Chapter 18

Dementia

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The concept of dementia, defined as "being out of one's mind," has been around since the time of the Roman poet Lucretius (50 BCE) (Berrios, 1987). Over the centuries, the term has evolved from one that described any change in intellect or judgment in the elderly, to a collection of cognitive and behavioral symptoms correlated with specific neuropathology. The aging process is thought to have three possible cognitive outcomes: (1) normal age-related decline, which is often described as normal and healthy aging; (2) age-associated memory impairment, which is not as severe and does not have all of the features of dementia; and (3) dementia, for which there are many types (Christensen & O'Brien, 2000). In addition, the diagnosis of *mild cognitive impairment* (MCI) has emerged for individuals demonstrating mild impairment, usually in only one domain (e.g., memory) and who do not meet the clinical criteria for dementia (Green, 2005). The *Diagnostic and Statistical Manual of Mental Disorders,* fourth edition, text revision (DSM-IV-TR) (American Psychiatric Association, 2000) defines dementia as an impairment in memory with related changes in another cognitive domain (language, abstract thinking, judgment, executive function) that cause significant social and occupational impairments. Dementia is distinguished from disturbances of consciousness such as delirium, which is typically an acute and treatable physical condition, and other psychiatric morbidities such as depression and anxiety disorders for which there are pharmacologic remedies (Ballard, 2000). Evidence of an organic cause of the memory and intellectual impairments is also required for a DSM-IV diagnosis of dementia.

Dementia, therefore, is a clinical syndrome of chronic and progressive symptoms that result from acquired brain disease. As many as 75 different disorders may cause dementia or chronic cognitive impairment including neurodegenerative diseases (e.g., Alzheimer disease, Pick disease, dementia with Lewy bodies), vascular diseases (e.g., multi-infarct dementia, Binswanger disease), endocrine disorders (e.g., diabetes, thyroid disease), vitamin deficiencies (e.g., B_{12}, thiamine), systemic diseases (e.g., respiratory diseases, anemia), other neurologic disorders (e.g., normal pressure hydrocephalus, head injury, tumors, multiple sclerosis), and infections (e.g., syphilis, encephalitis, HIV, Creutzfeldt-Jakob disease). Approximately 13% of cases have a potentially reversible cause of dementia, such as drug toxicity, depression, thyroid disease, vitamin B_{12} deficiency, and normal pressure hydrocephalus (Eastley & Wilcock, 2000). A comprehensive, multidisciplinary clinical assessment of cognitive and noncognitive symptoms is crucial for accurate diagnosis.

A careful documentation of the presenting complaint and history of symptoms helps to identify areas of cognitive functioning (e.g., language impairment, orientation, initiation and execution of activities, visuospatial difficulties) and noncognitive functioning (e.g., change in personality, behavioral disturbance, and psychiatric symptoms). The gradual onset of symptoms over time may help to confirm a neurodegenerative condition, whereas a sudden, acute episode

would suggest a cerebrovascular infarct or stroke. Family members or other significant others are often very helpful in supplementing patient information, particularly if they live with the person.

Review of the patient's medical conditions is important for determining if any existing medical condition could explain the symptoms. In particular, cardiovascular disease, diabetes, hypothyroidism, potentially anoxic or hypoxic conditions, liver and renal disease, and head trauma can all contribute to cognitive impairment. Follow-up blood screening is usually recommended to monitor known medical conditions and to detect any previously undiagnosed conditions.

Medication review is an increasingly vital component of the evaluation because of the incidence of polypharmacy in the elderly. Multiple medications for a range of physical illnesses can impact cognitive function and alter drug pharmacokinetics. Nonprescription drugs use, such as cold and sleep remedies, and herbal products, such as *Ginkgo biloba,* should also be documented for their potential contributions to impaired cognitive functioning and other side effects. Noncompliance with medication regimens often exacerbates known medical conditions, and can be the result of forgetting to take the drugs as prescribed. The neurotoxic effects of drug and alcohol abuse, often overlooked in the elderly, can be reversed if detected and treated appropriately.

Physical and neurologic examinations are necessary for revealing any evidence of cardiovascular-respiratory impairment as indicated by measuring the pulse and blood pressure and listening to the heart, lungs, and abdomen. Cranial nerve examination looks for signs of facial weakness, abnormal eye movements, and visual field defects; posture, gait, and movement disorders; grasp, sucking, and snout reflexes; and vibratory and proprioceptive sensation deficits that would signal specific medical or neurologic conditions. Assessment of the patient's mental status, language functioning, and mood help to differentiate focal impairments secondary to vascular lesions from psychotic symptoms related to psychiatric illness and the gradual deterioration of cognitive functioning in dementia. Clinical observations are usually correlated with radiologic evidence from computed tomography (CT) scans, magnetic resonance imaging (MRI), and single photon emission computed tomography (SPECT) scans, as well as electroencephalography (EEG) studies.

Family and social history information includes documentation of relatives with dementia or other high-risk medical conditions, patient's education and occupation, social supports and resources, and living arrangements.

◆ Pathophysiology

Changes in the brain are documented via radiologic procedures such as CT scans, MRI, positron emission tomography (PET), and SPECT scans. CT provides an x-ray image of intracranial structures to rule out brain tumors, cerebral lesions, cortical atrophy, and ventricular and white matter changes. CT is the scanning method of choice for cognitively impaired and agitated patients because it is faster and cheaper, but findings of cortical atrophy, ventricular enlargement, and reduced CT density may be similar to those seen with age-related changes and psychiatric disorders such as late-life depression and schizophrenia (Pearlson, Rabins, & Burns, 1991). Structural MRI uses electromagnetic forces to create a spatial representation of brain tissue, with improved resolution and superior soft tissue contrast of the images over CT scans. Because it does not use ionizing radiation, MRI can be used serially and for the study of normal controls (Barber & O'Brien, 2000).

Magnetic resonance imaging is helpful for differential diagnosis. In persons with suspected Alzheimer disease (AD), MRI data reveal generalized atrophy of the whole brain and ventricles; wider cortical sulci; and atrophy of the temporal lobes, hippocampi, and amygdala. Some of these changes are evident before dementia symptoms occur. MRI evidence in persons diagnosed with dementia with Lewy bodies includes less medial temporal lobe atrophy than in AD and relative preservation of hippocampal volume. Frontotemporal dementia is characterized by bilateral and symmetrical prefrontal and anterior temporal lobe and basal ganglia atrophy in the absence

of focal lesions. In vascular dementia a wide variety of focal cortical lesions, basal ganglia, thalamus, and white matter changes, generalized cerebral atrophy, and ventricular dilation are seen. MRI of persons with Huntington disease reveals reduced basal ganglia volume, and widened frontal horns of the lateral ventricles. White matter and periventricular hyperintensities are seen in most dementias, especially AD, vascular dementia (VaD), dementia with Lewy bodies (DLB), and multiple sclerosis (Barber & O'Brien, 2000).

Other types of imaging assess blood flow and biochemical changes for differential diagnosis. For example, functional MRI (fMRI) detects the modulation of hemoglobin during a task as blood flows through the brain. Magnetic resonance spectroscopy (MRS) studies biochemical changes by measuring radio frequencies (Frederick, Moore, & Renshaw, 2000). SPECT uses gamma-ray emitting substances to generate images that reflect the biochemical status of cells, including blood flow, synaptic density, and tumor metabolism. PET measures cerebral glucose metabolism by injecting radiolabeled glucose and recording the gamma rays produced when the isotope decays (Kennedy, 2000). The EEG technique for measuring the electrical activity of the brain often reveals increasing abnormalities with age usually in temporal regions, and the progressive slowing of alpha activity and an increase in beta, theta, and delta activity in AD. EEG findings are more normal in VaD than in AD, except where there are focal changes and more severe intellectual decline (Erkinjuntti, 2000).

Due to the limitations of these radiologic assessment procedures, definitive diagnoses are still not possible until postmortem examination of the brain. The neurohistologic features of AD include senile or neuritic plaques (composed of β-amyloid), neurofibrillary tangles (composed of cytoskeletal elements in the form of paired helical filaments and an abnormally phosphorylated isoform of tau, a glycoprotein), abnormal cytoplasmic structures called granulovacuoles, Hirano bodies, an estimated 36 to 46% decrease in neurons (particularly in the hippocampus), abnormal neurites, patterns of gliosis, vascular amyloid, and some white matter changes (leukoaraiosis) (Lantos & Cairns, 2000). The pathology of dementia with Lewy bodies (DLB) is similar to AD and Parkinson diseases, with the additional feature of Lewy bodies in both cortical and subcortical regions (e.g., substantia nigra as in Parkinson disease), fewer neurofibrillary tangles, minimal plaque, and the appearance of a different protein, α-synuclein (Barber, Newby, & McKeith, 2004; Ince, Perry, & Perry, 2000). The histology of frontotemporal dementia (FTD) includes microvacuoles, Pick bodies, and motor neuron abnormalities (Brun, Englund, Gustafson, Passant, Mann, Neary, et al, 1994). Creutzfeldt-Jakob disease (CJD), a virulent and rare dementia caused by prion protein mutations, is characterized by diffuse neuronal loss in the cortex, basal ganglia, thalamus, brainstem, and spinal cord (Cummings, 2003). Progress is being made in genotyping, imaging, and identifying biomarkers in neuropathologically confirmed dementia cases, as well as disease-specific molecules through biologic fluids such as cerebrospinal fluid (CSF), plasma, and urine (Diaz-Arrastia & Baskin, 2004).

◆ Nature and Differentiating Features

Alzheimer disease (AD), the most common form of dementia (60 to 70% of all cases), is reported to afflict approximately 6 to 10% of all individuals over the age of 65, and up to 33% at age 90, and is expected to quadruple in the next 50 years (Ballard, 2000; Hebert, Scherr, Bienias, Bennett, & Evans, 2003). The risk factors for AD include age, gender (women have a higher incidence), family history of dementia (increases risk by 5% up to age 70, 16% up to age 80, and 33% up to age 90), less education, and history of head trauma with loss of consciousness (increases risk by 80%) (Jorm, 2000; Richter & Richter, 2004). Several genetic factors for AD have been discovered in recent years including the mutation of the amyloid precursor protein gene on chromosome 21, presenilin genes on chromosomes 1 and 14, and the apolipoprotein E (Apo E) gene on chromosome 19. Of the three Apo E alleles (e2, e3, e4), the e4/e4 genotype was associated with 15 times the risk of AD compared with other genotypes (Jorm, 2000). Studies suggest that

antiinflammatory medications and replacement estrogen for postmenopausal women may have protective effects (Jorm, 2000).

Memory loss is the hallmark symptom of AD. Most models describe memory as the encoding or registering of information, the storage of information, and the access to or retrieval of information (Baddeley, 1995). Sensory information is held temporarily in working memory or short-term storage before it is responded to or processed into long-term storage for later retrieval. These three subsystems are controlled by a central executive system, which is particularly vulnerable to the encoding and retrieval difficulties of persons with dementia. Although working memory remains intact in early AD, central executive function is impaired (Paulesu, Frith, & Frackowiak, 1993). Semantic memory loss may be due to damage to memory stores or impaired retrieval (Hodges & Patterson, 1995). Remote, autobiographical memory gradually deteriorates over time (Greene, Patterson, Xuereb, & Hodges, 1996). These memory changes affect language and communication behaviors as well. In the early stages, individuals have difficulty with word finding, comprehending abstract language, and following complex conversation. They are aware of their lapses in attention and concentration and have intact phonologic, syntactic, and pragmatic skills. As the disease progresses, there is a gradual worsening of semantic abilities, including increased word-finding deficits, increased use of indefinite pronouns, and difficulty comprehending complex instructions. Short-term memory losses are reflected in increased forgetting of recent events, difficulty maintaining a topic of conversation, and repetitive verbalization of anxious, delusional, and obsessive thoughts. Phonology and syntax remain intact, as well as oral reading, simple writing, and automatic, procedural memory tasks, such as playing the piano or getting dressed. In the late stages, verbal language becomes severely impaired in expression and comprehension; ambiguous, echolalic, perseverative, and paraphasic utterances deteriorate to incoherent mumbling and eventual mutism. Individuals may respond to sensory stimuli, cues, and music with increased cooperation, smiling, and pleasant vocalizations (Bourgeois & Hickey, 2009).

Behavioral symptoms prevalent in 90% of patients with AD include personality changes (disengagement, disinhibition, apathy); delusions (e.g., theft, persecution, one's house is not one's real home, infidelity, abandonment, phantom boarder); hallucinations (visual, auditory, gustatory, olfactory, haptic); mood disorders (depression, mania, anxiety, anger); sleep, eating, and sexual disorders; and restlessness, pacing, wandering, and repetitive behaviors (Cohen-Mansfield, 2000).

Vascular dementia (VaD) is differentiated from other forms of dementia due to arteriosclerotic changes in the blood supply to the brain and cerebrovascular disorders. VaD accounts for 15 to 30% of dementia cases and is considered the second most common cause of dementia (Cummings, 2003). Other forms of VaD include multi-infarct dementia (MID) (large vessel or cortical disease) and Binswanger disease (small vessel disease, lacunar infarcts). These conditions usually have an abrupt onset of cognitive symptoms and a stepwise, fluctuating, and progressive course. Early memory loss, executive dysfunction, personality changes, and increased incidence of depression are common clinical features. Language changes may be focal in nature and coexist with hemiparesis, facial weakness, visual field defects, and extrapyramidal signs (Erkinjuntti, 2000).

Frontotemporal dementias (FTDs) include Pick disease, progressive aphasia (left perisylvian frontotemporal lobes are affected), and semantic dementia (bilateral and selective atrophy of the anterior temporal neocortex) (McKhann, Albert, Grossman, Miller, Dickson, & Trojanowski, 2001; Morris, 1993). It is estimated that 20 to 40% of dementia cases are FTD with a high familial incidence related to a specific chromosome 17 tau mutation (Morris, 1993). The onset of FTD is typically signaled by mood and personality changes such as depression, anxiety and excessive sentimentality. Language changes are mostly expressive initially, with reduced output, increasing reliance on stereotypical remarks, perseverative and then echolalic responses, and eventual mutism. Comprehension, naming, reading, and written output are usually well preserved; as well as visual perception and spatial and motor skills. Memory performance

is variable; recall is enhanced with specific cues and direct and multiple-choice questions. There is more difficulty with sustained and selective attention and other executive function tasks. Behavioral symptoms include profound changes in personality and social conduct, including disinhibition, inappropriate jocularity, restricted verbal repertoire, impulsiveness, high distractibility, hyperorality, hypersexuality, stereotyped and ritualistic behavior, and repetitive behaviors (Franczak, Kerwin, & Antuono, 2004; Mirea & Cummings, 2000).

Dementia with Lewy bodies (DLB) is characterized by attentional deficits and visuospatial deficits with relatively preserved memory early. There is a gradual increase of fluctuating cognition with recurrent visual hallucinations, delusions, and depression (McKeith, Dickson, Lowe, Emre, O'Brien, Feldman, et al, 2005). Symptoms of parkinsonism may eventually be exhibited in some patients, including tremor, rigidity, bradykinesia, gait abnormality, and postural change. On neuropsychological testing, persons with DLB are more impaired than those with AD on verbal fluency, psychomotor speed, executive function (problem solving, abstract reasoning), and visuospatial/constructional ability, but similarly impaired on episodic memory and language (Galasko, Salmon, Lineweaver, Hansen, & Thal, 1998).

Dementia affects approximately 10 to 15% of persons with Parkinson disease, with the prevalence increasing with age (Velakoulis & Lloyd, 2000). The extrapyramidal symptoms of tremor, hypokinesia, and rigidity precede global cognitive impairments and frontal dysfunction. Depression, anxiety, loss of self-esteem, suicidal thoughts, visual hallucinations, delusions, delirium weight change, fatigue, and sleep disturbances may be related to treatment with dopaminergic drugs; dopamine agonists cause psychosis and nightmares (Lieberman, 1998).

Dementia in Huntington disease (HD), which is hereditary and progressive, includes motor, cognitive, and psychiatric symptoms. Involuntary and voluntary movement abnormalities range from chorea, dystonia, athetosis, and myoclonus to gait abnormalities, bradykinesia, and saccadic eye movements. Language is generally intact until the later stages, when dysarthria, memory, and attentional problems are prevalent. Personality alterations, mood disorders (depression), psychosis, aggressive behavior, apathy, irritability, emotional lability, disinhibition, impulsivity, and suicide are common in HD (Ho, Sahakian, Brown, Barker, Hodges, Ané, et al, 2003).

Human immunodeficiency virus–associated dementia (HIV-D) was first identified as a neuropsychiatric outcome of HIV disease in the past decade (Everall, 2000). Primarily a disorder of cognition, there are also associated problems with motor and psychological functioning. Early effects on speech are extrapyramidal, including slow, labored, and dysarthric speech; language, memory, and cognition worsen with disease progression. Mood changes range from depression to marked lability, irritability, and violent outbursts; in the late stages behavior deteriorates to mutism, immobility, and incontinence (Ghafouri, Amini, Khalili, & Sawaya, 2006).

◆ Evaluation

It is important to assess the specific cognitive, communicative, and functional strengths and impairments associated with dementia to manage disease symptoms appropriately. Brief standardized measures of cognition, or mental status, are useful for screening a broad range of cognitive abilities, including memory, language (e.g., naming, repetition, auditory comprehension, writing), spatial ability/praxis, set-shifting/calculation, orientation, personal knowledge, abstract thinking, construction, perception, concentration, and attention. Performance-based cognitive measures include the Mini-Mental Status Exam (MMSE; Folstein, Folstein, & McHugh, 1975), the Burns Brief Inventory of Communication and Cognition (Burns, 1997), the Alzheimer's Quick Test (Wiig, Nielsen, Minthon, & Warkentin, 2002), the Cambridge Cognitive Examination (CAMCOG; Blessed, Black, Butler, & Kay, 1991), the Montreal Cognitive Assessment (MoCA; Nasreddine, Phillips, Bédirian, Charbonneau, Whitehead, Collin, et al, 2005), and the Severe Impairment Battery (SIB; Saxton, McGonigle-Gibson, Swihart, Miller, & Boller, 1990). These measures are reliable, but the age,

educational level, and cultural background of the person being assessed are known to influence performance and accuracy of identification of cognitive dysfunction (Sloan & Wang, 2005).

Mental status rating scales translate cognitive impairment into stages of disability, which can be useful for classifying patients and predicting relative treatment outcomes (Albert, 1994). Measures such as the Clinical Dementia Rating Scale (CDR; Hughes, Berg, Danziger, Coben, & Martin, 1982), the Global Deterioration Scale for Age-Related Cognitive Decline and Alzheimer's Disease (GDS; Reisberg, Ferris, deLeon, & Crook, 1982), and the Dementia Rating Scales (Mattis, 2001) involve a subjective evaluation of patients' cognitive skills (e.g., memory, orientation, judgment, problem solving, community affairs, home and hobbies, personal care, psychiatric symptoms, and performance on psychometric tests) by a skilled clinician who also may query family and other caregivers about behavioral functioning.

Comprehensive assessments batteries of cognitive and behavioral functioning include the Alzheimer's Disease Assessment Scale (ADAS; Rosen, Mohs, & Davis, 1984) that evaluates cognitive (memory, language, and praxis) and noncognitive (mood and behavior) functioning; the Consortium to Establish a Registry for Alzheimer's Disease (CERAD; Welsh, Butters, Mohs, Beekly, Edland, Fillenbaum, et al, 1994) battery that includes subtests of fluency, naming, praxis, memory (free-recall and delayed recall), word recognition; the Kaplan Baycrest Neurocognitive Assessment (Kaplan, Leach, Rewilak, Richards, & Proulz, 2000); the Neuropsychological Assessment Battery (Stern & White, 2003); and the Ross Information Processing Assessment (RIPA-2; Ross-Swain, 1996). Test batteries for specific cognitive domains that are typically impaired in dementia include the Delis-Kaplan Executive Function System (D-KEFS; Delis, Kaplan & Kramer, 2001) and the Test of Everyday Attention (TEA; Robertson, Ward, Ridgeway, & Nimmo-Smith, 1996).

The most pervasive symptom of dementia, memory impairment, has been assessed traditionally with the Wechsler Memory Scale (WMS-R; Russell, 1975) and its successors, the Wechsler Memory Scale–Revised (Wechsler, 1987) and the Wechsler Memory Scale–III (WMS-III; Wechsler, 1997). Murray and Clark (2006) reviewed other instruments that have been used to document the memory deficits of patients with dementia, including the Rivermead Behavioral Memory Test–II (Wilson, Cockburn, & Baddeley, 2003), the California Verbal Learning Test–II (CVLT; Delis, Kramer, Kaplan, & Ober, 2000), and verbal span tests such as the Digit Span (WMS-III), the Telephone Test (Crook, Ferris, McCarthy, & Rae, 1980), and the Sentence Repetition Test (Spreen & Strauss, 1998).

The increasing interest in memory, both from theoretical and applied perspectives, has led to the publication of measures of specific subtypes of memory such as episodic or semantic memory (e.g., Pyramids and Palm Trees Test; Howard & Patterson, 1992), recognition memory (Recognition Span Test; Moss, Albert, Butters, & Payne, 1986), retrograde amnesia (Autobiographical Memory Interview [AMI]; Kopelman, Wilson, & Baddeley, 1990), and long-term memory (Doors and People; Baddeley, Emslie, & Nimmo-Smith, 1994).

The language and communication disorders of persons with dementia have been assessed with a variety of comprehensive measures designed for patients with language impairments due to focal brain damage (e.g., Boston Diagnostic Aphasia Examination; Goodglass & Kaplan, 1983; Western Aphasia Battery; Kertesz, 1982). The Arizona Battery for Communication Disorders of Dementia (ABCD; Bayles & Tomoeda, 1993) was designed specifically to measure the receptive and expressive oral and written language deficits of patients with dementia, and is therefore used extensively in diagnostic settings. Overall, comprehensive assessment tools are important in the differential diagnosis of language impairments due to brain damage because they sample a wide range of behaviors efficiently, although the administration of an entire comprehensive measure in one sitting may not be possible due to the attentional limitations of patients with dementia. Other comprehensive language batteries include the Burns Brief Inventory of Communication and Cognition: Complex Neuropathology Inventory (Burns, 1997), and the Repeatable Battery for the Assessment of Neuropsychological Status (Randolph, 1998).

To document impairments in specific language domains, such as pragmatics, discourse,

semantics, syntax, and phonology, many measures from the aphasia assessment literature are administered to patients with dementia. For an analysis of dementia patient performance on standardized language measures, such as the Peabody Picture Vocabulary Test (Dunn & Dunn, 1981), the Boston Naming Test (Kaplan, Goodglass, & Weintraub, 1983), the FAS Word Fluency Measure (Borkowski, Benton, & Spreen, 1967), the Auditory Comprehension Test of Sentences (Shewan, 1979), and the Token Test (DeRenzi & Faglioni, 1978), see Bayles and Kaszniak (1987). Due to the many limitations on the use of these measures with patients with dementia, Bayles and colleagues developed their comprehensive assessment battery (the Arizona battery for communication disorders of dementia, ABCD) and standardized it with an extensive population of patients across the cognitive continuum. For reviews of other language and cognitive impairment measures, see Bourgeois and Hickey (2009) and Murray and Clark (2006).

Assessment of the daily functional status of patients with dementia is necessary for determining patients' level of need for rehabilitative services. Disability in this population can be documented for a variety of functional behaviors such as language, daily living skills, and problem behaviors, and in a variety of settings (e.g., hospital, work, home, and nursing home). Frattali (1994) reviewed measures used to screen functional skills, such as the Functional Linguistic Communication Inventory (FLCI; Bayles & Tomoeda, 1994), the Communication Outcome Measure of Functional Independence (COMFI; Santo Pietro & Boczko, 1997a), the Communicative Abilities in Daily Living–2 (CADL-2; Holland, Frattali, & Fromm, 1999), and the American Speech-Language-Hearing Association's Functional Assessment of Communication Skills for Adults (ASHA-FACS; Frattali, Thompson, Holland, Wohl, & Ferketic, 1995). The ASHA Task Force on Treatment Outcome and Cost Effectiveness has also developed the Functional Communication Measures (FCM) for rating (on a seven-point scale) 13 different communication disorders of any population. This tool was designed to measure change in FCM rating to demonstrate achievement of functional outcomes resulting from clinical intervention; Paul, Fratalli, Holland, Thompson, Wohl, and Ferketic (2004) documented the reliability and validity of the measure with persons with dementia.

The rehabilitation potential of persons with dementia is also determined by assessing the status of their activities of daily living (ADL), including dressing, bathing, toileting, transfer, feeding, and mobility, and instrumental activities of daily living (IADL), such as using the telephone, managing money, meal preparation, housework, and shopping. Some of the common tools for assessing ADL and IADL include the Alzheimer Disease Cooperative Study Activities of Daily Living Scale (ADCS-ADL; Galasko, Bennett, Sano, Ernesto, Thomas, Grundman, et al, 1997) and the Activities of Daily Living Questionnaire (ADLG; Johnson, Barion, Rademaker, Rehkemper, & Weintraub, 2004). For a review of measures see Bourgeois and Hickey (2009). Subtests of certain IADL measures may be relevant outcome measures for communication treatments because they include communication skills (using the telephone) and higher-order cognitive skills (money management, shopping).

The behavioral disturbances of patients with dementia also affect their everyday functional status. Teri and Logsdon (1994) review 28 measures of behavioral disturbance; some of the more popular rating scales include the Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD; Reisberg, Borenstein, Salob, Ferris, Franssen, & Georgotas, 1987), the Cohen-Mansfield Agitation Inventory (Cohen-Mansfield & Billig, 1986), the Nursing Home Behavior Problem Scale (Ray, Taylor, Lichtenstein, & Meador, 1992), and the Multidimensional Observation Scale for Elderly Subjects (MOSES; Helmes, Csapo, & Short, 1987), which also measures cognitive and psychosocial functioning.

The degree to which dementia symptoms influence the quality of the lives of the afflicted and the persons in their environments has been the focus of much recent research. Quality of life (QOL) is a broad concept that Lawton (1991) has proposed include measures of objective environment, self-perceived quality of life, psychological well-being, and behavioral competence (health, functional health, cognition, time use, and social behavior). Dementia-specific measures have been developed including the Alzheimer Disease-Related Quality of Life (ADRQL; Rabins, Kasper,

Kleinman, Black, & Patrick, 1999), the Quality of Life Assessment Schedule (QOLAS; Selai, Trimble, Rossor & Harvey, 2000), the Dementia Quality of Life Scale (DQoL; Brod, Stewart, Sands, & Walton, 1999), and the Quality of Life-AD (QoL-AD; Logsdon, Gibbons, McCurry, & Teri, 2000). When QOL is assessed using self-report questionnaires, the ability of persons with dementia, who may have memory and communication constraints, to reliably report their feelings may be in question. Many researchers circumvent the reliability of self-report data with observational measures and caregiver-completed rating scales of behaviors believed to approximate QOL indicators, such as affect, mood, depressive symptoms, and pleasant events. But proxy informants' ability to answer reliably for the person with dementia depends on the nature of the relationship, the amount of time spent with the person, the objectivity of the questions, and the severity of the person's cognitive and communicative deficits (Zimmerman & Magaziner, 1994). Observational measures have their own limitations. Schulz, O'Brien, and Tompkins (1994) reviewed tools for measuring the emotions, moods, and feeling states of the elderly; although most were self-report measures, the Philadelphia Geriatric Center Affect Rating Scale (Lawton, Van Haitsma, & Klapper, 1996) is completed by a clinician after a 10-minute observation period, during which the duration of affective states (pleasure, anger, anxiety/fear, sadness, interest, and contentment) are rated on a five-point scale. A measure of behaviors that have the potential to contribute to pleasant experiences of patients with dementia is the Pleasant Events Schedule–AD (PES-AD; Teri & Logsdon, 1991). This caregiver-completed inventory of pleasant experiences rates each of 54 items on their frequency, availability, and enjoyability during the past month, and has the potential to document change in patients' positive experiences.

The impact of dementia on caregivers cannot be overlooked. There is a burgeoning literature on the caregivers' role in maintaining the person in quality surroundings and the impact caregiving has on the care provider (Ory, Yee, Tennstedt, & Schulz, 2000). See Chapter 16 by Hancock for further details on caregiver burden and resources. Although caregiving for any disabled individual is burdensome, the range, frequency, and severity of cognitive deficits and problem behaviors associated with dementia can produce stresses that are physically demanding and unremitting. As the level of patient dysfunction increases, caregiver outcomes such as perceived burden and depression have been found to increase (Schulz & Martire, 2004). As a result, a plethora of caregiving interventions, ranging from information and resources, individual and family counseling, support groups, to reducing caregiver stress and teaching skills to manage patient behaviors, have appeared in the literature (Bourgeois, Schulz, Burgio, & Beach, 2002; Coon, Gallagher-Thompson, & Thompson, 2003; Kennet, Burgio, & Schulz, 2000). Specific techniques to improve communication (i.e., the Face-to-face, Orientation, Continuity, Unsticking, Structure, Exchange, Direct [FOCUSED] approach; Ripich, Ziol, & Lee, 1998) and cognition (Quayhagen, Quayhagen, Corbeil, Roth, & Rodgers, 1995) have utilized caregivers as trainers. Although it is too early for strong causal relationships to be seen, a working hypothesis of caregiver interventionists is that a happier, or less burdened, caregiver will make for a more contented patient and an overall improvement in the quality of life of all members of the patient's environment. In contrast, when caregivers are frustrated and burdened by caregiving challenges, patients are more likely to be institutionalized (Argimon, Limon, Vila, & Cabezas, 2005).

◆ Treatment

The two approaches to treatment of dementia are pharmacologic and behavioral. In the past 25 years neuropathologic advances have led to a cholinergic hypothesis of geriatric memory dysfunction and the resultant development of a series of cholinesterase inhibiting drugs that have produced statistically significant improvements in cognitive functioning in patients with dementia (Wilkinson, 2000). The first promising drug, tacrine (Cognex), showed significant improvements over placebo on cognitive testing, but serious liver function and gastrointestinal side effects prevented 70% of the patients from completing the 30-week study trial (Knapp, Knopman, Solomon, Pendlebury, Davis, & Gracon, 1994). Subsequent variant compounds, donepezil (Aricept), rivastigmine (Exelon), and gal-

antamine (Reminyl), have addressed many of the problems with side effects, dosing frequency, and tolerability, and have shown increased efficacy on measures of cognitive functioning and activities of daily living. A new drug, memantine (Namenda) has been developed to address a different neurotransmitter, glutamate, with encouraging results in moderate to severe AD and VaD (Reisberg, Doody, Stöffler, Schmitt, Ferris, & Möbius, et al, 2003). Unfortunately, the positive effects of these drugs do not maintain for longer than a couple of years when the degenerative nature of the disease continues its downward trajectory.

Many of the difficult behavioral symptoms of dementia, including mood disturbance, altered perception, agitation, aggression, anxiety, and sleep and appetite disturbances, are treated pharmacologically with a variety of antipsychotics, anxiolytics, sedatives, antidepressants, and other medications (Rosenquist, Tariot, & Loy, 2000). Because clinical trials and efficacy data for specific drugs and targeted behaviors are very limited, physicians are advised to prescribe drugs only after nonpharmacologic approaches have been exhausted. Further recommendations are to start with low doses, to increase the dose slowly, and to monitor target behaviors and signs of toxicity.

The nonpharmacologic, or behavioral, approaches to treating the challenging symptoms of dementia have seen an explosion in interest and publications in recent years. The old nihilistic attitude, that nothing could be done for the patient, so only focus on the caregiver, has been replaced by a more holistic and humanistic approach intended to maintain function and prevent excess disability (Clark, 1995). Since ASHA's Committee on Communication Problems of the Aging published its mandate for speech-language pathologist (SLPs) to increase their involvement in the evaluation and management of patients with dementia, there has been an increase in the development of treatment programs designed to facilitate or maintain functional communication and to improve the quality of life of these individuals and their families (American Speech-Language-Hearing Association, 2005). Professionals in disciplines ranging from physical, occupational, music, and recreation therapy to psychology, psychiatry, and nursing have produced a plethora of therapeutic strategies and approaches, some with empirical support, others steeped in clinical lore (Bird, 2000).

Memory Treatment Strategies

Treatment of memory impairment is either internal or external in focus. Internal strategies involve some mental manipulation of the information to be remembered, such as mnemonic techniques and visual association strategies, and may be more useful for people experiencing normal memory changes due to aging (Fogler & Stern, 1988). Even in the early stages of dementia, however, individuals might not have the learning ability or motivation to use these techniques; instead, techniques that aim to reduce the demand on a person's memory and compensate for the impairment may be more effective (Camp, Bird, & Cherry, 2000). External memory strategies take advantage of cues in the environment to trigger recall. For example, written reminders, calendars, memo boards, notepads, sticky notes, and designated places for objects can help individuals to remember to do a task, to keep an appointment, or to operate an appliance, such as the television remote control, especially if they are kept in close proximity to the relevant task or activity. Bourgeois (1990) explored the use of written and picture cues, in the form of "memory wallets," to assist in the retrieval of personal information necessary to maintain conversations between persons with AD and their caregivers. Simple declarative sentences, one per page, and a relevant photograph or illustration were sufficient to cue the reading of that sentence, to elicit elaborated comments about the topic, and to reduce the frequency of ambiguous and repetitive verbalizations. Increased turn-taking and topic maintenance and reduced partner prompting and conversational dominance were found with the use of memory aids (Bourgeois, 1993; Hoerster, Hickey, & Bourgeois, 2001). Subsequent studies demonstrated that persons with various degrees of cognitive impairment were able to improve their conversations using memory books that were modified to address their specific functional impairments (e.g., enlarging print size, making them wearable for wanderers; Bourgeois, 1992). Specific problem behaviors, such as repetitive questions about a dead relative or the status of a tax return, were addressed by including a page in the memory book that answered

the question (e.g., "Mary died in 1994 and is buried in Westlawn Cemetery"; "Your pension checks are deposited in the bank on Monday"). The repetitive verbalizations of patients with dementia were reduced by training spouses to use written cuing strategies (e.g., cue cards, memo boards, memory book pages) (Bourgeois, Burgio, Schulz, Beach, & Palmer, 1997). Institutional caregivers, nursing assistants, were trained to use portable, laminated memory books to increase comprehension and cooperation with care activities, such as bathing and grooming, by residents with dementia (Bourgeois, Dijkstra, Burgio, & Allen-Burge, 2001). Practical instructions and guidelines for using a variety of visual, graphic, and written cues in various formats for a continuum of problem behaviors are available for professional and family caregivers (Bourgeois, 2007).

A memory training procedure, spaced retrieval (SR), involves the retention of and ability to recall information for long time periods by recalling information over successively longer intervals (Brush & Camp, 1998). Based on the principles of classical conditioning, repetition priming, and errorless learning, SR takes advantage of the relatively preserved skills of reading, motor learning, and procedural memory to help patients remember specific facts (e.g., family members' names, their room number) and functional strategies (e.g., use of a memo board or scheduled activities card, safe swallowing steps). A review of the evidence supporting the use of SR as an effective training paradigm highlighted 15 studies of SR that provided class II and class III evidence, with strong evidence of maintenance of trained behaviors and some reported generalized training effects to functional daily activities (Hopper, Mahendra, Kim, Azuma, Bayles, Clearly, et al, 2005).

Environmental Strategies

Lindsley (1964) advocated the use of prosthetic environments, or more supportive physical and social environments, to overcome the declining competencies of old age. Successful dementia-specific environments, such as special care units in the nursing home, decrease the complexity of the environment, use sensory stimuli and cues to increase orientation and awareness, and create a low-stimulation and comfortable environment (Gitlin, Liebman, & Winter, 2003). A variety of other treatment approaches that change the stimulus characteristics of the environment, or something in the environment, have led to promising outcomes (**Table 18.1**). Listening to pleasant "white noise" (waterfall and nature sounds) via headphones reduced the disruptive vocalizations of nursing home residents with dementia (Burgio, Scilley, Hardin, Hsu, & Yancey, 1996). The delivery of verbal cues at regularly scheduled intervals is the basis of prompted voiding techniques for reducing incontinence due to forgetting (Schnelle, 1990). Visual barriers, in the

Table 18.1 Specific Treatment Tasks

When Memory Impairments Cause	Suggested Treatment Techniques
Impaired conversation (word finding problems, ambiguity, inaccuracy, repetition)	Memory wallets, memory books, reminder cards, interest albums Caregiver training
Encoding, short-term memory problems (repetitive questions, forgetting the answers to the questions, losing or misplacing things)	Variety of stimulus modalities for encoding information Repetition and practice: spaced retrieval Establish routines and schedules
Comprehension deficits (lack of cooperation)	Written cues: reminder cards, memo boards Use one-step verbal instructions
Information retrieval deficits	Written, auditory, tactile cues Use two-choice questions; use personal objects, pictures, music, smells to trigger memories
Confusion and agitation	Calming music and nature sounds, other sensory stimulation (tactile: stuffed animals, dolls; visual: interest albums)
Apathy, lack of interest	Activity programs: Montessori, music, therapeutic recreation, pet therapy
Swallowing problems	Written cues Spaced retrieval training to use cue card Caregiver training

form of stop signs, directional signs, grid lines on the floor, or nature posters, have been used to prevent exit seeking and to promote safe wandering (Namazi, Rosner, & Calkins, 1989). Age-, gender-, and culturally appropriate objects can affect mood, recall of fond memories, and provide a sense of security (Mahendra, 2001); dolls and stuffed animals improve conversation (Hopper, Bayles, & Tomoeda, 1998); and handmade, sensorimotor therapeutic items (e.g., activity apron, look-inside purse) decrease patient agitation and improve family visiting (Buettner, 1999). Subjects in a "Breakfast Club" intervention demonstrated increases in cross-conversation, questioning, use of each other's name, eye contact and topic maintenance when using a variety of verbal, visual, and tactile prompts (Santo Pietro & Boczko, 1997b). Lund, Hill, Caserta, and Wright (1995) used Video Respite tapes to increase engagement in a group activity as measured by the duration of time patients remained seated, were paying attention, and were smiling, laughing, and making verbal comments in response to the tape. Similarly, Orsulic-Jeras, Judge, and Camp (2000) documented significantly more constructive engagement, less passive engagement, and more pleasure when residents with dementia participated in Montessori-based activities (Camp, 1999). Music was demonstrated to reduce agitation during meals (Goddaer & Abraham, 1994. Cognitive skills training and a multitude of activity-focused techniques from various disciplines have produced skill maintenance and problem behavior reduction in persons with dementia (Arkin, 1999; Camp, 1999; Eisner, 2001; Hellen, 1992; Lawton & Rubinstein, 2000; Stevens, Camp, King, Bailey, & Hsu, 1998; Tappen, 1997; Volicer & Bloom-Charette, 1999).

Sidebar

Reversible conditions that can cause dementia symptoms (Green, 2005):

- Metabolic conditions (e.g., thyroid and liver disease, diabetes)
- Neoplasms
- Toxins (e.g., alcohol, heavy metals)
- Infections (e.g., meningitis, neurosyphilis, HIV)
- Autoimmune disorders (e.g., multiple sclerosis, lupus)
- Nutritional disorders (e.g., deficiencies in thiamine, folate, and vitamin B)
- Pharmaceutical drug effects
- Normal-pressure hydrocephalus (NPH)

Conclusion

The past two decades have seen vast advances in the diagnosis and treatment of dementia in its many forms. There is increasing hope that the causes of dementia will soon be identified and effective cures will follow in due time. In the interim, creative and effective management strategies are lessening the daily challenges of these unremitting diseases.

Sidebar

Types of Memory

I. Sensory memory	Involves attention, alertness, arousal processes; visual, auditory, tactile, olfactory stimuli; unconscious awareness
II. Short-term, working memory (Primary memory)	Involves encoding processes, temporary storage of limited capacity
III. Long-term memory (Secondary memory)	Involves retrieval processes, permanent storage of unlimited capacity
Declarative (explicit)	Person's knowledge base, conscious awareness
Semantic	Knowledge of the world, facts, ideas
Episodic	Knowledge of personal experiences (autobiographical)
Nondeclarative (implicit)	Person's knowledge of skills and action patterns unconscious awareness
Procedural	Sequenced motor tasks and perceptual tasks

Note: Adapted from Baddeley (1999) and Sohlberg & Mateer (2001).

Case Examples

Memory Book Use In End-Stage Dementia

Mr. Francis, the husband of a woman with Alzheimer disease who resided in a long-term-care facility, observed that other nursing home residents had memory books and decided that his wife should have one too. The SLP had not seen Mrs. Francis for speech-language services, because she thought that the woman had advanced to the point of not being able to benefit from skilled services. However, Mr. Francis persisted in his requests for a memory book, so the SLP instructed a volunteer to make one using large photos from Mrs. Francis's childhood and young-adult years accompanied by large print and simple text. Mr. Francis reported to the SLP that his wife really liked the book and that his visits were much more satisfying now. The SLP asked, "How do you know she likes it?" He reported, "She smiles and hums when she's looking at it!" The SLP learned that even persons with severe cognitive-communicative deficits might benefit from skilled services to design external memory and communication aids.

Memory Box

Mr. Harper, who worked as a mechanic for over 70 years, entered a long-term-care facility. He was not able to discuss details of his work, but frequently got into trouble as he wandered the facility looking for something to do. He did not engage in conversations with the other residents or staff, even when others initiated. An activities assistant made a memory box constructed from a toolbox, labeled with the name of the autobody shop where the resident worked for all those years. Inside, she put toy cars, pictures of cars and car parts, tools, and other memorabilia that would allow the resident to reminisce about his time as a mechanic. The staff was instructed to place the toolbox near the resident whenever he began wandering and looking for something to do. Mr. Harper's troublesome behaviors decreased and the staff was able to enjoy interactions with the resident related to his favorite topic.

Chapter Review

Discussion Questions

1. How can the preserved skills of persons with dementia be utilized in designing activities to enhance their quality of life?
2. Describe the types of cuing strategies that would help to maintain functional behaviors as the person's communication skills deteriorate.
3. What would you recommend to a family concerned about a parent's memory lapses? What information about the person and his or her daily activities would be helpful to the medical practitioners for an accurate diagnosis?

Test Questions

1. Alzheimer disease is a type of dementia. True or False
2. There are several effective medications available for reversing dementia symptoms, especially memory loss. True or False
3. Reading becomes too difficult for most people with dementia. True or False
4. Some types of dementia are reversible with appropriate medications. True or False
5. Visual cues in the form of text and pictures can be useful for modifying some challenging behaviors. True or False

Answers: 1: True; 2: False; 3: False; 4: True; 5: True.

Glossary

Alzheimer disease: the most common type of dementia, characterized by a gradual onset of memory, language, executive function, and behavioral deficits

Creutzfeldt-Jakob disease (CJD): degenerative neurologic condition with a rapidly progressive decline in cognitive abilities (within 6 months), early psychiatric symptoms (e.g., depression, delusions, agitation), and ataxia, myoclonus, and involuntary movements

Dementia: a clinical syndrome of chronic and progressive symptoms that are the result of acquired brain disease and of which there are over 75 different reversible and irreversible causes

Dementia with Lewy bodies (DLB): a type of dementia that has a distinctive pattern of early attentional, visuospatial, and executive function deficits but intact memory function

Frontotemporal dementia (FTD): a type of dementia characterized by changes in behaviors and language skills that precede memory loss, especially mood and personality changes and expressive language difficulties (e.g., reduced output, perseverative, stereotypical, and echolalic responses), which are evident early in the course of the disease

HIV-associated dementia: a type of dementia characterized by impaired attention and concentration, slowing of mental and motor speed, loss of initiative; may be accompanied by slow, labored, and dysarthric speech

Interest album: a memory book (see below) with minimal text in a large font and large pictures used to maintain interest in a familiar hobby or pastime

Memory book: larger version of a memory wallet (see below) containing personally relevant, biographical, and daily living content

Memory box: small container for objects, pictures, and other memorabilia that would prompt reminiscence about a particular themed event (e.g., hobby, occupation, holiday)

Memory wallets: collection of 3- by 5-inch pages on which one simple, declarative statement of fact is written and one illustrative picture or photograph is pasted

Montessori activities: a teaching method developed by Maria Montessori that uses individualized, active learning strategies through experimentation and exploration of sensorimotor activities to develop thinking skills from concrete to abstract understandings; activities involve repetition, immediate feedback, high probability of success, and gradually increasing complexity

Reminder cards: variation of memory wallet page; 3- by 5-inch index card on which is written the answer to a repetitive question, or a message that addresses other repetitive or noncompliant behaviors

Spaced retrieval: instructional technique in which clients recall a target behavior over increasing time intervals, using errorless learning procedures

Vascular dementia (VaD): A type of dementia characterized by an abrupt onset of cognitive changes due to focal cerebrovascular infarcts or a stepwise progression of symptoms due to multiple ischemic, small-vessel disease lesions

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