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# The Roles of Speech-Language Pathologists Working With Individuals With Dementia- Based Communication Disorders: Technical Report

*Ad Hoc Committee on Dementia*

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## About This Document

This technical report was developed by the American Speech-Language-Hearing Association (ASHA) Ad Hoc Committee on Dementia. Members of the committee included Kathryn Bayles, Michelle Bourgeois, Tammy Hopper, Danielle Ripich (chair), Susan Rowe, and Amy Hasselkus (ex officio). Celia Hooper, ASHA vice president for professional practices in speech-language pathology (2003–2005), served as monitoring vice president.

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## Introduction

The syndrome of dementia comprises multiple cognitive deficits including short- and long-term memory impairment and at least one of the following: aphasia, apraxia, agnosia, and/or impaired executive functioning (*Diagnostic and Statistical Manual of Mental Disorders—Fourth Edition*; American Psychiatric Association, 1994). Although the intellectual profiles of individuals diagnosed with dementia vary somewhat by etiology, the degree of intellectual deterioration is sufficient to interfere with social and occupational functioning.

The most common cause of dementia is Alzheimer's disease (AD), accounting for two thirds of the cases (Katzman & Bick, 2000). Other common causes are multiple infarctions, Lewy bodies, and Parkinson's disease. Among the less common causes are Pick's disease, Creutzfeldt-Jakob disease, progressive supranuclear palsy, Huntington's disease, Wilson's disease, and kuru. Though the aforementioned diseases are irreversible, dementia can be associated with potentially reversible conditions such as infection, normal pressure hydrocephalus, thyroid disease, depression, and drug toxicity.

The syndrome of dementia is most prevalent in older adults because AD and other common causes are age-related. An estimated 4.5 million Americans suffer from AD, a number that has doubled since 1980 (Hebert, Scherr, Bienias, Bennett, & Evans, 2003). By the year 2050 the number of affected individuals will rise to between 11.3 and 16 million. Because the elderly segment of the population (65+) will rise from its current proportion of 13% to 20% by 2030, people with dementia-associated communication problems are the profession's fastest growing clinical population (Kinsella & Phillips, 2005).

## Dementia-Associated Cognitive-Communication Disorders

The declines in memory and other cognitive functions that define the dementia syndrome inexorably affect the ability to comprehend and produce linguistic information (Bayles, Tomoeda, & Trosset, 1992). Additionally, behavioral problems that develop as a result of the neuropathology can interfere with communication, among them paranoia, hallucinations, and repetitiousness.

Individuals with early-stage AD, who rapidly forget what they have recently heard, seen, or thought, have difficulty following a conversation. Often they lose the topic, miss the point, and repeat themselves. Forgetting what they intended to say results in sentence fragments (Tomoeda & Bayles, 1993). Individuals in the middle stage of the disease, who are disoriented for time and place and have severe episodic memory deficits, have difficulty remembering recent events. Their verbal output is reduced and is less substantive, and they are less efficient in expressing information (Tomoeda & Bayles, 1993). By the late stages of AD, affected individuals no longer have the intellectual capacity to care for themselves.

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Perception, attention, encoding, retrieval, and executive functions are severely compromised. Semantic memory, or conceptual knowledge, is now degraded or inaccessible. The linguistic abilities of naming, describing, writing, and conversing are severely compromised (Bayles, Tomoeda, Cruz, & Mahendra, 2000). Much of the verbal output of latestage individuals appears nonsensical, and many latestage patients are unable to communicate even basic needs.

As recently as 1975, most Americans were unaware of AD, and few speech-language pathologists (SLPs) had training about its effects on communicative function. In fact, before 1975, scant literature existed on the effects of dementia on communicative functioning. The majority of health professionals held the view that little could be done for persons with progressive dementing diseases, and rehabilitation services generally were unavailable. Tests designed to evaluate the communicative functioning of individuals with dementia had yet to be developed. As health care and social planners came to understand the social and economic implications of the burgeoning prevalence of dementia, by virtue of the “graying” of the population, resources were made available to better understand dementing diseases and how best to care for affected individuals.

Beginning in the mid-1970s, the National Institute on Aging and the National Institutes of Mental Health funded longitudinal studies of the effects of AD, Parkinson's disease, and Huntington's disease on cognition, language, and communicative functioning. Study results provided information about deficits and spared abilities throughout the course of these diseases. With greater understanding of retained abilities (see Hopper, Bayles, & Kim, 2001, for a review), clinicians and researchers saw potential for helping individuals with dementia and their caregivers.

During this same period, research in cognition expanded our understanding of human memory as comprising multiple systems that can be differentially impaired. Behavioral scientists demonstrated that individuals with AD suffered greater deficits in declarative memory systems (memory for concepts, events, and words), than procedural memory systems (a general term referring to habit memory or the ability to perform motor and cognitive procedures) (Eslinger & Damasio, 1986; Heindel, Butters, & Salmon, 1988). These findings and others like them formed the foundation for research into interventions designed to help individuals with dementia capitalize on spared cognitive systems to compensate for damaged ones.

By the late 1980s, the concern of the American public for quality long-term care for people affected with dementia led to scrutiny of nursing homes. Results of Congressional investigations resulted in the passage of the Omnibus Budget Reconciliation Act (1987), which mandated evaluation of the physical and psychological status of residents in long-term care facilities at the time of admission and periodically thereafter (quarterly or after significant changes in function). Henceforth, nursing homes, desirous of Medicare reimbursement for resident care, had to conduct comprehensive evaluations of residents and thereafter develop care plans enabling them to function at the highest possible level of independence. The required evaluation, known as the Minimum Data Set (MDS), included questions about the ability of residents to hear, comprehend, and produce language. Although the law did not require that judgments about hearing and communicative function be made by SLPs, the inclusion of questions on the MDS

about hearing, speech, and language helped establish a role for SLPs with long-term care residents, and many SLPs were employed by nursing homes. Nonetheless, SLPs have struggled to gain recognition as the professionals best qualified to evaluate communicative function. Whereas Medicare claims reviewers increasingly recognized that SLPs could appropriately treat speech and language disorders, they often failed to understand the necessity of treating the cognitive deficits that caused the communication problems of dementia.

ASHA has played a significant role in educating third-party payers, legislators, and other health professionals about the beneficial role SLPs have in the management of individuals with dementia. Starting in 1987, ASHA has published a series of documents that help explain the relation of cognition to communication and the unique qualifications of SLPs, by virtue of their training, to assess and treat cognitive-communication disorders. In a 1987 technical report published by ASHA, it was stated that “The interrelationship between cognition and language serves as the basis for effective communication. A cognitive impairment can result in a communication breakdown, requiring speech-language intervention to improve functional ability” (ASHA, 1987, p. 53). In 1991, ASHA published guidelines for SLPs serving persons with “language, socio-communicative, and/or cognitive-communicative impairments” (ASHA, 1991) in which it was stated that “language learning and use are determined by the interaction of biological, cognitive, psychosocial and environmental factors” (p. 22). The term “cognitive-communicative” disorder was used to acknowledge the inseparability of cognition and communication.

The 1987 technical report also specified that SLPs have a role in evaluation and treatment of individuals with cognitive-communication impairments. In a position statement published in 1988, more specific mention was made of the need for services to older adults with cognitive-communication problems, reflecting greater concern about the communication needs of this growing segment of the population (ASHA, 1988).

In the 1991 guidelines publication, ASHA delineated five roles that clinicians have with individuals with cognitive-communication impairments, namely identification/assessment, intervention, inter-professional collaboration, case management, and education/advocacy. Also included in this publication was a list of the competencies required to work with individuals with cognitive-communication disorders, information that was used by many training programs in developing curricula. These roles were further elaborated in a 1997 ASHA publication titled *Preferred Practice Patterns for the Profession of Speech-Language Pathology*. This document has since been updated (ASHA, 2004d). Screening was recommended for all individuals, regardless of age, who have a condition that increases their risk for cognitive-communicative problems. Assessment was described as a process in which strengths and deficits related to cognitive problems are evaluated. In addition to specifying screening and in-depth assessment as preferred practice patterns, follow-up services also were recommended to “monitor cognitive-communicative status and insure appropriate intervention and support.” In 2004, ASHA published another technical report that contained the recommendations of a committee of representatives from ASHA and Division 40 (Clinical Neuropsychology) of the American Psychological Association on the responsibilities of SLPs and clinical neuropsychologists who

## Assessment Considerations

also assess and treat individuals with cognitive disorders (ASHA, 2004a). This document included formal recognition that both SLPs and clinical neuropsychologists have a role in assessing and treating cognition though each has a unique purpose and scope. SLPs were recognized as the only professionals who are certified and licensed to treat communication disorders associated with cognitive deficits.

More recently, in 2005, ASHA updated its statement of knowledge and skills needed by SLPs in the identification, diagnosis, and treatment of individuals with cognitive-communication disorders (ASHA, 2005b). This document specifically states that SLPs have a primary role in the screening, assessment, diagnosis, treatment, education, and counseling of adults with cognitive-communication disorders associated with dementia producing nondegenerative and degenerative neuropathologies.

In 1980, the World Health Organization (WHO) published a framework to describe health conditions called the *International Classification of Impairment, Disability and Handicap*. In 2001, a revised model called the *International Classification of Functioning, Disability and Health* (ICF; WHO, 2001) was released. According to the WHO (2001, p. 3), the purpose of the ICF classification is “to provide a unified and standard language and framework for the description of health and health-related states.” The ICF encompasses two parts, each with two components that can be expressed in positive and negative terms (WHO, 2001, p. 10):

### Part I. Functioning and Disability

- Body structures and functions (positive terms) and “impairments” in these structures or functions (negative terms)
- Activity and participation levels of functioning (i.e., execution of a task and involvement in a life situation, respectively; positive terms) and “limitations and restrictions” on these (negative terms)

### Part II. Contextual Factors

- Environmental factors (the physical, social, and attitudinal environment in which people live—can be facilitating or hindering)
- Personal factors (gender, age, and other variables that are not easily classified and vary by society and culture)

The ICF is a model that promotes evaluation of the interaction between a person's health condition (disease/disorder) and the environmental and personal factors (among them sensory functions) that serve as facilitators or barriers to functioning. Adherence to this model requires comprehensive evaluation of each individual's needs in relation to the health condition. When the dementia is caused by a progressive disease, periodic reevaluation and adjustment of care plans becomes essential to meet changing needs.

## Screening

Screening for sensory impairment should precede screening for dementia. Hearing loss is particularly common among older adults in long-term care settings (Hull, 1995; Voeks, Gallagher, Langer, & Drinka, 1990), as is visual impairment. Ideally, referral to an audiologist or physician to check for impacted cerumen should be made prior to screening. Also, hearing aids should be inspected to ensure that they work and, if possible, a pure-tone audiometric hearing screening should be administered together with an observation of word recognition abilities. Word

recognition involves single-word repetition, making it appropriate for individuals with dementia who typically retain the ability to repeat words even in the advanced stages of cognitive decline. During screening and in all interactions, SLPs should ensure adequate lighting, as older adults generally need more illumination.

Depression is common in individuals with dementia and can adversely affect test performance, making individuals seem more cognitively impaired than is the case. In fact, the cognitive changes associated with depression so resemble the cognitive changes associated with dementia that depressive symptoms are often referred to as “pseudodementia.” Thus, it is important that SLPs be knowledgeable of and sensitive to signs and symptoms of depression and make referrals to a neuropsychologist or clinical psychologist experienced with geriatric depression when those signs or symptoms are present.

Drug effects on cognitive-communicative function are also important considerations for speech-language pathologists. Polypharmacy, or the concurrent use of several medications, is common among older adults who have multiple medical conditions (Kaufman, Kelly, Rosenberg, Anderson, & Mitchell, 2002) and many medications prescribed to older adults may have side effects that include exacerbation of cognitive problems. If clinicians have questions about the effects of medication use on the cognitive-communication functioning of their clients, they should contact a pharmacist knowledgeable in geriatric pharmacy for further information.

When selecting cognitive-communication screening instruments and subsequent tests for comprehensive evaluation, clinicians must consider the cultural and linguistic background of the client. Tests that have normative samples of culturally and ethnically diverse groups should be used when available. For information on knowledge and skills required when working with culturally and linguistically diverse populations, see *Knowledge and Skills Needed by Speech-Language Pathologists and Audiologists to Provide Culturally and Linguistically Appropriate Services* (ASHA, 2004c).

Many standardized instruments with demonstrated reliability for screening for dementia are available. These instruments typically contain items that enable the clinician to identify an episodic memory problem and disorientation to time, place, and person. If screening reveals cognitive impairment, a comprehensive evaluation of communicative function should follow.

## Comprehensive Evaluation

As previously mentioned, comprehensive assessment of residents of long-term care facilities is mandated by law, and the MDS is the government-prescribed assessment tool. The MDS is designed to help health care professionals identify problem areas that need more in-depth evaluation. Although SLPs typically do not conduct the MDS evaluation in long-term care facilities, they should contribute screening and assessment information to allow the MDS coordinator to accurately complete sections relevant to cognitive-communicative functioning. Because the progressive cognitive deterioration that defines the dementia syndrome inevitably affects communicative functioning, all individuals with dementia should receive a comprehensive, in-depth evaluation of cognitive-communication functioning at the time of admission to a long-term care facility and periodically thereafter as indicated. The goal of the assessment is to establish the highest level of functioning

of which the dementia patient is capable. This information is needed for formulating the required care plan because care plans must be designed with specific goals to sustain residents at the highest possible level of functioning.

In doing a comprehensive assessment, SLPs should use assessment tools that have been demonstrated to produce a valid characterization of cognitive-communication strengths and weaknesses, including language comprehension and expression and integrity of working, declarative, and nondeclarative/procedural memory systems. Additionally, clinicians should identify cultural, environmental, and linguistic barriers that impede functioning. As always, per the ASHA *Code of Ethics* (2003), SLPs who conduct assessments of individuals with or at risk for dementia should have the requisite knowledge, education, and training.

Clinicians should select a test battery for comprehensive assessment that has been standardized on individuals with dementia. The selection process should involve scrutiny of the evidence for validity and reliability of results obtained using the battery. Further, consideration should be given to the severity level of the individual being tested. Some tests are too difficult for the individual with severe dementia and do not yield useful information because the individual fails most or all of the items. Tomoeda (2001) provides a review of cognitive-communication assessments for individuals with dementia.

Comprehensive evaluation of individuals with dementia should also include observation of the individual with dementia in several communicative contexts (e.g., different settings, different partners). Interviews also should be conducted with personal and professional caregivers. Information gleaned from these methods will supplement standardized test results, aid clinicians in assessing change in functioning over time, and help in determination of appropriate treatment goals.

### **Determining Candidacy for Treatment**

As a result of the progressive nature of most dementia-associated illnesses, clinicians are challenged to decide whether individuals with dementia have the potential to benefit from cognitive-communication interventions. Clinicians must justify to payers, families, and patients that recommended interventions are reasonable and necessary. To that end, they should identify positive prognostic factors, such as responsiveness to cues, ability to read, ability to follow simple directions and ability to converse (Bayles & Tomoeda, 1997) that demonstrate the feasibility of the proposed intervention. Some treatment programs (e.g., use of graphic and written cues in memory books, spaced-retrieval training) have short pretreatment assessment protocols that can assist clinicians in determining whether a client is a candidate for the particular treatment. In sum, assessment enables SLPs to identify residual abilities and deficits of clients, and this enables the SLPs to design appropriate care plans and to counsel professional and personal caregivers about how to best support the functioning of the patient.

### **Intervention Considerations**

Various dementing diseases result in unique profiles of cognitive-communication impairment because of differences in the distribution of neuropathology. Therefore, an underlying principle of dementia intervention programs is to increase reliance on spared systems and decrease dependence on impaired ones (Bayles & Tomoeda, 1997). For example, in individuals with AD, nondeclarative memory

## Direct and Indirect Interventions

systems such as procedural memory, habit memory, capacity for conditioning, and recognition memory may be relatively preserved compared with declarative memory systems until the later stages of the disease (Eslinger & Damasio, 1986; Heindel et al., 1988). In other types of dementia, such as that associated with Parkinson's disease, nondeclarative memory systems, particularly motor skill learning, may be more prominently affected (Heindel, Salmon, Shults, Walicke, & Butters, 1989). Regardless of the etiology, less impaired aspects of cognition and communication should be used as the basis for therapy programs aimed at facilitating function. Indeed, in recent years, researchers have demonstrated that even individuals with AD dementia who have difficulty recalling episodes or events can, nonetheless, learn new information and behaviors (see, e.g., Camp, 1989; Hawley & Cherry, 2004).

A second therapeutic principle for people with dementia is the strengthening of knowledge and processes that have the potential to improve. Repeated exposure to a stimulus-response pairing may result in the association being strengthened even though the individual lacks the ability to recall the learning situation. Importantly, techniques that limit a client's opportunity to make mistakes during learning create stronger engrams for the desired response. This approach is known as "errorless learning," and researchers are increasingly demonstrating that minimizing errors during learning trials is an integral component of therapy programs for individuals with dementia (see, e.g., Clare et al., 2000).

Finally, clinicians should design interventions that will evoke a positive emotion in the client. Elicitation of positive responses during therapy tasks increases the likelihood of engagement and learning. When stimuli and techniques are used that evoke negative emotion (including repeatedly correcting a person with dementia who incorrectly recalls information), the person may be distressed long after they have forgotten the stimuli.

To ensure relevance and appropriateness of treatment programs, decisions about goals, techniques, and stimuli must be made in collaboration with clients, their caregivers, and other health care professionals. Clinicians must consider the cultural background of their clients when designing treatment programs and adapt specific activities to their interests. Clinicians should refer to *Cultural Competence* (ASHA, 2005a) for further information on the ethical considerations of working with individuals with dementia who have culturally and linguistically diverse backgrounds.

Clinicians can work directly with individuals who have dementia to facilitate cognitive-communicative function ("direct" interventions; Clark, 1995) or indirectly through environmental modifications, development of therapeutic routines and activities, and caregiver training (Clark, 1995; Hopper, 2001). Some examples of direct interventions with research evidence to support their use are spaced-retrieval training (Bourgeois et al., 2003; Camp, 1989), reminiscence, the Breakfast Club (Santo Pietro & Boczeko, 1998), Montessori-based activities (Orsulic-Jeras, Judge, & Camp, 2000; Orsulic-Jeras, Schneider, & Camp, 2000), and the use of graphic and written cues in memory wallets and books (Bourgeois, 1990, 1992, 1993). These direct interventions are designed and implemented by

SLPs; however, all direct interventions should be taught to caregivers for use after individuals with dementia have been discharged from skilled SLP treatment programs.

Caregiver training is essential to facilitating optimal outcomes for individuals with dementia. Most caregivers lack understanding of how communicative functioning will be affected in the different stages of dementia, and will profit from periodic counseling as the dementing disease progresses. For this reason, and the fact that caregivers have continual (often daily) interactions with people with dementia, SLPs should consider caregiver training in any dementia management program. Caregiver communication training programs have been developed by some researchers (Clark & Witte, 1989 [as cited in Clark, 1995]; Ripich, 1994; Santo Pietro & Ostuni, 2003) and positive outcomes reported (Ripich, 1994; Ripich, Wykle, & Niles, 1995; Ripich & Zioli, 1999). Whereas direct interventions may not be appropriate for all individuals with dementia, indirect interventions, particularly caregiver training in communication strategies, are appropriate for individuals in all stages of dementia severity.

Both the environment and everyday routines are appropriate targets for management to improve functional communication abilities of individuals with dementia. In fact, SLPs and other clinicians have used linguistic stimuli, such as large-print signs, to indicate locations of importance, such as restrooms, bedrooms, and dining rooms. The techniques of using tangible stimuli and single-word cues are both consistent with the principle of capitalizing on cognitive-linguistic strengths in managing individuals with dementia. Increasing lighting; decreasing ambient noise; creating a home-like, culturally appropriate environment; and developing familiar routines are all among the recommended strategies for improving cognitive-communication skills and other functional abilities in dementia (Lubinski, 1991). Although anecdotal evidence is abundant in support of the benefit of these strategies on communicative functioning of individuals with dementia, research is needed to demonstrate their efficacy and effectiveness.

In summary, SLPs have a therapeutic role with both patients and their caregivers through direct and indirect interventions. When a clinician is involved from early in dementia until the terminal stage, both types of intervention are likely to be used.

### **Evidence-Based Practice Considerations**

The term “evidence-based practice” (EBP) is defined by Sackett, Rosenberg, Gray, Haynes, and Richardson (1996, p. 71) as “the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients... [by] integrating individual clinical expertise with the best available external clinical evidence from systematic research.” Patient values and preferences should be considered in framing care programs. In 2004, ASHA published a technical report, *Evidence-Based Practice in Communication Disorders: An Introduction*, which includes a short introduction on the underlying tenets of EBP (ASHA, 2004b).

In 2001, the Academy of Neurologic Communication Disorders and Sciences (ANCDS), together with ASHA support, committed to developing EBP guidelines for dementia-based communication disorders. A committee of researchers and clinicians was formed to review and evaluate published research. Whereas in 1975 little research was available about the communication disorders associated with

## Future Research Needs

the dementias, today there is extensive literature. Tests have been developed for identifying the cognitive-communicative impairments of individuals with dementia, and many interventions have been reported to produce positive effects on the functioning of these patients. The results of the work of the Committee to Develop Evidence-Based Practice Guidelines for Dementia Based Communication Disorders is being published in a series of articles (see Hopper et al., in press; Mahendra et al., in press-*a*, in press-*b*). Bayles and colleagues (in press) provide a description of the criteria used by committee members for evaluating the validity and reliability of the results of intervention studies.

Treatment efficacy and effectiveness studies related to indirect and direct therapy approaches for dementia are top research priorities for the profession. Questions related to intervention—what techniques are effective, with whom, for how long, and in what context—remain largely unanswered. The list that follows is a sample of topics important for future research and comes from the previously mentioned ANCDS technical report:

- Documentation of cognitive-communication profiles of individuals with different types of dementia and the response of these individuals to direct and indirect interventions
- Effects of environmental manipulations (e.g., routines and activities) on cognitive-communication abilities
- Influence of cultural and linguistic diversity on response to interventions (e.g., environment, accent of caregivers and persons with dementia and their communication interactions, presence and type of bilingualism)
- Use of technology in treatment for individuals with dementia (e.g., computer programs)
- Effects of modification of language on the comprehension and behavior of the person with dementia (e.g., simplifying syntax, modifying rate of speech, use of different question types)

As medical and pharmaceutical treatments for AD and other dementias continue to improve, individuals with dementia will be identified earlier and live longer. Already efforts are under way to test behavioral interventions that might be paired with pharmacological therapy to maximize cognitive-communication abilities (see, e.g., Chapman, Weiner, Rackley, Hynan, & Zientz, 2004). Indeed, there is reason to believe that cognitive-communication stimulation will be essential to gaining full benefit from drug treatment.

## Conclusions

With the growth of the older adult population and the increased incidence and prevalence of dementia, SLPs will increasingly be serving individuals with dementia. Because research related to managing individuals with dementia is burgeoning and evidence is growing about the value of intervention, clinicians are encouraged to keep abreast of developments and use an EBP approach to assessment and treatment. In summary, SLPs have a primary role in the screening, assessment, and treatment of dementia-associated cognitive-communication disorders, including caregiver training and counseling. Other roles include collaboration with team members, case management, education, advocacy, and research.

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