Determining Decisional Capacity: A Medical Perspective

Robert P. Roca

Recommended Citation

Determining Decisional Capacity: A Medical Perspective

DETERMINING DECISIONAL CAPACITY: A MEDICAL PERSPECTIVE

*ROBERT P. ROCA**

INTRODUCTION

PHYSICIANS, particularly psychiatrists, are often called upon to judge the decision-making capacity of elderly persons. Their special expertise in this determination derives from their knowledge of mental disorders and the effects of these disorders on the processes of decision-making. This is their only claim to special expertise in this matter; therefore, the most sensible question to ask a physician about decisional capacity is this: Does the patient have a mental disorder that compromises her ability to make or communicate choices and decisions? This Article describes the clinical methods by which a physician determines whether a mental disorder is present, reviews the conditions that most often compromise decisional capacity in the elderly, describes how it is determined whether the mental disorder is affecting decisional capacity, and demonstrates how these approaches are applied to particular cases.

I. THE DIAGNOSIS OF MENTAL DISORDERS

Clinical syndromes are clusters of symptoms, signs, and impairments that tend to occur together and have a distinct natural history. They may be attributable to one or more causes or pathogenic mechanisms. Fever, shortness of breath, and cough, for example, are components of the clinical syndrome termed "pneumonia." This syndrome is often caused by bacteria (e.g., *streptococcus pneumoniae*), but other infectious agents (e.g., viruses) may be implicated. The symptoms subside in most cases when appropriate antibiotic therapy is instituted. Recognizing the clinical syndrome is thus the first step in the process of clinical management, and this rule applies throughout general medicine.

Recognizing clinical syndromes is even more important in psychiatry because this is the principal—and in some cases the *only*—means of validating the presence of a condition; there is no biopsy, blood test, or X-ray to do the job. Psychiatric diagnosis has an historic reputation for being unreliable; however, the ability of psychiatrists to recognize and describe psychiatric syndromes has improved recently as a result of the growth of empirical research in psychiatry and the concerted effort of the American Psychiatric Association to standardize the use of diagnostic terms through the development of the Diagnostic and Statistical Manual of

Mental Disorders ("DSM").[1] This document demystifies psychiatric diagnosis, establishing explicit criteria for the assignment of diagnostic labels and improving the reliability of psychiatric classification, i.e., improving the odds that different examiners will agree about the diagnosis in a given case.

The clinical syndromes described in DSM are heterogeneous in many respects—including the nature of their causes and the degree to which these causes are understood. Some of these syndromes are associated with demonstrable disturbances in brain anatomy or physiology (e.g., dementia, delirium). Others are believed, but not yet proven, to be associated with brain abnormalities (e.g., schizophrenia, bipolar affective disorder). Still others are believed to be entirely psychological in their origins and have no basis whatsoever in bodily malfunction. As this Article will demonstrate, the disorders that often compromise capacity in the elderly are known or believed to be associated with disturbances of brain function and are therefore conditions about which physicians might be expected to speak with special authority. Before the conditions themselves are discussed, the clinical methods by which physicians arrive at diagnostic decisions and assess the degree of disability imposed by these conditions will be considered.

II. THE PSYCHIATRIC HISTORY AND MENTAL STATUS EXAMINATION

The purpose of the psychiatric history and mental status examination is to obtain information relevant to decisions about diagnosis and functional capacity. The psychiatric history is a biography, gathered from as many informants as possible, focusing on details relevant to these decisions. The most important components of the history are those bearing most directly on these details. In the case of dementia, for example, critical history includes information regarding the onset of forgetfulness, the rate of decline in cognitive functioning, and the specific impairments that have developed. But other kinds of history are relevant as well. Because dementia, like many psychiatric disorders, runs in families, it is important to ascertain whether any family members, particularly first-degree relatives, have experienced similar symptoms. In addition, because dementia, like many psychiatric disorders, precipitates functional decline in many domains, it is important to know the patient's maximal level of educational and occupational attainment to help determine whether deterioration has occurred.

The mental status examination is the formal process by which physicians discover the presence of signs and symptoms of specific psychiatric disorders. It is a brief sampling of the contents of consciousness, focusing on features that are diagnostically discriminating. The physician

---

1. *See* American Psychiatric Ass'n, Diagnostic and Statistical Manual of Mental Disorders (3d ed. rev. 1987) (4th ed. forthcoming) [hereinafter Diagnostic Manual].

watches for abnormalities in motor behavior, listens for disruptions in the coherence of speech, and asks specific questions designed to reveal disturbances in mood, belief (i.e., delusions), perception (hallucinations and/or illusions), and cognition.[2]

A. *Motor Activity*

The examiner looks for alterations in gross motor activity that suggest specific psychiatric disorders. Delirious persons often show levels of activity that fluctuate throughout the day (e.g., daytime somnolence and nocturnal agitation). Persons with serious depressive disorders may move more slowly than usual (i.e., "psychomotor slowing") or exhibit anxious hand-wringing. Persons with schizophrenia may show repetitive, apparently purposeless movements, gross excitement, or a profound motor passivity termed "waxy flexibility."

B. *Form of Talk*

The examiner listens to the person's talk for disruptions in the organization of thought. Disorganized rambling speech may be seen in delirium and dementia and is usually readily distinguished from the "loosening of associations" and "flight of ideas" seen in schizophrenia and mania. All such disturbances are termed generically "formal thought disorder."

C. *Mood*

Because serious mood disorders are characterized by persistent and pervasive changes in mood, self-esteem, and vitality, each of these dimensions must be evaluated in the course of the mental status examination. The examiner asks for a subjective self-report of mood and describes the patient's objective emotional appearance, or "affect" (e.g., irritable, indignant, elated). The examiner then inquires about feelings of worthlessness and guilt (e.g., "Do you feel that others would be better off without you?"), level of energy (e.g., "Have you been feeling unusually tired?"), interest in usual activities and capacity for pleasure (e.g., "Does anything perk you up when you're feeling down?"). It is critical for the examiner to ask not only about suicidality but also about passive wishes for death (e.g., "Have you wished that you would not wake up in the morning?").

D. *Belief*

Delusions are fixed, false, idiosyncratic beliefs. They are nonspecific indicators of serious psychiatric disorder that may occur in many psychiatric disorders. Most often persecutory in content, they may also be

---

2. *See* Robert P. Roca, *Psychosocial Aspects of Surgical Care for the Elderly, in* Surgical Clinics of North America (forthcoming 1994).

grandiose, guilty, or simply bizarre (e.g., "Someone is taking thoughts out of my head.").

E. *Perception*

Hallucinations are false perceptions in any sensory modality. Visual and auditory hallucinations are most common. Like delusions, they indicate the presence of a serious psychiatric disorder. While some persons spontaneously describe their "voices" or "visions," others are extremely reticent to describe these experiences because they fear that other people will think they are "going crazy" or, in some cases, because the "voices" threaten to harm them if they reveal their content. Psychopathologists distinguish hallucinations from illusions, in which actual stimuli are misperceived.

F. *Cognition*

Persons with delirium and dementia have primary disturbances in their ability to reason, remember, and orient themselves in time and space. While some diagnostic information is gained from asking orientation questions (e.g., "Where are you?" or "What day is it?") or asking patients to perform serial arithmetic (e.g., "Count backwards from 100 by 7's."), such maneuvers by themselves are inadequate screening tests for these common and important psychiatric disorders. For this reason, most examiners utilize a brief standardized test of cognitive functioning such as the Mini-Mental State Examination ("MMSE").[3] This is the subject of further discussion below.

III. PSYCHIATRIC DISORDERS THAT MAY COMPROMISE CAPACITY

A. *Dementia*

Dementia is a clinical syndrome characterized by generalized cognitive impairment and a normal level of consciousness (i.e., normal level of attention and wakefulness). Table 1 summarizes the current diagnostic criteria:

TABLE 1
DIAGNOSTIC CRITERIA FOR DEMENTIA[4]

1. Demonstrable evidence of impairment in short- and long-term memory
2. At least one of the following:
    Impairment in abstract thinking
    Impaired judgment
    Other disturbances of higher cortical function, such as aphasia,

---

3. *See* Marshal F. Folstein et al., *"Mini-Mental State": A Practical Method for Grading the Cognitive State of Patients for the Clinician*, 12 J. Psychiatric Res. 189 (1975).
4. *See* Diagnostic Manual, *supra* note 1.

apraxia (inability to carry out motor activities despite intact comprehension and motor function), agnosia (failure to recognize or identify objects despite intact sensory function), and "constructional difficulty" (e.g., difficulty copying a geometrical figure)

3. Personality change

4. The above disturbances significantly interfere with work or usual social activities or relationships with others

5. Not occurring exclusively during the course of Delirium

About five percent of persons over sixty-five and twenty percent of persons over eighty are affected severely. The primary deficits occur in the realms of orientation, memory, and reasoning; however, hallucinations, delusions, major depression, and a host of behavioral symptoms (e.g., wandering, yelling, banging, combativeness, "agitation") also may occur.

The single most common cause of dementia is Alzheimer's disease, a progressive degenerative disorder of multiple neuronal systems in the brain. Forgetfulness is usually the first symptom, followed by difficulty with language (aphasia) and difficulty carrying out complex motor behaviors such as dressing and eating with utensils (apraxia). Hallucinations, aggressiveness, agitation, and other behavioral symptoms often emerge as cognitive impairment worsens.

The cause of Alzheimer's disease is unknown, although recent evidence supports the primacy of genetic factors. There is no cure. The one drug approved for use in Alzheimer's disease helps only a minority of patients and even then is only modestly effective.

Dementia may also be a product of multiple strokes (i.e., multi-infarct dementia), other neurologic conditions (e.g., multiple sclerosis, Huntington's disease), various systemic medical disorders (e.g., hypothyroidism, vitamin B12 deficiency), and drug toxicity. Severe depression may also cause a dementia syndrome.

The prognosis of dementia depends on the cause. Because most dementing conditions are not reversible, most demented patients do not recover lost cognitive abilities. But there are important exceptions. Persons with dementia due to drug toxicity, depression, or treatable medical conditions, such as hypothyroidism, may recover completely. Furthermore, even persons with irreversible dementing conditions may improve somewhat in response to treatment of a superimposed medical condition (e.g., pneumonia, urinary tract infection).

B. *Dementia and Incapacity*

Because of the variability of the prognosis of dementia depending upon the cause, it is critical to know the cause of the dementia before making any pronouncement about incapacity, particularly about its likely duration. This generally means that the patient should have seen a physician for a complete medical history, a thorough physical examination, and laboratory testing, including measurement of blood chemistries, thyroid hormone concentration, and blood counts. Blood testing for syphilis, an

electrocardiogram, a chest x-ray, and urinalysis should be obtained. Many authorities would recommend some form of neuroimaging study (e.g., computed tomography or magnetic resonance imaging of the brain), although these tests often yield little of diagnostic or therapeutic importance, particularly when dementia has been chronic and slowly progressive. A mental status examination[5] also should be performed. When this work-up does not yield a specific treatable dementing condition, the odds are very high that the person has a progressive degenerative brain disease, usually Alzheimer's disease.

Demented persons with treatable conditions temporarily may lack decisional capacity but generally improve with treatment and may regain fully their ability to decide for themselves. Persons with progressive degenerative dementing diseases lose their decision-making capacity at some point in the course of their illness and do not recover. Early in their illness, however, they are able to make many kinds of decisions, and the clinician is faced with the difficult task of determining how long and for what purposes their decision-making capacity remains intact.

Persons with dementia, by definition, have experienced a global decline from a higher level of functioning, but this does not imply global incapacity at any particular point in the course of their illness, particularly among persons of superior intellect. The higher their premorbid baseline, the greater their residual cognitive capacity is likely to be at any point in time. It is not unusual for very intelligent persons to score in the "normal" range on tests of cognitive functioning early in the course of a dementing illness. This does not mean that they are not demented; after all, they have deteriorated in terms of their baseline functioning. But their remaining intellect may be sufficient to allow them to make competent decisions about many matters. So a diagnosis of Alzheimer's disease, even if fully justified, is not in itself the last word on decisional capacity.

Standardized tests are often used to help measure the severity of impairment and assist the clinician in judgments about the adequacy of cognitive functioning for decision-making. The most widely used brief "bedside" test of cognitive functioning is the MMSE.[6] It tests orientation, memory, attention and concentration, as well as language use, aptitude for serial subtraction, and the ability to copy a complex figure. Perfect performance earns thirty points. Scores below 24 are the rule in persons with dementia, and few demented persons score 24 or above. Persons with scores of 24 or above rarely are judged to have inadequate cognitive function for decision-making purposes. But many persons with scores below 24 are neither demented nor seriously impaired in their decision-making capacity. This is because dementia is not the only factor affecting scores on the MMSE. The greatest number of "false positives"

---

5. *See supra* part II.
6. *See* Folstein, *supra* note 3.

occurs in persons who have limited formal education, particularly those whose schooling ended at or before the eighth grade.[7] Overreliance on the usual "cut-off point" for the MMSE thus can lead to overestimation of the prevalence of dementia and of the severity of disability. In fact, no cut-off point perfectly distinguishes persons with and without decisional capacity.[8] For this reason, the results of standardized tests best are regarded as simply one source of information about capacity. The final judgment must integrate data from many sources.

C. *Delirium*

Delirium is a clinical syndrome of confusion in association with fluctuating levels of consciousness and attention. Its most distinctive feature—and the feature that distinguishes delirium from dementia—is a reduced ability to focus attention on external stimuli and to shift attention to new stimuli, usually accompanied by drowsiness or distractibility. Additional features include disorganized speech, visual and/or auditory hallucinations, paranoid delusions, disorientation, and memory impairment. These signs and symptoms generally develop over a period of hours or days and wax and wane over time; periods of profound confusion and agitation typically alternate with lucid intervals. Table 2 summarizes the current diagnostic criteria:

TABLE 2
DIAGNOSTIC CRITERIA FOR DELIRIUM[9]

1. Reduced ability to maintain attention to external stimuli (e.g. questions must be repeated because attention wanders) and to appropriately shift attention to new external stimuli (e.g., perseverates answer to a previous question)
2. Disorganized thinking
3. At least two of the following:
    Reduced level of consciousness
    Perceptual disturbances
    Disturbance of sleep-wake cycle
    Increased or decreased psychomotor activity
    Disorientation to time, place or person
    Memory impairment
4. Clinical features develop over a short period of time (usually hours to days) and tend to fluctuate over the course of a day

Delirium is the behavioral manifestation of diffuse brain dysfunction

---

7. *See* James C. Anthony et al., *Limits of the 'Mini-Mental State' as a Screening Test for Dementia and Delirium Among Hospital Patients*, 12 Psychol. Med. 397 (1982).
8. *See* Jeffrey S. Janofsky et al., *The Hopkins Competency Assessment Test: A Brief Method for Evaluating Patients' Capacity to Give Informed Consent*, 43 Hosp. & Community Psychiatry 132 (1992); L. Jaime Fitten et al., *Assessing Treatment Decision-Making Capacity in Elderly Nursing Home Residents*, 38 J. Am. Geriatrics Soc'y 1097 (1990).
9. *See* Diagnostic Manual, *supra* note 1.

due to underlying injury or medical illness. The list of relevant illnesses is long and includes the most common medical problems afflicting the elderly. Delirium may be a result of hip fracture, head injury, cardiovascular disease (e.g., myocardial infarction, or "heart attack"), cerebrovascular events (e.g., strokes), metabolic disturbances (e.g., low serum sodium concentrations or high or low glucose concentrations), infections (e.g., pneumonia, urinary tract infections), and many other conditions. Drugs are also important causes. While certain drugs (e.g., corticosteroids, sedative-hypnotics) may be especially "deliriogenic," most classes of drugs have been implicated as causes of delirium in individual cases, and any new drug—even an "over-the-counter" preparation—should be considered suspect if its prescription coincides with the onset of delirium.

Of course, most patients with the aforementioned illnesses do not become delirious; some people are more vulnerable than others to the potential deliriogenic effects of diseases and drugs.[10] The elderly, as well as persons with pre-existing brain disease, such as Alzheimer's disease or stroke, particularly are at risk for delirium. In addition, there also is evidence that persons who drink alcohol regularly are more vulnerable to delirium.[11]

While delirium often accompanies terminal illness and carries a poor prognosis, many delirious patients have treatable underlying medical conditions and recover fully. The challenge to the clinician is uncovering the cause of delirium and treating it promptly. Delirium generally clears as the underlying condition is treated, although full resolution of symptoms and signs may lag days or weeks behind the initiation of effective treatment for the etiologic illness. In the meantime, it may be necessary to use symptomatic treatments to help ameliorate the most dangerous symptoms of delirium (e.g., antipsychotic drugs to treat delusions and extreme agitation).

D. *Delirium and Incapacity*

Like dementia, delirium is characterized by significant impairment in cognitive functioning and therefore often compromises decision-making capacity. Unlike most dementia syndromes, delirium is usually transient and reversible, and therefore, delirium-related decisional incapacity is often temporary. For this reason, distinguishing delirium from dementia is very important in decisions about the likely duration of incapacity. An additional complication is that dementia and delirium may coexist because demented patients are particularly vulnerable to delirium in the face of superimposed medical illness or drug toxicity. The evaluating clinician who recognizes the presence of delirium may be justifiably reluctant to make a simultaneous diagnosis of dementia and may insist on

---

10. *See* Zbigniew J. Lipowski, Delirium: Acute Confusional States (1990).
11. *See* Pamela Williams-Russo et al., *Post-Operative Delirium: Predictors and Prognosis in Elderly Orthopedic Patients*, 40 J. Am. Geriatrics Soc'y 759 (1992).

waiting until the delirium clears before making a judgment about the degree of irreversible cognitive impairment and the likely duration of incapacity.

E. *Major Affective Disorders*

1. Major Depression

Sadness is a normal part of our emotional repertoire. It usually occurs in response to loss or disappointment and gradually subsides as we regain what was lost or adjust to its absence. In contrast, clinical (or "major") depression is a clinical syndrome of which sadness is just one component. It may be precipitated by loss or disappointment but ultimately takes on a "life of its own," compromising the ability to experience pleasure, feel hopeful, and believe in one's personal value and goodness. Without treatment, it may persist for months or years and lead to serious functional incapacity and even premature death. The principal diagnostic criteria for major depression are shown in Table 3:

TABLE 3
DIAGNOSTIC CRITERIA FOR MAJOR DEPRESSION[12]

1. Sleep disturbance
2. Loss of interest; anhedonia
3. Inappropriate guilt; irrational self-reproach
4. Diminished energy
5. Low mood
6. Diminished concentration
7. Change in appetite
8. Psychomotor retardation or agitation
9. Suicidality or passive death wish

To qualify for the diagnosis, persons must have either low mood or loss of interest in usual activities plus at least four additional symptoms or signs. These symptoms must have been present daily for at least two weeks in order to be considered manifestations of major depression. In fact, most patients with clear-cut major depression have been ill for several months and have more than five symptoms. The most characteristic and diagnostically-useful symptoms are pervasive sadness, a recent negative change in self-esteem (e.g., feelings of guilt, preoccupation with being a burden to others), and the loss of energy and capacity for pleasure. Depressed persons often acknowledge that death would be a relief even when they feel confident that they would never attempt suicide. Occasionally they experience delusions and/or hallucinations, and in such cases the psychotic themes are in keeping with their other symptoms (e.g., delusions of guilt and blameworthiness; auditory hallucinations accusing them of committing heinous crimes).

---

12. *See* Diagnostic Manual, *supra* note 1.

As devastating and disabling as major depression can be, the prognosis is excellent with appropriate treatment. Properly prescribed antidepressant medications are effective in the vast majority of cases within one or two months, and often much sooner. Complete recovery is the rule.

2. Bipolar Affective Disorder

Persons with bipolar affective disorder, or manic-depressive illness, experience episodes of mania as well as depression. In mania, as in depression, the most characteristic symptoms are in the dimensions of mood, vitality, and self-esteem, but the deviations are in the opposite direction—manic persons are elated, boundlessly energetic, grandiose in their self-appraisal, and unfailingly optimistic. Talk is rapid, pressured, and abundant. Sex interest is amplified, and multiple sexual partners may be engaged in a short period of time. Money is spent impulsively. Grandiose delusions of personal beauty, genius, or identity (e.g., "I'm the mother of God.") may occur. Without treatment, mania generally persists for months. In response to mood stabilizing medications such as lithium carbonate, manic symptoms generally abate within two or three weeks. Lithium is also prescribed to preserve mood stability in bipolar persons who are in remission.

3. Mood Disorders and Incapacity

In persons with major affective disorders, the clinical dimensions most relevant to decision-making capacity are hopefulness and self-esteem. Irrational hopelessness, a depressive symptom, and hopeless optimism, a manic symptom, both can disable reasonable decision-making. Feelings of worthlessness, a depressive symptom, and excessive confidence, a manic symptom, both can undercut the ability to make best-interest decisions. Furthermore, delusions and hallucinations, whatever the tone (e.g., self-aggrandizing or self-deprecating), can undermine the ability to assess realistically what one needs, desires, deserves, and can do.

Decisions about incapacity are relatively easy when psychotic symptoms (e.g., hallucinations and delusions) are present. When such symptoms are absent, these decisions are much more difficult and are subject to the influence of ageism—often disguised as empathy. The capacity of nondemented but severely depressed older persons to refuse potentially life-saving treatment may go unquestioned if the examiner believes it is normal and understandable for elderly people to feel depressed and wish to die; in contrast, similar decisions by younger depressed persons are usually challenged.

The best protection against ageism in the determination of decisional capacity is to adhere strictly to explicit diagnostic rules and to link judgments about capacity directly to demonstrations that clear-cut depressive symptoms are exerting irrational influences on the decision-making process. Sometimes it is necessary to treat depressive disorders before mak-

ing confident judgments about capacity.[13]

4.   Schizophrenia

Schizophrenia is a chronic mental disorder characterized by particular kinds of hallucinations and delusions, disorganized thinking, and impairments in occupational and interpersonal functioning. The diagnostic criteria are shown in Table 4:

TABLE 4
DIAGNOSTIC CRITERIA FOR SCHIZOPHRENIA[14]

1. Particular kinds of delusions or hallucinations
2. Impairments in work, social relations and self-care
3. Continuous signs of disturbance for six months. Prodromal or residual symptoms as well as "active" symptoms
4. Affective disorder and medical disorders have been ruled out

Although often regarded as an illness of the young, schizophrenia also occurs in elderly persons, most of whom have grown old with early-onset illnesses; however, a distinct minority develop their first symptoms in mid- or late-life. It was in recognition of this fact that the current edition of DSM does not include age of onset as a diagnostic criterion. Elderly schizophrenics commonly are encountered in public housing for indigent elderly or in nursing homes, where they may be misdiagnosed as demented.

5.   Schizophrenia and Incapacity

Persons with schizophrenia may have delusions that specifically interfere with particular decisions, and in such cases judgments about incapacity are not difficult. In other cases, however, the delusions have no relationship to the decisions under consideration, and patients show a fair understanding of the issues at stake. The diagnosis of schizophrenia does not in itself imply global decisional incapacity.

IV.   ROLE OF DIAGNOSIS IN CONSIDERATIONS OF CAPACITY

No diagnosis, in and of itself, invariably implies incompetency. Patients with dementia, delirium, schizophrenia, bipolar affective disorder, and other psychiatric conditions *may* be capable of making responsible decisions. Establishing that a patient lacks decisional capacity requires more than making a psychiatric diagnosis; it also requires demonstrating that the specific symptoms of that disorder interfere with making or communicating responsible decisions about the matter at hand. Because it is this practical, functional issue that is most critical, it might be argued that diagnosis is, at best, irrelevant to judgments about capacity and, at

---

13. *See* Case 1, *infra* part VII.A.
14. *See* Diagnostic Manual, *supra* note 1.

worst, seriously misleading in that diagnosis might be taken as grounds for incompetence in the absence of evidence of impaired decision-making capacity.

But the fact that diagnosis can be misused or overemphasized in judgments about competency does not imply that diagnosis should be discarded as a consideration. It is a critical anchor and validator in competency judgments. It is a short-hand means of describing the patient's symptoms in language that is understood by other informed persons, and, most importantly, it assigns patients to a clinical category about which there is knowledge of prognosis. For example, a diagnosis of dementia due to Alzheimer's disease—assigned after appropriate medical evaluation—implies that the patient's disabling forgetfulness will increase in the future and decisional capacity will only grow more impaired. In contrast, a diagnosis of major depression—a condition often accompanied by subjective memory impairment as well as by diminished performance on cognitive testing—implies that the accompanying cognitive symptoms will almost certainly remit as the depression improves and decision-making ability will improve as well.

The requirement for the demonstration of a recognized diagnosis made by explicit criteria has another important role in considerations of capacity: it helps preserve the freedom of the individual to make unpopular and even unwise choices. Consider an elderly man who refuses to stop smoking despite severe progressive obstructive pulmonary disease. His physicians inform him that he is hastening his demise by continuing to smoke. He retorts that he does not believe smoking is harming him and that in fact he relaxes and breathes more comfortably when he smokes. His choice is unwise, unreasonable, and at odds with general knowledge about the relationship between smoking and pulmonary disease. A psychiatric evaluation is requested and reveals no evidence of dementia, major depression, or any other capacity-compromising psychiatric syndrome. His refusal to accept commonly-held beliefs about the relationship between smoking and lung disease might lead ardent anti-smokers to question his "competency," and this challenge might be sustained if there were no requirement for the demonstration of a disabling psychiatric disorder. The existence of such a requirement protects the patient against such a challenge and in effect preserves his right to make an unpopular choice.

V. UNCERTAINTY, DANGEROUSNESS, AND INCAPACITY

So diagnosis is an essential consideration in decisions about capacity. But it is not the only one. It is also necessary to show that the symptoms of the disorder specifically compromise the ability of the patient to make the decision at hand. This is generally a more difficult decision than determining whether a psychiatric disorder is present. The judgment about the extent to which the symptoms interfere with decision-making is made with degrees of confidence or certainty ranging from a little bit to a great

deal. Most often the judgment is made with substantial confidence. There is, for example, usually little uncertainty about the incapacity of a severely demented person to consent to participate in a complex experimental protocol or about the incapacity of a delirious patient to refuse intravenous antibiotic therapy for meningitis.

But sometimes the judgment is made with much less confidence. The patient has a mental disorder and shows some evidence of decisional impairment but also has lucid intervals or at times gives somewhat reasonable explanations for the choices made. In such a case, do the psychiatric symptoms disable decision-making, or do they not? How does the examiner make a judgment in the face of substantial uncertainty?

Sometimes it is possible to reduce the level of uncertainty by obtaining more data or different kinds of data. For example, it is often helpful to learn how the patient decided on similar questions in the past when there was no reason to doubt her decisional capacity. Discovering that the current decision is in line with previously-expressed values and preferences increases the physician's confidence that the current decision is "competent."[15]
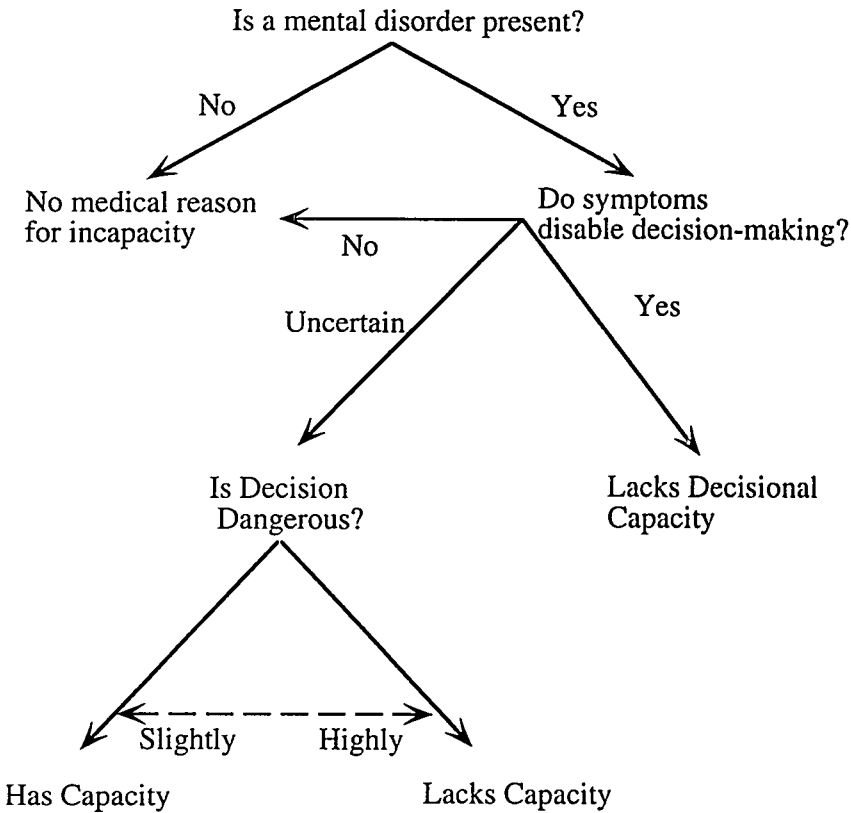
In some cases, however, uncertainty simply cannot be eliminated, and the clinician must nonetheless render a yes-no opinion regarding decisional capacity. What considerations tip the balance?

In practice, the examiner cannot resist taking into account the consequences of the decision the patient is making. If the patient's decision has little potential for causing harm, then a moderate degree of uncertainty regarding capacity is tolerable. On the other hand, if the patient is likely to be seriously harmed or to lose out on substantial benefit by virtue of her decision, then the examiner will tolerate much less uncertainty regarding decisional capacity. The physician will want to be as certain as possible that the patient knows what she is doing before rendering the opinion that the patient has the capacity to make the dangerous choice. The consequences of the patient's choice thus enter into the process of determining decisional capacity as modulating factors, influencing the level of confidence that the examiner requires in order to judge the person capable of making the decision at hand. Figure 1 shows the evaluation process schematically.

---

15. *See* Case 3, *infra* part VII.C.

FIGURE ONE

Is a mental disorder present?

No   Yes

No medical reason   Do symptoms
for incapacity   No   disable decision-making?

Uncertain   Yes

Is Decision   Lacks Decisional
Dangerous?   Capacity

Slightly   Highly

Has Capacity   Lacks Capacity

DANGEROUSNESS pertains to the risk of harm or lost benefit associated with the decision of the patient.

Dangerousness enters into judgments about capacity when there is uncertainty about whether symptoms are affecting the decision-making capacity of the patient. In such cases, the more dangerous the decision, the morelikely is the examiner to judge the person lacking incapacity.

VI. ETHICAL PRINCIPLES AND INCAPACITY

The ethical principle guiding most considerations about decisional capacity is the principle of autonomy.[16] But autonomy is not the only pertinent principle. Beneficence and nonmaleficence enter into the process under at least two circumstances: when decisional capacity is definitely compromised, and when it might be. Persons are assumed to be autonomous agents until proven otherwise. Mental illness abolishes the ability of the person to make an autonomous choice when the symptoms of the illness specifically interfere with the decision at hand. Enter beneficence and nonmaleficence. Given impaired autonomy, we are justified in making choices on behalf of the patient to promote her good (beneficence) and/or to prevent harm (nonmaleficence). Beneficence and nonmaleficence are relevant when autonomy is compromised.

But these principles also enter into the process when there is uncertainty regarding the degree to which psychiatric symptoms are affecting capacity. As discussed above, concerns about promoting good and preventing harm modulate the degree of uncertainty that will be tolerated in judgments about decisional capacity. If substantial lost benefit or great harm is at stake (i.e., if the decision is dangerous) very little uncertainty regarding decisional capacity will be tolerated. Instead the physician will lean toward judging the patient incompetent to choose, mobilizing the process of assigning a surrogate decision-maker. On the other hand, if the patient has little to gain or lose as a consequence of the decision (i.e., if the decision is not dangerous), uncertainty is much more tolerable, and the physician is less likely to declare the patient lacking in capacity given an identical level of uncertainty. To say it another way: When there is uncertainty about the extent to which the patient is capable of autonomous decision-making, beneficence and nonmaleficence come into the foreground.

VII. DETERMINING CAPACITY: CASES IN POINT

A. *Case 1*

An eighty-five-year-old woman was admitted to the hospital three days after falling and breaking her hip. She finally called an ambulance when the pain was unbearable. She was advised to undergo surgery but she flatly refused, even after the surgeons informed her that she might die of complications if she did not follow their recommendations. Psychiatric consultation was requested to determine whether she was "competent to refuse surgery."

She had no history of psychiatric illness. She lived with an alcoholic son who was of little help but did not otherwise abuse her. She felt that she had led a full life but was unhappy with her current circumstances,

---

16. *See* Tom L. Beauchamp & James F. Childress, Principles of Biomedical Ethics (2d ed. 1983).

saw little prospect for improvement, and looked forward to dying. She wanted pain relief and prompt discharge from the hospital.

On initial examination, she was alert and cooperative but readily tearful. She admitted she felt depressed. She had no interest in activities of any sort and gained pleasure from nothing. She was not self-blaming or guilty. She had little interest in eating. She slept adequately when medicated for pain. She felt that she had difficulty concentrating. She had no hallucinations or delusions, and her MMSE score was 24/30, suggesting slight impairment.

She met criteria for major depression. Her decision to refuse surgery seemed to be influenced by the depression because it was linked to an exceedingly negative view of her prospects and to a desire for death that emerged from this negative view. Furthermore, her refusal of surgery seemed to be at odds with her request for pain relief.

For all these reasons, it was deemed appropriate to try to persuade her to stay in the hospital while treating her depression and repeatedly reevaluating her wishes. She agreed to remain in the hospital and was given methylphenidate (Ritalin), a psychostimulant that is sometimes rapidly effective as an antidepressant. She responded with a conspicuous brightening of affect, improved appetite, and increased energy for interacting with nursing staff and visitors. Within three days she no longer appeared at all depressed. But her decision about surgery remained firm. She did not want an operation. She wanted to go home with pain medications as soon as possible. She understood that she might die and was willing to take the risk; indeed, she still looked forward to that possibility.

Although she continued to describe a passive wish for death, she had no other depressive symptoms and therefore no longer had evidence of a depressive disorder. Everyone involved with her care was convinced that she understood the risk she was taking and that she fully accepted that risk. Everyone involved with her care felt that she was making a free choice, acting autonomously, not unduly influenced by a pathologic negativity born of depression. There were no longer grounds for doubting her decisional capacity. The social worker arranged for an ambulance to take her home. She died the following day.

B. *Case 2*

A seventy-five-year-old woman with chronic schizophrenia was admitted to the hospital because of a hip fracture. When she refused operative repair, a psychiatric consultation was requested to determine whether she was "competent." When interviewed, she reiterated her stance against surgery, insisting that she had known many people who had done well following hip fracture without surgery. Besides, she explained, she had undergone gallbladder surgery many years ago, and the surgeons had intraoperatively implanted radiotransmitting equipment so that they

might monitor her whereabouts at all times. She was not going to put herself in such a vulnerable position again.

On examination she was calm and cooperative. Her talk was well-organized and intelligible. She said she was in a "good mood," and her affect was mildly indignant. She was not suicidal, and she did not wish for death. She described the delusions about the implantation of radio-transmitting equipment but had no other conspicuous delusions or hallucinations. Her MMSE score was 26/30.

She had a history of a chronic psychiatric illness and at the time of evaluation described paranoid delusions consistent with schizophrenia— her belief about intraoperative placement of radiotransmitting equipment. This delusion clearly interfered directly with her decision about surgery. Because of this direct link between symptoms and decisions, it was easy to see her refusal as a manifestation of her psychiatric illness and, therefore, *not* an autonomous act. On the other hand, she had at least one reasonable motive for refusing surgery, i.e., that others had avoided surgery successfully. This duality of motives created a dilemma: How does one judge decisional capacity when one set of motives is a manifestation of illness and the other is born of reason? In this case, an additional doctor was consulted. After further interviews, both consultants agreed that the principal motive for her refusal was her delusions, and that guardianship should be sought. By this time the surgeons were having second thoughts. They were reluctant to pursue surgery against her will because they feared that she would not cooperate with postoperative care. They decided to transfer her to a chronic hospital bed and to allow her to heal slowly. She went on to have an uneventful recovery and ultimately flew home to live with her children.

C. *Case 3*

A seventy-eight-year-old man, complaining of severe shortness of breath, fever, and confusion, was brought to the Emergency Room. A physical examination and chest x-ray demonstrated pneumonia involving portions of both lungs, and blood tests showed that he was going into respiratory failure. As the Emergency Room physicians prepared to intubate him and place him on a ventilator, he stated very clearly that he did not want to be intubated. They told him that he would probably die if he was not intubated, and he continued to refuse. At that point his physicians called over the consulting psychiatrist, who was seeing another patient, and asked for a quick consultation. He found the patient drowsy, inattentive, disoriented as to time, and definitely opposed to being placed on a ventilator. When asked why he was refusing treatment, he answered "I don't want to get old," but said little else. At that moment the psychiatrist recalled having interviewed this patient in the past following a similar episode of pneumonia. The patient had required treatment in an intensive care unit but had fully recovered within a few days. It turned out that the patient was a vigorous, active man who still

worked part-time and held leadership positions in many community or-
ganizations. He knew that he would not remain healthy and strong in-
definitely, and he abhorred the notion of growing old and frail. He went
on to tell the psychiatrist that he wished he had *not* been treated for
pneumonia—despite his excellent outcome—because he wished to die
painlessly at the height of his powers rather than to grow weak, infirm,
and dependent on others. He certainly would not want to be treated for
pneumonia in the future should he again have the opportunity for such a
desirable death. At this time the patient had no evidence of delirium,
dementia, major depression or any other potentially capacity-compro-
mising condition.

In contrast, today in the Emergency Room the psychiatrist found that
the patient clearly had a diagnosable mental disorder, i.e. delirium. But
the psychiatrist could not dismiss the patient's treatment refusal as a
product of delirium, because it was directly in line with a previous state-
ment made in a highly similar situation. Because the decision to refuse
treatment was in this case a very dangerous choice—one that carried a
mortality of nearly one hundred percent—the psychiatrist wanted to be
essentially one hundred percent certain that the patient's delirium was
not dictating the choice.[17] It was the psychiatrist's knowledge of the pa-
tient's prior statement that provided him with grounds for such cer-
tainty, allowing him to understand the patient's refusal of treatment as a
rational choice, not a product of fever and hypoxia. This knowledge of
previously-stated wishes made a particularly difficult judgment remarka-
bly straight-forward.

This case highlights an important aspect of capacity decisions: they
depend to some degree on the available data. In this case, knowledge of
the prior statement was pivotal. Without such knowledge the psychia-
trist could never have been certain that the patient's delirium was not
interfering with his decision-making and probably would have been influ-
enced by the dangerousness of the decision to err in the cautious direc-
tion and rule that the patient's decision-making was disabled by delirium.
This would have been wrong but understandable and probably the best-
possible judgment given the available data.

D. *Case 4*

A seventy-five-year-old man was being treated in an intensive care unit
for severe pulmonary disease. He appeared unable to understand his
medical problems and needs. Psychiatric consultation was obtained to
determine whether he was competent to make treatment decisions. On
examination he was fully awake and cooperative. He spoke when ques-
tioned, but his responses were rambling and bore no discernible relation-
ship to the questions asked. He gave no meaningful answers to questions

---

17. *See* Figure 1, *supra* part V.

designed to measure cognitive functioning and was unable to verbalize any understanding of his medical condition or treatment options.

On the advice of the nursing staff, the psychiatrist returned the following day with a voice amplifier and headphones. When reinterviewed wearing the headphones, the patient responded much differently; he was well-oriented, had a reasonable understanding of his medical problems and needs, and could express preferences rationally. His physicians were advised that his decision-making capacity was intact but that they should be sure to use this voice-amplifying device when discussing treatment options with him.

This case shows that decision-making may be hampered by factors that have nothing to do with capacity and that are in fact potentially easily remedied. It is critical look for such factors early in the process of capacity assessment.

CONCLUSION: AN APPROACH TO DETERMINING CAPACITY

The special role of physicians in determining decisional capacity lies in judging whether the symptoms of a mental disorder compromise the ability of a person to make a particular decision. Psychiatric diagnosis plays a major role in this judgment; it serves as an anchor and validator, helping protect persons against ageism and other inappropriate influences on capacity judgments. But psychiatric diagnosis is not sufficient. There must also be direct evidence that psychiatric symptoms are specifically interfering with decision-making. Thus the process of assessing decisional capacity has two principal components: (1) the psychiatric history and mental status examination—to determine whether a diagnosable psychiatric disorder is present—and (2) specific inquiry into the patient's understanding of and reasoning about the decision at hand—to determine whether psychiatric symptoms are disabling decision-making. When this process reveals that the symptoms of a psychiatric disorder are determining the patient's choice, a judgment of incapacity is clearly justified. But persons with psychiatric disorders, including dementia, may be quite capable of making particular decisions, and persons without psychiatric disorders may make unwise, unpopular or eccentric—but nonetheless competent—choices. Neither psychiatric disorders nor foolish choices by themselves signal incapacity.

The physician does not always arrive at conclusions about capacity with complete confidence. In particular, it is sometimes difficult to be certain that psychiatric symptoms are interfering with choice.[18] In such cases, it may be helpful to obtain other data (e.g., information about earlier choices about similar matters).[19] However, sometimes other data are unavailable or unilluminating, and a judgment must still be made. In such cases, the dangerousness of the patient's decision enters into consid-

---

18. *See* Case 2, *supra* part VII.B.
19. *See* Case 3, *supra* part VII.C.

eration: the more dangerous the decision, the more inclined the physician to lean toward safety and find the patient incapacitated.[20]

The principle guiding this approach is respect for the autonomy of the person. As long as the capacity for autonomous choice is intact, the patient is the unchallenged decision-maker. But when the capacity for autonomous choice is compromised by serious psychiatric symptoms, others must enter into the decision-making process to promote the patient's good and/or to prevent harm. The approach described is systematic and practical but is not failsafe. It is contingent on many factors: the skill of the examiner, the willingness of the patient to cooperate, the current medical status of the patient, the availability of history from other informants, and other variables. Even the best effort may require revision after an additional interview with the patient or a critical informant. For this reason it is best to view decisions about capacity as "best possible" judgments—well-reasoned opinions that are based on careful assessments but are subject to review and repair in the future if conditions change or new data become available. This is a modest stance—one born of respect for the difficulty of judgments about capacity in marginal cases and the important implications of such judgments in all cases. But it is also a bold stance, asserting that physicians are specially qualified to make judgments about the impact of sickness on decisional capacity and that these judgments can be made by explicit criteria. The protection of the sick—their autonomy and welfare—requires that their doctors be both modest and bold.

---

20. *See* Figure 1, *supra* part V.