

Complex Care Needs in Older Adults with Common Cognitive Disorders

Section A: Assessment and Management of Dementia

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Introduction

Impairment in cognitive function in older adults, whether acute and temporary or long-term and progressive, poses risks for safety, function, health maintenance, and length and quality of life. Because the incidence of cognitive impairment increases with age, older adults in any healthcare setting—primary care, home care, acute, or long-term care—should be routinely and regularly screened or assessed for cognitive function in order to plan care and intervene as appropriate. This is a two-part module in which we explore both the long term progressive changes in cognition associated with the dementias as well as those associated with acute onset and somewhat time-limited occurrences of cognitive impairment called delirium. For dementia, the focus of Section A of the module, we discuss assessment and care management principles to be individualized to type of setting and the elder's personal attributes and functional level. At the conclusion of this section, the learner will have mastered the following objectives:

1. Assess cognitive function using screening tools, such as the Folstein Mini-Mental State Examination or the Mini Cog, during various stages of dementia and in various clinical practice settings (Level 2)
2. Assess the older adult and caregiving situation for unsafe living conditions and make alternative plans of care (Level 2)
3. Develop and co-manage, with nursing staff, plans of care for older adults experiencing stable psychotic manifestations of dementia (paranoia, delusions, hallucinations) (Level 4)
4. Recognize the risk for delirium associated with acute illness superimposed on dementia (Level 5)
5. Identify modification in history taking and/or physical examination of older adults with aphasia from dementia (Level 1)
6. Co-contribute, as an interdisciplinary team member, to ethical discussions related to care of older adults experiencing dementia (Level 3)
7. Discuss with caregivers issues related to awareness of the impact of dementia on management of other medical conditions, and behavioral management to optimize cognitive, functional and psychosocial well-being (Level 2)
8. Evaluate with nursing staff a cognitively impaired older adult experiencing pain, unsafe living conditions, frequent falling, and/or urinary incontinence (Level 3)
9. Recognize stigma associated with cognitive impairment and intercede to counteract negative stereotypes in a selected clinical practice setting (unit, team) (Level 4)
10. Recommend plans of care for older adults with early-moderate and late-stage dementia in various clinical practice settings (Level 4).

Background

Definition and Demographics

The syndrome of dementia includes a plethora of disorders that have a profound impact on a person's day-to-day functioning, quality of life, and mortality. In 2004, it was the 7th leading cause of death (US Centers for Disease Control, 2006). The most common form of dementia is Alzheimer's disease (AD), a progressive neurodegenerative disorder that gradually erodes cognitive function, causes significant impairment in social and occupational function that represents a decline from a person's previous level of function and eventually causes death (Cummings & Cole, 2002 [Level VI]). Other forms of dementia include vascular dementia (VD),

Lewy Body disease, mixed types (e.g., AD and VD, AD and Lewy Body), fronto-temporal dementia, and dementia resulting from head trauma or anoxia. While the course of the disease differs somewhat by type, cardinal signs are shared. Foremost is memory impairment (amnesia), followed by one or more of the following: aphasia (impaired language), apraxia (inability to perform complex motor activities), agnosia (failure to recognize or use familiar objects or utensils), and/or abulia (disturbances in executive functions, e.g., planning, organizing, sequencing, abstracting, problem-solving) (Raskind, Bonner, & Peskind, 2004 [Level VI]).

Because of the length of time from diagnosis to death—typically from 5 to 15 or more years—and the requirement for increasingly intensive assistance with all activities of daily living, the cost of dementia to Americans is estimated at \$100 billion annually (NIA, 2002). One of the most disabling and burdensome of chronic health conditions, dementia affects an estimated 24.3 million people worldwide today, with one new case every 7 seconds and 4.6 million new cases every year. Global differences in prevalence rates have been forecast for the period 2001-2040, with developed countries expecting a 100% increase and India, China, and their south Asian and western Pacific neighbors a 300% increase. Currently, 4.5 million Americans are estimated to be afflicted with dementia, and this number is expected to double every 20 years (Ferri et al., 2005 [Level I]).

More than 10% of people age 65 and older and at least 20% of those older than 80 years have dementia severe enough to impair ability to live independently (Evans, 1990 [Level IV]). At least half of nursing home and assisted living facility residents are older adults with dementia (Rosenblatt et al., 2004 [Level IV]; USDHHS, 1998). The disease does not favor any one gender or racial/ethnic group, but research does suggest that the development of cognitive reserve, perhaps related to educational achievement, may, in fact, preserve function longer without symptoms, even in elders with brain vulnerabilities (Jones et al., 2006 [Level II]).

Pathology, Diagnosis, and Implications

The impairments in dementia arise from actual neuronal loss or structural damage in the brain. Characteristic in Alzheimer's disease (AD) is a high concentration of beta-amyloid plaques and neurofibrillary tangles seen on postmortem examination. While many theories – including genetic mutations, environmental exposures, and abnormalities in brain proteins or neurotransmitters – have been posited for explaining this neurobiological disease and are being tested, no single cause is yet determined.

In AD, the most common type, onset is insidious and progressive whereas in vascular dementia (VD) there is more often a stepwise progress and little memory impairment but increases in other cognitive losses as each new small stroke occurs. Executive and language disturbance may occur very early in fronto-temporal dementia. In dementias caused by brain injury or anoxia, where the onset is more sudden, progress of the disease may be halted and some improvement in function may actually occur (Raskind et al., 2004 [Level VI]). Regardless of the level of impairment, elders with dementia are at increased risk of delirium (Inouye & Ferracci, 2006 [Level VI]) and mortality (Dewey & Saz, 2001 [Level I]); for content on delirium, dementia and depression, see *Try This: Assessing and Managing Delirium in Older Adults with Dementia*, the *Try This Dementia Series*, and the *Evidence Based Geriatric Topic* on www.ConsultGerRN.org.

In addition to progressive cognitive impairment, up to 90% of persons with AD will be affected by other neuropsychiatric symptoms, including agitation, aggression, delusions, hallucinations, repetitive vocalizations, and wandering, and up to 50% also experience depression of AD (Lyketsos et al., 2006 [Level VI]). The diagnosis is primarily one of inclusion

and usually can be made using standardized clinical criteria in a systematic evaluation. Early detection, diagnosis and management of dementia are strongly recommended by the American Geriatrics Society (2003) in guidelines abstracted from the American Academy of Neurology.

By far the most important component of the evaluation is the history. Impairments in memory, however, often mean that the older adult may no longer be a complete or reliable informant, requiring supplemental interview data from friends, relatives, or others who are familiar with the patient. Mental status and physical and neurological examination are supplemented by review of medications, laboratory work, brief cognitive tests, and, pending these findings, neuro-imaging. In large part, the workup is aimed at identifying treatable causes for the symptomatology (e.g., adverse effects of medications, hypothyroidism, subdural hematoma, normal pressure hydrocephalus) and distinguishing the likely type of dementia, if present.

Depending on the degree of impairment, the elder with dementia may require considerable support from the family or nurse to be able to participate in an extensive and intrusive examination. Such a diagnostic workup usually is completed on an outpatient basis, when available, in a special memory disorders clinic. The findings are used to inform treatment decisions as well as to help patients, their families, and other caregivers to anticipate current and future needs, decisions, and actions. While there is no cure for dementia, the current treatment approach aims to delay disease progression and functional decline, improve quality of life, support dignity, control symptoms, provide comfort at all stages, and address the long-term well being of caregivers (Desai & Grossberg, 2005 [Level VI]; Lyketsos et al., 2006 [Level VI]).

Knowledge of the diagnosis of dementia is critical to quality of care for elders in health care settings ranging from home to hospital. Patients with dementia are most vulnerable to the stress accompanying transitions between home, nursing facility, and hospital, especially when the systems for transfer of care are fragmented or nonexistent (Stevenson & Naylor, 2005 [Level IV]). These elders likely will have difficulty identifying any changes in health state, describing symptoms of co-morbid conditions, asking clearly for pain relief, comprehending instructions or following directions for self-care and safety.

Dementia is a risk factor for the development of acute cognitive impairment or delirium (Inouye & Ferracci, 2006 [Level VI]; see also Section B), an acute and treatable condition that, nonetheless, adds to the functional impairment. Elders with dementia develop pneumonias, urinary tract infections, myocardial infarctions, cancers; they fracture hips, experience adverse effects from medications and suffer lacerations from falls. The first sign of a change in health state for an elder with dementia is most often a change in cognitive status or behavior, such as agitation. Thus, nurses need to know about the underlying dementia in order to provide safe, respectful, and individualized care. Lacking complete understanding of the underlying dementia and its manifestations, caregivers and health care workers alike may respond to the elder with infantilization and depersonalization, unintentionally contributing to further dysfunction (Borbasi, Jones, Lockwood, & Emden, 2006 [Level V]).

Preservation of Cognitive Function

While the incidence of dementia increases with advancing age, it is clear that it is not a normal consequence of aging. Thus, much work has been done to identify factors that might contribute to the prevention or at least the delay of symptomatology. Physical exercise is important to continued brain function and overall health and well being (Hodes, 2006 [Level VI]; Yaffe et al., 2001 [Level III]). Likewise, mental exercise, in the form of challenging tasks like

ballroom dancing, board games, crossword puzzles, playing a musical instrument, and reading have been shown to protect cognitive function into late life (Coyle, 2003 [Level IV]; Brummel-Smith, 2007, Level VI). The most recent evidence of the effects of cognitive training come from the NIH-funded ACTIVE trial (Wolinsky et al., 2006 [Level II]) that demonstrated protection against decline in health related quality of life five years after cognitive training in speed of processing, memory, or reasoning. The ‘use it or lose it’ adage often applied to physical function appears just as valid for preservation of mental function in aging. Thus, elders and their families should be coached to include both challenging mental activities and physical exercise as preventive strategies in their daily routine.

Assessment

Frequently a patient’s healthcare record will be devoid of any diagnosis of dementia, let alone any staging of illness. It is often assumed by providers and elders alike that cognitive impairment is a ‘normal’ aspect of aging and, thus, it is under recognized and under diagnosed (Naylor, Stephens, Bowles, & Bixby, 2005 [Level IV]). It is left to the nurse or caregiver to recognize that the person has impairment outside the norm and to deduce appropriate, individualized interventions to promote safety, function, good health and quality of life (see *Try This – Recognition of Dementia in Hospitalized Older Adults*). Even with information from a full workup, nursing assessment of status, function, and needs is critical to guide care. Use of standardized, objective screening and assessment tools to measure current cognitive function as well as to track changes over time is very helpful in identifying areas where the elder will need the nurse or family member to compensate for deficits in self care (Han et al., 2000 [Level I]). Information about the patient as a person will help to predict likely triggers for behavioral symptoms and ways to support normal function for as long as possible.

Some authorities have staged dementia, providing behavioral and functional cues to progress of the disease. While there is no strict “staging” from an evidence base, knowing something about the common course of progression can assist the nurse, patient, and family members to anticipate needs. Table 1 shows the associated impairments and functional implications for stages 1 through 7 (see www.zarcrom.com/users/alsheimers/st/10.html, accessed October 6, 2006).

In this section, several assessment methods are briefly reviewed; references to some tools are found in Appendix B of this module (see also www.ConsultGeriRN.org). When employing a standardized screening tool, best results will be obtained when the nurse creates a quiet and private environment, establishes rapport, displays attending behavior, and takes sufficient time (Sherrell & Iris, 2005 [Level VI]).

Screening Cognitive Status

Two tools are commonly used to screen for cognitive status or function: the Folstein Mini-Mental State Examination (MMSE) and the Mini-Cog. The MMSE has long been a standard assessment tool in dementia. More recently, the Mini-Cog (Borson et al., 2000 [Level III]) has been used, both in clinical settings and epidemiological studies, as a quick and accurate screen for cognitive impairment. The Mini-Cog combines a three-item word recall task with clock drawing (see below). It correlates well with the MMSE and, in fact, appears to be somewhat more sensitive for dementia. Another screening instrument gaining favor for clinical use is the Montreal Cognitive Assessment [MoCA], which also includes the following domains: visuospatial/executive function (including clock drawing), naming, immediate and short-term

recall, attention, language, abstraction, and orientation. This instrument compares very favorably with the MMSE and is available for open access use (see www.MoCAtest.org).

Some settings routinely include the clock drawing test as one component of screening for cognitive impairment. In the clock drawing test, the patient is given a paper with a 5" diameter circle drawn on it and is instructed to put the numbers in the face of the clock. When completed, the patient is asked to make the clock show "10 minutes after 11." For scoring, the clock is divided into equal quarters with 12 at the apex; with one point given for each of the numbers (1,2; 4,5; 7,8; 9,10) that fall in their respective quarters and one point each for a short and a long hand pointing at the appropriate numbers. Score on the clock drawing has been shown to correlate with score on the MMSE and with neuropsychological test scores; it indicates progressive difficulty with constructional apraxia, a common neuropsychological disturbance occurring early in dementia (Manos & Wu, 1994 [Level IV]; Moretti et al., 2002 [Level IV]; for more information visit www.ConsultGeriRN.org and select *Try This Series: Brief Evaluation of Executive Dysfunction: An Essential Refinement in the Assessment of Cognitive Impairment*).

Use of these tools should be viewed as a screen, not necessarily diagnostic. In fact, nurses should be aware that there are substantial numbers of false positive and negatives associated with the use of assessment instruments (Borson et al, 2005). Yet the data they yield can be very instructive to caregivers, both in terms of immediate ability to follow directions, retain instructions, clearly express self, and make judgments; when repeated on an ongoing basis, the screening information can also serve as a more objective indicator of worsening or improvement in function over time (Han et al., 2000 [Level I]).

Screening Function, Depression, Pain & Caregiver Stress

Depending on setting, the nurse may also administer one or more tools to measure areas of continuing functional strengths and limitation. Examples include the Katz ADL (see the *Try This* series) for self care (e.g., bathing, grooming, dressing, ambulating, toileting, eating) and/or Lawton's Instrumental Activities of Daily Living (Lawton & Brody, 1969 [Level IV]; for more information visit www.ConsultGeriRN.org and select *Geriatric Topics: Function*) for household management (e.g., paying bills, shopping, cleaning, cooking, laundry, using the telephone). Other functional tools are available that are more specific to dementia such as the Blessed Dementia Rating Scale.

To rule out depression as a cause of or contributor to the symptoms, a screen for depression such as the 30-item, yes/no Geriatric Depression Scale (Yesavage & Brink, 1983 [Level IV]; also available in a short form—for more information visit www.ConsultGeriRN.org and select *Evidence Based Geriatric Topics: Depression*) or a nonverbal observation tool may be used. It is important to identify depression in a person with dementia because, when present, it produces excess disability in function, which can be reversed upon treatment of the depression.

Paying close attention to pain and pain management is also important, because the experience of pain is often under-recognized and under-treated in people with dementia (Morrison & Siu, 2000), and pain may exacerbate cognitive and behavioral symptoms. Huffman and Kunik (2000 [Level VI]) reported a literature review on pain in dementia indicating that a moderate decrease in pain occurs in older persons with cognitive impairment, and that dementia patients' reports of pain tend to be as valid as those of intact patients. Pain assessment scales developed thus far for noncommunicative patients require improvement; this latter finding was upheld in the 2006 review by Herr, Bjoro, and Decker ([Level I]) and the 2007 review by van Herk, van Dijk, Baar, Tibboel, and deWit ([Level I]; no standardized tool is yet available for

recommended use with this population, although a few hold promise: In the interim, see *Try This – Assessing Pain in Older Adults with Dementia* (Flaherty, 2008 [Level VI]).

Finally, attention to family caregivers' level of burden, stress or strain, perceived adequacy of support system, and personal health are critical, as caregivers of elders with dementia are highly vulnerable to depression, medical illness and stress-response (Acton & Winter, 2002 [Level I]). It is important to inquire about personal status of the caregiver, not just the person with dementia. A standardized screen for caregiver burden or strain may be useful in specific practice settings (e.g., see the Caregiver Strain Index in the *Try This* series of Www.ConsultGerRN.org.)

Behavioral Assessment

Finally, gathering data about the patient's behavior-- typical patterns and responses-- and how current behavior is similar or different from usual is important in planning for safe, individualized care. Many behaviors common in dementia have been identified as symptoms that may require intervention. These include verbal and physical aggression (e.g., screaming, biting); repetitive vocalization; physical behaviors such as wandering, hoarding, rummaging, voiding in inappropriate places, shadowing, or resistance to care; affective symptoms such as anxiety, depression or anger outbursts; psychotic symptoms including delusions (e.g., intruder/robber, imposter, spousal infidelity), hallucinations and illusions (e.g., of the deceased); and vegetative symptoms such as sleep disturbances, sexual disinhibition, and poor food intake or hyperphagia. Some form of behavioral symptoms occur in over 80% of elders with dementia at some point in their disease progression (Smith & Buckwalter, 2005 [Level IV]). Desai and Grossberg (2001 [Level VI]) categorized behavioral symptoms into three areas related to causation: primary, or those that result from the neurochemical changes occurring within the brain; secondary, or those caused by comorbid medical conditions, delirium, medications, pain, personal need, or environment; and mixed behavioral disturbances, recognizing that primary and secondary behaviors may actually exacerbate each other. Distinguishing the type is important in planning for treatment approaches.

Recognizing and understanding behavioral symptoms is aided by current models such as the Progressively Lowered Stress Threshold (PLST) and Need-Driven Dementia-compromised Behavior (NDDDB), which have in common the close interplay between person, context and environment (Remington, Gerdner, & Buckwalter, 2005 [Level VI]). Both hold that behavior is used to communicate or express, in the best way the person has available, unmet needs (physiological, psychosocial, disturbing environment, uncomfortable social surroundings) and/or difficulty managing stress as the disease progresses. Keenly developed observation and validation skills are essential for the nurse to make sense of behavior in cognitively impaired elders with aphasia. After ruling out medical problems like pneumonia, dehydration, impaction, infection/sepsis, or depression as a cause, the precipitants and likely meaning of behavioral symptoms are best identified through a thorough history, assessment and use of a behavioral observation log over a 2-3 day period. The log can help track when—and under what circumstances—the particular behavior occurs, what helps, and the consequences (Smith & Buckwalter, 2005 [Level IV]; Talerico, Evans, & Kurlowicz, 2007). Such a log is invaluable in identifying patterns of behavior, its triggers, early warning signs, and unmet needs for targeted intervention with non-pharmacologic strategies. Fecal impaction, urge to urinate, hunger, discomfort, fear in an unfamiliar environment, loneliness, longing for the security of 'home' are needs that are often expressed through behavior, including 'wandering,' verbal or physical

aggression, agitation, etc. An important principle to remember is that “All behavior has meaning.”

Interventions

Patients and families often consult the nurse about the cost-benefit of initiating cognitive enhancing drugs, that is, the Cholinesterase Inhibitors (CEIs) like donepezil or Aricept. Recent recommendations and guidelines from The American Association of Geriatric Psychiatry (Lyketsos et al., 2006 [Level V]) and the American Geriatrics Society (AGS Clinical Practice Committee, 2003) are useful resources. Both recommend the use of CEIs that have appeared in clinical trials to affect stabilization or improvement in cognitive function and self care, at least for a period of time. A trial is recommended for at least 6 months. A meta-analysis of randomized controlled trials (RCTs) indicated that donepezil, galantamine, and rivastigmine each had beneficial cognitive effects as compared with placebo (Ritchie, Ames, Clayton, & Lai, 2004 [Level I]). Further, while evidence is insufficient to date, there may be utility in the combined use of CEI with memantine in treating cognitive symptoms of mild to moderate AD and should be considered for those without contraindications (Gauthier, Wirth & Mobius, 2005 [Level I]; Lyketsos et al., 2006 [Level VI]).

Consensus is apparent in the new guidelines and recent nursing literature that detection, management, and/or treatment of non-cognitive neuropsychiatric symptoms are key components of care for persons with dementia and that a trial of non-pharmacologic interventions should be the first response. Assuming availability and likelihood of their efficacy, such interventions should be selected based on the unique characteristics of the patient and caregiver. Non-pharmacologic interventions can be categorized as cognitive interventions (reorientation, reminders, cues, task sequencing, prompts); environmental modifications (adjusted noise level, familiar objects, reduced clutter, use of pictures as cues), change in activity demand (routines, scheduling, reduced amount, and complexity of activities), and interpersonal approaches (simplified language, use/avoidance of touch, eye contact, smiling); and a focus on patients' wishes, interests, strengths and concerns (AGS Clinical Practice Committee, 2003; Snowden, Sato, & Roy-Byrne, 2003 [Level V]). Formerly, the first response to many of the behavioral symptoms in dementia, including wandering and agitation, was the use of psychoactive medications and/or physical restraints. Research now indicates that these approaches are ineffective in most of the symptoms associated with dementia, and also produce harmful adverse events and side effects (Wang et al., 2005 [Level I]; Wang & Moyle, 2005 [Level I]); further, other preventive and management strategies are readily available (See *Avoiding Restraint in Patients with Dementia* in the *Try This* series, www.ConsultGeriRN.org; Evans & Cotter, 2008 [Level VI]). It is primarily the psychotic symptoms associated with dementia that may be appropriately managed pharmacologically, and then only after other interventions fail.

Behaviors in patients with dementia can be reduced through such evidence-based interventions as music therapy, walking, or other forms of light exercise. Other interventions with appeal but with insufficient research evidence to date include massage, simulated presence therapy, comprehensive psychosocial care programs, pet therapy, simple, clear commands issued at the patient's level of comprehension, bright light, white noise, and cognitive remediation (AGS Clinical Practice Committee, 2003). Two recent systematic reviews of behavioral management therapies and psychosocial interventions have been published. The first was for people with a milder dementing illness (Bates et al., 2004 [Level I]) in which only four studies covering reality orientation techniques, procedural memory stimulation and counseling met

inclusion criteria. There was some evidence for use of reality orientation, but not the others; samples were too small, however, for definitive outcomes and more studies are needed. The second (Burgener & Twigg, 2002 [Level I]), which focused on persons with irreversible dementia, yielded 157 studies between 1990 and 2000 that fit the criteria for inclusion in the synthesis, that is, descriptive, correlational, longitudinal, or intervention research. Key findings supported that cognitive behavioral interventions enhance cognitive function and memory and relieve depression in early dementia; function and activity maintenance and behavioral symptom alleviation in the middle stages can be achieved with environmental and behavioral approaches; and support and education are effective in managing nutritional intake, urinary incontinence, and problematic vocalization and other behavioral symptoms in later disease stages. Recent effects of community based caregiver skill-building programs (Gitlin et al., 2005 [Level II]) and review of nursing research studies (Kolanowski & Piven, 2006 [Level I]) reinforce these findings.

'Resistance to care' occurs most often in relation to personal care such as bathing, dressing, and toileting and can be reduced considerably with more individualized and sensitive approaches. Arthritic pain on movement, exposure to cold air and water, and perceived intrusiveness on privacy are often underlying reasons for elder responses that get classified as 'resistive,' 'agitated,' or 'aggressive.' Attention to making the caregiver approach and environment more responsive to the personal needs of the elder has been shown to result in much more 'cooperation' (Cohen-Mansfield, Pappura-Gill, & Golander, 2006 [Level III]; Rader et al., 2006 [Level VI]).

In recognition that psychotic symptoms diminish over the course of the disease, long term use of any antipsychotic or neuroleptic should regularly be reassessed beginning at 6 months. In one study, psychotic symptoms including delusions and hallucinations were reported in 41% of patients with AD; incidence increased progressively over the first 3 years of observation after which it plateaued. The symptoms lasted several months but became less prominent after 1 year (Ropacki & Jeste, 2005 [Level I]). It should also be noted that not all psychotic symptoms are troubling to the patient; these may be well tolerated by caregivers as well, with support and recognition that they will likely diminish over time. Those that are frightening or otherwise problematic to the patient or regularly result in aggressive behavior toward others should be referred to the physician for pharmacologic treatment. There is as yet no clear standard for which drug to use with which type of symptom. Recent evidence of adverse events from atypical antipsychotics and haldoperidol raise caution. Since 2005, the FDA has required a black box warning for 5 atypical anti-psychotics, primarily because of deaths of people with dementia who were treated off-label with these medications for their behavioral symptoms. All of the medications currently available for treatment of treating non-psychotic behavioral symptoms should be used cautiously with defined targets and under close monitoring. The nurse is key to observing and reporting beneficial as well as adverse effects. Tapering and discontinuation of drugs for behavioral symptoms should be initiated after 6 months of treatment (AGS & AAGP, 2003 [Level VI]).

General Intervention Principles

Individualized, person-centered principles for caring for persons with dementia advanced by the AAGP (Lyketsos et al., 2006 [Level VI]), AGS & AAGP (2003 [Level VI]), Smith & Buckwalter, 2005 [Level IV]), and the Alzheimer's Association dementia care practice recommendations

(www.alz.org/professionals_researchers_dementia_care_recommendations.asp) suggest that nurses should:

1. *Address safety.* For elders with dementia living in the community, several areas need to be addressed. These include assuring safety of continued driving, safety proofing the home against accidental poisonings or falls and providing for safe medication administration and a plan in the event the person wanders off and becomes lost (e.g., registration with the Alzheimer's Association *Safe Return* program, which can also be useful for people in assisted living and nursing homes). Many elders with dementia continue to live alone in the community. If by choice, then a network comprised of the elder, family, friends, neighbors, and health care providers should be organized to ensure continued safety and well being. When elders with dementia enter a new setting, such as the hospital or nursing home, the nurse must be alert to the impact of a strange environment on function, falls, wandering, and behavioral symptoms, as well as the likelihood of delirium development. Use of low beds without siderails, proper lighting, non-skid mats, proper footwear, no physical restraints, avoidance of intrusive treatment devices for longer than necessary, permanent staff assignments, orientation to place, and judicious use of surveillance will go a long way to ensure safety in the institutional environment.

2. *Structure daily living to maximize remaining abilities.* Living environments should be organized to enhance continued use of remaining functions, with minimization of limitations, for as long as possible. Being alert to the need to balance environmental demands with patient ability and stamina is important. Maintaining daily routines and preferences as much as possible, use of cueing techniques (signage, personal mementos from home, clocks/calendars) to supplement memory, and style of staff-person interaction all help preserve function and a sense of well being. Low lighting levels, music, and simulated nature sounds may enhance eating behavior, and intensive multimodality group training may improve ADLs but these interventions lack conclusive supporting evidence (AGS Clinical Practice Committee, 2003). Also believed to be effective, and shown in one or more studies, include special care units in long-term care facilities, Snoezelen multisensory environmental program to promote relaxation and sensory stimulation (Maloney, Volicer, & Hurley, 2000 [Level VI: Expert Opinion]), homelike settings with small groups of patients and flexibility in organizational structures (e.g., Cohen-Mansfield & Bester, 2006 [Level III]; Kane, Lum, Cutler, Degenholtz & Yu, 2007 [Level III]; Rabig, et al., 2006 [Level V]); respite services (including day care), provision of exterior safe spaces for walking and activities, remodeling corridors to simulate natural or home settings, and changes in the bathing and mealtime environments (AGS Clinical Practice Committee, 2003; Amella, Grant, & Mulloy, 2008 [Level IV]; Sloane, Hoeffler, Mitchell, McKenzie et al., 2004 [Level II]). To aid in continence, prompted voiding and scheduled toileting can be effective (AGS Clinical Practice Committee, 2003). Bright light has been shown to calm behavior and improve fragmented sleep in elders with dementia (Kim, Song, & Yhoo, 2003 [Level I]). Likewise, wandering behavior, once considered a major safety problem (Lai & Arthur, 2003 [Level I]), has been the focus of multiple studies using psychosocial, biomedical, or person-environment interaction models. Yet due to the differences in operational definitions and conceptual frameworks and small sample size, there are no clear efficacious interventions. While intuitively appealing interventions, particularly when individualized to the person, existing studies of activity therapies (Marshall & Hutchinson, 2001 [Level I]), Validation Therapy (Phillips, Neal & Briggs, 2006 [Level I]), aroma therapy (Thorgrimsen et al., 2006 [Level I]) and music therapy for agitation in dementia have weaknesses and limitations that preclude making a strong statement at this point (Lou, 2001 [Level I]).

3. *Monitor general health and impact of dementia on management of other medical conditions.* As previously noted, the first sign of a change in general health state is most often a change in

level of confusion or behavior. Because the person is less likely to be able to complain about symptoms in ways that are readily understood, the nurse and family must be alert to these subtle cues and investigate quickly to avoid untoward effects. Behavioral symptoms that are not responsive to non-pharmacologic methods or to drug therapy within 30 days should be referred to a mental health specialist (AGS & AAGP, 2003 [Level VI]).

4. *Support advanced care planning and advanced directives.* Because decisional incapacity is an inevitable outcome as dementia progresses, elders with this disorder should be offered the opportunity early in the course of their illness to think about and establish plans for future handling of estate and health care issues. Identifying a durable power of attorney for health care and setting advanced directives are ways they can be more assured that their preferences will be known and adhered to. Families need to be encouraged to discuss preferences for treatments and end-of-life care so that they will be informed surrogates should the need arise. During later stages of the illness, families should be assisted in using these advanced directives and conversations when making decisions regarding issues such as placement of gastrostomy tubes, treatment for pneumonia, hospitalization, and use of palliative care (for a more complete discussion of end-of-life care planning for persons with dementia see Volicer, 2005).

5. *Educate caregivers in the areas of problem-solving, resource access, long range planning, emotional support, and respite.* As mentioned, family caregivers for elders with dementia are at high risk for developing depression, sleep disorders, and ill health. Thus, attention early on to the needs of the primary caregiver is essential to assure well being and ability to stay for the long haul. Promoting comfort and function by understanding and managing the elder's personal, social, and physical factors that may trigger behaviors is paramount. Communicating unconditional positive regard to elders with dementia is a skill that can be taught and learned. Caregivers can learn to listen to what is being communicated underneath the behavior, to 'hear' needs being expressed in apparently 'nonsensical' words, to pay attention to signs of anxiety and restructure activities and expectations to better meet the person's needs, and to respond in loving and respectful ways that shore up the person's sense of worth and quality of life.

Both family and formal caregivers need instruction and coaching in specific tasks of care, such as bathing (Mahoney et al., 2006 [Level II]). Family caregivers as well as those working in institutions require ongoing education about dementia and behaviors. They need support, care, and help in learning problem-solving skills to creatively and proactively prevent and manage problems that arise. A range of psycho-educational, supportive, and networking interventions have been effective in reducing burden and depression or increasing knowledge in family members caring for older relatives with dementia (Acton & Winter, 2002 [Level I]) and are generally to be recommended (AGS Clinical Practice Committee, 2003 [Level VI]). Especially recommended are educating caregivers, teaching problem-solving skills, accessing resources, long-range planning, emotional support (including support groups, telephone, and internet support), and respite including day care. Evidence is mounting that support programs that involve caregivers in decisions about treatments are more effective in delaying time to institutionalization of older adults with dementia (Spijker, et al. 2008 [Level I]).

Nursing older adults who have dementia requires the sophisticated knowledge and skills of the professional nurse who also can model care for formal and informal caregivers. At home, families require guidance and instruction to anticipate needs, preserve function, and prevent behavior and sequelae. The disorder poses particular challenges in the acute care setting where continuity in disrupted and safety is at issue. And in long-term care, nurses are challenged to

create a therapeutic, homelike environment that fosters quality of life. Understanding general characteristics of the disorder and taking an individualized approach for each patient will result in the best outcomes.

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Appendix A: Levels of evidence cited in text.

Level I

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Level II

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Appendix A continued: Levels of evidence cited in text.

Level II

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Level VI

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Appendix B: Web-based resources

Visit Www.ConsultGeriRN.org and select *Try This Series*:

Assessing Pain in Older Adults with Dementia
Confusion Assessment Method
Caregiver Strain Index
Recognition of Dementia in Hospitalized Older Adults
Brief Evaluation of Executive Dysfunction: An Essential Refinement in the Assessment of
Cognitive Impairment
Therapeutic Activity Kits
Wandering in Hospitalized Older Adults
Communication Difficulties: Assessment and Interventions in Hospitalized Older Adults with
Dementia
Assessing and Managing Delirium in Older Adults with Dementia
Decision Making in Older Adults with Dementia
Working with Families of Hospitalized Older Adults with Dementia
Eating and Feeding Issues in Older Adults with Dementia: Part I: Assessment
Eating and Feeding Issues in Older Adults with Dementia: Part II: Interventions

Visit ConsultGeriRN.org. and select *Geriatric Topics*:

Function
Dementia
Delirium

Other helpful resources:

Alzheimer's Association website, available at: www.Alz.org
University of Pennsylvania School of Nursing HCGNE website for GeroTips, available at:
www.nursing.upenn.edu/centers/hcgne/gero_tips/RES_default.htm
Family Caregiver Alliance website for caregiver information, visit www.caregiver.org
Stages of AD and FAST found at www.zarcrom.com/users/alzheimers/st-10.html on October 6,
2006.

American Psychiatric Nursing Association

Appendix C: Example of a Teaching Pedagogy for Care of Older Adults with Dementia

Content Area: Topic	Recommended Pedagogies
1. Assessment of an older adult for cognitive impairment and/or behavioral problems associated with dementia	<ol style="list-style-type: none"> <li data-bbox="856 607 1570 643">1. Obtain the MMSE [Mini-Mental State Examination] <li data-bbox="856 756 1623 860">2. Review with students the 5 main areas of cognition contained on the MMSE that represent executive function (for example immediate, recent and long-term recall). <li data-bbox="856 902 1608 1045">3. Ask students to identify how an impairment in cognitive function such as loss of immediate or recent recall could impact ability to execute an activity of daily living such as driving, cooking, bathing or taking medications. <li data-bbox="856 1088 1644 1230">4. Have students identify all life threatening situations which may result from cognitive impairment in daily activities (for example, burns or fires at home, getting lost while driving, malnutrition). <li data-bbox="856 1273 1623 1370">5. Ask students to list the types of questions they should include on a review of systems to elicit from caregivers if difficulties in daily living have occurred.

6. Obtain a video clip on cognitive impairment and review with students. For more information visit www.nursing.upenn.edu/centers/hcgne/gero_tips/RES_default.htm Identify and list common behaviors associated with dementia. Identify with students approaches to patient care should these problems occur.
7. Assist student to administer the MMSE (or Mini-Cog [Try This: Mental Status Assessments of Older Adults: The Mini-Cog, www.ConsultGeriRN.org], or MoCA) to a stable older adult with chronic dementia who does not display any behavioral problems.
8. Ask student to sum the score on the screening tool used [above] and to comment on the areas of impairment. Ask students to evaluate if the total score is normal or abnormal.
9. Ask student to develop a plan of care for an older adult with chronic stable dementia who demonstrates impairment in recent recall. Ask student to identify for what the patient is at risk. Ask the students to identify appropriate nursing interventions to minimize these risks? Ask students to list appropriate caregiver instructions.

Table 1. The Stages of Alzheimer's Disease¹

Level	FAST Scale Stage	Characteristics	Description
1	Normal Adult	No functional decline.	No symptoms of Alzheimer Disease are seen.
2	Normal Older Adult	Personal awareness of some functional decline.	Very mild cognitive decline, e.g., problems such as vagueness about where familiar objects are located, complaints about not remembering well, forgetting names once well known; there is however, no loss of abilities in social interactions or in employment situations.
3	Early Alzheimer Disease	Noticeable deficits in demanding job situations.	Mild cognitive decline, e.g. problems such as getting lost when traveling to a familiar location, noticeably lowered performance level at work, trouble finding words and names, little retention from reading, little or no ability to remember names of new people, loss of valued objects, and trouble concentrating.
4	Mild Alzheimer Disease	Requires assistance in complicated tasks such as handling finances and planning parties.	Moderate cognitive decline, e.g., displays problems like decreased knowledge of current and recent events; loss in memory of personal history, decreased ability to handle travel or finances; inability to perform complex tasks. Appropriate responsiveness to outside stimulation decreases quickly. Denial of any problem, and withdrawal from challenging situations are common.
5	Moderate Alzheimer Disease	Requires assistance in choosing proper attire.	Moderate severe decline, e.g., person can no longer survive without some assistance, cannot remember names of familiar people or places, may be disoriented about time and dates; they will, however, require no assistance when using the bathroom or eating, but may need help getting dressed.
6	Moderately Severe Alzheimer Disease	Requires assistance in dressing, bathing, and toileting. Has urinary and fecal incontinence.	Severe cognitive decline, e.g. the person may forget the name of the spouse and be unaware of events in his/her life, is entirely dependent on others for survival, may have trouble sleeping in a regular pattern.
7	Severe Alzheimer Disease	Speech ability declines to about a half-dozen intelligible words. Progressive loss of abilities to walk, sit up, smile and hold head up.	Very severe cognitive decline, e.g., all verbal abilities are lost and s/he needs help eating and using the bathroom. Eventually loses ability to walk; the brain appears to no longer be able to tell the body what to do.

¹ The Reisberg Functional Assessment Staging (FAST) Scale allows professionals and caregivers to chart the decline of people with Alzheimer's disease. Adapted from Stages of AD and FAST found at www.zarcrom.com/users/alzheimers/st-10.html on October 6, 2006.