symptoms of this form of dementia are very similar to late-onset AD and confirmation of diagnosis can only be made via autopsy.

Synucleinopathies. This class of disorders involves the protein alpha-synuclein abnormally accumulating inside brain neurons. Symptoms in these disorders include problems with movement, cognitive changes, autonomic changes, visual hallucinations, muscle rigidity and sleep disturbances (Karantzoulis & Galvin, 2011).

Lewy body dementia. LBD is typically associated with cognitive symptoms such as severe memory impairment, visuospatial disturbances, prosopagnosia, color agnosia, ideomotor apraxia, visual distractibility (Reilly et al., 2010). Lewy bodies are protein aggregates that accumulate inside neurons and disrupt their function. Language symptoms in LBD usually include perseveration, difficulty naming common objects, reduced verbal fluency and confabulation. Disease progression involves profound memory disturbance, Parkinsonism's, neuroleptic reactions, REM sleep behavior disorder, and disproportionate visuospatial deficits (Reilly, et al., 2010). Eventually impairment of cognitive function leads to complete dependence on others for care.

Parkinson's disease dementia. PDD, a dementia associated with PD, can affect memory, language, reasoning and social judgment. Post mortem exams have shown amyloid plaques and tau tangles similar to those found in AD are present with PDD (National Institute on Aging [NIA], 2015). As PD progresses, 70 to 80 % of patients convert to PDD with core diagnostic criteria involving at least two of the four domains: attention, executive functioning, visuospatial processing and verbal free recall (Reilly, et al., 2010). They must also demonstrate one behavioral symptom such as apathy, depression, delusions, hallucinations or excessive daytime sleepiness.

Vascular Dementia. VaD describes a heterogeneous group of dementias associated with cerebrovascular damage and results from cerebrovascular damage secondary to subcortical strokes, hypoxemia, aneurysm, small vessel ischemic changes and genetic cerebrovascular disease interrupting blood flow to the brain (Reilly, et al., 2010). The DSM-IV diagnostic criteria for VaD include impaired ability to learn new information or recall information previously learned along with one or more of the following: apraxia, agnosia, and problems with executive function activities. These difficulties must significantly impair social and/or occupational functions and represent a significant decline from baseline functioning (American Psychological Association [APA], 2000). Focal neurological symptoms or lab results showing evidence of cerebrovascular disease must support the cause of the deficits and they must not occur exclusively during episodes of delirium.

Mixed Dementia. Mixed dementia or multi-factorial dementia, as it sounds, is dementia involving more than one etiology. Abnormal protein deposits seen in Alzheimer's dementia exist along with vascular problems seen in VaD and may also coexist with Lewy bodies (Alzheimer's Association, 2014).

Concepts and Conceptual Definitions

Behavioral and Psychological Symptoms of Dementia. These behaviors are a significant source of stress to patients, families and caregivers and are a major reason for institutionalization or seeking help with caregiving activities (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012). The most prevalent BPSD in dementia patients include depression, apathy, irritability, agitation and anxiety, while euphoria, hallucinations and disinhibition occur less frequently (Cerejeira et al., 2012). Depression, anxiety and apathy are the most clinically significant symptoms; at least 50% of dementia patients exhibit at least four BPSD simultaneously (Frisoni, et al., 1999).

Studies have identified that specific types of BPSD are more likely to occur with certain types of dementia. Hallucinations and aggressiveness have a higher incidence with LBD while FTD is more commonly associated with activity disturbances such as wandering or purposeless activity (Chiu, Chen, Yip, Hua, & Tang, 2006)). AD has a higher incidence of anxiety and phobias while VaD is more often characterized by paranoia, delusions and affective disturbances such as tearfulness or depression (Chiu, et al., 2006).

Assisted Living Facilities. Assisted Living Facilities, also known as residential care facilities, is a long-term care option that provides housing and services for close to 1 million older adults in the U.S. (Beeber, et al., 2014). ALF's are an attractive alternative to nursing homes as this setting is designed to be more home-like and emphasize the individual through concepts such as autonomy, privacy and independence (Beeber, et al., 2014). Staff in these facilities is usually comprised of UAP rather than nurses, as these facilities were originally intended to accommodate those requiring low levels of care. Due to chronic illness and aging of the population, the level of need and dependency in the ALF setting has been increasing for many years (Dudman & Meyer, 2012). These facilities have been the most rapidly expanding type of residential care setting for older adults, and their growth is expected to increase by 40% in the next 20 years (Mass & Buckwalter, 2006). In 2010, 40% of all residential care residents received assistance with three or more ADL's and over 40% carried a diagnosis Alzheimer's disease or another form of memory impairment (Caffrey et al., 2012).

Unlicensed Assistive Personnel. The National Clearinghouse Direct Care Workforce estimates that direct care workers, such as UAP's, provide 70 to 80 % of paid care to persons who receive care in home-based settings, adult day cares, hospice services or who live in ALF settings (Hyer, Molinari, Kaplan, & Jones, 2010). Limitations in knowledge and skills may

influence care outcomes for persons with dementia, who often do not participate in decisions related to their care (Jones, Moyle, & Stockwell-Smith, 2013).

Aging in Place. Older adults with dementia are choosing to “age in place” in ALF’s due to the homelike setting and availability of supportive care. Aging in place refers to promoting resident’s independence while meeting their individual care needs; allowing them to live with dementia in a more homelike environment, as opposed to a skilled care setting (Rasin et al., 2007).

Cost of Caring. The cost of providing care for dementia is currently estimated at \$604 billion per year in U.S. dollars; this cost is expected to greatly increase given the increase of disease prevalence in the coming decades (World Health Organization [WHO], 2012). Per capita costs of dementia care in the U.S. was estimated to be \$41,000 to \$56,000 as of 2010, with an increase of nearly 80% in total societal costs by 2040 due to aging of the population (Hurd, Martorell, Delavande, Mullen & Langa, 2013).

Theoretical Framework

The selected framework for this project is Rosswurm and Larrabee’s Model for Evidence-Based Practice. This six-step model is derived from theoretical and research literature related to evidence-based practice, research utilization and change theory (Rosswurm & Larrabee, 1999). The model guides practitioners through the entire process of change to evidence-based practice involving six steps. “Evidence-based practice is more likely to occur in practice settings that value the use of new knowledge and provide resources to access that knowledge” (Rosswurm & Larrabee, 1999, p. 317). It is hoped this project will draw attention to the educational needs of UAP caring for dementia patients in the ALF setting, create awareness leading to change in their education requirements and support them in the caregiving role.

Step one in the model is to assess the need for change in practice. It involves collection of internal and external data on current practice and problem identification. Stakeholders should be included in this process. With respect to this project, stakeholders would be the UAP, directors of the ALF facilities and “memory units” within those facilities and any nursing staff who supervise or interact with the UAP providing patient care.

Step two of the model involves utilization of standardized language and classification systems to identify potential interventions and activities and select outcome indicators. Classification systems help to define concepts and organize knowledge (Rosswurm & Larrabee, 1999). For the scope of this project, UAP will be defined (their type of training, scope of practice, continuing education requirements) and their knowledge of dementia, specifically AD and BPSD, will be assessed using the ADKS. Long-term care will pertain to assisted living facilities only since less research exists on UAP’s working in this setting versus skilled nursing facilities.

Step three of the model involves synthesizing best evidence. A literature review has been conducted on UAP working in the ALF setting and their knowledge of dementia and BPSD. This review revealed a lack of dementia specific training and lack of dementia related knowledge of UAP in the ALF setting. Improving this level of knowledge in a local ALF is one aspect of this study.

Step four of the model is to design a practice of change. This involves defining a proposed change and planning an implementation process. Definition of outcomes is also part of this step. The results of this study can be used to define standards of change in dementia related training of UAP in the ALF setting.

Step five is to implement and evaluate the change in practice. The scope of this study is to evaluate the UAP's level of knowledge of dementia and BPSD, administer an educational intervention and then reassess the knowledge level and assess if the UAP feel more prepared to care for dementia patients and more effectively deal with BPSD. The results of this study will contribute to the body of knowledge in the literature and can hopefully guide future changes in practice for UAP in the ALF setting.

Step six of the model is integration and maintenance of change in practice. This involves communication of recommended changes to stakeholders, presenting an educational in-service on the change in practice to staff and integration of the changes into the standard of practice (Rosswurm & Larrabee, 1999). Successfully maintaining the changes will require a monitoring process. This framework is designed to support evidence-based change in a healthcare setting and should lend itself well for this type of project focused on showing a need in a change in practice.

Project Setting and Population

An ALF in a moderate sized southeastern city was the setting for this project. This facility has a total of 56 occupied beds, with 30 memory-care beds dedicated to moderate and late stage dementia patients. The facility has 3 shifts that provide 24-hour care and assistance; 45 total for the facility with 20 staff members dedicated to the memory-care unit. A “champion” from each shift was identified to help promote staff participation with the project. A particular need identified after an initial meeting with the program director is 3rd shift staff experiencing uncooperative or aggressive behavior by some patients as they attempt to awaken them and get them up and moving for the day.

Literature Review

Search Strategy

An initial search of the literature was performed in the CINAHL, MEDLINE, and the PubMed databases using the following search terms: “assisted living”, “unlicensed assistive personnel”, “care assistant”, “care staff”, “dementia”, “staff knowledge”, and “Alzheimer’s dementia”. The MeSH search terms of dementia/assisted living/staff knowledge yielded 632 results. The MeSH search terms of dementia/staff knowledge yielded 230 results. The MeSH search terms of assisted living staff/training yielded 28 results. The MeSH search terms of dementia/staff knowledge/direct care worker yielded eight results. A period of ten years was searched in the literature since information on the ALF setting has only recently become prominent. Only sources from peer reviewed evidence and validated information on dementia, such as from *Dementia: A Public Health Priority*, a 2012 publication of the World Health Organization, were utilized. The Johns Hopkins Nursing Evidence-based Practice Rating Scales (JHNEBP) was used to evaluate the evidence utilized for this project.

“Dementia is not a specific disease; instead it is a descriptive term for a collection of symptoms that can be caused by a number of disorders that affect the brain, with memory loss being the predominant symptom” (Stefanacci & Haimowitz, 2012, p. 222). AD is responsible for the overwhelming majority of dementia; correct diagnosis is necessary to guide treatment and management and help families deal with the devastating consequences of the disease (Stefanacci & Haimowitz, 2012). Dementia is characterized by deterioration in cognition, function and behavior; progressive cognitive decline leads to full dependence on caregivers before death (Reitz, Brayne, & Mayeux, 2011).

Meeting DSM-5 criteria for a major neurocognitive disorder requires evidence of significant cognitive decline in the areas of memory, language or learning, and it must interfere with independence in everyday activities such as paying bills or managing medications (Alzheimers Association, 2014). Many recognized vascular risk factors for ischemic heart disease and stroke are also risk factors for dementia: diabetes, hypertension, smoking and obesity (Reitz, et al., 2011). Other risk factors for dementia include advanced age, usually 65 or older, family history, genetic predisposition, lower levels of formal education and a history of traumatic brain injury (Alzheimers Association, 2014).

There is a lack of awareness and understanding of dementia; by some it is still considered a normal part of ageing, especially the early stage symptoms (World Health Organization [WHO], 2012). There is also a need for better understanding of the risk factors for dementia. Timely diagnosis is crucial not only to promote better outcomes for patients and allow family members more time to make financial, healthcare and legal arrangements, but also for the costs of care. “There is generally an increase in healthcare costs when dementia is not treated appropriately” (Magsi & Malloy, 2005, p. 297), as a result of delayed treatment and higher costs to treat comorbidities.

“During the natural course of dementia a heterogeneous group of clinical phenomenon is subjectively experienced by the patient and/or observable by an examiner consisting in disturbed emotions, mood, perception, thought, motor activity and altered personality traits” (Cerejeira, et al., 2012, p. 1). These clinical phenomena are referred to as BPSD, with the most common symptoms being apathy, depression, irritability, agitation, anxiety, euphoria, hallucinations and disinhibition. Approximately 25% to 33% of persons residing in ALF’s suffer with BPSD such as depression, delusions and hallucinations and 34% to 50% of residents exhibit behavioral

symptoms such as aggression, wandering and repetitive vocalization (McKensie, Teri, Pike, LaFazia, & van Leynseele, 2012). UAP's provide the majority of care for this patient population, but are less likely to recognize these symptoms. Training is markedly less than that required in nursing homes, with limited training related to caring for residents with cognitive impairment being reported by ALF staff (McKensie et al., 2012).

Much of ALF caregiver's knowledge about caring for people with dementia comes from life experiences or is learned with on the job training. A recurrent theme identified in review of the literature was the limited amount of training that UAP working in the ALF setting receive on dementia and BPSD. The significance of this, given the projected increase in ALF population in the next 20 years due to increase in incidence of new dementia cases, is great. Adequate knowledge of dementia among health care staff has been shown to affect critical issues in care, including implementation of interventions and quality of care delivered (Smyth et al., 2013).

The ADKS was modified from Alzheimer Disease Knowledge Test (ADKT), which was published in 1988 and consisted of 20 multiple choice items to assess what people knew about AD (Carpenter, Balsis, Otilingam, Hanson, & Gatz, 2009). Since its original publication, knowledge about AD diagnosis, symptoms, treatment and management has evolved and contents of the ADKT have become dated. The ADKS was developed to reflect updated knowledge about dementia. "The ADKS is designed for use in both applied and research contexts, capable of assessing knowledge about Alzheimer's disease among laypeople, patients, caregivers, and professionals" (Carpenter et al., 2009, p. 236). The knowledge of some professional caregivers may be limited to what they learn from their direct work with patients, leaving gaps in their knowledge of general facts about AD (Carpenter, Zoller, Balsis, Otilingam, & Gatz, 2011). People acquire knowledge about dementia from a variety of sources, which can influence the

accuracy of that knowledge. The lack of national standards for UAP training in the ALF setting along with the projected increase in ALF residents and dementia cases exemplifies the necessity of this study.

Methodology

Design. This is a pre-test/post-test design that assessed knowledge levels before and after staff education and also assessed if staff felt adequately prepared to care for patients with BPSD. Outcome objectives for this project were first to identify that knowledge gaps exist in the area of UAP caring for patients with dementia in the ALF setting. This was accomplished by administering a slightly modified version of the ADKS to reflect a lower reading level (see Appendix B). In addition to using the modified ADKS, a chart review for the previous three months was conducted. The review collected information on diagnoses of dementia or cognitive impairment as well as use of certain classes of medication such as antidepressants, anxiolytics, antipsychotics, and cholinesterase inhibitors. Second, utilization of those knowledge gaps guided implementation of an educational intervention for UAP at a local ALF to increase staff awareness of dementia and BPSD and teach effective ways to deal with these problematic behaviors.

The ADKS was administered again, after the educational intervention, to reassess the UAP knowledge level of the dementia process and associated behaviors. The staff members were assessed to determine if they felt better prepared to manage BPSD after the educational intervention. Information on the educational intervention was submitted to the Department of Health and Human Services and was approved for continuing education hours for the participating UAP.

Sample. Out of 45 staff members, 15 UAP completed the initial ADKS questionnaire and out of those initial 15 participants, 7 participated in the educational intervention and completed the subsequent ADKS questionnaire. They provided feedback on how they felt the educational intervention impacted their sense of confidence in their ability to function as caregivers.

Methods. The modified ADKS was administered to UAP at a local assisted living facility to gauge their existing knowledge of the dementia process and BPSD. A retrospective chart review for a three-month period was conducted at the ALF to demonstrate a need for dementia specific education for the UAP. Out of a total of 56 residents at the facility, 35 residents carried a diagnosis of dementia; one resident carried a diagnosis of amnesia, one a diagnosis of cognitive impairment and one a diagnosis of altered mental status. Out of those 38 residents, 37 were receiving a cholinesterase inhibitor, NMDA receptor antagonist, antidepressant medication, atypical anti-psychotic, or a benzodiazepine.

An educational program aimed at providing UAP with training and knowledge on the dementia disease process and management of BPSD that accompany the moderate to later stages of dementia was administered. The program is entitled “*When you forget that you forgot: Recognizing and managing Alzheimer’s type dementia*” and is part of The Geriatric Mental Health Training Series for the Hartford Center of Geriatric Nursing Excellence at the College of Nursing at the University of Iowa (Smith, 2003) and will be described in more detail later. The modified ADKS was then re-administered as a follow up to reassess the UAP’s knowledge level regarding the dementia process and BPSD. Information was collected to determine if the UAP felt the education enhanced their knowledge of dementia and BPSD. They were also assessed whether the Progressively Lowered Stress Threshold (PLST) provided them with effective ways to deal with BPSD.

Protection of Human Subjects. Approval of the East Carolina University Institutional Review Board (IRB) was obtained in January 2015 for this project (Appendix E). An IRB amendment was approved in April 2015 (Appendix F) for the chart review and utilization of the slightly modified ADKS tool. All information collected during this project was maintained in a secure, locked location with only the author having access to the information. Any personal information collected, such as names, was de-identified for the data analysis and reporting. Informed consent was obtained from all participants before any data was collected; participants were instructed of their option to withdraw their consent at any time during the project and provided with a contact number to address additional questions or concerns.

During the chart review, no resident names, dates of birth, dates of admission or other identifiable information was collected for this project. Only general information on diagnosis and medication categories was collected to establish the need for staff education. Permission for the chart review was obtained from ALF administration (Appendix G).

Instruments. The Alzheimer's Disease Knowledge Scale (ADKS) is a tool designed specifically to evaluate knowledge of AD (Smyth et al., 2013). It has been validated and proven reliable to assess knowledge about AD, based on current understanding of the disease (Carpenter et al., 2009). The tool covers risk factors, assessment and diagnosis, symptoms, course, life impact, caregiving, and treatment and management, and was designed to be used with students, health care professionals and the general public (Carpenter et al., 2009). It consists of 30 true/false items (Appendix A). After evaluation of this tool, this author determined this tool was written at the tenth grade reading level and that a lower reading level would be better utilized for this study based on the educational level of UAP's.

The ADKS was slightly modified and the reading level was re-assessed. This slightly modified version was calculated to be on a sixth grade level of reading which was determined to be appropriate for this study, given the average education level of the UAP (see Appendix B). The author of the original version of the ADKS was contacted regarding the revisions to the ADKS and permission was received to utilize this version (see Appendix D).

Program. The educational program “*When you forget that you forgot: Recognizing and managing Alzheimer’s type dementia*” is part of The Geriatric Mental Health Training Series for the Hartford Center of Geriatric Nursing Excellence at the College of Nursing at the University of Iowa (Smith, 2003). This program consists of two parts and was developed to educate members of the health care team, including UAP in the long-term care setting, on dementia and depression and associated behavioral issues (Appendix H). The training module was developed following the Nursing Home Reform Act of the Omnibus Reconciliation Act of 1989 and the recognized need of improved staff training needed as the numbers of residents in long-term care facilities increase due to the aging of the population and the number of older persons who experience some type of mental disorder (Smith, 2003). Permission is granted for individuals to print, copy and use these materials in an unaltered form for in-service education programs, continuing education programs and personal development activities, for which no fee or personal profit is collected.

The series covers topics derived from a needs assessment survey such as the various types of dementia (AD, vascular dementia, frontotemporal dementia, Lewy body dementia, and reversible conditions that can mimic dementia), stages of AD, and common behavioral problems associated with the disease process (Smith, 2005). Information is covered on avoidance of negative labeling and on the concept of person-centered care. The training teaches principles

from the Progressively Lowered Stress Threshold (PLST) model to describe interventions and efforts to help staff manage BPSD that can be part of the disease process. This model uses interventions to reduce stress and promote more functional behavior in the dementia patient. Emphasis is placed on managing the environment, adjusting routines and communication strategies and using validation methods (Smith, 2005).

Data Collection. Data collection commenced in May 2015 with obtaining informed consent of participants followed by collection of the initial modified ADKS. The chart review was performed in May 2015, after the initial round of ADKS. Permission was obtained from the Data collection was completed in June 2015 with the educational intervention and collection of the second modified ADKS and additional feedback from the UAP.

Data Analysis. A paired sample T-test was performed comparing the pre-ADKS and post-ADKS scores. Descriptive statistical analysis was performed with the information collected from the chart review on diagnosis and medication information.

Results and Interpretation

Analyzing the information collected from the chart review, 92.1% (n=56) of the residents carried a diagnosis of dementia. Out of the 56 charts reviewed, 68.4 % (n=56) were prescribed a cholinesterase inhibitor, 31.6% (n=56) were prescribed an NMDA receptor antagonist and 65.8% (n=56) were prescribed antidepressant medication. Benzodiazepines were prescribed for 36.8% (n=56) of residents with anti-psychotic medication prescribed for only 7.9% (n=56) of residents (Appendix K).

Of the seven participants who completed both pre-ADKS and post-ADKS questionnaires, a 2-point increase was noted between pre-test and post-test scores which was significant

($t(df\ 6) = 2.898, p = .027$) (Appendix J). UAP provided feedback at the completion of the project, following the pre and post ADKS questionnaires and the educational intervention. Staff noted that they acquired new information regarding risk factors for dementia, such as hypertension and hyperlipidemia. They also took away ideas from the PLST model; such as administration of medications other than meal times/busy times can lower the stress burden for dementia patients. Other comments received include the UAP felt what they learned will enable them to provide better care to the residents and it provided a better understanding of the dementia process. Staff indicated they gleaned information that will assist them in communicating with the residents. A final comment received was that the information they received reminded them to be more sympathetic to and cognizant of their residents needs.

Limitations

Limitations with this project include the small sample group size of UAP who participated in this project, which resulted from a decreased population at the ALF during the time of the project. In addition, only seven participants from the initial group were able to complete both pre and post questionnaires and attend the educational offering.

Triple Aim

The Institute for Healthcare Improvement's Triple Aim initiative (2015) involves three dimensions designed to achieve optimal performance of health systems. These dimensions are: improving the patient experience of care (includes quality and satisfaction), improving population health and reducing the per capita cost of health care (Institute for Healthcare Improvement [IHI], 2015). Enabling UAP's to be better informed and prepared as caregivers not only improves the experience for them, but also for the resident and their families. The ability to differentiate between dementia and the normal aging process and manage BPSD with non-

pharmacological strategies can result in better care. Minimizing the use of medication to control BPSD will decrease the chance of side effect related injuries such as falls and respiratory depression which not only improves care but decreases cost associated with these injuries. This project adds to the body of nursing knowledge for the aging population which will be expanding rapidly over the next several decades. Preparing UAP to better care for this population will be essential to meet care needs. Findings from this project can be extended to various geographical regions as dementia affects all populations and caregiving needs exist worldwide.

Conclusion

This author feels the analysis supports the need for the project by demonstrating that UAP caring for dementia patients in a local ALF could benefit from more knowledge regarding the dementia process and BPSD and that an educational program provided them with new ideas and resources to manage BPSD in this patient population. Given the aging population increasingly seeking the option of assisted living and with their multiple comorbidities, UAP working in this setting will require the knowledge to effectively care for these residents. Supporting UAP in their role as caregivers in the ALF setting will enable and empower this group to meet the challenging demands of caring for this population. The need for their service will only increase in the coming decades as the numbers of elderly persons increase worldwide and the demand for assistance with care grows.

Also of importance is the ability to provide UAP with non-pharmacological resources to manage BPSD. Education on strategies to minimize and manage these problematic behaviors provide staff with necessary knowledge and tools to lower the stress threshold which diminishes the rate of behavior occurrence and need for psychotropic medication. Less use of medication directly results in reduction of medication related side effects leading to adverse outcomes and

injuries that may occur as a result of falls. Fewer adverse outcomes and injuries promotes the health of this population and also decreases healthcare expenditures for resultant treatment.

Guidance for this project was provided by Dr. Candace Harrington, a Doctor of Nursing Practice (DNP) faculty member at East Carolina University, and Professor Tomika Williams, also a faculty member in the College of Nursing at East Carolina University. Both committee members have backgrounds that involve working with the geriatric population.

Timeline for completion of this project was July 2015 with a final manuscript for submission to the *Journal of Gerontological Nursing* completed by November 2015. The proposed budget for this project was \$1000, the majority of which was allocated for printing of training materials (Appendix I).

The dissemination plan for this project includes submission to a scholarly journal for publication along with a public presentation on the campus of East Carolina University in the fall of 2015. Options to present at grand rounds or local conferences are being considered. Plans for dissemination beyond graduation include possible conference presentations such as the Gerontological Advanced Nurses Association annual conference, which is being held in Phoenix September 2016. Another worthy conference to consider for presentation is the ACHA/NCAL Inaugural Quality Summit in Antonio in February 2016. NCAL is the National Center for Assisted Living and advocates for assisted living legislation and leads efforts for education and professional development in the areas of assisted living.

Another option for disseminating the findings is at seminars and classes offered thorough the local AHEC (Area Health Education Center) which attract many healthcare professionals. These are usually day long events that offer CE credit for nurses and other medical professionals

and will have a display of research posters and break time during the day for attendees to circulate and view the posters and discuss with the authors.

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Appendix A**Alzheimer's Disease Knowledge Scale**

Below are some statements about Alzheimer's disease. Please read each statement carefully and circle whether you think the statement is True or False. If you aren't sure of the right answer, make your best guess. It's important to circle an answer for every statement, even if you're not completely sure of the answer.

- | | | |
|------|-------|---|
| True | False | 1. People with Alzheimer's disease are particularly prone to depression. |
| True | False | 2. It has been significantly proven that mental exercise can prevent a person from getting Alzheimer's disease. |
| True | False | 3. After symptoms of Alzheimer's disease appear, the average life expectancy is 6 to 12 years. |
| True | False | 4. When a person with Alzheimer's disease becomes agitated, a medical examination might reveal other health problems that caused the agitation. |
| True | False | 5. People with Alzheimer's disease do best with simple, instructions given one step at a time. |
| True | False | 6. When people with Alzheimer's disease begin to have difficulty taking care of themselves, caregivers should take over right away. |
| True | False | 7. If a person with Alzheimer's disease becomes alert and agitated at night, a good strategy is to try to make sure that that person gets plenty of physical activity during the day. |
| True | False | 8. In rare cases, people have recovered from Alzheimer's disease. |
| True | False | 9. People whose Alzheimer's disease is not yet severe can benefit from psychotherapy for depression and anxiety. |
| True | False | 10. If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer's disease. |
| True | False | 11. Most people with Alzheimer's disease live in nursing homes. |
| True | False | 12. Poor nutrition can make the symptoms of Alzheimer's |

disease worse.

- | | | |
|------|-------|--|
| True | False | 13. People in their 30's can have Alzheimer's disease. |
| True | False | 14. A person with Alzheimer's disease becomes increasingly likely to fall down as the disease gets worse. |
| True | False | 15. When people with Alzheimer's disease repeat the same question or story several times, it is helpful to remind them that they are repeating themselves. |
| True | False | 16. Once people have Alzheimer's disease, they are no longer capable of making informed decisions about their own care. |
| True | False | 17. Eventually, a person with Alzheimer's disease will need 24 hour supervision. |
| True | False | 18. Having high cholesterol may increase a person's risk of developing Alzheimer's disease. |
| True | False | 19. Tremor or shaking of the hands or arms is a common symptom in people with Alzheimer's disease. |
| True | False | 20. Symptoms of severe depression can be mistaken for symptoms of Alzheimer's disease. |
| True | False | 21. Alzheimer's disease is one type of dementia. |
| True | False | 22. Trouble handling money or paying bills is a common early symptom of Alzheimer's disease. |
| True | False | 23. One symptom that can occur with Alzheimer's disease is believing that other people are stealing one's things. |
| True | False | 24. When a person has Alzheimer's disease, using reminder notes is a crutch that can contribute to decline. |
| True | False | 25. Prescription drugs that prevent Alzheimer's disease are available. |
| True | False | 26. Having high blood pressure may increase a person's risk of developing Alzheimer's disease. |
| True | False | 27. Genes can only partially account for the development of Alzheimer's disease. |

- True False 28. It is safe for people with Alzheimer's disease to drive, as long as they have a companion in the car at all times.
- True False 29. Alzheimer's disease cannot be cured.
- True False 30. Most people with Alzheimer's disease remember recent events better than things that happened in the past.

Source. Carpenter, B.D., Balsis, S., Otilingam, P.G., Hanson, P.K., & Gatz, M. (in press). The Alzheimer's Disease Knowledge Scale: Development and psychometric properties. *The Gerontologist*.

Appendix B

Revised Alzheimer's Disease Knowledge Scale

1. People with Alzheimer's disease are more likely to have depression. **T / F**
2. Mental exercise can prevent a person from getting Alzheimer's disease. **T / F**
3. After symptoms of Alzheimer's disease appear, a person is expected to live on average another 6 to 12 years. **T / F**
4. When a person with Alzheimer's disease is agitated, a medical exam may reveal other health problems causing the agitation. **T / F**
5. People with Alzheimer's disease do best with simple, instructions given one step at a time. **T / F**
6. When a person with Alzheimer's disease begins to have problems taking care of themselves, it is best for another person to take over caregiving right away. **T / F**
7. If a person with Alzheimer's disease becomes alert and agitated at night, a good strategy is to try to make sure that the person gets plenty of physical activity during the day. **T / F**
8. In rare cases, people have recovered from Alzheimer's disease. **T / F**
9. People whose Alzheimer's disease is not yet severe can benefit from psychotherapy for depression and anxiety. **T / F**
10. If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer's disease. **T / F**
11. Most people with Alzheimer's disease live in nursing homes. **T / F**
12. Poor nutrition can make the symptoms of Alzheimer's disease worse. **T / F**
13. People in their 30's can have Alzheimer's disease. **T / F**
14. A person with Alzheimer's disease is more likely to fall down as the disease gets worse. **T / F**
15. When people with Alzheimer's disease repeat the same question or story several times, it is helpful to remind them that they are repeating themselves. **T / F**

16. Once people have Alzheimer's disease, they are no longer able to make informed decisions about their own care. **T / F**
17. Eventually, a person with Alzheimer's disease will need 24-hour supervision. **T / F**
18. Having high cholesterol may mean a person is more likely to develop Alzheimer's dementia. **T / F**
19. Tremor or shaking of the hands or arms is a common symptom in people with Alzheimer's disease. **T / F**
20. Symptoms of severe depression can be mistaken for symptoms of Alzheimer's disease. **T / F**
21. Alzheimer's disease is one type of dementia. **T / F**
22. Trouble handling money or paying bills is a common early symptom of Alzheimer's disease. **T / F**
23. Sometimes people with Alzheimer's disease may believe that other people are stealing their things. **T / F**
24. When a person has Alzheimer's disease, using reminder notes is a crutch that can contribute to decline. **T / F**
25. There are medications available that can prevent Alzheimer's dementia. **T / F**
26. Having high blood pressure may increase a person's risk of developing Alzheimer's disease. **T / F**
27. Genes may be part of the reason people develop Alzheimer's dementia. **T / F**
28. It is safe for people with Alzheimer's disease to drive, as long as they have a companion in the car at all times. **T / F**
29. Alzheimer's disease cannot be cured. **T / F**
30. Most people with Alzheimer's disease remember recent events better than things that happened in the past. **T / F**

Appendix C

Permission from author of ADKS

Dear Randa,

Thanks for your interest in the ADKS. You have our permission to use the scale in your research, and there's no need to contact the other authors. We only ask that you acknowledge our original paper in any publication that might result from your work. At the link below you'll find additional information about the scale that may be helpful:

<http://pages.wustl.edu/geropsychology/adks>

Please let me know if you have any questions, and good luck with your project. It sounds very worthwhile.

Regards,
Brian

Brian D. Carpenter, Ph.D.
Associate Professor
Psychology Department
CB 1125
Washington University
#1 Brookings Drive
St. Louis, MO 63130-4899
phone: [\(314\) 935-8212](tel:(314)935-8212)
fax: [\(314\) 935-7588](tel:(314)935-7588)

Appendix D

Permission to use revised ADKS

Dear Randa,

Thank you for sending along the revision to the scale and the update on your project. It sounds fine to me to use this modified version of the scale if you think it better suits your sample. I'm sure you'll discuss the revisions to the original ADKS in any written work, and we appreciate your careful consideration of the scale. In fact, as we start to think about a revision to the original scale, we may be in touch to discuss the literacy issue with you further. Thanks again, and good luck with the next phase of your project.

Regards,
Brian

Brian D. Carpenter, Ph.D.
Associate Professor
Psychology Department
CB 1125
Washington University
#1 Brookings Drive
St. Louis, MO 63130-4899
phone: [\(314\) 935-8212](tel:(314)935-8212)
fax: [\(314\) 935-7588](tel:(314)935-7588)

Appendix E

Initial IRB Approval

EAST CAROLINA UNIVERSITY**University & Medical Center Institutional Review Board Office**

4N-70 Brody Medical Sciences Building · Mail Stop 682

600 Moye Boulevard · Greenville, NC 27834

Office 252-744-2914 · Fax 252-744-2284 · www.ecu.edu/irb

Notification of Initial Approval: Expedited

From: Social/Behavioral IRB

To: [Randa Eury](#)

CC:

[Nanette Lavoie-Vaughan](#)

Date: 1/27/2015

Re: [UMCIRB 14-001857](#)

Educational Needs of Unlicensed Assistive Personnel

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) is for the period of 1/27/2015 to 1/26/2016. The research study is eligible for review under expedited category #7. The Chairperson (or designee) deemed this study no more than minimal risk.

Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be used to consent participants (consent documents with the IRB approval date stamp are found under the Documents tab in the study workspace).

The approval includes the following items:

Name	Description
ADKS	Surveys and Questionnaires
ECU CITI	Additional Items
Informed Consent	Consent Forms
Project Participant Letter.docx	Consent Forms
Recognizing and Managing Alzheimer's Type Dementia Part 1	Additional Items
Recognizing and Managing Alzheimer's Type Dementia Part 2	Additional Items
SP project protocol, revised	Study Protocol or Grant Application

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

Appendix F**IRB Amendment Approval**

Notification of Amendment Approval

From: Social/Behavioral IRB

To: [Randa Eury](#)

CC:

[Nanette Lavoie-Vaughan](#)

Date: 4/29/2015

Re: [Ame1_UMCIRB 14-001857](#)

[UMCIRB 14-001857](#)

Educational Needs of Unlicensed Assistive Personnel

Your Amendment has been reviewed and approved using expedited review for the period of 4/29/2015 to 1/26/2016 . It was the determination of the UMCIRB Chairperson (or designee) that this revision does not impact the overall risk/benefit ratio of the study and is appropriate for the population and procedures proposed.

Please note that any further changes to this approved research may not be initiated without UMCIRB review

except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems

involving risks to participants and others must be promptly reported to the UMCIRB. A continuing or final review

must be submitted to the UMCIRB prior to the date of study expiration. The investigator must adhere to all

reporting requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be used to consent

participants (consent documents with the IRB approval date stamp are found under the Documents tab in the

study workspace).

The approval includes the following items:

Document Description

ECU Waiver of Authorization(0.02) HIPAA Authorization

Morningside HIPAA form.pdf(0.01) HIPAA Authorization

Revised ADKS reading level.docx(0.01) Surveys and Questionnaires

SP project protocol, revised.docx(0.01) Study Protocol or Grant Application

Faculty Supervisor Change: Dr. Lavoie-Vaughn to Dr. Harrington

6/11/15, 8:46 PM

<http://epirate.ecu.edu/app/Doc/0/T1FD07UDUG8K5250RKL37LVFE4/fromString.html> Page 2 of 2

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

Appendix G**HIPAA Acknowledgement****Your Personal Commitment to Five Star Quality Care's****HIPAA Policies and Procedures**

I acknowledge that I have received training on Five Star's HIPAA policies and procedures and that I understand the HIPAA policies and procedures and my obligation as an employee or volunteer to comply with them.

Signature

A handwritten signature in dark ink, appearing to read "Randa Eury", written over a horizontal line.

Printed name

The name "Randa Eury" written in a cursive, handwritten style over a horizontal line.

Date

The date "3-20-15" written in a handwritten style over a horizontal line.

This signed and completed form must be returned to your facility's Human Resources representative.

Appendix H

1 When You Forget that You Forgot: Recognizing and Managing Alzheimer's Type Dementia, Part I.

Revised by M. Smith (2003) from K.C. Buckwalter and M. Smith (1994), "When You Forget That You Forgot: Recognizing and Managing Alzheimer's Type Dementia," *The Geriatric Mental Health Training Series for the John A. Hartford Center of Geriatric Nursing Excellence, College of Nursing, University of Iowa*

2 Goals for Today

- Describe essential features of dementia
- List common types of dementia
- Identify "reversible" causes of dementia
- Describe behaviors in each of 4 stages
- Discuss the PLST model

3 More than "confusion"

- Many things can interfere with memory
 - Being overloaded: having too much going on at one time
 - Medications, even ones taken according to directions
 - Illness and disease that are unrelated to brain disease
 - Unfamiliar surrounding such as relocation or hospitalization

4 Dementia

- Permanent loss of mental abilities caused by damage to brain cells
- NOT a "normal" part of aging!
- The common end result of many entities
 - diseases
 - traumas
 - infections
 - drugs

5 Dementia: Essential Features

Progressive loss of intellectual abilities ...

- MEMORY impairment
 - Short-term early
 - Long-term later
- Loss of LANGUAGE
 - Loss of ability to express oneself
 - Loss of ability to understand what is said

6 Dementia: Essential Features

- Loss of PURPOSEFUL MOVEMENT
 - Has the physical ability
 - Can't perform the task (e.g., getting dressed)
- Loss of ability to accurately interpret SENSORY INFORMATION
 - Cannot understand what is seen, heard, felt
 - Not related to sensory impairment

7 Dementia: Essential Features

- Impairments in ...
 - Abstract thinking
 - Ability to reason
 - Judgement
 - Impulse control
 - Personality changes
 - Not "him/herself"

8 Dementia: Essential Features

- Lost abilities result in CHANGES ...
 - Personality
 - Behavior
 - Emotion

Get away from me, you big fat idiot! You didn't!

"My mother would never say such a thing!"

9 Who has dementia?

- Dementia is a "generic term"
 - Many different types
 - Alzheimer's disease → Most common type
- Risk increases with advancing age
 - 25% of 80 year olds
 - 33% of 85 year olds
 - 50% of 90 year olds

10 Who has dementia?

- Common problem among nursing home residents: 50% to 80% have dementia
- Increasing problem among those in assisted living: 50% to 67%
- Many at home, cared for by family

11 Dementia: Types

- Alzheimer's Type a.k.a. Alzheimer's Disease
 - 360,000 new cases annually
 - 4 million Americans afflicted
 - 4th leading cause of death
 - 14 million (1 out of 45) by the year 2050
 - 80% of population in nursing homes
 - Leading cause of behavioral symptoms

12 Dementia: Types

- Vascular, a.k.a., Multi Infarct
 - Step-wise, "patchy" loss of abilities
 - Sudden onset, slower course, more variable
- Mixed dementia
 - AD and another type (e.g., vascular, Lewy Body Dementia)

13 Dementia: Types

- Frontotemporal Dementia (FTD)
 - a.k.a. frontal lobe; Pick's disease one type
 - Affects younger age group
 - More common in women than men
 - Insidious onset, like AD
 - Personality changes, language problems early, memory loss later

14 Dementia: Types

- Diffuse Lewy Body Dementia (LBD)
 - More fluctuation in impairment
 - Visual hallucinations common, often vivid
 - Parkinson-like features
 - Repeated falls common
 - Particular sensitivity to antipsychotics

15 Dementia: Types

Dementia due to ...

- Medical disease like HIV Disease
- Neurological disease
 - Parkinson's Disease
 - Huntington's Disease
- General medical conditions
 - Anoxia
 - Vitamin deficiency

16 Dementia: Types

Bottom Line: All Alzheimer's is DEMENTIA ... but not all DEMENTIA is Alzheimer's!!

17 Dementia: Types

- LOTS of variability in presentation!
 - Within specific types ...
 - BETWEEN types ...
- Overlapping syndromes are common
 - Dementia AND delirium
 - Mixed dementia

18 "Reversible" Dementia

- Multiple health problems may cause "confusion"
- Always explore alternative causes
- Treatment of underlying physical problem may arrest losses
- Problems not fully "reversible" but remaining capacity may be preserved

19 D-E-M-E-N-T-I-A

Drugs
Emotion
Metabolic
Endocrine
Nutrition
Trauma
Infection
Intoxication

Like working a puzzle ...

20 Stages of Dementia

- Early - Forgetful
- Middle - Confused
- Later - Ambulatory
- Terminal - Endstage

21 Early: Forgetful

- Short-term memory impaired
 - Losses things
 - Forgets
- Blames stress, fatigue
- Compensates with lists, memory aids
- Depression common

22 Later: Confused

- Loss of memory
 - Increasing disorientation
 - Time
 - Place
 - Person
 - Things

23 Confused: Example

- "Helen" crochets using a single simple stitch but doesn't remember that she is retired - and sometimes puts her bra on over her blouse.
- "Harold" greets everyone like his oldest friend ("Nice to see you! So good of you to drop by! I'm great! How are you?") but doesn't know his own wife.

24 Confused: Example

- "Mildred" avoids the question "How old are you" with "Jack Benny and I are both 29." When asked what she had for lunch, she replied, "I went to the Riviera and had pink champagne and caviar."
- "George" got lost walking in his neighborhood of 30 years - as soon as he could no longer see his own house.

25 Later Still: Ambulatory Dementia

- Progressive loss of ability to interact with FUNCTION
- Increasingly withdrawn and self-absorbed
- Depression tends to resolve

26 Ambulatory: Functional losses

- Willingness and ability to bathe
- Grooming
- Choosing among clothing
- Dressing
- Gait and mobility
- Toileting
- Communication, reading, and writing skills

27 Ambulatory: Behaviors

- Behavioral symptoms more common
 - Irritability
 - Agitation
 - Anxiety
 - Pacing
 - Reduced tolerance for stress
 - Resistiveness to care

28 Endstage Dementia

- All abilities lost
 - Mute
 - No longer walks
 - Little purposeful activity
 - Forgets to eat, chew, swallow
 - Complications are common

29 Symptoms: Not in distinct stages!

- Losses and symptoms vary from person to person, depending on
 - Extent of brain cell death and loss
 - Location of brain cell death and loss
 - Speed with which losses occur

30 Common Behavioral Symptoms

- Concealed memory losses
- Wandering
- Sleep disturbance
- Loosing and hiding things
- Inappropriate sexual behaviors

- Repeating questions
- Repetitious actions
- Territoriality
- Hallucinations
- Delusions
- Illusions

31

- Agitation
- Combative/ness
- Confusion
- Fearfulness
- Night waking
- Noisy behavior
- Purposeful wandering
- Sudden withdrawal from activities
- "Sundown" syndrome

Unsuspected, intense, and "out of proportion" reactions to a situation...

32

STRESS THRESHOLD MODEL

- Developed by nurse researchers in Iowa (Hall & Buckwalter)
- Emerges from observations of persons with dementia
- Based on theories of "person-environment fit"

33

Basic principles:

- Some behaviors result from losses associated with dementia
- Other behaviors result from environmental stress
- Stress takes many forms in dementia
- Stress threshold is lower in dementia

34

Goals

- Define "stress" for person with dementia
- Recognize lowered stress threshold
- Interpret behavior as anxiety that increases to cause dysfunctional behavior
- Manage stress for person with dementia
- Modify stressors, approaches
- Monitor personal, social, environmental stress

35

PLST: Normal Stress Threshold

36

PLST: Lowered Threshold

37

PLST Behaviors

- Increased anxiety
- Night awakening
- Catastrophic behaviors
- "Sundowning" syndrome
- Purposeful wandering
- Confusion, agitation
- Combative behavior
- Diminished reserve

More likely to occur as stress increases

38

PLST: Catastrophic Behaviors

39

PLST: Sources of Stress

- Fatigue
- Multiple competing stimuli
- Noise, confusion
- Television, radio, public address
- Too many people
- Too many things going on at once
- Eating dinner
- Taking medications
- Meal-time entertainment

40

PLST: Sources of Stress

- Physical Stress
 - Illness, medication side-effects
 - Hunger, thirst, discomfort
- Changes
 - Caregiver
 - Routine
 - Environment

41

PLST: Sources of Stress

- Demands that exceed abilities
 - Decisions that are too complex
 - Tasks that are outside abilities
- Negative and restrictive feedback
 - "Don't do that!"
 - "Your parents are dead"
 - "Eat this 12 your house"
 - "No, you're not going to work"

42

PLST: Care Planning Goal

GOAL - To act like a "prosthetic device" that supports the person do what what he/she is able to do

- Interventions serve like memory "crutch" that fills in for lost abilities
- Supports person to be autonomous in spite of lost abilities
- Keeps stress at manageable level throughout the day

43

PLST: Care Planning Goal

44

PLST: Summary

- Consider...
- Safety needs of client & other residents
- Disruptive behaviors
- Inability to participate in care
- Disturbances to other residents
- Family needs
- Increased care time and need for staff

45

Dementia: Incurable - Not Untreatable!

- Preserve and enhance remaining abilities
- Avoid unnecessary stress and overstimulation
- Treat illness or other complications
- Provide education and guidance for families and other caregivers

46

When You Forget That You Forget: Recognizing and Managing Alzheimer's Type Dementia, Part II

Revised by Melvin Smith (2002) from K.C. Buckwalter and M. Smith (1995), "When You Forget That You Forget: Recognizing and Managing Alzheimer's Type Dementia," The Geriatric Social Health Training Series for the John A. Huxford Center of Geriatric Nursing Excellence, College of Nursing, University of Iowa

1

Goals for Today

- Review common sources of stress for people with dementia
- Review care principles based on the Progressively Lowered Stress Threshold (PLST) model
- Apply basic principles to care routines and approaches

2

Behaviors in Dementia

- New "language" of dementia care
- Behavioral and Psychological Symptoms in Dementia (BPSID)
- Need-Driven Dementia-Compromised Behaviors (NDB)
- PLST Behaviors
- Avoid negative labeling; focus on unmet needs

3

PLST Behaviors

- Increased anxiety
- Night awakening
- Catastrophic behaviors
- "Sundowning" syndrome
- Purposeful wandering
- Confusion, agitation
- Combative behavior
- Diminished reserve
- Resistance

More likely to occur as stress increases

4

PLST: Sources of Stress

- Fatigue
- Multiple competing stimuli
- Noise, confusion
- Television, radio, public address
- Too many people
- Too many things going on at once
- Eating dinner
- Taking medications
- Meal-time entertainment

5

PLST: Sources of Stress

- Physical Stress
 - Illness, medication side-effects
 - Hunger, thirst, discomfort
- Changes
 - Caregiver
 - Routine
 - Environment: Internal (hunger, pain) and external (noise, confusion, stimulation)

6

PLST: Sources of Stress

- Demands that exceed abilities
 - Decisions that are too complex
 - Tasks that are outside abilities
- Negative and restrictive feedback
 - "Don't do that!"
 - "Your parents are dead"
 - "Eat this 12 your house"
 - "No, you're not going to work"

7

PLST: Care Planning Goal

GOAL - To act like a "prosthetic device" that supports the person do what what he/she is able to do

- Interventions serve like memory "crutch" that fills in for lost abilities
- Supports person to be autonomous in spite of lost abilities
- Keeps stress at manageable level throughout the day

8

PLST: Care Planning Goal

9

Interventions

PREVENTION is truly "the best medicine" in dementia care!

- Keep stress at a manageable level
- Use person-centered approaches

10

Interventions

- Person-Centered care: Think about the person "behind the disease"
 - Lifelong habits, preferences, coping methods
 - Long-standing personality
 - Personal history
 - Life experiences
 - Personal strengths, abilities, resources

11

Interventions

- Multiple factors influence quality of care and life:
 - Environmental influences
 - Personal: internal feelings, unmet needs
 - Physical: objects, activities, sensory input
 - Social: people, interactions
 - Facility and care routines
 - Disease-related disability
 - Person's strengths/limitations

12

Interventions: PLST Principles

Underlying Assumptions:

- All people need some control over themselves and their environment
- All behavior has meaning
- Behavioral symptoms are a sign of discomfort
- Persons with dementia live in a 24-hour continuum

13

Interventions: PLST Principles

Six basic ways to improve care:

- Maximize safe function by supporting losses in a prosthetic manner
- Provide unconditional positive regard
- Use anxiety and avoidance to gauge activity

14

Interventions: PLST Principles

- "Listen" to the person with dementia (what does the behavior "tell you"?)
- Modify the environment to support losses and enhance safety
- Encourage caregivers to participate in ongoing education, support, self-care, and problem-solving

15

Interventions: PLST Principles

- Many ways principles are applied in practice
- Highly individualized
- Basic strategies reviewed here



16

PLST: Care Planning

- Reduce ENVIRONMENTAL STRESS
 - Calisthenics
 - Misleading stimuli
 - Unending spaces
 - Unneeded noise
 - Extra people
 - Large rooms, unending spaces

17

PLST: Care Planning

- Compensate for lost abilities by adjusting APPROACHES
 - Use calm consistent approach & routine
 - Do not try to reason
 - Do not ask to "try harder"
 - Do not try to teach new routines
 - Do not encourage to recover lost skills

18

PLST: Care Planning

- Compensate for lost abilities by adjusting ROUTINES
 - Limit choices to ones person can make
 - Monitor changes in environment
 - Reduce, eliminate changes in pace
 - Reassurance - Familiarity and comfort
 - Repetition does not become "boring" to person with dementia

19

PLST: Care Planning

- Allow for LOWERED STRESS threshold
 - Plan rest periods in morning and afternoon
 - Maximize routines
 - Alternate low and high stimulus activities
 - Reduce stimuli when reactions occur
 - Look for triggers
 - Document incidents in specific terms: *Be descriptive!*

20

PLST: Care Planning

- Provide unconditional POSITIVE REGARD
 - Use 1:1 communication, gentle touch
 - Eliminate "you are wrong" messages
 - Distract vs. confront
 - Simplify communication
 - Use Validation vs. Reality orientation
 - Don't confront hallucinations or delusions

21

Positive Regard: Communication

- Adjusting communication strategies shows respect and helps increase
 - Cooperation
 - Comfort
 - Dignity



22

Communication Strategies

- First, simplify the MESSAGE!
 - Short understandable words
 - Simple sentences
 - One noun + one verb = ENOUGH
 - No lengthy or complex messages
 - Take pronouns out
 - Avoid "there, that, those, they, him, her, it"
 - Use nouns instead
 - "Sit in the Chair" vs. "Sit here"

23

Communication Strategies

- Simplify the message, continued...
 - Tell the person you are
 - Call the person by name
 - Use the person by providing information
- Next, simplify your STYLE!
 - Slow down
 - Say words clearly
 - Avoid slang or other unfamiliar words

24

Communication Strategies

- Simplify your style, continued...
 - If you repeat a question, repeat it EXACTLY
 - Do not "re-phrase" to clarify
 - Ask same simple question again
 - Wait for an answer
 - Go ahead - Laugh
 - Self-included humor is okay
 - Don't be afraid to laugh at yourself or the situation - just don't laugh at the person!

25

Communication Strategies

- Third, pay attention to NONVERBAL messages
 - Extend a room of people: are watching, listening to your nonverbal style
 - Use gestures to help them understand
 - Point
 - Demonstrate
 - Use your hands, face, body to help them get the meaning

26

Communication Strategies

- Make sure you have and keep their attention
 - Stand in front of the person
 - Make eye contact: smile
 - Move slowly
 - Don't threaten with sudden movements
 - Avoids catastrophic reactions
 - Walk with the person
 - Over emphasize & exaggerate expressions

27

Communication Strategies

- Last, AVOID "You are wrong" messages
 - No, you're not going to work today.
 - No, you can't visit your father. He's dead.
 - No, this is your home now.
 - No, that isn't yours. Put it back.
 - No, you can't go now.
 - No, we just talked about that!

28

Positive Regard: Validation

- Show respect through use of "validation"
 - Caregivers are often taught to use "reality orientation" (RO)
 - In dementia, Validation Therapy principles are more valuable
- So what is the difference?!

29

Reality Orientation

- Basic Beliefs:
 - Person may respond to approach "in the moment" but not retain information
 - Disoriented person needs to be in "here and now"
 - Orient person to surroundings
 - Time, place, person, things
 - Assumes disoriented person can return to present if given enough information



31

Reality Orientation

- Advantages
 - Works well with person who is "temporarily" confused
 - Dilemma (acute confusion)
 - Disorientation due to relocation
 - Gentle, "conversational" orientation useful with chronically confused
 - Tell person what is going on
 - Avoid "Do you know...?" questions (testing)



32

Reality Orientation

- Disadvantages
 - Person with progressive memory loss not able to retain information
 - Contradiction of their "reality" functions as negative and restrictive feedback
 - Increases frustration, anxiety, anger
 - Reduces self-esteem
 - Can feel like "being tested"



33

Validation Therapy

- Stresses importance of "going with the person" to their reality
- Validates feelings in whatever "time" is real to them
- Views all behavior as purposeful
 - Listens carefully for meaning
 - Respond to "emotional" message



34

Validation Therapy

- Advantages
 - Reduces risk of sending "You are Wrong" messages
 - Addresses person in more positive way
 - Often leads to reminiscence, review of life events
 - Promotes self worth
 - Person-centered approach



35

Validation Therapy

- Disadvantages
 - Person may respond to approach "in the moment" but not retain information
 - Fails reassured briefly then forgets again
 - Repeats questions over and over
 - May not be successful in reassuring person
 - Irritability, anxiety may continue



36

Validation Therapy

- Don't confront the person's mis-belief. Distract and redirect instead.
 - Person: "I'm going home!"
 - Don't: "Your house has been sold. You live here now."
 - Do: "It's too late to go home now. Stay here with me. We'll go tomorrow."



37

Validation Therapy

- Validate the person's reality. Avoid "You Are Wrong" messages.
 - Person: "Papa's coming to get me."
 - Don't: "Papa is dead. He's been dead for years."
 - Do: "Papa loves you. Papa's a good man. I forget. Tell where Papa lives." "Papa called. He'll come tomorrow, not today."



38

Validation Therapy

- Listen carefully to "non-sense." What might message mean in person's reality?
 - Person: "Hurry up! Up, up, up, up there! Go! Go! Go! Up there! Up there! Whoaaaaa!"
 - Don't: Assume message has no meaning
 - Do: Ask family significant other "where" person might "be" in his/her reality. Do words make sense based on history?



39

Validation Approaches

- Do:
 - Distract them to a different subject, activity
 - Accept the blame for misunderstandings (even if/when you know better!)
 - "I'm sorry I didn't mean to frighten you."
 - "I'm sorry if that hurt."
 - Leave the room to avoid confrontations
 - "I'm going to the kitchen now. I'll be back."
 - "Let's stop now. We'll do this later."



40

Validation Approaches

- Do:
 - Respond to feelings, not words
 - Be patient, cheerful, reassuring
 - Go with the flow



41

Validation Approaches

- Do:
 - Listen carefully to type and extent of false beliefs
 - Monitor level of distress experienced by the person
 - Persistent, severe, and troubling beliefs may reduce comfort and function
 - Short-term, low-dose medication may be needed
 - Try all other approaches first!



42

Validation Approaches

- Do:
 - Allow time for your message to "sink in"
 - Slow down. Take your time - even when you are in a hurry
 - Take "bad" out of your vocabulary
 - "But we just talked about that"
 - "But I just told you why not"
 - "But that's a tomorrow, not today"
 - "But that's not yours"



43

Validation Approaches

- Do:
 - Respond to feelings, not words
 - Be patient, cheerful, reassuring
 - Go with the flow



44

Validation Approaches

- Do:
 - Listen carefully to type and extent of false beliefs
 - Monitor level of distress experienced by the person
 - Persistent, severe, and troubling beliefs may reduce comfort and function
 - Short-term, low-dose medication may be needed
 - Try all other approaches first!



45

PLST Care Planning

- Problem-solving requires good documentation!
 - Demanding?
 - In what way?
 - Disoriented?
 - To time? Place? Or person?
 - Delusional?
 - What about? What did she say? Do?



46

PLST: Care Planning

- Evaluate Care
 - Sleep patterns
 - Weight
 - Food & fluid intake
 - Incidents and outbursts
 - How often?
 - How long?
 - How severe?
 - Medication use



47

Summary

- Dementia is INCURABLE but not UNTREATABLE!
 - Preserve remaining abilities
 - Avoid unnecessary stress
 - Treat overlapping illness that makes symptoms worse
 - Provide education & guidance to families

48

Appendix I

Project Budget	
Supplies and Materials	\$187.25
Printing	\$276.20
Hours	500+

Appendix J

Paired Differences

	Mean	Std. Dev.	Std. Error Mean	95% CI		t	df	Sig. 2 tailed
				Lower	Upper			
Pair 1 Post Score/Pre Score	2.000	1.826	.690	.311	3.689	2.898	6	.027

Appendix K

Chart Review Results

Dementia	92.1% (n=56)
Cholinesterase Inhibitor	68.4% (n=56)
NMDA Receptor Antagonist	31.6% (n=56)
Antidepressant	65.8% (n=56)
Benzodiazepine	36.8% (n=56)
Antipsychotic	7.9% (n=56)