3 Informed Consent

The following account by an anonymous correspondent describes an incident that takes place away from the setting of clinical medicine and that might seem remote from the issue of informed consent to medical treatment:

The scene was a church committee meeting. The business at hand was not especially exciting, so my mind was wandering. As I glanced around the circle of people, I noticed that a physician member of the committee (who had obviously also lost interest in the discussion) was staring intently at the young woman sitting next to him. What was unusual was that the object of his attention was the woman’s left foot—and he was neither a podiatrist nor an orthopedic surgeon.

I looked at her foot to see what he found so interesting, and I spotted it immediately—a sizeable round bump on the top of her foot. (It looked like the sort of super-large callus which develops as a result of months of crouching on a surf board for long hours every day. However, this woman was certainly not an habitual surfer.) As I watched my physician friend study the bump, it occurred to me that he was completely absorbed in this medical puzzle. (The thought occurred to me that this would be a good example to cite sometime to show that physicians can never stop being physicians, even in their off-hours.) However, my idle fascination soon turned to shock and a growing feeling of impending horror, for I saw my friend slowly (and somewhat absent-mindedly) bend and reach towards the woman until, finally, he touched the bump on her foot and began to palpate it.

The result was explosive! The woman screamed and jumped out of her chair to escape this man groping at her foot. This produced startled cries and movements from others in the group, and thus the whole committee meeting was disrupted.

It is clear from the story that the physician intended this woman no harm. He had become absorbed in a medical puzzle and had forgotten where he was and whom he was encountering. After all, he had come to this meeting straight from his office, where he had spent much of the day palpatting various body parts of his patients.

However, the woman was surprised and shocked by his act, and she was genuinely offended, in spite of the fact that she had worked with this man on this and other church projects for a number of years and considered him a friend. But palpatting her foot was not something she was ready to have a friend do. It might be okay for her doctor to do such a thing, but this man was not her doctor—especially not at this place and time.

3.1 The Legal and Moral Requirement of Informed Consent

The impropriety of this physician’s action involves more than a breach of etiquette or social convention. Our society acknowledges the seriousness of invasions of physical privacy by making violations criminal acts. The crime of “battery” is
defined in the law to include any willful act of touching a person without her or his consent. This is one of the two primary roots of the legal and moral requirement of informed consent; the anecdote illustrates why it is important. People do, indeed, feel strongly about the barriers to physical access included in our civil right to privacy.

3.1.1 The Scope of the Requirement This source of the informed consent requirement has important implications for its scope. Some form of consent is required for any procedure involving touching the patient’s body in any way (including, it might be argued, the prescription of medications to be ingested). However, this contrasts markedly with actual practice, as shown in Table 1-2.

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Written Consent</th>
<th>Oral Consent</th>
<th>Both</th>
<th>Neither</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient surgery</td>
<td>81%</td>
<td>3%</td>
<td>15%</td>
<td>0</td>
</tr>
<tr>
<td>Minor office surgery</td>
<td>26%</td>
<td>58%</td>
<td>9%</td>
<td>7%</td>
</tr>
<tr>
<td>Setting bones</td>
<td>39%</td>
<td>42%</td>
<td>9%</td>
<td>8%</td>
</tr>
<tr>
<td>General anesthesia</td>
<td>83%</td>
<td>3%</td>
<td>12%</td>
<td>1%</td>
</tr>
<tr>
<td>Local anesthesia</td>
<td>21%</td>
<td>57%</td>
<td>7%</td>
<td>15%</td>
</tr>
<tr>
<td>Diagnostic x-rays</td>
<td>45%</td>
<td>35%</td>
<td>8%</td>
<td>10%</td>
</tr>
<tr>
<td>involving injections</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood tests</td>
<td>2%</td>
<td>52%</td>
<td>0</td>
<td>45%</td>
</tr>
<tr>
<td>Prescriptions</td>
<td>1%</td>
<td>43%</td>
<td>2%</td>
<td>54%</td>
</tr>
<tr>
<td>Radiation therapy</td>
<td>63%</td>
<td>18%</td>
<td>11%</td>
<td>4%</td>
</tr>
</tbody>
</table>

[President's Commission (1982a, 108)]

Current professional practice may not fall as far short of the ideal as these figures suggest. In the first place, there is no legal requirement that consent be obtained in written form for any procedure except research protocols. Nor does the moral requirement of informed consent require a written form. What is important is that the patients (1) receive the information necessary to make an autonomous decision, (2) be free from influences that would render their decision involuntary, and (3) willingly agree to the procedure. The chief advantage of written documentation of these elements is that it carries greater evidentiary weight than reports of a verbal exchange. If verbal consent is obtained, a detailed account should be entered in the medical record; however, if the issue goes to court, the patient may dispute accounts of what was said or agreed to, whereas challenging a signed document is more difficult.

Furthermore, it is not clear that even a formal process of obtaining oral consent is required in all situations. Opportunities for a patient to register consent to or
refusal of treatment recommendations are part of the social structure of health care in a variety of ways. For example, if a patient decides not to follow the medication regimen the physician has prescribed, he may do so by not having the prescription filled, or having it filled but not using it.

Thus, in spite of the fact that 54% of physicians reported that they obtain neither written nor oral consent for prescriptions, there is still opportunity for consent or refusal by the patient. What may be lacking, however, is information on the basis of which the patient can make an intelligent decision. Relevant information should be imparted even if no formal process of seeking consent for the prescription is carried out.

Similarly, patients take the initiative to visit a physician; showing up at the physician’s office establishes the presumption that patients consent to routine measures of diagnosis and treatment. However, it is a mistake to read too much into this presumption. On the first visit, it is wise to inform the patient in advance of virtually every procedure you propose to perform—e.g., by saying “I am going to check your pulse rate now” just before you reach for an arm. This gives the patient the opportunity to register any objection or refusal if, for some reason, his or her general consent does not extend to this procedure. On subsequent visits, after the patient has had a chance to learn your routines, explaining each and every procedure may not be necessary. This allows you to move more efficiently—for example, by conducting the physical examination at the same time you are talking through the review of systems with the patient, or by conducting multiple elements of the examination at once.

3.1.2. Who Should Obtain Consent? This source of the doctrine has implications for the question of who should obtain consent. Written consent forms for surgery or invasive diagnostic procedures are sometimes handled like hot potatoes in hospitals and clinics. Everybody tries to delegate to someone else the task of getting them signed. The root of the requirement in the legal concept of battery makes clear that consent is to be obtained by anybody and everybody involved in the acts of touching. Carried to the extreme, then, the entire surgical or diagnostic team would come by the patient’s room to discuss the procedure and obtain informed consent for their role in it. This may be excessive, but it is at least required that the surgeon (as “captain of the team”) confirm the consent, even if some of the formal details are delegated to others.

For other procedures, the specialists or technicians who carry them out must confirm the consent for themselves. It is not enough to rely totally on the assurance of other parties that the patient has been informed about the procedure and has agreed to it.

3.1.3 The Sources of the Requirement In addition to the foundation in the law of battery, Anglo-American law has acknowledged another root of the legal
requirement of informed consent. In an important court opinion in 1960, Kansas Supreme Court Justice Alfred Schroeder declared:

Anglo-American law starts with the premise of thorough-going self-determination. It follows that each man is considered to be master of his own body, and he may, if he be of sound mind, expressly prohibit the performance of life-saving surgery, or other medical treatment. A doctor might well believe that an operation or form of treatment is desirable or necessary but the law does not permit him to substitute his own judgement for that of the patient by any form of artifice or deception. [Natanson v. Kline, 186 Kan. 393, 350 P.2nd 1093 (1960)]

Participation by the patient in decision making is also indicated on the basis of several other factors:

1. The potential for personal gain by the professional may offer a temptation to exploit the patient; a requirement for an explanation to and ratification by the patient serves as a countervailing check on professional choice.

2. The requirement for negotiation with the patient serves also as a check against sexist or paternalistic attitudes by the professional. It is psychologically difficult to sustain such attitudes while recognizing the legitimacy of having the patient share in decision making.

3. More fundamental, enlisting the patient’s participation in decision making embodies a respect for persons important as a general moral principle and as a demand of professional ethics: Section I of the AMA Principles of Medical Ethics reads: “A physician shall be dedicated to providing competent medical service with compassion and respect for human dignity.” The last phrase states the principle referred to here as a basis of the consent requirement.

4. The requirement also protects the authority and esteem of the profession by discouraging unfounded claims of knowledge. If explanations and answers to questions must be provided, one is likely to think twice before spouting off an unsupported claim.

5. Taking total responsibility for the patient’s life creates a feeling of isolation and an awesome moral burden. This may be necessary on occasions when patient and family are genuinely unable to share in decision making. However, it is unnecessary to impose this burden on oneself when others are capable of sharing it, and it is self-aggrandizing to assume that others are unable to share in this task or to exaggerate one’s own importance.

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18. For a description of this concept of self-determination, see the discussion of autonomy (another name for the same concept) in Chapter 2, Section 2.3.1.
19. For further discussion of this principle, see Appendix 1, Section 2.2.
6. The requirement can be seen as an application of democratic principles to the physician-patient relationship. Just as citizens expect to have a voice in political decisions, they expect to participate in medical decisions. And just as we are convinced that political decisions are improved by being shared, the same may be true of medical decisions.\textsuperscript{20}

3.1.4. The Spirit of the Requirement The President's Commission captures the spirit of informed consent in a sound and helpful way: "Ethically valid consent is a process of shared decision-making based upon mutual respect and participation, not a ritual to be equated with reciting the contents of a form that details the risks of particular treatments." (1982a, 2; cf. 36–39, 50–51). The Commission's report points out that a focus on the legal aspect of the requirement, as it has developed in court cases, shapes our understanding in some unfortunate ways:

1. "Cases that find their way to court invariably involve interventions that did not go well" (p. 25).
2. "Courts see only those cases in which particular allegedly undisclosed risks associated with medical procedures have led to actual injuries" (p. 25). Thus, "the inquiry concerns whether that particular risk was disclosed, rather than whether the overall course of care, and the extended process of disclosure, were properly respectful of the patient's right of self-determination" (p. 26).
3. "Courts must grapple with . . . the impact of hindsight on the litigation process" (p. 26).
4. "Courts must determine whether required disclosures were in fact made" (p. 28), which leads to reliance on written documentation (although this is not otherwise required and may, indeed, become a barrier to useful exchange of information and shared decision making).
5. "The structure of lawsuits requires the naming of particular defendants who will bear financial responsibility" (p. 29).

In contrast, the spirit of the requirement of informed consent focuses not on specific items of medical information or rituals of obtaining signatures, but on "discussions between professional and patient that bring the knowledge, concerns, and perspective of each to the process of seeking agreement on a course of treatment. Simply put, this means that the physician or other health professional invites the patient to participate in a dialogue in which the professional seeks to help the patient understand the medical situation and available courses of action, and the patient conveys his or her concerns and wishes" (President's Commission 1982a, 38). Clearly, this is closely related to the phase of recommendation and negotiation discussed in Section 1.2.4.B.2.

\textsuperscript{20} Cf. "So fundamental is this right of self-determination in a democratic society that to limit it, even in ordinary medical transactions, is to propagate an injustice" (Pellegrino 1979, 98–99).
To see the contribution patients can make here, we need to recognize that management of a patient's illness rests on value judgments as well as technical decisions of medical science. In prescribing medication for pain in the postsurgical patient, for example, not only must you determine which dosage will be effective in relieving the discomfort without risking toxic side effects (essentially a technical problem, although it rests on an assumption that death is a disvalue), but a choice must also be made between fundamental values. Many pain-killing drugs dull the mind, and many such drugs can lead to addiction. Hence the decision about how long to continue such medication rests on a choice between the value of relief from discomfort and the competing values of maximum mental acuity and freedom from the danger of dependency. Furthermore, the mind may be affected by the medication in a way that alters the experiencing of events. (This is one of the arguments offered, for example, by proponents of natural childbirth.) All of these are acknowledged values, but in the situation at hand it is not possible to preserve all of these values at once. Hence a judgment must be made as to which of the sets of values in conflict is the most important.

One obvious reason for not taking this decision on your shoulders is that your ranking of these values might not match that of the patient. You might be motivated to favor relief of pain, for example, on the basis of either (1) your own preference between these competing values, or (2) a feeling of kindness, or even (3) your careful judgment of the patient's best interests. In contrast, the patient might have a stoic attitude toward pain and prefer to endure it and maintain a clear head.

However, even if your value rankings coincide perfectly with your patient's in a given case, there is still a moral reason not to make the final decision yourself. There is intrinsic value in controlling one's own life, a value that reveals itself in concrete situations. Suppose, for example, that in the situation described above you recognized the patient's stoicism and made a decision to withhold medication in acknowledgment of the patient's values. This approach leaves out an important moral element. There is a morally significant difference between choosing for oneself to face the pain and having the decision made on one's behalf by another; the moral quality of the first of these alternatives (which amounts to a sort of courage) is denied to the patient if you, the physician, make the decision entirely on your own initiative.

3.2 Practical Applications

How does this translate into practice? Let us follow further the drama of Lynn Languish. The extended, gradual process of information exchange earlier described in her case is a process of multiple informed consents.
3.2.1 Initial Diagnostic Steps  At the outset, when the axillary lump is discovered, the situation is one of numerous diagnostic possibilities, some of which are serious (e.g., breast cancer, AIDS) but most of which are relatively benign. Since various of the benign possibilities are both (1) much more probable and (2) treatable if discovered expeditiously, clinical wisdom would dictate pursuing them first in the diagnostic work-up. Indeed, it was recommended earlier that specific serious possibilities such as breast cancer, tuberculosis, and AIDS not be mentioned explicitly to the patient at this time (although indication should be given that serious possibilities do exist but that their probability is low).

3.2.2 Patient Anxiety  However, if the patient's response to an explanation of this approach indicates that she is extremely anxious about the threat of breast cancer and will not rest easy until it has been ruled out, this may be reason enough not to postpone diagnostic tests to explore this possibility. Undoubtedly this would be the case if the test in question were both low-risk and low-cost.

But what if the test were expensive? This becomes a question of putting a price on achieving reassurance for the patient. There are limits to the level of expenditure justified for this purpose, but those limits are not easy to define. The situation can be explained to the patient (along with a reminder of the low probability of this diagnosis), and she can participate in the determination.

What if the tests were invasive and/or involved considerable risk to the patient? Again, there is no ready basis for determining what degree of discomfort, risk, etc., is worthwhile to achieve reassurance except to consult with the patient about the matter.

If you disagree strongly with the choice favored by Lynn, you face these options:

1. If you are convinced that Lynn is still not fully aware of the relevant medical information or is not taking it into account in formulating her preference, you should continue the discussion until satisfied that she is fully informed.
2. If disagreement persists, you should carefully examine the basis of your conclusions. Be sure that the values at stake are ones sufficiently important to you that compromise would violate your integrity.
3. If the values are *not* this central to you, try to negotiate a compromise position that both you and Lynn could accept.
4. Even if they are central, give some serious thought to the possibility of a "middle ground." Perhaps there is an alternative not considered that could preserve the key values of both parties.
5. If the values at stake are core values for you both *and* there is no way to resolve the conflict between these values, then perhaps no physician-patient accommodation is possible between the two of you on this occasion. Help her find another physician who is more likely to achieve an accommodation with her.
3.2.3 Diagnostic Decisions  Similarly, the patient’s wishes can play a central role in determining whether to pursue diagnostic trails involving risky or painful tests that might detect treatable conditions.

3.2.4 Preparation for Knowledge and Action  As the diagnostic work-up proceeds, explanation of the purpose of the various tests can lead naturally to discussion of the nature of the condition that might be discovered, its degree of seriousness, and the range of treatments available for it.

3.2.5 Useless Knowledge  If the stage is reached, for example, in which (1) the possibility of a serious diagnosis is strong, (2) treatment is advisable or impossible (perhaps due to other serious health problems the patient has), and (3) the definitive test is risky, then the patient might agree to forego the knowledge of the precise cause of her condition.

3.2.6 Treatment Choices  If the process has proceeded as suggested, then the choice usually identified with an informed consent (i.e., the selection of a major treatment modality) need not stand out as such a momentous event and difficult task. The information to make a decision about treatment will not come to the patient as a bolt out of the blue. She will have been prepared for this decision gradually and thus have had opportunities (with proper support and assistance) to work through the emotional reaction to the information, and the intellectual task of understanding and weighing the factors relevant to negotiating a decision with her physician.

If informed consent were restricted to a single session in which information were presented and the patient were required to reach a decision on the basis of it (as happens all too often in actual practice), then a standard such as the following would be overwhelming and impossible:

The Commission believes the core elements [of substantive issues to be discussed by professional and patient] fall under three headings: (1) the patient’s current medical status, including its likely course if no treatment is pursued; (2) the intervention(s) that might improve the prognosis, including a description of the procedure(s) involved, a characterization of the likelihood and effect of associated risks and benefits, and the likely course(s) with and without therapy; and (3) a professional opinion, usually, as to the best alternative. Furthermore, each of these elements must be discussed in light of associated uncertainties. (President’s Commission 1982a, 74)

However, if the process is gradual, as recommended here, the task of conveying all this information is not nearly so formidable.

3.2.7 Standards of Disclosure  Many discussions of informed consent offer detailed lists of information to be disclosed in the informed consent process. This is especially true of discussions focusing on informed consent to experimental
procedures, but the same is often applied to consent to therapeutic procedures. At least two states have incorporated into legislation specific disclosure requirements concerning treatment of breast cancer. Others have tried to develop a specific criterion for disclosure; every risk with frequency greater than 1:1000, for example. Court cases have dwelt on more abstract criteria, such as whether the standard should be the prevailing practice in the professional community, or what the "rational patient" would want to know, or whatever would influence the decision of the individual patient.

3.2.8 Varying the Discussion In contrast to these general criteria, the President's Commission (1982a, 38) "encourages, to perhaps a greater degree than is explicitly recognized by current law, the ability of patients and health care professionals to vary the style and extent of discussion." The spirit of the requirement, as opposed to an exclusive focus on the legal dimensions, allows for variability to fit the interests of particular patients and professionals. The Commission report continues:

Such variations might take any of several directions: in one relationship, the patient might prefer not to be burdened by detailed discussion of risks unlikely to arise or to affect the decision; in another relationship, a patient might request unusually detailed information on unconventional alternative therapies; in a third, a patient with a long-standing and close relationship of trust with a particular physician might ask that physician to proceed as he or she thinks best, choosing the course of therapy and revealing any information that the physician thinks would best serve the interests of the patient. Inherent in allowing such variations is the difficulty of ensuring they are genuinely agreeable to both parties and do not themselves arise out of an imbalance in status or bargaining power. (President’s Commission 1982a, 39)

3.3 The Paradox of Autonomy

The third variation described in the Commission report gives rise to a paradox: autonomy is compromised whichever way you respond to patients’ requests to make decisions on their behalf without their active participation. The request may be assumed to be an expression of the patients’ autonomy; to deny it would be a failure to respect their present autonomy. However, to grant the request would be to compromise the patients’ future autonomy, since future decisions would be made on the patients’ behalf (as they request), and thus these would be instances of paternalism. Furthermore, even if patients decided that they wanted to share in

22. Cf. The Patient’s Bill of Right (American Hospital Association); The Model Patient’s Bill of Rights (The American Civil Liberties Union).
certain decisions in the future, their contribution would not be fully autonomous if some information had been withheld. Thus the question is "Autonomy today or autonomy tomorrow?" Autonomy on both occasions cannot be achieved.

This text argues strongly for bringing patients into an active role in decision making whenever possible, even if this means going against their wishes (and thus violating present autonomy). Informed consent is not a discretionary right to be exercised or waived as one wishes. It is, instead, one legal and ethical expression of a responsibility for one's life; this responsibility cannot simply be handed to another. Patients should be guided (gently and with supportive counseling) to accept responsibility for decisions affecting their own lives.

3.4 Mental Competence

Of course, this goal is not always possible to achieve. Some patients lack the capacity for autonomous participation in decision making; in these cases, there may be no alternative to having others exercise paternalism by making decisions on their behalf to promote their best interests.

Infants and small children undeniably lack capacity for exercising autonomy. The only serious question arising here is who should give "proxy consent" on their behalf. (It should be noted that "proxy consent" is not, strictly speaking, an alternative variety of consent by the patient. Rather it is a form of paternalism that serves as a substitute for consent by the patient himself.) To see how the AMA Judicial Council deals with this issue in one especially difficult circumstance, see the second paragraph of "Quality of Life" (Section 2.14) from Current Opinions, quoted in Chapter 4, Section 2.1.

For older children, determining whether they possess the mental capacity to give consent is much more problematic. For example, in Tennessee no child under age 18 is legally qualified to consent to medical treatment on his or her own behalf (except for abortion procedures and perhaps birth control). Yet many 17-year-olds possess the mental capacity to give consent for almost any medical procedure. However, it is much less clear what to say about a child of 15 or 10 or 7.

More controversial cases arise with patients afflicted with mental dysfunctions; patients whose judgment is clouded by chronic, severe pain; or patients in the grip of overwhelming compulsions such as alcoholism. Consider the following case sketches. Which of these patients are competent to consent to or refuse treatment?

1. A 70-year-old widow living alone in a condemned dilapidated house with no heat was brought against her will to the hospital. Her thinking was tangential and fragmented. Although she did not appear to be hallucinating, she seemed delusional. She refused blood tests, saying "You just want my blood to spread it all over the city. No, I'm not giving it."

24. The issue of proxy consent will be discussed in detail in Chapter 4 in connection with life-and-death decisions, where it has its most momentous application.
2. A 60-year-old woman was found wandering on a city street. When questioned, she could not give her home address. She was unable to remember when her sister, her son, and her husband had died. She also showed what were diagnosed as paranoid tendencies, believing that government agencies had taken her pension away from her. When commitment to the state psychiatric hospital was proposed to her, she said: "I don't want to go to that place. Leave me alone and let me go home!" She was diagnosed as suffering from organic brain syndrome with arteriosclerosis.

However, she was able to find her way to her home (smoothly managing a fairly complicated series of transfers on public transportation), even though she could not recite the address. Furthermore, her government pension had indeed been cut off several years earlier, and an active review of this action was underway (and had been for more than a year). The downtown street on which she had been "wandering" was on the route from the bus stop to the governmental office where she had just gone (as she had many times before) to inquire about the review of her pension status. She does have periods of confusion and mild loss of memory, interspersed with times of mental alertness and rationality.

3. A 54-year-old businessman refuses a treatment that had been recommended, saying "I understand that I am running quite a risk by foregoing this treatment, but I have decided that I don't want it. And I don't think I owe you an account of my reasons. I consider the matter closed."

4. When asked why he has not been taking his medicine for hypertension, the 41-year-old man says, "I mean to take it, but I keep forgetting about it."

5. When asked why she has not been taking her medicine for hypertension, the 40-year-old professional woman says, "I have been following a megavitamin program someone at work told me about. He said it was a natural remedy, and that it would control my blood pressure without any of the dangers of medicines."

What is mental competence and how can it be determined? Charles Culver and Bernard Gert (1982) relate mental competence to more general statements of competence or incompetence (as in "John is a competent architect" or "Henry is incompetent to design a house"). They point out that "to say of someone that he is incompetent demands a context. A person is not simply incompetent; he is incompetent to do x, or x and y, or x, y, and z... How is one to decide if such a person is competent to do some particular type of activity? The more precisely described the activity, the more likely it is that one can decide whether or not someone is competent to perform it" (Culver and Gert 1982, 54). On this basis, they offer the following elements of a general standard of competence: "Two necessary features for being competent to perform an activity are that one understands what that activity is and knows when he is performing it" (Culver and Gert 1982, 54).
Some view this much as nearly enough to form a sufficient criterion of competence to consent to or refuse treatment:

The individual in question must have sufficient intellectual capacity to 
1) understand the simple nature and purpose of the act itself in lay terms—"My 
consenting to medical care means that you can't do it unless I say okay."; 
2) comprehend the basic facts of the case—"You say I have this disease even 
though the doctor I saw before said I had another disease."; 3) recognize 
alternative ways of acting—"The choices are an operation or radiotherapy or both 
or neither." (Lipp 1977, 66)

However, this seems too broad. Using this criterion, all patients in the case 
sketches above would be considered competent. Even the woman in case 1 appears 
to understand that the choice is hers to make, and she also understands the 
explanation given by the physicians for the blood test—she does not believe them, 
but she does understand! Similarly, the patient in case 4 could recite what he has 
been told about the importance of controlling his blood pressure. (And the patient 
in case 5 might be able to do the same thing with what she has been told about the 
nature of the recommended drug treatment.) Thus, at some level, they understand 
this reasoning. Their problem is in carrying this understanding into action by 
complying with the recommended treatment.

Furthermore, if this set of criteria is too broad, the same is true of the generalized 
mental status exam as a test of competence to consent. That the patient is oriented 
to time, place, person, etc., does not imply that he has the mental capabilities 
needed to give acceptable informed consent or refusal. More (and other) capacities 
than this are necessary.

The roots of the requirement of informed consent in autonomy and self-
determination suggest that the conditions of autonomy could serve as the standard 
here. This fits the way of developing a criterion suggested by Culver and Gert.

However, if we consider the conditions of autonomy,\(^\text{25}\) it is obvious that none of 
the patients in our case sketches would qualify as autonomous—indeed, none of us 
would qualify as \textit{fully} autonomous, since this requires a complete and coherent set 
of life goals and deliberation in terms of them for every action we undertake. This 
is then too strong a criterion. What must be found is a way of measuring the degree 
of partial autonomy marking the borderline between mental competence and 
incompetence to give consent to medical treatment.

The President's Commission (1982a, 57) offers such a criterion in the 
following:

Any determination of the capacity to decide on a course of treatment must relate 
to the individual abilities of a patient, the requirements of the task at hand, and the 
consequences likely to flow from the decision. Decisionmaking capacity 
requires, to greater or lesser degree: (1) possession of a set of values and goals; 
(2) the ability to communicate and to understand information; and (3) the ability 
to reason and to deliberate about one's choices.

\(^{25}\) NOTE: These are discussed at some length in Chapter 2, Section 2.3.1.
How would the patients in the preceding case sketches rate in terms of this criterion? The patient in case 1 appears clearly not to fit. Her “tangential and fragmented” patterns of thinking show she lacks the capability to reason and deliberate about her choices.

The patients in cases 4 and 5 seem competent by this criterion. For the patient in 4, the problem comes not at the level of ability to reason, deliberate, or understand, but rather in translating the conclusions of this deliberation into action. The patient in 5 is carrying through deliberations, but, tragically, on the basis of misinformation supplied to her by a no doubt well-meaning, but misguided associate.

The problematic cases here would be 2 and 3, since neither of these demonstrates the ability to communicate relevant information, especially the results of their deliberation. However, the President’s Commission (1982a, 62) adds another element to the criterion: “An assessment of the patient’s decisionmaking capacity begins with a presumption of such capacity.” On this basis, the patient in case 3 must be regarded as competent to refuse consent. He has not done anything to demonstrate his inability to make a deliberative decision, and thus we must assume he is capable of doing so. Similarly, the patient in case 2 was ruled as incompetent prematurely, on the basis of an inability to communicate, which is not crucial for her to manage her daily life, i.e., she can manage to find her way home, even if she cannot recite the address. So she, too, would have to be ruled as competent once her actual capabilities are discerned.

Cases 2–5 must be classified as examples of mistaken decisions, rather than incompetency per se. The President’s Commission (1982a, 60) offers the following directive: “The obligation of the professional is not to declare, on the basis of a ‘wrong’ decision, that the patient lacks decisionmaking capacity, but rather to work with the patient toward a fuller and more accurate understanding of the facts and a sound reasoning process.”

3.5 Manipulation

“Work with” must be distinguished from “manipulate” (as must “guide,” “negotiate,” and other related terms). If the result is to be genuine shared decision making, then you as a physician must be on guard against overt or covert forces that influence the patient in nonrational ways. The authority of your position, the vulnerability of the patient due to the emotional impact of illness and the institutional complexities of care, and the strength of your personality and outlook may influence the patient too much.

Some physicians say, “I can get patients to consent to anything I want.” This is undoubtedly often true, but it is achieved through manipulation. The challenge is to avoid this nonrational influence—or, at least, to minimize it if it cannot be avoided entirely.

The goal is to move patients toward autonomous decision making, in which they
take responsibility for their own lives. This may require steps on your part to neutralize coercive forces and guard against unduly influencing the patient yourself.

4 Confidentiality

Confidentiality is extremely important to patients and has historically been regarded with great respect by health care professionals. In this section, you will explore the values and ethical principles behind the principle of confidentiality. Why does it matter so much to patients? What values does it promote, and what is the source of its importance? The answer may help one decide when the principle has reached its limit so that information about a patient should be revealed.

4.1 The Importance of Confidentiality

"Why should people be so concerned about confidentiality? If they have done nothing wrong, they should have nothing to hide. And, if they have done something wrong, perhaps we should not assist them in hiding it."

This expresses a common sentiment about confidentiality. Some of the cases in this section involve people who do have something shameful or some sort of wrongdoing to hide, and these may confirm this attitude toward confidentiality.

However, there are reasons for privacy that do not necessarily involve shame or wrongdoing, and it is these that provide the background for the principle of confidentiality. Every society has a sphere of life kept shrouded in secrecy, a private realm. The content of this realm may differ from culture to culture (and from person to person within a culture). Some cultures may not be particularly "up-tight" about nudity but will have other areas of life about which they are as reticent and discreet as our society is about nudity. For example, another domain of secrecy in our culture is money. Ask someone his annual income or net worth, and you are likely to be met with elaborate evasion instead of a straight answer. Of course, some do not share this reticence but may be secretive about some other issues, e.g., political leanings or religious attitudes, about which others, in turn, may be more open.

We would guess that you have some secrets yourself. Stop and think about it briefly. Use the following questions to guide you.

1. Would you be troubled if your mind suddenly became an "open book," i.e., such that everyone could tell exactly what you were thinking at any moment?

2. Identify three things about yourself you have never told anyone. (CAUTION: Do NOT write these down! Somebody might discover your list, which could be embarrassing.)