

Chapter 8

**Patient Assessment and
Eligibility for Services**

CONTENTS

	<i>Page</i>		<i>Page</i>
Uses of Structured Assessment		Who Pays for the Assessment?	314
Procedures and Instruments	273	Issues and options	315
Research, Clinical, and Legal		Chapter 8 References	318
Applications	274		
Public Policy Applications	275		
Assessment of Cognitive Abilities	279		
Instruments To Measure Cognitive			
Abilities.	280		
Reliability and Validity of Cognitive			
Assessment Instruments.	281		
problems That Complicate the			
Assessment of Cognitive Abilities .. .	282		
Cognitive Assessment and			
Differential Diagnosis	286		
Cognitive Rating Scales	289		
Public Policy Applications	289		
Assessment of Self-Care Abilities	292		
Instruments To Measure Self-Care			
Abilities.	292		
Reliability and Validity of ADL and			
IADL Instruments	294		
Public Policy Applications	299		
Relationship Between Cognitive			
Deficits and Self-care Abilities.	299		
Assessment of Behavior	301		
Instruments To Measure Behavioral			
problems	302		
Reliability and Validity of Behavioral			
Measures	303		
Public Policy Applications	304		
Relationship Between Cognitive			
Deficits and Behavioral Problems .. .	305		
Multidimensional Assessment			
Instruments	305		
General Multidimensional Instruments ..	305		
Reliability and Validity of General			
Multidimensional Instruments	307		
Dementia Rating Scales	307		
Assessment of Caregiver Burden.	309		
Instruments To Measure Caregiver			
Burden	310		
Reliability and Validity of Measures			
of Caregiver Burdens	310		
Public Policy Applications	311		
The Assessment Process	311		
Who Should Do the Assessment?	311		
Where Should the Assessment			
Be Done?	312		

Tables

<i>Table No.</i>			<i>Page</i>
8-1.	Information-Memory-Concentration		
	Test	280	
8-2.	Mental Status Questionnaire	281	
8-3.	Mini-Mental State Examination .. .	281	
8-4.	Short Portable Mental Status		
	Questionnaire	281	
8-5.	Major Clinical Features Differentiating		
	Depression-Induced and Primary		
	Degenerative Dementia	288	
8-6.	Items Related to Cognitive Status:		
	New York State Patient Assessment		
	Instrument	291	
8-7.	Dementia Scale	298	
8-8.	Functional Activities Questionnaire ..	298	
8-9.	ADLs from New York State		
	Patient Review Instrument	300	
8-10.	Serious Behavioral Problems		
	Among Nursing Home Residents	302	
8-11.	Behavioral and Mood Disturbance		
	Scale	303	
8-12.	Relatives' Stress Scale.	303	
8-13.	Behaviors: New York State Patient		
	Review Instrument.	304	
8-14.	Topic Areas in the Comprehensive		
	Assessment and Referral		
	Evaluation	306	
8-15.	The Burden Interview	310	

Figures

<i>Figure No.</i>			<i>Page</i>
8-1.	Index of Independence in Activities		
	of Daily Living	293	
8-2.	The Functional Life Scale	296	
8-3.	Behavior Scale: Psychogeriatric		
	Dependency Rating Scale	303	
8-4.	Multidimensional Assessment for		
	Dementia Scale: Clinical Profile,		
	Course/Disability and ADLs for an		
	Early Alzheimer's Disease Patient and		
	a Multi-infarct Disease Patient	309	

Patient Assessment and Eligibility for Services

In the context of dementia research and treatment of persons with dementia, assessment is the process of identifying, describing, and evaluating individual characteristics associated with the dementing illness. Assessment can focus on cognitive deficits, changes in self-care abilities, behavioral problems, or all three. It can also focus on the impact of the person's functioning on the caregiver.

Diagnosis and assessment are related, but distinct. Since dementia is defined as the decline of memory and other cognitive abilities in an individual with no disturbance in consciousness (see ch. 2), assessment of cognitive abilities is a prerequisite for the diagnosis of dementia and diseases that cause dementia. However, diagnosis and assessment also differ in several ways. Diagnosis results in the identification of a specific disease, while assessment results in a description of the impact of the disease on the patient. A diagnosis of Alzheimer's or of another disease that causes dementia does not provide information about the severity of the condition, and individuals with such diagnoses vary greatly in their cognitive and self-care abilities and behavior, and therefore in their care needs. Assessment provides information about a person's current functioning and care needs but generally does not distinguish among the diseases that can cause dementia. This distinction is important because some dementias (an estimated 2 to 3 percent) are reversible with treat-

ment, and diagnosis is essential for identifying these conditions. Both diagnosis and assessment are necessary for good patient care, and neither is sufficient by itself (18)74,179),

Assessment of persons with dementia is often an unstructured process in which a physician or another health care or social service professional evaluates the person based on conversations with the person, the family, and other caregivers and on informal observations of the person's behavior. Structured assessment procedures and instruments have been developed to assist in this process. They include questions to be asked of the person, performance tasks to measure cognitive and self-care abilities, and lists of cognitive and self-care abilities and behaviors that can be used to rate the person.

This chapter discusses the role of assessment in the study of dementia and treatment of persons with a dementing illness; the kinds of assessment procedures and instruments that are used to evaluate cognitive, self-care, and behavioral deficits and caregiver burden; and problems that affect the accuracy of these procedures and instruments. The primary focus of the chapter is the potential use of such procedures and instruments in identifying long-term care needs and in establishing eligibility for publicly funded long-term care services.

USES OF STRUCTURED ASSESSMENT PROCEDURES AND INSTRUMENTS

Clinicians, researchers, and caregivers agree in theory that cognitive abilities are diminished or lost in individuals with a dementing illness, that self-care abilities such as bathing, dressing, eating, and continence are frequently lessened, and that many caregivers have difficulty managing these individuals. When these concepts are ap-

plied to specific individuals and their caregivers, however, agreement often ends. In practice, clinicians, researchers, and caregivers may disagree about answers to the following questions:

- Does this individual have a dementing illness?
- How severe is the dementia?

- Which cognitive abilities have been diminished or lost?
- How does the cognitive deficit affect the individual's ability to care for himself or herself?
- Which self-care functions does the person need help with?
- How much help does he or she need?
- How burdensome are these care requirements for family members or others who take care of the person?

Structured assessment procedures and instruments are intended to provide objective answers to these questions.

One reason for disagreement about the answers is that many of the terms used in the questions are vague and have different meanings to different people. With no definitive physiological markers for dementia and no precise physical methods for measuring the severity of cognitive, behavioral, or self-care deficits, it is difficult for clinicians, researchers, and caregivers to communicate clearly with each other about the condition and its impact. Thus, several individuals observing the same person can disagree about whether to call his or her cognitive or self-care deficits mild, moderate, or severe. Structured assessment procedures and instruments provide a common methodology for evaluating deficits and a common language for communication among those who study, diagnose, treat, and care for persons with dementia. In the absence of precise physical markers, these measures provide the only operational definitions of the terms "dementia," "cognitive impairment," "behavioral and self-care deficits," and "caregiver burden."

Structured assessment procedures and instruments can be used for a variety of purposes, and the purpose of the assessment determines which procedure or instrument should be used and the extent and type of errors that are acceptable (75,172). For some applications, it is necessary to identify only those individuals who certainly have a dementing illness; false positives are unacceptable. Appropriate instruments in these situations may miss some mild or borderline cases. Other applications require identification of all individuals with any possible dementia; false negatives are unacceptable. The appropriate procedures

and instruments in this case will sometimes classify cognitively normal individuals as having dementia.

Research, Clinical, and Legal Applications

Almost all formal research on dementia uses structured assessment procedures and instruments to identify and classify research subjects. In fact, many available instruments were developed for research projects. Measures of cognitive abilities are used in survey research to identify individuals with dementia; they are used in clinical research to identify symptoms of diseases that cause dementia, to describe the course of the diseases, and to study the relationship between cognitive abilities and physiological findings, such as the results of brain imaging tests.

The measures are also used to evaluate outcome in research on experimental treatments, such as drug therapies and behavioral interventions. In long-term care research, findings based on assessment of cognitive and self-care abilities, behavioral problems, and caregiver burden are compared with information about service use to determine why, for example, some persons with dementia are placed in nursing homes while others can be maintained at home. For each of these research applications, accurate and reliable assessment procedures are important, because the research findings can only be as good as the measurement procedures that have been used (21,93).

Clinical applications for these assessment procedures and instruments are numerous and diverse. Measures of cognitive abilities can be used to screen for dementia and to assist in its diagnosis. Behavioral measures can be used to identify disturbing behaviors that can be treated and controlled even if the underlying cause of dementia is not treatable, thus allowing some families to maintain patients at home. Physicians and case managers who assist families with decisions about long-term care can use measures of cognitive and self-care abilities to determine whether the person should continue to live independently and what long-term care services are needed (127,166,187). In nursing homes, adult day care

centers, and home care agencies, these instruments can be used to plan appropriate services, to determine the number and type of staff needed to provide them, and to monitor patient progress. Finally, measures of caregiver burden, which have thus far been used almost exclusively for research, might help to identify supportive services needed by families and other caregivers.

In geriatric assessment centers and specialized health care settings, such as teaching nursing homes and some teaching hospitals, structured assessment procedures and instruments are part of a comprehensive multidisciplinary evaluation of persons with probable dementias. In most cases, such an evaluation results in accurate identification of deficits associated with dementia, and frequently the cause of dementia can also be specified (45,78)(138)185).

Yet, most persons with probable dementias are not seen in these specialized settings. In community hospitals, nursing homes, adult day care centers, home care agencies, and the offices of general practitioners—the settings where persons with probable dementias are most often seen and treated—comprehensive multidisciplinary evaluation is usually not available, and structured assessment procedures and instruments are seldom used. Instead, health care and social service providers in these settings often make intuitive judgments about an individual's abilities based on informal observations. Many experts believe that structured assessments could increase the accuracy of these judgments, facilitate communication among caregivers, and assist health care and social service providers in identifying an individual's long-term care needs (6,73,74,187).

Assessment procedures that are acceptable for research applications may be unsatisfactory for clinical applications, where errors or inaccuracy could have serious implications for the health care, safety, and quality of life of patients. In a research study, the failure of an assessment instrument to correctly identify a few individuals with dementia among a large number of subjects or, conversely, the incorrect classification of a few cognitively normal individuals as having dementia may have negligible statistical impact. In clinical settings, however, the same errors can cause seri-

ous problems, including inappropriate treatment and the failure to provide needed services and supervision. Since available assessment instruments are sometimes inaccurate, many experts advocate their use for initial screening only, to be followed by a comprehensive clinical evaluation of the individual (3,34,39,169,187).

In the future, structured assessment procedures and instruments may be used for legal purposes. For example, current procedures for determining competence to make legally binding decisions have been criticized for lack of objectivity. Particularly troublesome is the observation that the competence of individuals who agree with the decisions of their caregivers is rarely questioned, whereas individuals who do not agree with caregivers' recommendations are more frequently judged incompetent (see ch. 5) (16,146). Assessment instruments could provide a more objective measure of cognitive abilities.

Assessment instruments are rarely used for legal purposes at present, although assessing cognitive and self-care abilities as a basis for decisions about guardianship has been suggested (116). Since assessment focuses on the individual in relation to his or her physical and social environment, that suggestion would appear to fit well conceptually with the growing enthusiasm among legal and health care experts for the idea of "decision-specific competence" (i.e., competence for a specific decision rather than as a general attribute of a person (see ch. 5 and ref. 15).

The questions raised about the reliability and validity of assessment instruments for research and clinical applications are also relevant to legal applications. Careful testing of the reliability and validity of any instrument to be used for legal purposes is essential, since errors in the assessment could wrongfully deprive individuals of the right to make their own decisions, on the one hand, or wrongfully deny them protective services, such as guardianship, on the other hand.

Public Policy Applications

Public policy applications for structured assessment procedures and instruments include:

- establishing eligibility for publicly funded services,

- determining level of reimbursement for publicly funded services,
- measuring patient outcome for quality assurance programs, and
- identifying persons with dementia in health services research—the results of which are used by government agencies and others to plan and evaluate long-term care services.

Establishing Eligibility for Services

Eligibility for most publicly funded long-term care services is based on medical and nursing care needs. As described in chapter 6, eligibility for Medicare reimbursement for long-term care services depends on medical diagnosis, prognosis, and physician certification that the individual needs the services. Eligibility for Medicaid long-term care services varies from State to State, but generally depends on a need for medical and health-related services (in addition to income, assets, and other criteria discussed in ch. 11). Some States provide Medicaid funding for intermediate-level nursing home care based on an individual's need for personal care services supervised by a nurse. Although the need for personal care is clearly related to the self-care deficits of the patient, most States do not use an assessment of these abilities to determine eligibility. For Veterans Administration (VA) long-term care services, eligibility depends on medical and health care needs, age, income, whether the individual has a service-connected disability, and whether a bed is available in a VA facility.

The focus on medical and health care needs in Medicare, Medicaid, and VA eligibility requirements means that some persons with dementia do not receive the long-term care services they need. Others receive these services only because they have been given another diagnosis or certified by a physician to have medical, skilled nursing, or health care needs that make them eligible. Distorting the person's diagnosis and care needs, however, interferes with appropriate treatment.

Concern in Congress about Medicare, Medicaid, and VA eligibility requirements that may exclude persons with dementia from long-term care services has led to the introduction of several bills to make the necessary services available. Similar

legislation is expected to be introduced in future sessions. The framers of this legislation face the difficult task of defining which individuals and groups will be eligible for services. Some of the proposed bills describe an eligible individual as:

- one who “suffers from Alzheimer's disease (or a related organic brain disorder) and is physically or mentally incapable of caring for himself, as determined by a physician”;
- one “who is diagnosed as having Alzheimer's disease or a related disorder (including dementia)”;
- one who is “diagnosed by a physician as having senile dementia of the Alzheimer type”;
- and
- one who is a victim “(of Alzheimer's disease or a related memory disorder. ”

If these or other bills are enacted, Federal agencies will be responsible for formulating regulations to implement them, based primarily on the intent of Congress as expressed in debate prior to enactment. These regulations will further define how eligibility will be determined and whether structured assessment procedures and instruments will be used in the process. **The terms used to describe eligible individuals in Federal legislation and the methods of determining eligibility established by Federal regulations have serious implications for the numbers and kinds of individuals who are eligible and, therefore, the public cost of any such programs.**

One approach to defining eligibility is to identify specific diseases as a criterion. For example, each description just cited identifies individuals with Alzheimer's disease as eligible. This theoretically simple approach would correct biases against such persons in existing Federal programs, but it might also introduce new problems. At present, many middle-aged and elderly individuals who cannot care for themselves independently because of a variety of physical, mental, or emotional problems do not meet the eligibility requirements for publicly funded long-term care services. As indicated in chapter 3, the diagnosis of Alzheimer's disease is often an uncertain one. Given that uncertainty and the commitment of most physicians to the welfare of their patients, legislation that

provided services specifically for individuals with Alzheimer's disease would create strong incentives for physicians to diagnose their patients who need these services as having that disease.

With no physiological marker for Alzheimer's disease, there would be no definitive method for disputing the diagnosis, and many individuals who do not have Alzheimer's disease would be mislabeled. That would have serious implications for the kinds of health care these "Alzheimer's disease patients" would receive. Long-term care facilities would be filled with "Alzheimer's disease patients" and systematic errors would be introduced into research findings about the prevalence of this illness. In addition, the number of individuals eligible for services and the public cost would be higher than anticipated based on current prevalence estimates.

A second approach, as indicated, is to identify more general conditions such as "related disorder (including dementia), " "organic brain disorder, " or "related memory disorder" as criteria for eligibility. That approach would eliminate incentives for the overdiagnosis of Alzheimer's disease. Yet diagnosis of these general conditions maybe more susceptible to error and misinterpretation and more difficult to verify than the diagnosis of Alzheimer's disease. Thus, estimates of the number of individuals eligible for services based on these criteria and predictions about the public cost of services would be subject to significant errors. Terms such as "related memory disorder" raise additional questions because memory disorders can be due to many conditions, including Korsakoff's syndrome, depression, chronic schizophrenia, chronic alcoholism, and, to a lesser extent, normal aging. Legislation that created eligibility for services based on memory disorders could mandate services for individuals with any of these conditions.

Basing eligibility on either specific diseases or general conditions, such as dementia, creates another problem because these criteria do not account for the severity of a person's condition or for his or her need for services. One proposal just cited incorporates a measure of severity and need for services by requiring a physician's determination that the person is "physically or mentally

incapable of caring for himself ." These terms are vague, however, and permit wide possible interpretation. An alternative is to use assessment instruments that measure cognitive and self-care deficits to establish eligibility.

Although it is possible that no legislation to provide expanded services for persons with dementia will be passed soon, the pressure on Congress to enact legislation to improve services for such persons will continue. Being aware of the implications of defining eligibility in one way or another and understanding the kinds of assessment procedures and instruments that might be used for this purpose could result in legislation that accurately reflects the intent of congressional sponsors and that avoids potential problems in implementation.

Determining Reimbursement for Services

Availability of publicly funded services for persons with dementia is affected not only by eligibility requirements but also by regulations that set the reimbursement levels for these services. Most States reimburse nursing homes for the care of Medicaid patients at flat rates that do not reflect differences in the cost of caring for individuals with different needs. That reimbursement policy creates a strong incentive for nursing homes to admit individuals who require relatively little care and refuse those who require a lot of care, many of whom are persons with dementia. An alternative that has been adopted by at least five States (Illinois, Maryland, New York, Ohio, and West Virginia) is to adjust Medicaid reimbursement for different patient characteristics and care needs (42,165).

Several methods have been developed for grouping persons with similar characteristics and care needs (42, 103,165). Known as "case mix formulas)" these methods can focus on medical care indicators, such as diagnosis and prognosis; patient characteristics, such as cognitive, self-care, and behavioral deficits; or specific treatment needs, such as oxygen therapy or intravenous feeding. Case mix formulas based entirely or in part on patient characteristics use the assessment procedures discussed in this chapter. The specific characteris-

tics that are included can encourage or discourage admission of persons with dementia to nursing homes. For example, formulas that assess cognitive status could encourage admission of persons with dementia, assuming that the level of reimbursement is high enough to meet the cost of caring for them. Similarly, formulas based on self-care abilities or behavioral problems and tied to adequate reimbursement rates could encourage admission of such persons.

The Health Care Financing Administration is currently developing a case mix formula for Medicare reimbursement to nursing homes. It maybe based primarily on medical care indicators and thus biased against Medicare reimbursement for nursing home care for persons with dementia. If a measure of patient characteristics is included, however, Medicare reimbursement for nursing home care might become available for some persons with dementing illnesses.

Measuring Patient Outcome for Quality Assurance Programs

Government programs that regulate quality of care in nursing homes have focused on inputs—physical aspects of the facility, staffing, and caregiving procedures. An alternative is to focus on patient outcome as an indicator of quality of care. With this approach, changes in patients' physical condition and cognitive, self-care, and behavioral characteristics are monitored to determine quality of care. Aspects of this approach have been incorporated in the new survey instrument now being used in facilities that serve Medicare and Medicaid patients (see ch. 10). However, many nursing home administrators and others fear that the inspectors who use the new survey instrument will make subjective judgments about patient characteristics. Use of assessment procedures and instruments that have been shown to be reliable and valid could increase their confidence in the objectivity of the survey process.

Government quality assurance programs have legal status because they are based on Federal, State, and local law and because they can impose legally binding financial and administrative penalties on facilities and service providers that are out of compliance with regulations. Likewise, govern-

ment regulations that mandate eligibility requirements and level of reimbursement for services have legal status because they define the rights of individuals to receive services and the contractual obligation of government to pay for the services. The legal status of government programs and regulations suggests the need for highly precise and reliable assessment procedures.

The available procedures generally lack that high degree of accuracy, as discussed in this chapter. Yet they have been proposed and are being used in some instances to replace less satisfactory methods of establishing eligibility for services, determining level of reimbursement, and monitoring quality of care. Although the existing methods are generally precise and relatively easy to use, they do not measure the aspects of patient functioning that are most relevant to the need for long-term care and quality of care received. For example, measuring quality of care in terms of the hot water temperature in a nursing home or the number of square feet per patient in an adult day care center is easier and more precise than measuring quality of care in terms of patient outcome in either setting. Precision and ease of measurement are not the only important considerations, however, and public policy must balance these concerns with the need for assessment procedures that reflect the true intent of government programs.

Identifying Dementia Patients in Health Services Research

Information about the prevalence of specific diseases, the characteristics of affected persons, their care needs, patterns of service utilization, and cost of care is derived primarily from large-scale surveys and smaller studies of specific population groups and care settings. Almost all this research is sponsored by agencies of the Department of Health and Human Services (e.g., the National Center for Health Statistics, the National Center for Health Services Research, the National Institutes of Health, the National Institute of Mental Health, the Office of the Assistant Secretary for Planning and Evaluation, the Office of Human Development Services, and the Health Care Financing Administration) and by VA. Research findings are used to plan and evaluate services.

In general, persons with dementia have not been identified as a distinct group in health services research (100). Information about patient diagnosis is routinely obtained in many studies but is often unreliable. That is partly because of the difficulty of differential diagnosis in dementia but more often because the individual's diagnosis is obtained either from family members or other informants who do not know or may report it incorrectly, or from hospital or nursing home medical records that may be out of date or unreliable for other reasons. Furthermore, as indicated, diagnosis alone is not a good indicator of care needs.

Relatively few studies have used cognitive assessment instruments, and in some studies where these instruments were included, they were not administered to the subjects who were most likely to be cognitively impaired—i.e., those for whom a proxy was interviewed. As a result, although it is clear that persons with dementia constitute some proportion of the subjects in many studies of elderly and long-term care populations, their identity can only be inferred by combining information about diagnosis, self-care deficits, behavioral problems, and excessive caregiver burden (100). More accurate procedures for identifying these individuals are essential for government policy analysis and program planning and evaluation.

The remainder of this chapter discusses assessment of cognitive abilities, self-care abilities, be-

havior, and caregiver burden. Multidimensional assessment instruments that measure a wide range of patient and family characteristics are also discussed. Each section describes some of the available procedures and instruments, their reliability and validity, their capacity to differentiate between different patient groups, and their potential usefulness for public policy applications.

Some researchers and clinicians use the term “functional abilities” to refer to some or all of the cognitive and self-care abilities and behaviors discussed in this chapter, and some refer to the process of identifying and evaluating such abilities and behaviors as “functional assessment.” Their use of the word “functional” emphasizes the concept that these patient characteristics are more closely related to the individual's ability to care for himself or herself independently and to the individual's need for long-term care services than factors such as diagnosis and medical care needs. While recognizing the validity of that concept, OTA finds that the term functional is used by different people to mean different patient characteristics and different combinations of characteristics. For that reason, it is not used in this chapter, and its use in legislation would create problems in implementation.

ASSESSMENT OF COGNITIVE ABILITIES

Cognitive impairment is the central feature of dementia and the primary cause of self-care and behavioral problems associated with it. The cognitive abilities that can be diminished or lost in dementia include memory, intelligence, learning ability, calculation, problem solving, judgment, comprehension, recognition, orientation, and attention. Many structured assessment procedures and instruments measure some or all of these.

The most commonly used method for evaluating cognitive abilities in persons with possible dementia is the clinical mental status exam in which a physician evaluates the person, based on ver-

bal responses and behavior during an interview. Most clinicians ask questions to determine orientation—i.e., whether the individual knows who he or she is, who others are, where he or she is, and the date or day of the week. Mathematical questions and proverb interpretation are often used to measure higher cognitive functions. Yet there is considerable variation in the specific questions included and the cognitive functions evaluated (74,85,108). The result of a mental status exam is a judgment by the clinician, based on observations, experience, and intuition, about the person's cognitive abilities. Although that judgment may be accurate in many cases, lack of uniformity in

questions asked and in cognitive abilities evaluated by different clinicians leads to uncertainty about the results.

In some cases, no mental status evaluation is done, and the cognitive impairments of patients are not identified. One study in a hospital medical ward found that ward physicians and nurses failed to identify cognitive impairments in 37 and 55 percent, respectively, of the affected patients (84). Other studies have noted the same problem in a rehabilitation hospital (46), in a medical inpatient service (109,144), in a neurology inpatient service (28), in a geriatric inpatient service (118), and for elderly persons in the community (190). The researchers suggest that routine use of assessment instruments could improve identification of patients with cognitive deficits.

Results of one study that tested that approach do not support their contention, however. The study involved the use of a brief cognitive assessment instrument, the Short Portable Mental Status Questionnaire (SPMSQ), to assess patients in a general internal medicine practice. Its use resulted in increased recording of patients' mental status: cognitive status was recorded in 35 percent of patient charts before the study began and 65 percent of the charts when the SPMSQ was used. Yet, routine use of the SPMSQ did not raise the proportion who were found to have cognitive deficits (about 9 percent in both periods) (193). Replication of the study is needed in other settings and using other cognitive assessment instruments.

Instruments To Measure Cognitive Abilities

Some instruments used to measure cognitive abilities in persons with dementia are derived from tests first used by psychologists and educators to measure intelligence quotient (IQ) in young people. An example is the Wechsler Adult Intelligence Scale (WAIS), developed in 1955 and used widely today to assess healthy and cognitively impaired adults (12,89). The WAIS includes subtests that can be used separately or combined into verbal and performance IQ scores.

Other instruments focus primarily on memory. The Wechsler Memory Scale (WMS), the most

widely used of these, includes subtests that measure orientation; ability to recite the alphabet and count by threes; and ability to remember words, numbers, and geometric designs (132). Another such instrument is the Object Memory Evaluation (OME), in which an individual is presented with 10 easily recognized objects; the objects are then removed, and the person is asked to name them (44).

A third type of cognitive assessment instrument is derived from the clinical mental status exam described above. Examples (see tables 8-1,8-2,8-3, and 8-4) include the Information-Memory-Concentration Test (9); the Mental Status Questionnaire (MSQ) (73); the Short Portable Mental Status Questionnaire (127); and the Mini-Mental State Exam

Table 8-1 .Information"Memory-Concentration Test

Information test:

Name
Age
Time (hour)
Time of day
Day of week
Date
Month
Season
Year
Street
Town
Type of place (e.g., home, hospital, etc.)
Recognition of persons (cleaner, doctor, nurse, patient, relative; any two available)

Memory-

1. *Personal*
Date of birth
Place of birth
School attended
Occupation
Name of siblings or name of wife
Name of any town where patient had worked
Name of employers
2. *Nonpersonal*
Date of World War I
Date of World War II
Monarch
Prime Minister
3. *Name and address (5-minute recall)*
Mr. John Brown
42 West Street
Gateshead

Concentration:
Months of year backwards
Counting 1-20
Counting 20-1

SOURCE: G. Blessed, B.E. Tomlinson, and M. Roth, "The Association Between Quantitative Measures of Dementia and of Senile Change in the Cerebral Grey Matter of Elderly Subjects," *British Journal of Psychiatry* 114:797-811, 1968

Table 8-2.—Mental Status Questionnaire (MSQ)

1. What is this place?
 2. Where is this place located?
 3. What day in the month is it today?
 4. What day of the week is it?
 5. What year is it?
 6. How old are you?
 7. When is your birthday?
 8. In what year were you born?
 9. What is the name of the president?
 10. Who was president before this one?
- SOURCE: R. L. Kahn, A. I. Goldfarb, M. Pollack, et al. "Brief Objective Measures for the Determination of Mental Status in the Aged," *American Journal of Psychiatry* 117:326-328, 1963.

Table 8-3.—Mini.Mental State Examination (MMSE)

- Orientation:**
What is the (year) (season) (date) (day) (month)?
Where are we (State) (hospital) (floor)?
- Registration:**
Name three objects: One second to say each. Then ask patient all three after you have said them. Repeat them until he learns all three. (Count trials.)
- Attention and calculation:**
Begin with 100 and count backwards by 7 (stop after five answers). Alternatively, spell "world" backwards.
- Recall:**
Repeat the three objects above.
- Language:**
Show a pencil and a watch and ask subject to name them.
Repeat the following: "No 'ifs' 'ands' or 'buts.' "
A three-stage command, "Take a paper in your right hand; fold it in half and put it on the floor. "
Read and obey the following: (Show subject the written item).
CLOSE YOUR EYES
Write a sentence.
Copy a design (complex polygon as in Bender-Gestalt).
- SOURCE: M. R. Folstein, S. Folstein, and P. R. McHugh, "Mini-Mental State" A Practical Method for Grading the Cognitive State of Patients for the Clinician," *Journal of Psychiatric Research* 12:189-98, 1975

(MMSE) (39). Designed specifically for evaluating individuals with probable dementia, these instruments are shorter than the WAIS and WMS because such individuals frequently cannot tolerate lengthy assessment procedures. Test items are generally simpler than items on the WAIS.

All four of these instruments measure orientation and memory. Both the MMSE and SPMSQ measure ability to subtract a number from 100 and continue subtracting serially. In fact, many items on the four tests are similar and can be combined with slight rewording into a single test with fewer than 40 questions (78). A]] four measures

Table 8-4.—Short Portable Mental Status Questionnaire (SPMSQ)

1. What is the date of today? (month) (day) (year)?
2. What day of the week is it?
3. What is the name of this place?
4. What is your telephone number?
- 4a. What is your street address? (Ask only if patient does not have a telephone.)
5. How old are you?
6. When were you born?
7. Who is the President of the United States now?
8. Who was the president just before him?
9. What was your mother's maiden name?
10. Subtract 3 from 20 and keep subtracting 3 from each new number, all the way down.

SOURCE: E Pfeiffer, "A Short Portable Mental Status Questionnaire for the Assessment of Organic Brain Deficits in Elderly Patients," *Journal of the American Geriatrics Society* 23 "433-441, 1975

have been used extensively in research and clinical settings.

A fourth type of assessment instrument uses neurological tests to differentiate between cognitively normal individuals and those with organic dementias. An example is the Face-Hand Test (FHT) in which the person is touched simultaneously on the face and the hand, first with his eyes open and then with eyes closed. Persons with organic dementias frequently report only one of the two stimuli (36).

Many other cognitive assessment instruments have been developed for research and clinical applications. This chapter focuses on the instruments just described because they are used most often in the United States.

Reliability and Validity of Cognitive Assessment Instruments

The accuracy of assessment instruments in identifying individuals with cognitive deficits depends on two factors—reliability and validity. Reliability is the capacity to produce the same results when used by two different raters (interrater reliability) or at different times (test-retest reliability). Interrater reliability has not been reported for all the assessment instruments just mentioned, but it has been shown to be high for those that have been tested. Although raters are usually trained to use the instrument beforehand, some instruments, such as the MMSE, are designed for use by untrained raters, and these too have demonstrated

high interrater reliability (3). Test-retest reliability has not been reported for all the instruments but has been high when reported (38,127,169).

Validity is the capacity of an instrument to measure cognitive abilities accurately and to distinguish between individuals who are cognitively impaired and those who are not. Experience with the four types of assessment instruments described indicates that they usually distinguish correctly between cognitively normal individuals and those with moderate or severe cognitive impairments; they are less accurate, however, in identifying individuals with mild cognitive impairments. In addition, some persons with obvious cognitive impairments do well on these tests, and some persons who are cognitively normal do poorly (3)36)39,89,125).

Validity of these instruments is usually tested by comparing the results of one test with another or with the judgment of a clinician who evaluates the same person in an unstructured or semistructured interview. Often the subjects in these studies have been previously identified as either cognitively impaired or cognitively normal; individuals with questionable cognitive status or characteristics that might complicate cognitive assessment are not included. When tested in this way, the instruments are generally effective in differentiating between those who are cognitively impaired and those who are not (3,36,80,166).

When the same instruments are used with subjects who have not been previously screened, however, their ability to correctly identify individuals with cognitive deficits is significantly reduced. For example, when the MMSE was used recently for a large survey in Baltimore, a significant proportion of individuals were incorrectly identified as cognitively impaired (14 to 33 percent, depending on which cutoff score was used) (38).

Similarly, when the MMSE was used to evaluate hospital patients on a general medical ward, 33 of the 97 subjects were identified as cognitively impaired on the basis of the test, but only 20 were so judged on the basis of a comprehensive clinical evaluation by a psychiatrist. That is a false positive rate of 39 percent. Eleven of the 13 false positives had an eighth grade education or less, and level of education was not known for the other

two. In contrast, there were no false positives among those who had more than an eighth grade education. More false positives were also noted for those aged 60 and over than for those under 60 (3). Thus, educational background and age appear to affect the validity of the MMSE.

The use of cognitive assessment measures for long-term care decisionmaking, as eligibility criteria, or in survey research requires evaluation of individuals with a wide range of cognitive functioning who have not been previously screened for such cognitive impairments. Many are over 60, and many have less than an eighth grade education. Thus, there may be serious drawbacks to using the MMSE or similar assessment instruments alone for these purposes. The authors of the MMSE have not suggested such use and emphasize that it is a screening instrument and should be followed by clinical evaluation of the patient (39). It is considered here only as a prototype of the kind of instrument that might have public policy applications.

Research indicates that cognitive test items differ in their tendency to produce false positive or false negative findings (83). Orientation items often produce false negatives—that is, some persons with dementia answer these questions correctly. Conversely, cognitively normal individuals seldom miss these questions. Other test items, such as spelling a word backwards or remembering three items after five minutes, tend to result in false positives—that is, some cognitively normal individuals miss these items. Conversely, dementia patients seldom get them right. These findings suggest the possibility of varying the mix of test items for different applications depending on the acceptability of each kind of error.

Problems That Complicate the Assessment of Cognitive Abilities

A variety of problems affect performance on cognitive tests and, therefore, complicate the assessment process. Many are related to the fact that most individuals with possible dementia are elderly and have physical, psychological, and sociodemographic characteristics that can reduce test performance even when there is no real cognitive impairment. Just as prevalence of demen-

tia increases with increasing age, so does the prevalence of problems that interfere with accurate assessment.

One overriding problem is that the diagnosis of dementia requires a decline in cognitive function. Individuals of all ages, but especially the elderly, vary widely in cognitive ability (89), and a given level of performance on a cognitive test may be normal for one individual but indicate serious cognitive loss for another. Thus, poor test performance can indicate either a low level of intelligence that has been characteristic of an individual throughout life or a decline in cognitive abilities associated with dementia. Similarly, an average score can indicate either normal cognitive status or a significant decline in an individual who once had high intellectual ability.

Few elderly people have taken these tests earlier in life, and test results are seldom available for those who have; thus, there is no personal standard against which to measure change. Furthermore, age-related norms have not been developed for most instruments (110). Since verbal skills change less in old age than other cognitive functions, some experts have suggested that measures of such skills may reflect an individual's previous cognitive abilities (74,89,147). These findings have not been sufficiently documented, however, to form a basis for long-term care decisionmaking or for establishing eligibility for services.

Many experts recommend interviewing a relative or friend of the person to determine the person's previous cognitive abilities (147, 163). Sometimes, however, no well-informed relative or friend is available. Even when information is available, it is often difficult to evaluate since relatives and friends may have a different frame of reference from the clinician for judging cognitive abilities.

The difficulty of determining whether there has been a decline in cognitive abilities is a serious problem in the assessment of patients with dementia (40,172). For research applications, averaging of data may minimize the effect of this problem, but for long-term care decisionmaking or eligibility determination, errors in classification of individuals due to lack of information about previous intellectual ability cannot be averaged out.

Physical Conditions

Visual impairments, hearing loss, speech impairments, acute and chronic diseases, and the effects of various medications can reduce cognitive test performance and complicate the assessment of cognitive abilities. Although individuals with these conditions are often excluded from studies that test the validity of assessment instruments, they are part of the population that must be assessed for long-term care decisionmaking, eligibility determination, and other public policy purposes.

About 14 percent of those over 65 have visual impairments (173), and prevalence increases in successively older age groups. On cognitive tests that involve visual stimuli, individuals with visual impairments perform poorly despite normal cognitive abilities (25). If this problem is recognized, test items can be modified. But in some testing situations, especially when assessment instruments are used by untrained persons or for large-scale screening, visual impairments that affect test performance may not be noticed.

Hearing impairments are also very common among the elderly and can interfere with performance on tests that involve verbal instructions or a verbal response (53). As with visual impairments, assessment procedures can be modified if the hearing loss is recognized; however, many people are unaware of or try to hide such impairments. If they answer questions they have not heard clearly, it is extremely difficult to determine whether errors are caused by failure to hear the question or by cognitive impairments. A comprehensive multidisciplinary evaluation conducted by a trained professional lessens the chance of mistaking hearing loss for cognitive impairment, but when less well trained observers conduct the assessment and a single instrument involving verbal stimuli is used, there is a much greater probability of error.

Some individuals have both hearing loss and cognitive impairment. Among those over 65, at least 28 percent have moderate to severe hearing loss, and coexistence of hearing loss and dementia is not uncommon (171,174). Among nursing home residents and those over 80, prevalence of both conditions is higher, and many of these individuals are both hearing impaired and cognitively impaired. In such cases, identification of cogni-

tive deficits and measurement of their severity is particularly difficult.

Speech impairments also affect cognitive test performance when verbal responses are required. In some cases, inability to communicate verbally is a symptom of dementia, resulting directly from the disease or other condition that causes the dementia. (Certain kinds of speech impairment are associated with specific diseases that cause dementia, and careful evaluation of an individual's speech impairment may facilitate differential diagnosis.) In other cases, inability to communicate verbally is unrelated to cognitive ability; yet it is often perceived by laypersons and many health care and social service providers as a sign of cognitive impairment (174). For a patient who can write, assessment procedures can be adapted, but for those who can neither write nor speak clearly, accurate assessment is difficult, whether done in a structured or unstructured clinical interview, and with or without an assessment instrument.

Acute and chronic diseases that are common among the elderly affect cognitive test performance. Because of the sensitivity of the aged brain to any changes in physical condition, almost all diseases can affect cognitive ability. Infections, cardiovascular disease, dehydration, electrolyte disturbances, nutritional deficiencies, and many other conditions can lessen cognitive functioning (174). Pain or fatigue associated with acute or chronic disease can also take a toll. Furthermore, fluctuations in cognitive functioning associated with pain, fatigue, or episodes of acute disease can result in different evaluations of a person's cognitive abilities by observers who see the person at different times.

For research purposes and some clinical applications, assessment can be postponed until acute conditions have been treated and cognitive functioning has returned to normal; however, long-term care decisions and eligibility determination often cannot be postponed. Elderly individuals with diminished cognitive abilities frequently live independently until a medical crisis brings them to a hospital, where discharge plans based at least in part on an assessment of cognitive abilities are often made before they are entirely well. Indeed, the Medicare Prospective Payment System and

other government and private initiatives that encourage early discharge of hospital patients are now increasing the pressure on hospital staffs to formulate discharge plans, including plans for nursing home placement, while patients are still acutely ill. For example:

Mrs. C., a 75-year-old woman who had been living alone, was admitted to the hospital after a friend called an ambulance because Mrs. C. had become weak, confused, and incontinent. In the hospital, an infection was diagnosed and treatment begun. Mrs. C. was definitely confused in the hospital. Informal evaluation by the physician indicated poor orientation to time and place, memory loss, and poor judgment. The doctor and the hospital social worker had to decide quickly whether it was safe for Mrs. C. to go home alone or whether she should be placed in a nursing home. This decision depended primarily on whether her confusion would lessen as the infection subsided. They both knew that the infection could be causing the confusion; there was no way to accurately assess her cognitive abilities while it continued. They both also knew that if she was placed in a nursing home now, discharge to home would be unlikely at a later time.

In this hypothetical case that represents an increasingly common occurrence in hospitals, most physicians and social workers would rely on a history of the patient illness and prior functioning to make a tentative judgment about her underlying cognitive abilities. Structured assessment procedures and instruments would not provide accurate information about her long-term cognitive functioning.

Eligibility for long-term care services, such as Medicaid funding for nursing home care, is often determined at times when a person is acutely ill and accurate measurement of cognitive abilities is difficult. Eligibility determinations based on cognitive test performance would be subject to frequent errors at these times.

Many medications affect cognitive functioning, particularly in the elderly (78,170,174). Even if reversible, such cognitive deficits are real and affect both test performance and the results of informal patient evaluation (36). Some clinicians may not be aware of the effect of drugs on cognitive functioning (66), but even those who are aware

have no way to evaluate a person's cognitive abilities in a drug-free condition without stopping the drugs, which is dangerous for some patients. As with acute illness, a history of the patient functioning prior to the use of medications may help determine underlying cognitive abilities. Use of structured assessment procedures and instruments usually cannot differentiate between patients with medication-induced cognitive deficits and those with primary degenerative dementias.

Emotional and Psychological Conditions

Depression and other emotional and psychological conditions common among elderly people can complicate assessment of cognitive abilities. Severe depression, particularly in the elderly, can cause cognitive deficits that are the same or similar to those associated with multi-infarct disease, Alzheimer's disease, and other degenerative brain diseases. Less severe depression causes some elderly individuals to doubt their own cognitive abilities and exaggerate the importance of minor memory lapses. Their complaints about memory loss seldom reflect real cognitive deficits (25,41, 110, 133), but they can complicate the assessment process.

Other psychological and emotional characteristics common among elderly people can affect test performance even for those with no cognitive deficits. Elderly people are more cautious than younger people on cognitive tests and tend to be less confident about their answers (10,25,89). They may respond more slowly and omit items they are unsure of, resulting in lower test scores. Such behavior is especially a problem on timed tests (120,25).

Cognitive testing is a familiar experience for many young people today but is often something new for elderly people, and anxiety related to an unfamiliar test situation can reduce test performance. Any actual errors on the test can also increase anxiety (25,36). Research indicates that success on one test item increases the probability of success on the next item (4), and some experts advise that testing should at least begin with items that allow a high rate of success in order to alleviate anxiety and increase the validity of the results.

That is an important consideration in test design and administration for persons with Alzheimer's disease who may have very limited cognitive abilities and limited tolerance for stress and may become so agitated by failures that they have a catastrophic reaction and are unable to complete the assessment [36,190].

The validity of cognitive tests depends on the assumption that the individual is attentive (89), but research indicates that some cognitively normal elderly people do not concentrate on tests that have no meaning to them. Lack of attention can reduce performance on simple tests, such as the Face-Hand Test (FHT) (31), and on tests of rote memory, such as recalling random numbers. Inability to concentrate, however, can be an integral part of dementia, affecting both cognitive test performance and the individual's ability to function independently. Distinguishing between poor test performance due to lack of attention and poor test performance due to dementia maybe easy when the clinician knows the person and several tests are used. In large-scale screening, when the clinician does not know the person or when only one measure is used, that distinction can be difficult.

Sociodemographic Characteristics

Educational level attained, ethnic and cultural background, and language barriers all affect cognitive test performance (172). The relationship between educational background and cognitive test performance has been noted frequently (3,38,67, 70,89,127). Test items that are especially difficult for individuals with limited formal education include orientation to time (3,113) and serial subtraction tests in which the individual is asked to subtract a number from 100 and continue subtracting repeatedly (3,65,89).

The FHT has been recommended for cognitive assessment because it uses an unlearned perceptual task that is not affected by educational background (73,89). Alternatively, some experts have recommended adjusting the scoring of cognitive tests, depending on the educational level of the individual (82,127). Others have suggested that new test items should be devised that are less affected by educational background (3). In a recent survey, subjects who could not complete the serial

subtraction test were offered an alternative—spelling the word “(world” backwards. All those with an eighth grade education or less had to resort to this alternative, and some who were not cognitively impaired were, nevertheless, unable to complete the item correctly (3).

In a related area, some studies of hospital or nursing home patients have replaced test items such as the name of the President with more personally relevant information, such as the name of a head nurse or a neighbor. Surprisingly, at least one study has indicated that these items were more difficult for subjects (31). It has been suggested that the new items may tap different cognitive functions than the original items (78).

Ethnic and cultural background also affect cognitive test performance, but little research has been done on this issue. Some test items may have little meaning or a different meaning for subjects from different ethnic backgrounds (89). For example, research indicates that Hispanics in Los Angeles had more difficulty with the MMSE items “state,” “season,” and “country” than non-Hispanics, possibly because many had recently immigrated from Mexico or other Latin American countries where these concepts are seldom used (33). Similarly, anecdotal evidence indicates that time orientation may be different for some minority group individuals (175). Some ethnic and cultural minority groups have negative attitudes about psychological testing and mental health professionals that can distort cognitive test performance. In addition, clinicians may have problems evaluating background information about clients from ethnic or cultural minority groups different from their own.

To compensate for language barriers, test instruments can be translated, but some items, such as proverb interpretation, lose their meaning in translation. When the test is in English, those for whom English is a second language may have particular difficulty with items such as vocabulary. Some will switch back and forth between English and their native language during the interview, and it can be difficult for the clinician to tell whether that behavior indicates regression associated with dementia, resistance to the test situation, or the person's normal behavior (23).

Ethnic minority groups of color (black Americans, Native Americans, and Asian Americans) constitute about 10 percent of the elderly population, and an additional 3 percent of the elderly are of Spanish origin (97). These percentages will increase as life expectancy rises for ethnic minority groups. In addition to these groups, many other elderly individuals immigrated to this country and retain cultural and language characteristics that reflect their countries of origin. Assessment procedures that can be adapted for these individuals are needed for research and clinical applications, for accurate evaluation of cognitive abilities related to long-term care decisionmaking, and for potential use in eligibility determination and other public policy applications.

Cognitive Assessment and Differential Diagnosis

Federal legislation that defines eligibility in terms of specific diseases or general conditions would require a method for differentiating among cognitive deficits associated with normal aging, depression, and organic brain diseases such as Alzheimer's, Pick's, and Huntington's diseases. Although physiological markers and lab tests can help identify some conditions, there are no definitive markers or tests for others. While diagnosis of these diseases and conditions is often accomplished in an unstructured or semistructured clinical evaluation, assessment procedures and instruments are sometimes used.

Age-Related Cognitive Decrements

Extensive psychological research indicates that cognitive functions such as response speed and short-term memory are often diminished in elderly people (110, 172, 176). Experts disagree, however, about the extent and inevitability of cognitive loss associated with aging. Some studies show that average cognitive test scores for elderly subjects are 30 percent below those of younger subjects (195). Yet it appears that up to one-third of the elderly show no age-related cognitive loss (110).

Age-related cognitive decrements differ from dementia in that they usually do not progress to the point of interfering with independent func-

tioning. At any one time, however, it can be difficult to distinguish between age-related cognitive decrements and those that signal early stages of dementia (24)110).

The assessment instruments used most often for this purpose are subtests of the WAIS, the WMS, the OME, and similar measures (11,91,111, 121). For example, one study differentiated with 98 percent accuracy between cognitively normal elderly persons and those with mild dementia using four tests (WMS logical memory, Trailmaking A, word fluency, and WMS mental control) (168). Another study identified a battery of three tests (Visual Retention Test, Controlled Oral Word Association Test, and Temporal Orientation) that correctly classified 87 percent of the subjects (34).

A third study showed that individuals with age-related cognitive loss could be differentiated from those with dementia on the basis of short-term (3-minute) memory and from younger controls on the basis of longer (24-hour) memory (119). Finally, one group of researchers found that scores on two measures (the WAIS digit symbol test¹ and an aphasia battery) were the best predictors of whether individuals with mild cognitive deficits would progress to moderate or severe dementia over a 1-year period (5).

Some researchers and clinicians have used the term “benign senescent forgetfulness” to describe significant memory loss that does not interfere with the individual’s functioning and is not expected to progress (87,86). Research suggests, however, that such memory loss may not be benign in some people:

In a prospective study of 488 volunteers, age 75 to 85 years, who were nondemented on initial examination, approximately 50 developed an unequivocal dementia over a 3-year period. Extensive neuropsychological tests had been carried out annually; the best predictor of dementia was the score on the Blessed mental status test. Subjects who initially made zero to two errors (out of 33 possible errors) on this mental status examination

¹The digit symbol test involves showing the subject a sheet on which the digits 1-9 are paired with 9 geometric figures. The subject is then asked to draw the appropriate geometric figure after each digit on a test sheet. He or she is allowed to look back at the original sheet on which the digits and figures are paired (Berg, et al., 1984 b),

developed dementia at a rate of less than 1 percent per year; those who made five to eight errors developed dementia at a rate over 10 percent per year. But only one-third of those who made five to eight errors have developed dementia as yet. The latter subset of subjects may be best described as an “at risk” group (78).

Even a comprehensive clinical evaluation using the best neuropsychological tests cannot predict which of the individuals with mild cognitive loss will develop progressive dementias (78).

Cognitive Deficits Caused by Depression

As noted earlier, depression can cause significant cognitive impairment, especially in the elderly, and much of the research on cognitive assessment for dementia has focused on methods of differentiating between depression-induced dementia and primary degenerative dementia.² The impetus behind research on cognitive assessment for dementia is that the cognitive deficits caused by depression are sometimes reversible if the depression is treated (60,129,135,156,194).

Several clinical features are said to distinguish depression-induced dementia from primary degenerative dementia (see table 8-5). Inconsistent performance on cognitive assessment tests is one such feature, but several researchers have been unable to confirm its validity (81,130). Likewise, “I don’t know” responses have been identified as characteristic of depression-induced dementia, but several studies have found no significant differences in the number of these responses given by the two groups of patients (107,196). One study (180) found that depressed individuals have more difficulty remembering random than nonrandom words, while individuals with dementia have equal difficulty with random and nonrandom words.

An individual’s history, behavior, and mood can provide clues for differentiating between the two conditions (48,184), and a multidimensional assessment instrument (discussed later in this chapter)

²A review of instruments to assess depression is beyond the scope of this report. In the context of differential diagnosis, however, it is important to note that some researchers and clinicians believe that many of the commonly used instruments do not assess the symptoms of depression most common in elderly people (Weiss, et al., 1986) and are of little value in evaluating them (Garcia, et al., 1981; Katzman, et al., 1986).

Table 8.5.—Major Clinical Features Differentiating Depression-Induced and Primary Degenerative Dementia

Depression-induced dementia	Primary degenerative dementia
Clinical course and history	
Family always aware of dysfunction and its severity	Family often unaware of dysfunction and its severity
Onset can be dated with some precision	Onset can be dated only within broad limits
Symptoms of short duration before medical help is sought	Symptoms usually of long duration before medical help is sought
Rapid progression of symptoms after onset	Slow progression of symptoms throughout course
History of previous psychiatric dysfunction common	History of previous psychiatric dysfunction unusual
Complaints and clinical behavior	
Patients usually complain much of cognitive loss	Patients usually complain little of cognitive loss
Patients' complaints of cognitive dysfunction usually detailed	Patients' complaints of cognitive dysfunction usually vague
Patients emphasize disability	Patients conceal disability
Patients highlight failures	Patients delight in accomplishments, however trivial
Patients make little effort to perform even simple tasks	Patients struggle to perform tasks
Patients do not try to keep up	Patients rely on notes, calendars, etc., to keep up
Patients usually communicate strong sense of distress	Patients often appear unconcerned
Affective change often pervasive	Affect labile and shallow
Loss of social skills often early and prominent	Social skills often retained
Behavior often incongruent with severity of cognitive dysfunction	Behavior usually compatible with severity of cognitive dysfunction
Nocturnal accentuation of dysfunction uncommon	Nocturnal accentuation of dysfunctions common
Clinical features related to memory, cognitive, and intellectual dysfunctions	
Attention and concentration often well preserved	Attention and concentration usually faulty
"Don't know" answers typical	Near-miss answers frequent
On tests of orientation, patients often give "don't know" answers	On tests of orientation, patients often mistake unusual for usual
Memory loss for recent and remote events usually equally severe	Memory loss for recent events usually more severe than for remote
Memory gaps for specific periods or events common	Memory gaps for specific periods unusual ^a
Marked variability in performance on tasks of similar difficulty	Consistently poor performance on tasks of similar difficulty

^aExcept when due to delirium, trauma, Seizures, etc.

SOURCE: C.E. Wells, "Pseudodementia," *American Journal of Psychiatry* 136:895-900, 1979.

has been developed for this purpose (59). In addition, some have recommended a trial with antidepressant medications or electroconvulsive therapy for cases that are otherwise impossible to diagnose accurately (107,110).

The relationship between depression-induced and primary degenerative dementia may be considerably more complex than indicated by this discussion. Research indicates that the two conditions coexist in as many as one-fourth of cognitively impaired elderly persons (139). Differentiating persons with coexisting conditions from those with only depression is extremely difficult. Furthermore, several studies have shown that some persons who were originally identified as having depression-induced dementia go on to develop primary degenerative dementia (87,107,137). It has been suggested that depression and primary degenerative dementia may be biologically related in some as yet unexplained fashion (78,102).

Given the difficulty of distinguishing between depression-induced dementia and primary degenerative dementia, programs designed to serve persons with Alzheimer's and other organic dementias will probably also serve those with dementia caused by depression and those with coexisting depression and primary degenerative dementia. Federal legislation and regulations that restrict eligibility to those with primary degenerative dementias would create incentives for physicians to diagnose individuals with depression-induced dementia as having organic dementias. Conversely, legislation and regulations that extend eligibility to individuals with depression-induced dementias would encourage correct diagnosis and appropriate treatment for these individuals but might also result in overdiagnosis of depression.

Diseases That Cause Dementia

Diagnosis of the specific diseases that cause dementia is often made on the basis of factors such

as age of onset, course of the disease, associated motor disorders, and other physical findings (see ch. 3). Differences in typical cognitive functioning in each of the diseases have been noted, however (50,60), and some researchers have tested the ability of cognitive assessment instruments to differentiate among these diseases. For example, one study used six WAIS subtests to assess cognitive impairment in patients with multi-infarct dementia or Alzheimer's disease: 74 percent of the patients were correctly classified (123). Another used cognitive tests to compare test performance in patients with Alzheimer's and Pick's diseases and multi-infarct dementia (72).

In an attempt to differentiate Alzheimer's from other diseases that cause dementia, researchers have developed an assessment procedure based on the concept that Alzheimer patients with obvious cognitive deficits retain normal motor functions longer than patients with other diseases (26). In a retrospective study of 50 patients, that assessment procedure, which involves rating patients on five cognitive functions and five motor functions (speech, psychomotor speed, posture, gait, and involuntary motor disturbances), successfully classified all Alzheimer patients and all but two of the non-Alzheimer patients (one with Pick's disease and one with post-traumatic dementia). The researchers point out that the procedure is least useful in the earliest stage of dementia when cognitive deficits are mild and in the latest stage when motor functions have deteriorated, and that it may misclassify Alzheimer patients with atypical presentations. Further validation of this assessment procedure is needed.

Differential diagnosis is complicated by the coexistence in some patients of diseases that cause dementia. For example, some patients have both Parkinson's and Alzheimer's diseases (14,94). Similarly, autopsy research indicates that 12 to 25 percent of patients with dementia show physiological signs of both multi-infarct dementia and Alzheimer's disease. Coexistence of these conditions is particularly common in the very old (16,43).

Assessment instruments have been used for differential diagnosis primarily in the context of comprehensive multidisciplinary evaluations that include physical examination, lab tests, a patient history, and neurological, psychiatric, and social

work evaluation. Even with such a comprehensive assessment, differential diagnosis is often difficult, and some individuals are misclassified (7,162,172). For legislative purposes, it is important to recognize the difficulty of differential diagnosis when considering proposed legislation that would provide eligibility for individuals with specific illnesses, such as Alzheimer's disease, while excluding those with others that cause dementia.

Cognitive Rating Scales

Some assessment instruments have been used not only to identify and describe cognitive impairments but also to rate them from mild to severe. Most such instruments combine measures of cognitive, self-care, and behavioral deficits; these multidimensional scales are discussed later in this chapter. One instrument that focuses only on cognitive abilities is the Dementia Rating Scale (DRS), which is based on a series of tests that measure attention, memory, and other cognitive abilities (106). DRS has shown high test-retest reliability over a 1 week interval and significant correlation with a measure of self-care deficits. However, one study suggests that the cutoff point between normal cognitive functioning and mild dementia is set too high because cognitively normal persons are sometimes classified by the test as having a mild dementia (177).

Most of the other cognitive assessment instruments discussed earlier also result in numerical scores that have been used to differentiate mild, moderate, and severe dementia. Although such scores convey an impression of precise measurement, it should be remembered that selected cutoff points in this process are somewhat arbitrary, and that individuals found to have mild, moderate, or severe dementia on the basis of one test may be classified differently on the basis of another test. Any cognitive rating scale to be used for eligibility determination or in other public policy applications would require extensive validation of its cutoff scores,

public Policy Applications

Establishing Eligibility for Services

As discussed earlier, eligibility for most publicly funded long-term care services is based on medi-

cal and health care needs, with the result that some persons with dementia are ineligible for services they need. An alternative-determining eligibility on the basis of structured assessment procedures and instruments—could benefit such persons if the assessment focused on areas of disability that are common among them. The obvious choice is a measure of cognitive deficits. Yet the research cited earlier points to many problems that limit the reliability and validity of cognitive assessment procedures. These include:

- visual, hearing, and speech impairments;
- acute and chronic diseases, pain, and medications that affect cognitive abilities;
- anxiety, depression, or lack of attention that affect cognitive test performance;
- limited educational background, ethnic and cultural minority group status, and language barriers; and
- the difficulty of differentiating between cognitive deficits caused by normal aging and those caused by dementia.

These problems suggest that despite the recognized ability of individual practitioners and specialized assessment centers to correctly identify dementia, with or without the use of structured assessment procedures and instruments, no available procedure or instrument is sufficiently reliable and valid to be used alone as a basis for eligibility. This finding does not dispute the value of these procedures and instruments for research and clinical applications. Nor does it mean that cognitive measures cannot be used along with diagnosis and other measures of patient care needs to establish eligibility. However, it does indicate a need for continued research to refine and validate cognitive assessment procedures for the diverse population served by publicly funded long-term care services.

Determining Reimbursement for Services

An evaluation of the patient's cognitive status is included in the case mix formulas used to determine the level of Medicaid reimbursement for nursing home care in Illinois and West Virginia (165) but not elsewhere. New York has recently instituted a reimbursement system based on research that compared a large number of patient

descriptors (including diagnosis, prognosis, medical and skilled nursing care needs, cognitive and self-care abilities, and behavioral problems) with the amount of staff time required to care for nursing home residents with those characteristics,

Results of one phase of this research showed that differences among patients in mental status were less effective than other patient characteristics (such as self-care abilities and behavioral problems) in explaining differences in the amount of staff time spent caring for them. The cognitive measure used in this research was a judgment by the rater about the person's "mental status," with six choices for ratings: clear, minimal confusion, moderate confusion, severe confusion, comatose, or not determined (42). The research also showed that diagnoses indicating dementia, such as "senile dementia," "presenile dementia," and "Alzheimer's disease," were not helpful in explaining differences in the amount of staff time spent caring for patients (159).

In a second phase of the research in New York, other, less direct measures of cognitive status were used (see table 8-6). Together these items accounted for 12 to 15 percent of the differences in staff time required to care for residents. They were highly correlated with measures of self-care abilities, and the self-care items were more effective in explaining differences in staff time needed to care for individual residents. The cognitive items were not included in the final assessment instrument because they did not add to the accuracy of the instrument in accounting for staff time once the other factors in the assessment—primarily self-care items—were accounted for. In addition, the researchers concluded that the cognitive items were less reliable, more difficult to define, and more difficult for auditors to review than self-care items (114,158).

Since most long-term care providers agree that the care of persons with dementia is difficult and time-consuming, it is significant that the New York State research did not show a stronger and more direct relationship between cognitive status and staff time required to care for patients. One possible explanation is that the providers are incorrect. Alternatively, the measures of cognitive status that were used may not be valid indicators of the cognitive deficits that are most closely re-

**Table 8-6-items Related to Cognitive Status:
New York State Patient Assessment Instrument**

Learning ability—*Process of understanding and retaining concepts or instructions.*

1. Listens, retains, and comprehends directions or teaching instructions. Knows what to do and when.
2. Difficulties retaining or comprehending instructions. Needs clues or continuous reminding.
3. Cannot comprehend and retain instructions. Must be shown every time.
4. Cannot comprehend and retain instructions. No instructions given.
5. Cannot determine.

Motivation—*Process of stimulating one self to perform activities without external influence.*

1. High—Initiates activity, keeps appointments, willing to tolerate discomfort/pain to achieve goals.
2. Moderate—Will work toward goals but needs external support and urging.
3. Minimal—Passive, participates in activities when told or when it is required. Activities may be performed in a slow, mediocre or inaccurate fashion.
4. Poor—Resists activity, feels someone else should do everything.
5. None—Due to organic causes.
6. Cannot determine.

Resusal to care for one's self—*Physically capable but mentally unwilling to perform routine activities.*

(This is not due to physical limitations.)

1. Performs routine activities (e.g., Activities of Daily Living (ADLs)) to the extent physically capable.
2. Performs routine activities (e.g., ADLs) but not to the extent physically capable. Activities are performed incompletely or of mediocre quality.
3. Resists assistance by others in performing routine activities (e.g., ADLs), though needs assistance from others.
4. Refuses to perform routine activities (e.g., ADLs) of which physically capable. Staff must perform the activities.
5. Unable mentally to perform routine activities (e.g., ADLs), regardless of willingness.

SOURCE: New York State Department of Health and Rensselaer Polytechnic Institute, New York State Patient Assessment Instrument, Albany, NY, March 1984.

lated to care needs. Another possibility is that severity of cognitive deficits is not accurately reflected in the response categories used. Since wide variations among patients in severity of cognitive deficits are manifested in wide variations in care needs, accurate measures of severity and careful analysis of the data in terms of severity would be needed to test the view of providers that dementia patients are particularly difficult to care for. Retrospective analysis of the New York State data for OTA showed that within each category of patients defined by self-care and behavioral measures and by nursing care needs, dementia patients were more impaired and required more

care than patients who did not have dementia (37) (see also ch. 6). Further research is needed to define the cognitive deficits and severity measures that are most closely associated with care needs.

Measuring Patient Outcome for Quality Assurance Programs

Government quality assurance programs primarily affect nursing homes at present. Since all the physical conditions that complicate cognitive assessment are common among nursing home residents, using the available instruments to measure changes in residents' cognitive status as an indicator of quality of care is premature. Analysis of the relationship between cognitive status and quality of care and a better understanding of how cognitive abilities can be expected to change over time in persons with dementia are both needed before cognitive assessment instruments are used as an outcome measure in quality assurance programs.

Identifying Dementia Patients in Health Services Research

Measures of cognitive status have been used with varying degrees of success in health services research. The MMSE was used in the Epidemiologic Catchment Area (ECA) Survey in 1981 and was successfully administered to 869 of the 923 respondents; 54 respondents were not or could not be tested (40). (Questions that arose in the ECA about the validity of MMSE for elderly respondents and those with less than an eighth grade education were discussed earlier.)

The 1982 to 1984 Long-Term Care Survey, a nationally representative survey of the Medicare population over 65, also incorporated a measure of cognitive status, the Short Portable Mental Status Questionnaire. However, the SPMSQ was not administered to many of the respondents with diagnoses suggesting dementia because a proxy answered the questionnaire for them (100). As a result, information cannot be derived from the survey about the relationship between cognitive status, self-care abilities, caregiver burden, and service utilization.

Finally, the pretest for the 1985 National Nursing Home Survey included a special study of men-

tal status and mental health problems. However, the response rate for the special study was somewhat lower than for the other sections of the survey, and it was eliminated after the pretest (100). Thus, potentially valuable information about the relationship between the individual's mental status and other aspects of his or her functioning and care needs cannot be derived from the survey results. The pretest data, however, provide a source of pertinent information for the study of dementia among nursing home residents (100).

Supplementing Current Procedures

Although available cognitive assessment procedures frequently lack the accuracy needed for public policy applications, their use in conjunc-

tion with other measures would help to focus the attention of the long-term care system on the needs of persons with dementia. **Just as current procedures for establishing eligibility determining reimbursement, monitoring quality of care, and identifying patients in health services research emphasize medical and health care needs, new procedures that require assessment of cognitive status would emphasize the role of cognitive impairment in long-term care and ensure at a minimum that the cognitive deficits of patients would be identified.** That beneficial side effect is an important consideration in public policy decisions about the use of cognitive assessment procedures and instruments.

ASSESSMENT OF SELF-CARE ABILITIES

Self-care abilities include those related to personal care (such as bathing, dressing, eating, and using the toilet) commonly referred to as activities of daily living (ADLs) and abilities related to independent living, commonly referred to as instrumental activities of daily living (IADLs). IADLs include handling money, using the telephone, shopping, cleaning, and preparing meals.

Although cognitive deficits are the most basic and universal feature of dementia, it is the deterioration in patients' self-care abilities that most often necessitates long-term care. Assessment of such abilities can help to identify activities an individual needs help with and the services he or she needs. Patient response to various treatment approaches can also be monitored in terms of changes in self-care abilities (151). Since decline in self-care abilities results from cognitive loss, assessment of self-care abilities is sometimes used in research as an indicator of the severity of the cognitive loss. Finally, measures of self-care abilities are less affected by ethnic, cultural, or educational background than measures of cognitive abilities, and may therefore be a more valid indicator of an individual's condition and care needs than cognitive test performance.

Research indicates that self-care deficits are more closely correlated with institutional place-

ment than either diagnosis or the need for specific medical or skilled nursing care services (183). As a result, some experts have suggested that measures of self-care abilities should be used to determine eligibility for nursing home care. Although that approach has not yet been tried, some States are using these measures to determine level of Medicaid reimbursement for nursing home residents (as discussed later in this section).

Instruments To Measure Self-Care Abilities

Most assessment instruments to measure self-care abilities were developed for physically impaired individuals. The Index of Independence in Activities of Daily Living, the most widely used measure of ADLs, was developed for evaluation of patients with hip fractures (77). Also known as the Katz ADL Scale, it assesses six abilities: bathing, dressing, going to the toilet, transferring from bed or chair, continence, and feeding (see figure 8-1). Other ADL instruments include these personal care abilities plus others, such as grooming. Items related to mobility, such as walking, using a wheelchair, climbing stairs, and going outside, are included in some ADL scales but are considered as a distinct area of functioning in other assessment batteries (74,76).

Figure 8-1.—Index of Independence in Activities of Daily Living

Independence means without supervision, direction, or active personal assistance, except as specifically noted below. This is based on actual status and not on ability. A patient who refuses to perform a function is considered as not performing the function, even though he or she is deemed able.

Bathing (sponge, shower, or tub):

Independent: assistance in bathing a single part (as back or disabled extremity) or bathes self completely.

Dependent: assistance in bathing more than one part of body; assistance in getting in or out of tub or does not bathe self.

Dressing:

Independent: gets clothes from closets and drawers; puts on clothes, outer garments, braces; manages fasteners; act of tying shoes is excluded.

Dependent: does not dress self or remains partly undressed.

Going to toilet:

Independent: gets to toilet; gets on and off toilet; arranges clothes, cleans organs of excretion (may manage own bedpan used at night only and may or may not be using mechanical supports).

Dependent: uses bedpan or commode or receives assistance in getting to and using toilet.

Transfer:

Independent: moves in and out of bed independently and moves in and out of chair independently (may or may not be using mechanical supports).

Dependent: assistance in moving in or out of bed and/or chair; does not perform one or more transfers.

Continence:

Independent: urination and defecation entirely self-controlled.

Dependent: partial or total incontinence in urination or defecation, partial or total control by enemas, catheters, or regulated use of urinals or bedpans.

Feeding:

Independent: gets food from plate or its equivalent into mouth (precutting of meat and preparation of food, as buttering bread, are excluded from evaluation).

Dependent: assistance in act of feeding (see above); does not eat at all or parenteral feeding.

For each area of functioning listed below, check description that applies. (The word "assistance" means supervision, direction of personal assistance.)

Bathing—either sponge bath, tub bath, or shower:

<p style="text-align: center;">n</p> <p>Receives no assistance (gets in and out of tub by self if tub is usual means of bathing)</p>	<p style="text-align: center;">L]</p> <p>Receives assistance in bathing only one part of body (such as back or a leg)</p>	<p>Receives assistance in bathing more than one part of body (or not bathed)</p>
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Dressing—Gets clothes from closets and drawers—including underclothes, outer garments, and using fasteners (including braces, if worn):

<p style="text-align: center;">L]</p> <p>Gets clothes and gets completely dressed without assistance</p>	<p style="text-align: center;">L]</p> <p>Gets clothes and gets dressed without assistance except for assistance in tying shoes</p>	<p style="text-align: center;">()</p> <p>Receives assistance in getting clothes or in getting dressed, or stays partly or completely undressed.</p>
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Toileting—Going to the "toilet room" for bowel and urine elimination; cleaning self after elimination and arranging clothes:

<p style="text-align: center;">L</p> <p>Goes to "toilet room," cleans self, and arranges clothes without assistance (may use object for support, such as cane, walker, or wheelchair and may manage night bedpan or commode, emptying same in morning)</p>	<p style="text-align: center;">[1</p> <p>Receives assistance in going to "toilet room" or in cleaning self or in arranging clothes after elimination or in use of night bedpan or commode</p>	<p style="text-align: center;">[1</p> <p>Does not go to room termed "toilet" for the elimination process</p>
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Transfer:

<p style="text-align: center;">[1</p> <p>Moves in and out of bed as well as in and out of chair without assistance (may be using object for support such as cane or walker)</p>	<p style="text-align: center;">[1</p> <p>Moves in or out of bed or chair with assistance</p>	<p style="text-align: center;">[1</p> <p>Does not get out of bed</p>
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Continence:

<p style="text-align: center;">[1</p> <p>Controls urination and bowel movement completely by self</p>	<p style="text-align: center;">[1</p> <p>Has occasional "accidents"</p>	<p style="text-align: center;">[1</p> <p>Supervision helps keep urine or bowel control; catheter is used or is incontinent</p>
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Feeding:

<p style="text-align: center;">[1</p> <p>Feeds self without assistance</p>	<p style="text-align: center;">[1</p> <p>Feeds self except for getting assistance in cutting meat or buttering bread</p>	<p style="text-align: center;">[1</p> <p>Receives assistance in feeding or is fed partly or completely by using tubes or intravenous fluids</p>
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SOURCE S Katz, A.B. Ford, R.W. Moskowitz, et al., "Studies of Illness in the Aged, The Index of ADL: A Standardized Measure of Biological and Psychosocial Function," *Journal of the American Medical Association* 185:914-919, 1983.

IADL scales measure a wider range of activities. For example, the Philadelphia Geriatric Center Instrumental Activities of Daily Living Scale assesses patient ability to use the telephone, use public transportation, take medications, handle finances, prepare meals, and do housework and laundry (92). The OARS Instrumental ADL Scale measures most of these items plus shopping (30). The Performance Activities of Daily Living Scale includes telling time, signing one's name, locking the door, and turning faucets and lights on and off (90).

Although some consensus has developed about the most important ADL items to measure, there is less agreement about IADL items because of uncertainty about which activities are necessary for independent functioning (74). Since IADL items are primarily used to assess individuals who are living in the community, differences in lifestyle and living arrangements affect which test items are relevant. For persons who live alone, all the IADL items just listed maybe relevant, while those who have someone to live with may not need to perform any of them. The sex and role responsibilities of the person also affect which IADL items are relevant (74,79,92). Thus, inability to cook and shop may not be considered a serious self-care deficit for a married man because it is assumed that his wife will perform these tasks (at least among the current cohort of older Americans). Yet the same deficits are regarded as a serious problem for a married woman who has always performed these tasks for her family.

Some instruments to measure self-care abilities are designed for self-rating, but most are designed to be completed by a caregiver, such as a nurse, nurse's aide, relative, or friend. Some instruct the observer to ask the individual to perform some of the ADL functions being rated (77,79).

Reliability and Validity of ADL and IADL Instruments

At first glance, the determination of whether someone can bathe, dress, and feed himself or herself would seem to be relatively simple and straightforward. Certainly ADLs can be more easily measured than some aspects of cognitive functioning, and when ADL measures have been tested

using trained observers, standardized definitions of each item, and standardized assessment procedures, interrater reliability has been high. Interrater reliability may be higher for some ADL items than for others (122), but little research has been reported on this question. Interrater reliability is lower for IADL than ADL measures, but it is still acceptable (76)189). observers can and sometimes do disagree about how to rate a given patient on these scales for several reasons.

First, there can be disagreement about how to rate a patient who is physically capable of performing a certain activity but does not perform it. As it is the individual's actual behavior rather than latent capabilities that determines that person's need for services, researchers and clinicians generally agree that self-care ratings should be based on whether the individual does perform a certain activity rather than whether he or she is capable of it (74,157,167). That approach seems appropriate for persons with dementia because little is known on a theoretical level about how cognitive deficits affect their capabilities.

A second problem is how to rate individuals who do not have an opportunity to perform certain activities. For example, patients in hospitals and nursing homes are seldom allowed to bathe without supervision. Yet they may be quite able to bathe themselves independently at home. Reliable measurement requires agreement about how to score activities an individual has no opportunity to perform (74).

A third problem is how to rate individuals who are neither completely independent nor completely dependent in certain activities—that is, those who need some assistance or who perform activities very slowly or in an unsatisfactory manner. The Katz ADL scale offers the rater three choices for each activity—complete independence, partial dependence, or complete dependence—but in the final rating, partial and complete dependence are combined, giving a dichotomous scale (77). Other ADL instruments use rating scales that include more options for categorizing the patient, but there is disagreement about the effect on reliability of the number and type of rating points. Some researchers assert that multiple rating points increase agreement between observers

(79) and that raters can be trained to correctly use scales with up to seven points. Others disagree.

The Functional Life Scale (157) has a complex system that involves rating the individual on 44 activities on the basis of overall efficiency in performing the activity, speed, frequency, and self initiation (see figure 8-2). For each category, individuals are scored on a five-point scale, from 0 (“does not perform the activity at all”) to 4 (“normal”). This scale has been criticized for being too complex to be either reliable or useful (74). Initial testing indicated high interrater reliability for the points at each end of the scale, but lower reliability for the three intermediate points (157).

Assessment instruments with many rating points are inappropriate for certain settings because the amount of detail included is greater than the distinctions that can be made accurately. The appropriate amount of detail should be determined by the time available for assessment, the background and expertise of the raters, and the purpose for which the assessment will be used (74)186). When complex rating scales are used in nursing homes with limited staff and few professionally trained nurses to complete the assessment, reliability may suffer. In contrast, the same instruments may have high interrater and test-retest reliability in research or specialized care settings, where highly trained raters have time to carefully consider fine line distinctions between levels of self-care functioning.

The reliability of ADL and IADL instruments is also affected by raters’ biases. One study that compared ratings by patients, their nurses, and a relative or friend on three ADL and IADL scales showed that patients generally rated themselves higher than their nurses did (154). Family members and friends rated the patients lower than the nurses did, and spouses tended to rate patients lower than other relatives or friends did. The researchers suggested that patients may rate themselves high because they deny their disabilities, while family members and friends may exaggerate patients’ disabilities in order to emphasize their caregiving role and the burden of caring for the patient. Others have found that staff of an adult day care center rated patients much higher on self-care abilities than their families did (192).

Another study looked at ADL and IADL ratings of the same individuals by trained observers using an assessment questionnaire and by physicians and “health visitors” who had known the individuals over a period of time (179). The three rating sources agreed about ADL ratings in most cases but agreed less often about IADLs. Physicians’ ADL ratings tended to match the ADL ratings based on the questionnaire, while health visitors’ IADL ratings agreed more often with the IADL ratings based on the questionnaire. These findings suggest that self-care ratings derived from different sources may not be directly comparable (79,154).

Validity of ADL and IADL instruments has been evaluated by comparing findings from different tests or by comparing findings with patient outcome or clinical judgment (74). In general, however, ADL instruments have been assumed to be valid—that is, a rating of an individual’s ability to get dressed is assumed to be a valid indicator of his or her ability to get dressed, and ability to dress oneself is assumed to be an essential aspect of independent functioning. Thus, the rating of ability to dress oneself is assumed to be a valid indicator of self-care ability. IADL items are also assumed to be valid measures of the activities they measure, but their validity as indicators of self-care ability is less certain because of the difficulty of determining which IADL items are relevant for various individuals.

More importantly in the context of this OTA report, ADL and IADL instruments are assumed to be valid indicators of self-care abilities for cognitively impaired people even though most such instruments were developed to measure self-care abilities in physically impaired people. There has been little analysis or formal testing of reliability and validity of these instruments for people with dementia, thus raising several theoretical and practical questions about their use with these individuals,

- **How do fluctuations in self-care abilities of persons with dementia affect the reliability and validity of self-care measures?**

For reasons that are only partially understood, fluctuations in self-care abilities are quite common in people with dementia and may be more

Figure 8-2.— The Functional Life Scale

	Not applicable	Self-initiation	Frequency	Speed	Overall efficiency	Total
Cognition:						
1. Is oriented for time (e.g., hour, day, week)						
2. Uses "yes" and "no" appropriately						
3. Understands speech (e.g., simple commands, directions, television)						
4. Calculates change (money)						
5. Does higher calculation (balance checkbook, etc.)						
6. Uses appropriate gestures in lieu of speech (not applicable for patients without speech impairment)						
7. Uses speech for communication						
8. Reads (e.g., street signs, ability to follow written instructions, books)						
9. Writes (e.g., signs name, writes or types letters) (include motor disability)						
10. Social behavior is appropriate						
11. Able to shift from one task to another with relative ease and speed						
12. Aware of self (e.g., of mistakes, inappropriate behavior, poor judgment, etc.)						
13. Attempts to correct own errors (e.g., of judgment, mistakes)						
14. Has good memory (e.g., names of people, recent events)						
Activities of daily living:						
15. Able to get about (with or without brace, wheelchair, etc.)						
16. Does transfers						
17. Feeds self						
18. Uses toilet						
19. Grooms self (e.g., wash, brush teeth, shave)						
20. Dresses self						
21. Bathes self (including getting in and out of tub or stall)						
Home activities:						
22. Prepares simple food or drink (e.g., snacks, light breakfast)						
23. Performs light housekeeping chores (e.g., meals, dishes, dusting)						
24. Performs heavy housekeeping chores (e.g., floor or window washing)						
25. Performs odd jobs in or around house (e.g., gardening, electrical, auto, mending, sewing)						
26. Engages in solo pleasure activities (e.g., puzzles, painting, reading, stamps)						
27. Uses telephone (e.g., dialing, handling. Do not rate speech proficiency)						
28. Uses television set (e.g., changing channel)						
29. Uses record player or tape recorder						
Outside activities:						
30. Engages in simple pleasure activities (e.g., walk, car rides)						
31. Goes shopping for food						
32. Does general shopping (e.g., clothes, gifts)						
33. Performs errands (e.g., post-office, cleaner, bank, pick up newspaper)						
34. Attends spectator events (e.g., theatre, concert, sports, movies)						
35. Uses public transportation accompanied (mass transportation)						
36. Uses public transportation alone (rate NA if item 35 is 0)						
37. Takes longer trips accompanied (plane, train, boat, car)						
38. Takes longer trips alone (rate NA if item 37 is 0)						
Social interaction:						
39. Participates in games with other people (e.g., cards, chess, checkers)						
40. Participates in home social activities (e.g., family gathering, party, dancing)						
41. Attends social functions outside of home (e.g., home of friend, dining at restaurant, dance)						
42. Participates in organizational activities (e.g., religious, union, service club, professional)						
43. Goes to work or school at comparable premorbid level (not housekeeping at home) (Do not rate if item 44 is to be rated)						
44. Goes to work or school at lower than premorbid level (Do not rate if item 43 has been rated) (Multiply item 43 or 44 by 2)						

SOURCE: J.E. Sarno, M.T. Sarno, and E. Levita, "The Functional Life Scale," *Archives of Physical Medicine and Rehabilitation* 54:214-220, 1973.

frequent and more extreme than in people with physical impairments. For example, some Alzheimer patients become more confused and agitated in the late afternoon, probably as a result of fatigue and the cumulative impact of overstimulation throughout the day. Self-care abilities may be markedly reduced at this time (called the “sundowning” period) than in the morning when they are well rested. Extreme fluctuations also occur at night, when persons with dementia frequently become much more confused. For example, some persons with dementia who are continent in the day become incontinent at night.

Because of fluctuations in self-care abilities, assessments for one individual completed by day, evening, and night staff in nursing homes can look like they observed three different people. Although some of these differences may reflect the way patients are handled by the three shifts and differences in opportunity (e.g., at night patients who need to go to the bathroom may be unable to get assistance or to get out of bed over the bed rails), others indicate real changes in self-care abilities. On a theoretical level, research is needed on how fluctuations in self-care abilities are related to cognitive deficits. On a practical level, research is needed to determine how fluctuations in self-care abilities affect the reliability and validity of ADL and IADL measures for persons with dementia.

•How does environment affect the reliability and validity of ADL and IADL measures for persons with dementia?

For physically impaired people, self-care abilities primarily depend on individual characteristics that remain constant from one setting to another, although the availability of assistive devices and the lack of environmental barriers affect self-care functioning to some extent. For persons with dementia, however, environment *seems* to affect self-care abilities in a more pervasive and fundamental way. Anecdotal evidence suggests that persons with dementia test better at home (101). They become more confused in an unfamiliar setting, and therefore less able to perform ADLs and IADLs. Yet little is known about the aspects of setting that are most important. Better understanding of the relationship between self-

care abilities and setting is a necessary prerequisite for evaluating the validity of ADL and IADL measures for these patients.

•Do ADL and IADL instruments measure the aspects of independent functioning that are most often affected in dementia?

The activities usually included in ADL and IADL instruments and the rating choices provided may not encompass the aspects of functioning that are most often affected in dementia. For example, while persons with physical impairments that cause weakness or restrict movement can be relatively easily rated as independent, partially dependent, or completely dependent in dressing, persons with dementia are more difficult to rate because they are often physically capable of getting dressed but lack judgment about when to do so and what to put on. Similarly, dependence in eating is easier to assess for physically impaired persons who cannot feed themselves due to weakness or limitations in use of their arms and hands than for those with dementia who sometimes feed themselves independently but other times wander away from the table without eating, take food off the trays of other patients, or attempt to eat things that are not edible.

When ADL and IADL instruments are used to project care needs, the differences between self-care deficits of the physically impaired and dementia patients become evident. For example, physically impaired individuals may be unable to shop because of weakness, poor vision, inability to walk, or inability to carry their purchases; they need someone to shop for them. In contrast, persons with dementia may be unable to shop because they cannot find the store or remember what to buy, but they can remember that it is necessary to shop; thus, they need someone to shop for them and someone to stop them from wandering off to “go shopping.” **The tendency of a person with dementia to try to perform certain activities he or she is no longer capable of performing safely or effectively is not included on most ADL or IADL instruments. Yet it is an important aspect of the individual’s functioning and has important implications for the kind of care the person needs.** In fact, that tendency often results in the need for 24-

hour supervision—a need that distinguishes persons with dementia from many physically impaired people.

To the extent that ADL and IADL instruments do not measure aspects of functioning that are often affected in dementia, they lack validity for these individuals. ADL and IADL instruments designed specifically for persons with dementia include two sections of the Dementia Scale (9) and the Functional Activities Questionnaire (126) (see tables 8-7 and 8-8). Both instruments use items that are particularly relevant for individuals with

Table 8-7.—Dementia Scale

Changes in performance of everyday activities

1. Inability to perform household tasks
2. Inability to cope with small sums of money
3. Inability to remember short list of items, e.g., in shopping
4. Inability to find way about indoors
5. Inability to find way about familiar streets
6. Inability to interpret surrounds (e.g., to recognize whether in hospital, or at home, to discriminate between patients, doctors and nurses, relatives and hospital staff, etc.)
7. Inability to recall events (e.g. recent outings, visits of relatives or friends to hospital, etc.)
8. Tendency to dwell in past

Changes in habits

9. Eating:
 - Cleanly with proper utensils
 - Messily with spoon only
 - Simple solids, e.g., biscuits
 - Has to be fed
10. Dressing:
 - Unaided
 - Occasionally misplaced buttons, etc.
 - Wrong sequence, commonly forgetting items
 - Unable to dress
11. Complete sphincter control
 - Occasional wet beds
 - Frequent wet beds
 - Doubly incontinent

Changes in personality, interests, drive

- No change
- 12. Increased rigidity
- 13. Increased egocentricity
- 14. Impairment of regard for feelings of others
- 15. Coarsening of affect
- 16. Impairment of emotional control, e.g. increased petulance and irritability
- 17. Hilarity in inappropriate situations
- 18. Diminished emotional responsiveness
- 19. Sexual misdemeanor (appearing *de novo* in old age)
- Interests retained
- 20. Hobbies relinquished
- 21. Diminished initiative or growing apathy
- 22. Purposeless hyperactivity

SOURCE: G. Blessed, B.E. Tomlinson, and M. Roth, "The Associations Between Quantitative Measures of Dementia and of Senile Change in the Cerebral Grey Matter of Elderly Subjects," *British Journal of Psychiatry* 114:797-811, 1988.

Table 8-8.—Functional Activities Questionnaire

Writing checks, paying bills, balancing checkbook
 Assembling tax records, business affairs, or papers
 Shopping alone for clothes, household necessities, and groceries
 Playing a game of skill, working on a hobby
 Heat water, make a cup of coffee, turn off stove
 Prepare a balanced meal
 Keep track of current events
 Pay attention to, understand, discuss TV, book, magazine
 Remember appointments, family occasions, holidays, medications
 Travel out of neighborhood, driving, arranging to take buses

SOURCE: R.1. Pfeffer, T.T. Kurosaki, C.H. Harrah, et al., "Measurement of Functional Activities in Older Adults in the Community," *Journal of Gerontology* 37:323-329, 1982.

dementia—for example, self-care items defined in terms of memory and attention deficits that are characteristic of dementia patients.

The ability to give and receive information and to interact verbally with others is an important aspect of independent functioning. One study found, for instance, that receptive and expressive communication were highly correlated with the amount of staff time required to care for nursing home residents (42). Language difficulties are common in persons with dementia. Yet ability to communicate is not part of most commonly used ADL instruments (76).

In many research and clinical settings, assessments are conducted by health care professionals trained to notice and evaluate communication problems. For public policy purposes, however, assessment instruments may be used by individuals who are not trained to assess communication problems. If communication difficulties are not incorporated into the assessment instrument, deficits relevant to an individual's safety and ability to function independently will not be noted.

• What effect does the medical care emphasis in many agencies and facilities that serve individuals with dementia have on the validity of self-care assessment?

Medicare and Medicaid regulations focus on medical and physical care needs, and facilities and agencies that serve Medicare and Medicaid patients tend to adopt this focus—to provide primarily physical care, to perceive their patients as needing medical and physical care, and to use assessment procedures and instruments that

measure medical and physical care needs. Within this context, it may be difficult for nurses and nurse's aides, who are often responsible for assessment in long-term care agencies and facilities, to recognize other characteristics and care needs of dementia patients. This is especially true since the background and training of nurses and nurse's aides are usually in physical care. Moreover, when the assessment instrument that is used includes only two rating choices, dependent and independent, nurses and nurse's aides may have difficulty rating as dependent both a person with dementia who is physically able to bathe, dress, or feed himself or herself but needs supervision and reminders and a person with terminal cancer who is often too weak to bathe or get dressed.

Public Policy Applications

Establishing Eligibility for Services

Use of self-care measures to determine eligibility for federally funded health care and social services would increase access for persons with dementia because they frequently have self-care deficits but often do not have the medical and health-related needs currently used to establish eligibility. Clearly, the specific self-care items chosen as eligibility criteria would affect the number of such persons who would be eligible. Other variables that would affect which individuals would be eligible include the training given to staff members who perform the self-care ratings and administrative decisions about how to rate fluctuations in patient abilities at different times and in different settings and about how to define the selected self-care items.

Using self-care measures to determine eligibility would also make services available to many people without dementia who have other physical, emotional, and psychiatric conditions that cause self-care deficits. The public cost of services for these individuals would be considerably higher than that for dementia patients alone, and some people may oppose using self-care measures to determine eligibility for this reason.

Determining Reimbursement for Services

Several States include self-care measures in the case mix formulas they use to determine Medicaid reimbursement for nursing home care. Since 1983, for example, Maryland has used an assessment instrument that measures five ADLs (mobility, bathing, dressing, continence, and eating) to determine reimbursement levels. New York State uses four ADLs (eating, mobility, transfer, and toileting) in addition to other items concerned with medical care needs and patient behavior (32).

The impact on persons with dementia of using ADL items in case mix formulas depends partly on the relative reimbursement provided for groups with high ADL needs compared with other patient groups. It also depends on the specific ADL items and rating choices included. The Maryland system requires a rating of either independent or dependent on each item, so the problems in rating persons with dementia as completely independent or dependent apply to this system. The New York system offers rating choices that more adequately describe the problems dementia patients have with ADL functions (see table 8-9).

Measuring Patient Outcome for Quality Assurance Programs

Measures of self-care abilities provide a patient-oriented index of quality of care to replace the facility- and resource-oriented standards that have been used. However, validation of these measures for dementia patients is needed.

Relationship Between Cognitive Deficits and Self-Care Abilities

Cognitive loss associated with dementia is known to lessen self-care abilities, but little is known about the specific relationship between the two [13,63, 178]. It is often assumed that the cognitive deficits measured by commonly used assessment instruments are directly related to self-care deficits. Yet researchers and clinicians report that

Table 8-9.—Activities for Daily Living (ADLs) from the New York State Patient Review Instrument

Eating: process of getting food by any means from the receptacle into the body (for example, plate, cup, tube).	
1. Feeds self without supervisions or physical assistance. May use adaptive equipment.	3. Requires continual help (encouragement/teaching/physical assistance) with eating or meal will not be completed.
2. Requires <i>intermittent</i> supervision (i.e., verbal encouragement/guidance) and/or minimal physical assistance with minor parts of eating, such as cutting food, buttering bread or opening milk carton.	4. Totally fed by hand; patient does not manually participate. (Include syringe feeding.)
	5. Tube or parenteral feeding for primary intake of food. (Not just for supplemental nourishments.)
Mobility: how the patient moves about.	
1. Walks with no supervision or human assistance. May require mechanical device (e.g., a walker), but not a wheelchair.	4. Wheels with <i>no</i> supervision or assistance, except for difficult maneuvers (e.g., elevators, ramps). May actually be able to walk, but generally does not move.
2. Walks with intermittent supervision (that is, verbal cueing and observation). May require human assistance for difficult parts of walking (e.g., stairs, ramps).	5. Is <i>wheeled</i> , chairfast or bedfast. Relies on someone else to move about, if at all.
3. Walks with <i>constant</i> one-to-one supervision and/or constant physical assistance.	
Transfer: process of moving between positions, to/from bed, chair, standing, (exclude transfers to/from bath and toilet).	
1. Requires not supervision or physical assistance to complete necessary transfers. May use equipment, such as railings, trapeze.	4. Requires <i>two</i> people to provide constant supervision and/or physically lift. May need lifting equipment.
2. Requires <i>intermittent</i> supervision (i.e., verbal cueing, guidance) and/or physical assistance for difficult maneuvers only.	5. Cannot and is not gotten out of bed.
3. Requires <i>one</i> person to provide constant guidance, steadiness and/or physical assistance. Patient participates in transfer.	
Toileting: process of getting to and from a toilet (or use of other toileting equipment, e.g., bedpan), transferring on and off toilet, cleansing self after elimination, and adjusting clothes.	
1. Requires no supervision or physical assistance. May require special equipment, such as a raised toilet or grab bars.	4. Incontinent of bowel <i>and/or</i> bladder and is not taken to a toilet.
2. Requires <i>intermittent</i> supervision for safety or encouragement; <i>or minor</i> physical assistance (e.g., clothes adjustment or washing hands).	5. Incontinent of bowel <i>and/or</i> bladder, but is taken to a toilet every 2 to 4 hours during the day and as needed at night.
3. Continent of bowel <i>and</i> bladder. Requires constant supervision and/or physical assistance with major or all parts of the task or task will not be completed.	

SOURCE: D. El-Aini, D. Schneider, and M. Desmond, *The New York State Patient Review Instrument* (Albany, NY: New York State Department of Health, 1985).

some patients who do poorly on cognitive tests are nevertheless able to function independently (46)181,189,191).

The correlations between individual scores on cognitive and self-care measures are far from perfect (12,31,192,194). For example, one researcher compared the scores of nursing home residents on the Short Portable Mental Status Questionnaire (SPMSQ) and on three self-care items—dressing, eating, and ambulation (191). Not surprisingly, among patients with normal or only slightly impaired cognitive abilities, none had impaired self-care abilities due to cognitive impairment.

Among those with moderate or severe cognitive impairment, however, half were completely independent in self-care abilities or required assis-

tance only because of physical impairments, while another one-third of the subjects required assistance only with dressing. Thus, most individuals who scored low on the measure of cognitive abilities were able to care for themselves, and the statistical correlation between the SPMSQ and self-care abilities was small (37). A stronger correlation (47) was found between the results of a semi-structured clinical evaluation of the person and the assessment of self-care abilities. The researcher concluded that some aspects of functioning evaluated in the clinical interview, such as ability to respond sensibly to questions, may be more directly related to self-care abilities than the cognitive functions assessed by the SPMSQ.

Others assessed persons with Alzheimer's disease living in the community by using items from

the Mini-Mental State Exam and the Dementia Rating Scale to measure five cognitive abilities: attention, calculations, recognition memory, recall, and orientation. ADLs and IADLs were also measured. The results indicated that measures of attention and the ability to recognize a design were associated with ability to perform ADLs, while other test items, such as ability to follow a three-step command, orientation to time, math score, and design recognition, were related to ability to perform IADLs (178).

These findings suggest that at least some commonly used cognitive test items may not be directly related to ability to function independently. In some cases, the test item may not be a valid indicator of the cognitive ability it is intended to measure (124,198). In other cases, the cognitive ability measured may be irrelevant to self-care abilities. Although assessment of such cognitive abilities may be valuable for research and clinical applications, it is less helpful in determining a person's need for long-term care or establishing eligibility for services. Further research on the relationship between cognitive and self-care abilities could identify measures of cognitive function that are closely correlated with the need for services.

Many researchers and clinicians have suggested that some persons with dementia have areas of

cognitive functioning that are relatively unaffected by the illness or have personality characteristics that should be seen as strengths in assessing the person's overall functioning (22,63,75,191). These patient strengths may explain some of the lack of correlation between cognitive and self-care deficits. Methods of measuring patient strengths have not received much attention, and research is needed on this issue.

Because of the apparent complexity of the relationship between cognitive and self-care deficits, measures of self-care abilities maybe more reliable and valid than even the best cognitive measures for public policy applications such as establishing eligibility and determining reimbursement for long-term care services. Still, many persons with self-care deficits do not have cognitive impairment. Thus measures of self-care abilities are clearly not valid indicators of cognitive status. Likewise, they are inadequate for planning clinical and long-term care for persons with and without cognitive impairment. For these purposes, knowledge of the individual's cognitive status and the relationship between his or her cognitive abilities and self-care deficits is essential.

ASSESSMENT OF BEHAVIOR

Behavioral problems of persons with dementia can include wandering and getting lost; agitation; pacing; emotional outbursts; suspiciousness and angry accusations; physical aggression; combativeness; cursing; socially unacceptable sexual behavior; chronic screaming or noisiness; repetition of meaningless words, phrases, or actions; withdrawal and apathy; hoarding; and sleep disruption that results in nighttime wakefulness (see ch. 2). Obviously, not all persons with dementia exhibit these behaviors, but many go through stages in which they exhibit some of them.

Some researchers and clinicians refer to some of these problem behaviors as "mood disturbances." Although that term may accurately describe the problems from the patient's point of

view, the focus here is on behaviors that are problems for caregivers. "Mood disturbances" are therefore included only when they are manifested as behaviors that affect caregivers.

Cognitive deficits are the most basic and universal effects of dementia, and impaired self-care abilities usually cause the need for informal and formal long-term care services, but behavioral problems are often the most burdensome aspect of dementia for caregivers (see ch. 4). For family members and other caregivers, these behaviors can cause anxiety, embarrassment, fear, anger, exhaustion, and in some cases the decision to place the patient in a nursing home. In nursing homes, the same behaviors upset other residents and are disruptive and time-consuming for staff.

Some behavioral problems of persons with dementia are treatable even if the underlying disease is not (8)61,64)134). Yet in many settings these problems are not systematically identified. One study of nursing homes in upstate New York found that 23 percent of all residents had behavioral problems that were considered serious by the researchers (see table 8-10) (199). Attending physicians for these residents had noted problem behaviors in fewer than 10 percent of the cases. Nurses were much more likely to have documented the problems in the resident's chart. Since such problems are often treatable, methodical and thorough procedures for identifying them are essential for good patient care.

Table 8.10.—Serious Behavioral Problems Among Nursing Home Residents

Types of problem behaviors	Percent exhibiting the behavior
Endangering others:	
Physically aggressive (deliberate striking, biting, etc.)	8.3
Indirectly endangering (unfastening others' restraints, dangerous smoking habits, etc.)	0.4
Endangering self:	
Physical self-abuse (scratching, banging head, removing catheter, etc.)	4.3
Dangerous ambulation (into unsafe areas, escaping restraints, etc.)	5.4
Physically resistive to care (spitting out medication, refusing to eat, etc.)	11.4
Other possibly endangering (verbal suicidal expression, severe agitation, etc.)	4.2
Disturbing to others:	
Verbally (noisy, abusive, etc.)	12.6
Inappropriate ambulation (into others' rooms, beds, etc.)	3.8
Physically disruptive (throwing food and objects, lying on floor, etc.)	2.5
Taking others' belongings and food	1.1
Inappropriate urination/defecation (urinating in waste baskets, smearing feces, etc.)	1.0
Sexually disturbing (exposing self, masturbating publicly, etc.)	0.4
Other bothersome behaviors	1.6
Nonendangering or disturbing to others but of concern to staff:	
Reclusive (refusing to leave room, socialize, etc.)	5.0
Hoarding (food, clothes, etc.)	0.6
Other	2.8

SOURCE: Adapted from J.G. Zimmer, N. Watson, and A. Treat, "Behavioral Problems Among Patients in Skilled Nursing Facilities," *American Journal of Public Health* 74:1 118-1121, 1984.

Instruments To Measure Behavioral Problems

All assessment instruments that measure behavioral problems of persons with dementia are based on ratings by caregivers. Dementia rating scales are designed to measure the severity of dementia, and many of these instruments include some questions about patient behavior. For example, the Dementia Scale (9) includes questions about impairment of emotional control, diminished initiative, and purposeless hyperactivity. Other rating scales that assess patient behavior are the Alzheimer's Disease Assessment Scale (145), the Global Deterioration Scale (141), the Haycox Behavioral Scale (62), and the Clinical Dementia Rating Scale (69). Although these are useful in identifying some behavioral problems, none includes the full range of behavioral problems common among persons with dementia.

Assessment instruments developed for use by nurses and aides in evaluating psychiatric patients are sometimes used to assess behavior in persons with dementia. Examples are the Psychogeriatric Dependency Rating Scale (PGDRS) (186) (see figure 8-3); the Nurses' Observation Scale for Inpatient Evaluation (NOSIE) (68,164), and the Physical and Mental Impairment of Function Evaluation (PAMIE) (55). The Sandoz Clinical Assessment Geriatric Scale (SCAG) (161) and the Brief Psychiatric Rating Scale (BPRS) (121) were designed to measure treatment effects, including response to drug treatments. Although all these instruments include many of the behavioral problems seen in dementia patients, they were developed for psychiatric patients and do not include all the problem behaviors common among persons with dementing illnesses.

One behavioral instrument designed specifically for dementia patients living in the community (54) is illustrated in table 8-11. Relatives are asked to rate the frequency and severity of each item on a five-point scale. A companion instrument measures the impact on the caregiver of the patient's behavioral and mood disturbances (see table 8-12). One study that used these instruments found that passive and withdrawn behavior was much more distressing to caregivers than cognitive deficits, self-care deficits, or actively disturbed behavior

Figure 8-3.—Behavior Scale: Psychogeriatric Dependency Rating Scale

N	O	F	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Disruptive
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Manipulating
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Wandering
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Socially objectionable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Demanding interaction
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Communication difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Noisy
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Active aggression
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Passive aggression
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Verbal aggression
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Restless
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Destructive (self)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Destructive (property)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Affect—elated
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Delusions/hallucinations
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Speech content

N = Never
 O = Occasionally = 2 to 5 days or less
 F = Frequently = 3 to 5 days or more

SOURCE: I. A. Wilkinson and J. Graham-White, "Psychogeriatric Dependency Rating Scales (PGDRS): A Method of Assessment for Use by Nurses," *British Journal of Psychiatry* 137:558-565, 1960

(54). Another assessment instrument includes 52 questions about patient behaviors and problems the family experiences in caring for the individual (134). Researchers using this instrument found that violent behaviors, memory disturbance, and incontinence were the most disturbing behaviors for family caregivers. Using a third behavioral instrument, researchers found that no cognitive, self-care, or behavioral variables were related to the caregiver's perception of burden (197). Analysis of the differences among the three assessment instruments could explain these divergent findings and indicate changes that are needed in the behavioral measures.

Reliability and Validity of Behavioral Measures

Since most of the instruments described here include questions about a variety of patient characteristics, reliability and validity figures for the instruments as a whole do not provide information about the reliability and validity of the behavioral items. Several studies indicate, however, that reliability is lower for behavioral than for self-care items (122, 145,186). One reason is that the terms used for behavioral problems have different meanings for different people. A second reason is that behavior is profoundly affected by

Table 8-11.—Behavioral and Mood Disturbance Scale

1. Does not take part in family conversations
2. Does not read newspapers, magazines, etc.
3. Sits around doing nothing
4. Does not show an interest in news about friends and relations
5. Does not start and maintain a sensible conversation
6. Does not respond sensibly when spoken to
7. Does not understand what is said to him/her
8. Does not watch and follow television
9. Does not keep him/herself busy doing useful things
10. Fails to recognize familiar people
11. Gets mixed up about where he/she is
12. Gets mixed up about the day, year, etc.
13. Has to be prevented from wandering outside the house
14. Hoards useless things
15. Talks nonsense
16. Appears restless and agitated
17. Gets lost in the house
18. Wanders outside the house at night
19. Wanders outside the house and gets lost
20. Endangers him/herself
21. Paces up and down wringing his/her hands
22. Wanders off the subject
23. Talks aloud to him/herself
24. Seems lost in a world of his/her own
25. Mood changes for no apparent reason
26. Becomes irritable and easily upset
27. Goes on and on about certain things
28. Accuses people of things
29. Becomes angry and threatening
30. Appears unhappy and depressed
31. Talks all the time
32. Cries for no obvious reason
33. Looks frightened and anxious
34. Gets up unusually early in the morning

SOURCE: J. G. Greene, R. Smith, M. Gardiner, et al., "Measuring Behavioural Disturbance of Elderly Demented Patients in the Community and Its Effects on Relatives: A Factor Analytic Study," *Age and Aging* 11(2): 121-126, 1982

Table 8-12.—Relatives' Stress Scale

1. Do you ever feel you can no longer cope with the situation?
2. Do you ever feel that you need a break?
3. Do you ever get depressed by the situation?
4. Has your own health suffered at all?
5. Do you worry about accidents happening to?
6. Do you ever feel that there will be no end to the problem?
7. Do you find it difficult to get away on holiday?
8. How much has your social life been affected?
9. How much has the household routine been upset?
10. Is your sleep interrupted by?
11. Has your standard of living been reduced?
12. Do you ever feel embarrassed by?
13. Are you at all prevented from having visitors?
14. Do you ever get cross and angry with?
15. Do you ever feel frustrated at times with?

SOURCE: J. G. Greene, R. Smith, M. Gardiner, et al., "Measuring Behavioral Disturbance of Elderly Demented Patients in the Community and Its Effects on Relatives: A Factor Analytic Study," *Age and Aging* 11(2): 121-126, 1982.

many factors, including the person's physical condition, the time of day, the presence of different staff and family caregivers, and environmental factors such as noise and commotion. The fact that patient behavior changes in response to all these factors reinforces the importance of identifying problem behaviors; it also means that test-retest reliability ratings may be low.

Public Policy Applications

Although it is clear that assessment of problem behaviors is essential for good patient care, it is unclear whether behavioral measures are appropriate for public policy applications. At present, these measures are not being used for eligibility determination, but they are included in some case mix formulas to determine the level of Medicaid reimbursement for nursing home residents. Behavioral items are used, for example, in the New York State assessment instrument (see table 8-13).

In contrast, the assessment instrument used in Maryland does not include behavioral problems. Nursing home administrators in that State have argued that behavioral problems should be assessed and that reimbursement should be higher for residents with behavioral problems because these individuals require significantly more staff time than other residents. A study to evaluate these assertions found that behavioral problems, such as wandering and abusive, disruptive, and inappropriate behavior, do significantly increase the amount of staff time needed to care for these residents. However, no change was made in the assessment instrument or the reimbursement system. The State argued that residents with and without behavioral problems had been included in the original research that measured staff time requirements, so that the reimbursement level derived from that research covers the cost of caring for all residents (1).

In response, Maryland nursing home administrators have pointed out that the current reim-

Table 8-13.—Behaviors: New York State Patient Review Instrument

Verbal disruption: by yelling, baiting, threatening, etc.	
1. None during the past 4 weeks. (May have verbal outbursts which are not disruptive.)	4. Unpredictable, recurring verbal disruption <i>at least once per week</i> for no foretold reason.
2. Verbal disruption one to three times during the past 4 weeks.	5. Patient is at level #4 above, but does not fulfill the active treatment and psychiatric assessment qualifiers (in the instructions).
3. Short-lived disruption at least once per week during the past 4 weeks or <i>predictable</i> disruption regardless of frequency (e.g., during specific care routines, such as bathing).	
Physical aggression: assertive or combative to self or others with intent for injury . (For example, hits self, throws objects, punches, dangerous maneuvers with wheelchair).	
1. None during the past 4 weeks.	4. Unpredictable, recurring aggression at least once per week during the past 4 weeks for no apparent or foretold reason (i.e., not just during specific care routines or as a reaction to normal stimuli).
2. Unpredictable aggression during the past 4 weeks (whether mild or extreme), <i>but not at least once per week</i> .	5. Patient is at level #4 above, but does not fulfill the active treatment and psychiatric assessment qualifiers (in the instructions).
3. Predictable aggression during specific care routines or as a reaction to normal stimuli (e.g., bumped into), regardless of frequency. May strike or fight.	
Disruptive, infantile or socially inappropriate behavior: childish, repetitive or antisocial physical behavior which creates <i>disruption with others</i> (e.g., constantly undressing self, stealing, smearing feces, sexually displaying oneself to others), exclude verbal actions. Read the instructions for other exclusions.	
1. No infantile or socially inappropriate behavior, whether or not disruptive, during the past 4 weeks.	4. Disruptive behavior at least <i>once per week</i> during the past 4 weeks.
2. Displays this behavior, but is not disruptive to others (e.g., rocking in place).	5. Patients is at level #4 above, but does not fulfill the active treatment and psychiatric assessment qualifiers (in instructions).
3. Disruptive behavior during the past 4 weeks, but <i>not</i> at least once per week.	
Hallucinations: experienced at least once per week during the past 4 weeks, visual, auditory or tactile perceptions that have no basis in external reality.	
1. Yes	3. Yes, but does not fulfill the active treatment and psychiatric assessment qualifiers (in the instructions).
2. No	

SOURCE: D El-Ani, D. Schneider, and M. Desmond, *The New York State Patient Review Instrument* (Albany, NY: New York State Department of Health, 1985).

bursement level is fair only if the mix of patients with and without behavioral problems is the same in all nursing homes and at all times, which it clearly is not. Consultants hired by the State have suggested that nursing homes should be reimbursed separately for programs and services designed to resolve behavior problems. The consultants remain convinced, however, that behavioral problems are too changeable to be used to determine level of reimbursement (1).

The use of behavioral measures for quality assurance programs is also problematic. The prevalence of behavioral problems and an unexpected deterioration in patient behavior may be useful indicators of quality of care. However, questions about the reliability and validity of behavioral measures and the lack of well-documented information about the relationship between treatment methods and patient behavior limits the current utility of this approach.

Relationship Between Cognitive Deficits and Behavioral problems

Although many persons with dementia exhibit behavioral problems at times during the course of their illness, some may never exhibit such problems. Conversely, many people with behavioral problems do not have dementia. Data from the Epidemiologic Catchment Area (ECA) survey in

Baltimore show that persons with dementia make up about 9 percent of the population over 65, but they account for 15 percent of persons over 65 with behavioral disorders. Thus, persons with dementia are more likely to have behavioral disorders than those without dementia. At the same time, among all persons with dementia aged 65 to 74, one-fourth had no behavioral disorders. Among persons with dementia aged 75 to 84, more than a third had no behavioral problems. Finally, among persons with dementia who were over 85, about one-fifth had no behavioral problems. Conversely, almost one-fifth of persons who were not demented had behavioral problems (136).

These findings indicate that the relationship between cognitive deficits and behavioral problems is neither simple nor straightforward. In retrospective analysis of data from studies that did not collect information about the cognitive abilities of subjects, some analysts have used findings about behavioral problems along with other indices, such as self-care deficits, to try to identify subjects with probable dementia. In fact, several OTA contractors have used this procedure, which, while necessary for analyzing studies that did not include a measure of cognitive abilities, is far from ideal. Assessment of behavioral problems is clearly not a valid substitute for cognitive assessment for most purposes. Such studies in the future should include a measure of cognitive abilities.

MULTIDIMENSIONAL ASSESSMENT INSTRUMENTS

Multidimensional assessment instruments focus on some or all of the following: diagnosis, physical condition, cognitive status, self-care abilities, emotional and behavioral characteristics, family and social supports, financial status, and health and social service utilization patterns. Thus, they combine many of the elements of assessment instruments already discussed in this chapter.

Some multidimensional instruments are designed for evaluation of all elderly individuals. Others are designed specifically for persons with dementia and are referred to as dementia rating scales. Assessments using multidimensional instruments are recommended for elderly individuals because the physical, mental, emotional, and so-

cial aspects of their functioning are closely related, and information gathered about one area is frequently relevant to others as well (48,59,74,120). For persons with dementia, these instruments are valuable because dementia is manifested differently in each area of functioning in different individuals (29), and treatment planning requires evaluation of all aspects of functioning.

General Multidimensional Instruments

Many multidimensional assessment instruments have been developed for general use with elderly individuals. Each of the four described here has

been used in research and, to a lesser extent, for clinical purposes and long-term care planning.

The Older American's Research and Service Center Instrument (OARS) (30) is a 105-item questionnaire that assesses physical and mental health, self-care abilities, social and financial resources, and patterns of formal and informal service utilization. No measure of behavioral problems is included. The Short Portable Mental Status Questionnaire is used to measure cognitive status. Once the questionnaire has been completed, a trained interviewer rates the individual based on the questionnaire results (74). These ratings are potentially unreliable because they involve raters' subjective judgments, and a computerized rating procedure has been developed to replace them for some applications (48).

The Functional Assessment Inventory (FAI) (128) is a shortened version of OARS that takes about 30 minutes to complete, compared with about an hour for OARS. Like OARS, FAI uses the SPMSQ to assess cognitive status and also measures physical and mental health, self-care abilities, social and financial resources, and service utilization. A trained interviewer rates the subject based on responses to the questionnaire. FAI has fewer response categories for each item than OARS and a somewhat different coding scheme (17,128).

The Comprehensive Assessment and Referral Evaluation (CARE) (58) is a lengthy multidimensional instrument developed to compare health and social problems of community dwelling elderly in New York and London (see table 8-14 for the topic areas covered). The Mental Status Questionnaire and Face-Hand Test are used along with other items to evaluate cognitive status, and some items from OARS are also included. As with OARS and FAI, the subject is rated by the interviewer based on responses to the questionnaire. While CARE evaluates many of the same patient characteristics as OARS and FAI, it has a stronger emphasis on assessment of medical and psychiatric problems (59).

SHORTCARE is an abbreviated version of CARE that includes 143 items to assess dementia, depression, subjective memory impairment, sleep

Table 8-14.—Topic Areas in the Comprehensive Assessment and Referral Evaluation (CARE)

Identifying data/Dementia 1:	census type data/country of origin/race/length of time spoken English
Dementia II:	Error in length of residence/telephone number General enquiries about main problems Worry/depression/suicide/self-depreciation Elation Anxiety/fear of going out/infrequency of excursions Referential and paranoid ideas Household arrangement/loneliness Family and friendly relationships/present and past isolation index/closeness Emergency assistance Anger/family burden on subject Obsessions/thought reading Weight/appetite/digestion/difficulties in shopping and preparing food/dietary intake/alcohol intake Sleep disturbance Depersonalization
Dementia III:	subjective and objective difficulty with memory/ tests of recall Fits and faints/autonomic functions/bowel and bladder Slowness and anergia/restlessness Self-rating of health Fractures and operations/medical and nonmedical attention/ examinations/medicines or drugs/drug addiction Arthritis/aches and pains Breathlessness/smoking/heart disease/hypertension/chest pain/cough/hoarseness/fevers Limitation in mobility/care of feet/limitation of exertion/simple tests of motor function Sores, growths, discharges/strokes/hospitalization and bed-rest Hearing/auditory hallucinations Vision/visual hallucinations Hypochondriasis Disfigurement/antisocial behavior Loss of interest/activities list History of depression Organizations and religion/educational and occupational history Work and related problems/retirement history Income/health insurance/medical and other expenses/handling of finances/shortages Housing facilities and related problems Ability to dress/do chores/help needed or received Neighborhood and crime Overall self-rating of satisfaction/happiness/insight Mute/stuporose/abnormalities of speech Additional observations of subject and environment/communication difficulties

SOURCE: B. Gurland, J. Kurlansky, L. Sharpe, et al., "The Comprehensive Assessment and Referral Evaluation (CARE) —Rationale, Development and Reliability," *International Journal of Aging and Human Development* 8(11):9-42, 1977-78.

disorders, somatic symptoms, and overall disability (57). Rating scales developed for SHORTCARE have been used to differentiate between depression-induced and primary degenerative dementia.

Reliability and Validity of General Multidimensional Instruments

The comprehensive nature of multidimensional assessment instruments may create the impression that they are more reliable and valid than instruments that measure only one area of functioning. In fact, the segments that measure cognitive status often incorporate instruments such as the MMSE and SPMSQ or use similar instruments. As a result, they are subject to the same reliability and validity questions that apply to instruments that assess only cognitive status. Similarly, segments of multidimensional instruments that measure self-care abilities and other patient characteristics are subject to the same errors as instruments that measure only these characteristics.

The reliability and validity of summary ratings derived from multidisciplinary instruments are uncertain for several reasons. First, the potential for subjective bias is high because summary ratings are based on an interviewer's judgment rather than on the respondent scores on each segment. With trained interviewers, interrater reliability has been acceptable (17)35,52,57). However, the level of reliability that is acceptable for research purposes may be inadequate for public policy decisionmaking where, for example, eligibility for services might depend on the results of the assessment procedure.

A second problem that affects the validity of summary ratings is that they are based on assumptions about the relative importance of individual items or segments of the questionnaire. Such assumptions are seldom stated explicitly and may not be justified in some cases (74).

Establishing the validity of multidimensional instruments is difficult because there is no accepted alternate procedure for measuring many of the patient characteristics that are assessed. Most attempts to establish validity have compared assessment results with clinical judgments about a patient's status. Although such comparisons may work well for mental health items, they are less satisfactory for self-care abilities and social and environmental items, for which clinical assessment

procedures are less well developed. Some studies have tested validity by comparing findings from one instrument with those from another that may include some identical items. Other studies have used statistical techniques to group test items into discrete domains—a procedure that may not be a meaningful test of validity (74).

Dementia Rating Scales

Dementia rating scales are multidimensional instruments that define levels of patient functioning from least to most impaired. Some purport to track the progression of an underlying disease process from onset to severe impairment; these instruments, usually designed to assess degenerative dementias such as Alzheimer's disease, focus on similarities among patients and the regular progression of dementing illnesses. Others focus on the heterogeneity of persons with dementia; these describe categories of patients, with less emphasis on the regular progression of an underlying disease. The two types of scales (examples of each are described in this section) represent two different views about the nature of dementia, its etiology, and manifestations.

Because persons with dementia vary greatly in their functioning, depending on the severity of the dementia, some method of classifying them is needed for research purposes. For example, studies that compare physiological findings about brain structure or function with patient disability need to characterize patients' conditions as more or less severe. Similarly, research on all types of treatment must categorize patient status in order to measure change in response to treatment (140). Finally, efforts to describe the course of diseases that cause dementia require an agreed-upon method for categorizing patients in terms of severity. As research on dementia increases in response to public concern and more government funding, the need for reliable, valid, and generally accepted dementia rating scales also increases (145).

The Clinical Dementia Rating Scale (CDR) is designed primarily to measure progressive dementias. It describes five stages of dementia in terms of six factors: memory, orientation, judgment and

problem solving, community affairs, home and hobbies, and personal care (see table 2-3 in ch. 2). An interviewer rates the subject on each factor on the basis of a medical and psychiatric evaluation, testing with several instruments (the Dementia Scale, the Short Portable Mental Status Questionnaire, and the Face-Hand Test), and an interview with a relative or other informant about the history of the illness and the patient's self-care abilities. Once the interviewer has assigned the subject to a CDR stage on each factor, the ratings are combined according to instructions provided by the authors, and the subject is assigned to a CDR stage overall.

Good interrater reliability has been obtained with this instrument using trained interviewers. Validity has been tested by comparing the results of some parts of the initial evaluation with the final rating and by measuring change in patients over time. However, the authors point out that true validity can only be demonstrated by following patients for a period of years to test the usefulness of the stages and by comparing CDR scores with autopsy data after a patient dies (69).

The Global Deterioration Scale (GDS) describes seven stages of primary degenerative dementia, which the authors describe as "a unique clinical syndrome with a characteristic onset and progression" (141). The GDS focuses on cognitive functioning but also assesses the impact of cognitive deficits on self-care abilities, mood, and behavior. Positive correlations between the GDS and the results of other assessment procedures and physiological measurements based on brain imaging techniques have been reported (140). In addition, anecdotal evidence indicates that families of some dementia patients have found this scale helpful because it describes the course of primary degenerative dementia, allowing family members to understand the disease and anticipate and plan for later stages (143). The scale has been criticized for underplaying the heterogeneity of persons with dementia and variations in the progression of primary degenerative dementia. Its authors suggest, however, that a significant deviation from the progression of stages in the GDS indicates that an individual may not have a primary degenerative dementia or may have other coexisting pathology (142).

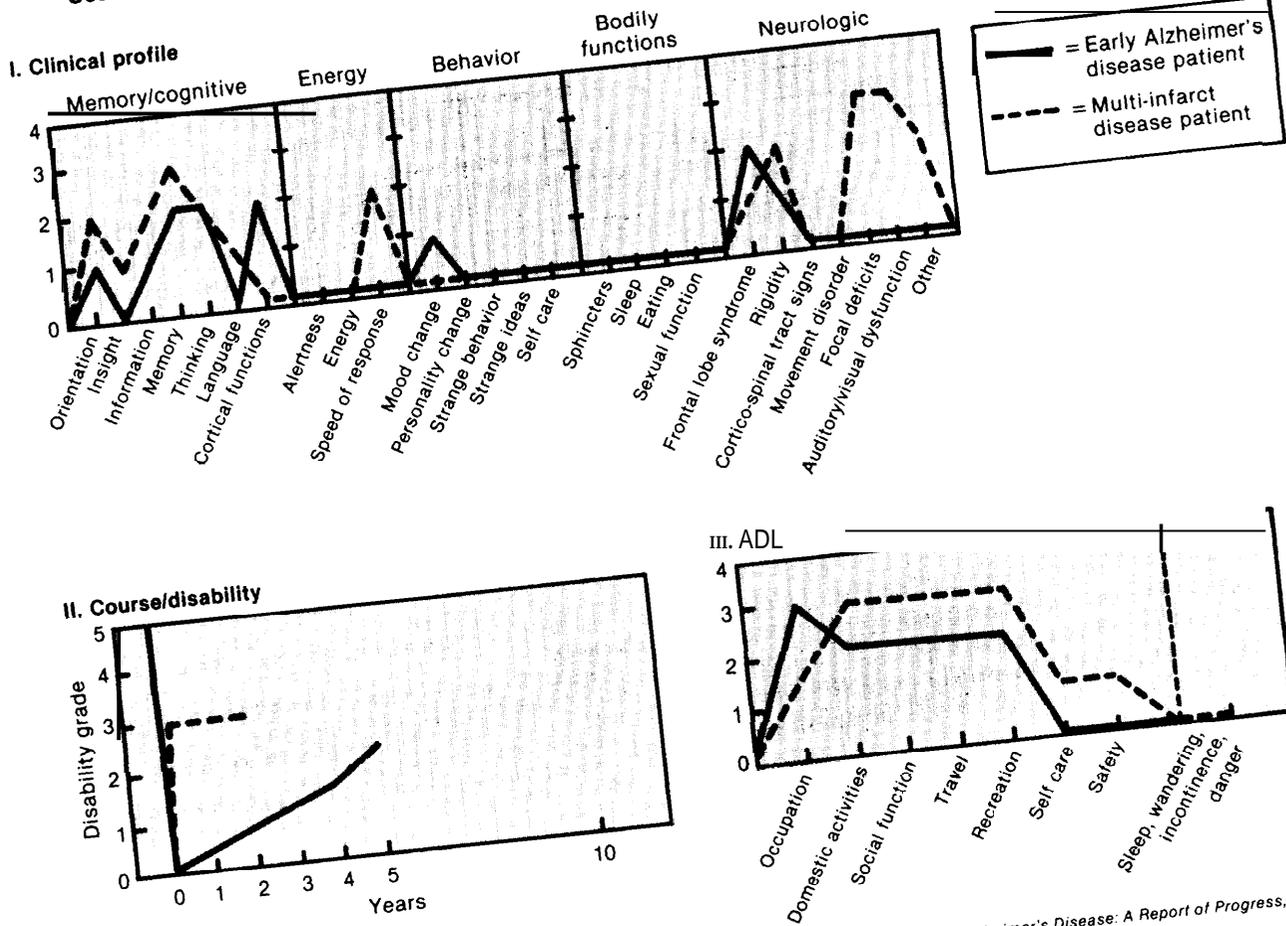
The Multidimensional Assessment for Dementia Scale (MAD) (29) adopts a very different approach emphasizing the heterogeneity of persons with dementia. The MAD scale portrays these differences graphically. For each individual, results of a comprehensive clinical evaluation are charted on seven graphs. Figure 8-4 compares two patients—one with early Alzheimer's disease and one with multi-infarct dementia—on three of the seven MAD scales. Graphs that describe different individuals are compared to identify subsets of dementia patients. The authors have noted different patterns among patients with multi-infarct dementia, Jakob-Creutzfeld disease, and Alzheimer's disease. Differences among Alzheimer's disease patients have also been noted (29).

Other dementia rating scales include the Alzheimer's Disease Assessment Scale (145) and the Criteria for the Diagnosis and Severity of Dementias (56), a scale used with the multidimensional CARE instrument described earlier. These instruments are not discussed in this section because of space limitations, and no implication about their relative value is intended.

Dementia rating scales are used as staging instruments. Staging is useful for describing an individual's condition over time and predicting the course of the illness, for monitoring response to treatment, and for determining the patient need for services (see ch. 2). Negative aspects of staging are the difficulty of clearly separating one stage from another in progressive dementias and differences in the clinical manifestations and the course of the various diseases that cause dementia. Another major concern from the point of view of assessment technology is the reliability and validity of staging procedures. Questions raised in this chapter about the reliability and validity of instruments that measure cognitive, self-care, and behavioral deficits are also relevant to staging instruments. Combining findings in each of these areas with a staging instrument compounds the potential for error.

Clearly some method of staging is essential for research, and a concept of stages in dementia is useful for treatment decisions and for counseling family members about long-term care plans. **However, despite the obvious theoretical rela-**

Figure 8-4.—Multidimensional Assessment for Dementia (MAD) Scale: Clinical Profile, Course/Disability, and ADLs for an Early Alzheimer's Disease Patient and a Multi-infarct Disease Patient



SOURCE: D. A. Drachman, P. Fleing, and G. Glosser, "The Multidimensional Assessment for Dementia Scales," *Alzheimer's Disease: A Report of Progress*, S. Corkin, et al., (eds.) (New York: Raven Press, 1982).

relationship between stages of dementia and each patient's need for health care and social services, the state of the art in assessment is not

yet at a point where these scales can be used for public policy purposes.

ASSESSMENT OF CAREGIVER BURDEN

The impact on family members and other informal caregivers of caring for patients with dementia is discussed at length in chapter 4, and findings from studies that define and document caregiver burden are also covered there. This section briefly discusses assessment instruments used

to measure caregiver burden and some of the problems that limit their reliability and validity.

Caregiver burden includes the physical, psychological, emotional, social, and financial problems experienced by family members and other infor-

mal caregivers (49). A better understanding of these problems is needed because families provide most of the care for dementia patients. Assessment of caregiver burden can provide information about the problems faced by families and can suggest interventions that might provide effective support for them (197).

Instruments To Measure Caregiver Burden

Some instruments to measure caregiver burden focus primarily on the caregivers' subjective or emotional reactions. The Burden Interview (197) is one example (see table 8-15). Others focus on more objective indices, such as changes in the caregiver's physical health, increased use of alcohol and psychotropic drugs, and worsened financial status. Many instruments measure both subjective and objective indices.

Research on caregiver burden is in an early stage, and many studies are primarily descriptive. The assessment instruments are frequently long questionnaires that include questions about the caregiver's physical, mental, emotional, social, and financial status; the relationship between the caregiver and the patient; and the physical, cognitive, self-care, and behavioral deficits of the patient. One example is a 24-page questionnaire used to study families of dementia patients in Michigan (20). A similar instrument was developed to study caregiver burden in families caring for elderly patients with and without cognitive impairment (47).

A different approach to assessing caregiver burden involves in-depth structured interviews with caregivers concerning the problems they face in caring for the patient and their methods of coping with these problems. One group used this method and an Inventory of Hypothetical Problem Situations to study caregiver coping mechanisms (95).

Reliability and Validity of Measures of Caregiver Burden

Many theoretical and practical problems affect the reliability and validity of measures of caregiver burden. Yet most studies do not report on the reliability or validity of the instruments used.

Table 8.15.-The Burden Interview

1. I feel resentful of other relatives who could but who do not do things for my spouse.
2. I feel that my spouse makes requests which I perceive to be over and above what she/he needs.
3. Because of my involvement with my spouse, I don't have enough time for myself.
4. I feel stressed between trying to give to my spouse as well as to other family responsibilities, job, etc.
5. I feel embarrassed over my spouse's behavior.
6. I feel guilty about my interactions with my spouse.
7. I feel that I don't do as much for my spouse as I could or should.
8. I feel angry about my interactions with my spouse.
9. I feel that in the past, I haven't done as much for my spouse as I could have or should have.
10. I feel nervous or depressed about my interactions with my spouse.
11. I feel that my spouse currently affects my relationships with other family members and friends in a negative way.
12. I feel resentful about my interactions with my spouse.
13. I am afraid of what the future holds for my spouse.
14. I feel pleased about my interactions with my spouse.
15. It's painful to watch my spouse age.
16. I feel useful in my interactions with my spouse.
17. I feel my spouse is dependent.
18. I feel strained in my interactions with my spouse.
19. I feel that my health has suffered because of my involvement with my spouse.
20. I feel that I am contributing to the well-being of my spouse.
21. I feel that the present situation with my spouse doesn't allow me as much privacy as I'd like.
22. I feel that my social life has suffered because of my involvement with my spouse.
23. I wish that my spouse and I had a better relationship.
24. I feel that my spouse doesn't appreciate what I do for him/her as much as I would like.
25. I feel uncomfortable when I have friends over.
26. I feel that my spouse tries to manipulate me.
27. I feel that my spouse seems to expect me to take care of him/her as if I were the only one she/he could depend on.
28. I feel that I don't have enough money to support my spouse in addition to the rest of our expenses.
29. I feel that I would like to be able to provide more money to support my spouse than I am able to now.

SOURCE: S.H. Zarit, K.E. Reever, and J.M. Bach-Peterson, "Relatives of the Impaired Elderly: Correlates of Feelings of Burden," *The Gerontologist* 20:649-655, 1980.

One problem that affects validity in some cases is the difficulty of identifying the caregiver. For example, if an adult child assists one parent in caring for the other, it is unclear who the primary caregiver is (49). Although both caregivers can be interviewed for a descriptive research study, public policy applications would require a method for identifying the primary caregiver.

A second problem is the difficulty of identifying a control group, without which it is impossible to determine which caregiver problems are

related to the caregiving situation and which predate it. Yet deciding who is an appropriate member of a control group raises difficult theoretical and practical problems. For example, instruments developed to measure caregiver burden include many questions about caregiving functions, and therefore the control group cannot include non-caregivers (49). A solution is to use instruments that measure caregiver characteristics, such as physical health, emotional well-being, and financial status, without specific references to the caregiving situation. Many such instruments have been used previously with various population groups so that the problems of identifying an appropriate control group are reduced (49).

Experts have pointed out that many problems reported by caregivers may be unrelated to the caregiving situation. For example, depression could predate a person's caregiving responsibilities (131), and family problems unrelated to caregiving maybe blamed on the caregiving situation (115). Moreover, assessments generally rely on self-reports of the caregiver, and accuracy is

thus limited by the person's self-awareness, objectivity, and willingness to report problems, feelings, and events accurately.

Public Policy Applications

The many practical and theoretical problems that surround assessment of caregiver burden suggest that these measures should not be used for public policy purposes with legal or quasi-legal impact—for example, allowing publicly funded respite care to some families and denying it to others on the basis of findings from one of the available assessment procedures. Nevertheless, research on caregiver burden is important for government policymaking because it can help to identify programs that support caregivers and that minimize incentives for premature or inappropriate institutionalization of persons with dementia. Development and validation of improved procedures for measuring caregiver burden is an integral part of this research effort,

THE ASSESSMENT PROCESS

This chapter has focused on assessment procedures and instruments, their reliability and validity, and their potential use in establishing eligibility for services, determining level of reimbursement, measuring quality of care, and identifying persons with dementia in health services research. Questions that have not yet been addressed are: Who should do the assessment? Where should it be done? And who pays for it?

Who Should do the Assessment?

Considerable data, some of which have been discussed earlier, indicate that different observers vary in their judgments about the cognitive, self-care, and behavioral deficits of individuals with dementia. These variations reflect the training and orientation of the observer, his or her relationship to the individual with dementia, and other factors. While assessment instruments provide a common frame of reference for evaluating a pa-

tient, interrater reliability is not perfect even using the simplest instruments and is further reduced when the assessment instrument requires a judgment or rating by an observer instead of a simple notation that an individual did or did not answer a question correctly.

The appropriate person or persons to do the assessment depends on its purpose and the instrument that is used. In the simplest case—a research or screening project using an instrument on which an individual's response to specific questions is recorded verbatim and only one answer is correct—an observer who has no clinical training and only a brief orientation to the instrument may be adequate. In the most complex case, in which a multidimensional instrument requiring judgments by an observer is used to plan treatment approaches and identify appropriate long-term care services, a multidisciplinary team, including one or more physicians, a nurse, a social worker, and others, may be needed.

One important question is the amount and type of clinical expertise required for reliable and valid assessment of persons with dementia. While the concept of a brief assessment procedure that can be completed by an individual with no clinical training is attractive in terms of cost and efficiency, the state of the art in assessment of dementia is not sufficiently advanced to support this approach in most situations. Questions about how cognitive test performance is affected by patient characteristics, such as visual, hearing, and speech impairments and educational, ethnic, and cultural background, and about how fluctuations in self-care and behavioral characteristics over time and in different settings affect reliability and validity suggest that considerable clinical expertise is needed for accurate assessment of persons with probable dementia. Such expertise includes knowledge about the physical, cognitive, and behavioral manifestations of dementia, functional mental disorders, and normal aging, in addition to interviewing skills and familiarity with the assessment instruments being used. Untrained observers lack this expertise. In fact, few health care or social service professionals have formal training and experience in all these fields. As a result, many experts advocate the multidisciplinary team approach for both assessment and treatment of persons with dementia (see ch. 9).

With regard to multidimensional assessment instruments, it is unclear whether different results are obtained when one observer evaluates the person in all domains as opposed to a multidisciplinary team in which each professional completes the section of the assessment in his or her area of expertise. OTA is not aware of any research that compares these two approaches to multidimensional assessment.

For purposes of establishing eligibility for services, determining level of reimbursement, measuring quality of care, and identifying persons with dementia in health services research, the question of who does the assessment is extremely important. The clinical knowledge, interviewing skills, and familiarity with assessment instruments of people who perform these functions for Federal, State, and local government agencies vary widely between agencies and in different localities. How that variability affects assessment out-

comes and thus access to care, quality of care, and the validity of research findings is an important consideration that has received insufficient attention. Clearly, painstaking procedures for selecting and refining an assessment instrument cannot overcome problems of reliability and validity that arise from the way the assessment is conducted.

Where Should the Assessment Be Done?

Assessment of dementia patients is currently done (formally or informally and with or without the use of assessment instruments) in the offices of individual physicians and other health care and social service professionals; in hospitals, nursing homes, and other residential settings; and in all public and private agencies that provide services of any kind for elderly people. The type and quality of assessment, whether assessment instruments are used, who does the assessment, and how it is paid for are all related to the setting in which it is done.

Research findings indicate that primary care physicians often fail to recognize mental and behavioral disorders in people of all ages, and particularly in elderly people (51,71,104). Studies cited earlier in this chapter show that dementia is frequently not recognized in a variety of in-and out-patient medical care settings. Although data are not available, it is likely that dementia is also frequently not recognized in social service and other community agencies.

Many solutions for these problems have been proposed. First, training in the assessment of persons with dementia could be provided for primary care physicians and other health care and social service professionals and nonprofessionals who interact regularly with people at risk of dementia (see ch. 9). That approach would make assessment available in the places where patients are most likely to be seen. However, training for such a large number of individuals would be costly and difficult to implement. In addition, their other responsibilities and time constraints could limit the quality of assessment some of them would be able to provide.

A second approach is to train primary care physicians and other health care and social service providers to screen for dementia and then refer probable cases to a specialist for comprehensive assessment. Although that might improve the quality of assessment, it would also involve increased cost and at least one additional appointment for the patient and family. Since the specialist is unlikely to know the patient, he or she may be less able than the primary care physician or other care provider to determine whether there has been a change in the patient's cognitive or other abilities. Furthermore, there is disagreement about whether the appropriate specialist is a physician—a neurologist or psychiatrist, for example—or a clinical psychologist, psychiatric social worker, psychiatric nurse, or other mental health professional.

As discussed in chapter 6, fewer elderly than younger people are seen by mental health professionals. Many reasons for this have been cited, including the preference of many such professionals to work with younger patients, negative attitudes about the efficacy of treatment for elderly patients, lack of training programs in geriatric mental health, and the preference of many elderly people to seek treatment from a physical rather than mental health care provider. The extent to which these obstacles can be overcome is unclear, and it is therefore unclear whether government initiatives to increase access to assessment for persons with dementia should focus on increasing referrals from primary care providers to mental health specialists.

Geriatric assessment centers (GACs) are another setting for assessment of persons with dementia. GACs are common in Britain but have been introduced in the United States only in the last 8 to 10 years. They are generally hospital-based and are designed to provide multidisciplinary assessment focused on functional status and medical, psychological, and social needs, in addition to short-term treatment and assistance with long-term care planning for elderly patients (150). Most GACs serve inpatients, but some also provide services on an outpatient basis (105,112,153,188). Both in- and outpatient GACs evaluate persons with dementia. In fact, data from two outpatient centers show that 46 and 32 percent of their patients re-

spectively were diagnosed as having dementia (105,188).

Advantages of GACs for assessment of persons with dementia are the availability of a multidisciplinary team; the focus on physical, mental, emotional, and social aspects of patient functioning and their interrelationship; the emphasis on identification and treatment of physical conditions that frequently cause excess disability; and the availability in the hospital setting of a variety of health professionals, including physical therapists, occupational therapists, dietitians, neurologists, psychiatrists, urologists, and other physician specialists who can assist with diagnosis and treatment for these patients. Possible disadvantages are cost and their relative scarcity.

Until recently, there have been few GACs in this country, *so that* patients and their families had to travel considerable distances to the nearest center. The number of centers is increasing, and anecdotal evidence and reports in the literature suggest that some hospitals that do not have a GAC instead have a multidisciplinary geriatric consultation team that provides assessment for patients throughout the hospital (19,98, 160). In many hospitals, however, such services are not available.

Evaluation and treatment in inpatient GACs is expensive. As a result, some experts have suggested that use of GACs should be limited to certain types of elderly patients for whom its benefits have been clearly demonstrated in terms of longer survival, improved functional status, and decreased use of institutional services (149,152). Patients with severe dementia (defined as those with well-diagnosed dementia who can perform no more than three ADLs) are excluded from one well-known VA geriatric assessment center because research indicates that the GAC intervention has less effect on outcome for them than for other patient groups (150,151). Other VA geriatric assessment centers continue to admit patients with severe dementia, however (117). Geriatric assessment in outpatient centers is less expensive. In addition, the patients are still living in the community—thus allowing a truer impression of their functional status and family supports (10.5).

The specialized dementia research centers funded by the National Institute on Aging and the

National Institute of Mental Health are another setting for comprehensive assessment of persons with dementia. Expanding the number of these centers will increase access to assessment. In addition, legislation enacted in 1986 authorizes the creation of 5 to 10 Alzheimer's disease diagnosis and treatment centers to provide multidisciplinary assessment in addition to a variety of other services for persons with dementia and their families. The advantages of such centers are the concentration of expertise in one setting and the unitary focus on dementia. One disadvantage is that patients and their families have to travel considerable distances to reach a center. Furthermore, the relatively small number of centers cannot cope with the large number of patients needing assessment.

In some communities, assessment for dementia patients is provided by community mental health centers and public health and social service agencies. However, the extent of such services varies greatly in different localities. Studies cited in chapter 6 suggest that many community mental health centers currently provide no special services for persons with dementia, and no information is available about services provided for these persons by other community agencies. One advantage of providing assessment services in the local community is ease of access by the patient and family. In addition, local agencies may have greater awareness of long-term care services in the community than a regional dementia research, treatment, and education center would.

In addition to the settings already discussed, comprehensive assessment for persons with dementia can be provided in nursing homes and in the individual's home. Some community mental health centers provide outreach services in nursing homes, including patient assessment and consultation with the nursing home staff about medications and management techniques for residents with emotional and behavioral problems (2,99). Some outpatient geriatric assessment centers may provide similar services.

Comprehensive assessment in the patient's home is standard in Great Britain but rarely available in this country. Home health care agencies here routinely provide a general nursing assessment in the home and less frequently an evaluation by a social worker. However, these procedures usu-

ally do not focus on cognitive status and self-care and behavioral problems associated with dementia. Physician evaluation is seldom provided at home.

Some reports of comprehensive geriatric assessment in the patient's home have appeared in the literature (27,96). Advantages of this approach are the opportunity to observe the home environment and the interaction of family members directly, and to observe the patient at his or her optimal level of functioning, in the environment that he or she is most familiar with. Disadvantages are the time it takes for highly paid health care professionals to travel to the person's home and the consequent cost of home assessment compared to outpatient assessment in a GAC or a community mental health center.

Who Pays for the Assessment?

Medicare and Medicaid pay for physician diagnosis of disorders that cause dementia and lab tests associated with diagnosis. It has been noted, however, that the level of reimbursement is generally inadequate for the time required to complete a history, physical and neurological examination, to do a mental status exam, and to discuss the problem with the family (78, 187). In addition, reimbursement is generally not provided for non-physician professionals, such as nurses and social workers, who are frequently involved in the assessment process. Changes in these reimbursement policies could increase access to assessment for dementia patients.

Inpatient assessment is not covered directly under the Medicare Prospective Payment System (PPS). Some experts believe that the PPS discourages inpatient geriatric assessment because it creates incentives for shorter hospital stay while inpatient assessment often increases length of stay. (This is because patient conditions are identified that might otherwise have been missed and treatment of those conditions may extend the period of hospitalization (148)). While agreeing with that position, others point out that comprehensive geriatric assessment can improve quality of care for elderly patients and may thus benefit hospitals in communities where there is competition for patients (160). In addition, comprehensive assess-

ment can help to identify patients who may be difficult to discharge (and thus costly for the hospital) so that the discharge planning process can begin early in their hospital stay. No information

is available about whether the number of inpatient GACs has increased or decreased since the beginning of PPS in 1983.

ISSUES AND OPTIONS

Although many questions have been raised in this chapter about the reliability and validity of assessment procedures and instruments that measure cognitive, self-care, and behavioral deficits and caregiver burden, it is clear that they address the aspects of patient functioning that are important for determining long-term care needs and identifying appropriate services. In general, they are better indicators of patient functioning and long-term care needs than diagnosis alone or the patient's medical or skilled nursing care needs—thus suggesting that they should be more widely used for research, clinical, and public policy purposes.

Congressional policy options related to the use of assessment instruments to establish eligibility for publicly funded long-term care services and to identify persons with dementia in health services research are discussed here, along with options for increasing access to assessment for persons with probable dementias. Issues and options related to determining level of reimbursement for long-term care services and measuring quality of care are discussed in chapters 10 and 12.

ISSUE 1: Should the eligibility criteria for publicly funded long-term care services be changed to increase access for dementia patients?

Option 1: *Retain existing eligibility criteria for publicly funded long-term services.*

Option 2: *Include a measure of cognitive abilities in the eligibility criteria for some or all publicly funded long-term care services.*

Option 3: *Include self-care and behavioral measures in the eligibility criteria for some or all publicly funded long-term care services.*

Option 4: *Develop and test a multidimensional assessment instrument to establish eligibility for publicly funded long-term care services.*

The existing eligibility criteria for publicly funded long-term care services focus on medical and health care needs and tend to restrict access to services by persons with dementia who require primarily nonmedical long-term care services, such as personal care and supervision. Option 1 would maintain that situation. The inclusion of a measure of cognitive abilities in the eligibility criteria for Medicare, Medicaid, and VA services (option 2) would increase access to services for these persons. It would also make services available to persons with cognitive deficits resulting from other conditions, including depression, mental retardation, and chronic mental illness, unless these groups were specifically excluded.

Some advocates of increased publicly funded long-term care services for persons with dementia believe that services should also be available to persons with cognitive impairments caused by other conditions. Others maintain that only individuals with dementia or dementia caused by specific diseases should be covered. The requirements for a cognitive assessment instrument to be used for eligibility determination differ depending on which of these positions is chosen. At present, however, the state of the art in cognitive assessment is not sufficiently advanced to serve as a basis for allowing publicly funded services to people with cognitive impairment caused by demerit - ing illnesses but not by other conditions. Such distinctions would be particularly unreliable for elderly patients and ethnic minority groups because of questions about the validity of cognitive assessment procedures and instruments for them.

Nor are currently available procedures and instruments able to differentiate between different diseases and conditions that cause dementia with sufficient accuracy to support Federal programs directed specifically toward those with Alzheimer's disease, multi-infarct dementia, or other designations that have been suggested. At the same time, inclusion of a cognitive measure in the eligibility criteria for publicly funded long-term care services would insure identification of cognitive deficits and generate valuable information about persons with cognitive impairment who apply for these services and about assessment of cognitive status in this population.

Inclusion of self-care and behavioral measures in eligibility requirements (option 3) would increase access to publicly funded long-term care services for persons with dementia. If used alone, these measures would also make services available to individuals with a wide variety of cognitive, emotional, and physical conditions that limit self-care abilities. As with cognitive impairment, some people oppose extension of services to this large group of individuals, while others do not.

Self-care and behavioral deficits are generally easier to measure than cognitive impairments. Some experts argue that they are also more highly correlated with patient care needs than cognitive impairments and that cognitive measures are not needed to establish eligibility for services or determine the appropriate level or locus of care. Others argue that the long-term care needs of persons with cognitive impairments are significantly different from those with physical impairments and that cognitive deficits should be measured in addition to self-care and behavioral deficits. Research is needed to evaluate these opposing views and to define more clearly the relationship between cognitive, self-care, and behavioral deficits, and long-term care needs.

Option 4, the development of a multidimensional instrument for eligibility determination, would also require research on the relationship between patient characteristics and long-term care needs. Development and validation of such an instrument would pose difficult problems of reliability and validity, but its eventual use to establish eligibility for services would reflect current knowledge

about the factors that cause a need for long-term care much more closely than existing eligibility criteria do. Such an instrument might also reflect the experience of families and other caregivers about which patient characteristics are most difficult to manage and might therefore be perceived by families and others as fairer than the existing criteria.

ISSUE 2: Should measures of cognitive, self-care, and behavioral deficits or of caregiver burden be required in federally funded surveys of the elderly and long-term care populations?

Option 1: Retain current procedures for selecting survey items to be included in federally funded surveys.

Option 2: Include measures of cognitive status in some or all federally funded surveys of the elderly and long-term care populations.

Option 3: Include measures of cognitive, self-care, and behavioral deficits and of caregiver burden in some or all federally funded surveys.

Congressional involvement in the selection of patient and caregiver characteristics to be measured in survey research would be unusual. Yet many recent federally funded surveys of elderly and long-term care populations have not included measures of cognitive status that permit the identification of people with cognitive deficits. Thus information about the number and proportion of survey respondents with dementia and the severity of their cognitive deficits cannot be derived from survey data. Lack of such information hinders the development of appropriate government policies for the care of these persons.

Many recent federally funded surveys have included measures of self-care and behavioral deficits, and some have included measures of caregiver burden. However, lack of information about the cognitive status of survey respondents means that correlations between cognitive status and self-care and behavioral deficits and caregiver burden cannot be derived from the survey findings. Furthermore, the data cannot be used to deter-

mine the relationship between patient characteristics, caregiver burden, long-term care needs, and service utilization.

The Department of Health and Human Services (DHHS) maintains that for Federal policy purposes the long-term care needs of cognitively impaired people are not significantly different from those of physically impaired people. That position may be reflected in the relatively small emphasis on cognitive status v. self-care abilities and other patient characteristics in DHHS-funded research. Although that view may ultimately prove to be correct, available data are insufficient to justify it at present. Thus a congressional mandate may be needed to include cognitive status in addition to other patient and caregiver characteristics in federally funded survey research.

In February 1985, the directors of the five Alzheimer Disease Research Centers funded by the National Institute on Aging agreed to use two cognitive assessment instruments, the Information-Memory-Concentration Test (9) and the Mini-Mental State Examination (39) as part of a common assessment protocol. In October 1985, the directors of the six Alzheimer Disease Diagnostic and Treatment Centers funded by the State of California also agreed to use an instrument that combines the Blessed and MMSE tests as part of their common assessment protocol (78). The combined instrument, which addresses cognitive, ADL, and IADL deficits, is given in appendix C. Although designed for clinical evaluation, it might also be adapted for survey research.

ISSUE 3: What steps, if any, should Congress take to increase access to comprehensive assessment for persons with dementia?

Option 1: Do not take any steps to increase access to comprehensive assessment for persons with dementia.

Option 2: Increase reimbursement through Medicare and Medicaid for assessment by individual physicians and other health care and social service professionals.

Option 3: Increase reimbursement through Medicare and Medicaid for comprehensive

multidisciplinary assessment in geriatric assessment centers or by multidisciplinary geriatric consultation teams on an inpatient or outpatient basis.

Option 4: Set up a program of regional centers to provide comprehensive assessment in addition to other services for persons with dementia and their families.

Option 5: Designate comprehensive assessment of persons with dementia as a mandatory service of existing community-based agencies, such as community mental health centers, and provide supplemental funding for this service.

The VA provides comprehensive multidisciplinary assessment for eligible veterans, and some Alzheimer's disease research centers have negotiated agreements with Medicare and Medicaid for full coverage of comprehensive assessment for their patients. In general, however, Medicare and Medicaid reimburse physicians for diagnosis of dementia, but the level of reimbursement is often not commensurate with the amount of time needed for comprehensive assessment. In addition, reimbursement is frequently not provided for nonphysician professionals who may be involved in the assessment process. Increasing Medicare and Medicaid coverage and reimbursement for assessment by individual physicians and other health care and social service professionals (option 2) would be costly but would also increase access to this important service. Since many health care and social service professionals have not been trained in comprehensive assessment of persons with dementia, federally funded training programs might also be needed to develop the requisite skill base (see ch. 9).

Increasing access to multidisciplinary inpatient assessment would require changes in Medicare coverage or reimbursement policies that might involve:

- exempting inpatient GACs from the Medicare Prospective Payment System,
- creating a special reimbursement category for multidisciplinary assessment,
- designating dementia as a co-morbidity that

would increase reimbursement for hospital stays for persons with dementia in some or all reimbursement categories, or

- allowing inpatient assessment in a GAC or by a multidisciplinary geriatric consultation team as a covered exception for patients who met certain criteria.

Similar changes would be required of Medicaid and private insurance to increase access to inpatient assessment for persons under 65.

Analysis of the feasibility and cost of these alternatives is beyond the scope of this report. However, Congress could direct the Health Care Financing Administration to evaluate these and other alternatives and to report back with recommendations for implementation within a designated period. Instead or in addition, Congress could direct the Health Care Financing Administration to fund demonstration projects to test the efficacy of these and other approaches.

Increasing access to outpatient multidisciplinary assessment would require changes in Medicare, Medicaid, and private insurance that might involve:

- a special funding category for outpatient assessment by a multidisciplinary team;
- a significant increase in the current level of reimbursement for physician diagnosis to cover the cost of multidisciplinary assessment; or
- direct reimbursement for nurses, social workers, and others who are involved in patient assessment but are not usually eligible for direct reimbursement.

Again, analysis of the feasibility and cost of these alternatives is beyond the scope of this report. The analysis could be provided to Congress by the Health Care Financing Administration with

options for implementing these or other such changes.

A program of regional Alzheimer's disease or dementia centers (option 4) would provide a locus for professional expertise in assessment and other services for persons with dementia and their families. While many experts endorse this model of service delivery, the number of such centers to be developed is limited by available funding. Requiring patients and their families to travel long distances to a regional center might impose hardship. Ideally, dementia patients should be periodically reevaluated during the course of their illnesses, and travel may become increasingly difficult as the patient's condition worsens. In addition, regional centers may have only limited awareness of the long-term care services available in the patients' own communities.

The provision of comprehensive assessment in existing community agencies, such as community mental health centers (option 5) could solve the problems of travel distances and awareness of local long-term care services that limit option 4. However, most such settings do not have medical staff to diagnose or treat physical problems that cause excess disability. In addition, the Federal role in defining services provided by community mental health centers has decreased greatly in recent years, and Federal funding for community mental health centers has also decreased. Implementation of option 5 would require further analysis of the impact of federally mandated services for dementia patients on the capacity of community mental health centers to provide services for other patient groups. Similar analysis would be needed before mandating the provision of comprehensive assessment for persons with dementia in other community-based agencies.

CHAPTER 8 REFERENCES

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