The Communication Process

The final element of effective patient participation in health care decisionmaking is the actual communication between patient and professional of the facts, values, doubts, and alternatives on which decisions must ultimately be based. This process should transcend the professional’s legal “duty to warn” of the risks associated with a proposed medical intervention. Indeed, from the Commission’s perspective, the law’s near-exclusive focus on the disclosure of risks—which has often led to standardized forms and recitations of risks, but not to a full dialogue with patients—has had an unfortunate impact on the very objectives the informed consent process is designed to achieve.  

Further, this preoccupation with risks is undoubtedly responsible for much of the medical community’s skepticism about informed consent. In this section, therefore, the Commission seeks to reorient the discussion of “informing”—and of patient-professional communication generally—in directions more likely to produce the objective of all health care: improved well-being and self-determination.  

Two major objectives are promoted through the communication process between patient and professional. The first is therapeutic, in many circumstances, patients knowledgeable about their condition and involved in the decisionmaking process are likely to emerge from therapy in better health. A number of recent studies indicate that informed patients tend

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2 As well as looking beyond an excessive preoccupation with disclosure of risks, this section seeks to take account of the diversity of situations and individual preferences that characterize the real world of medical practice. Accordingly, the discussion is based in significant part on the substantial body of empirical literature on informed consent and professional-patient communications.
toward greater compliance with certain therapeutic regimens, reduced levels of anxiety, faster recovery from surgery, and enhanced ability to protect their own well-being—by detecting errors in dosage or type of medication, for example, or by recognizing untoward side effects.  

Second, patients making informed decisions are likely to better advance their own life plans. As discussed in Chapter Two, for self-determination to be meaningful, patients must have some understanding of the alternatives and what they entail. The obligation of health care professionals, who typically will have a greater command of this information than patients, is to communicate that information in an understandable fashion.

The Nature and Scope of Disclosure

Much confusion has arisen, both in legal contexts and in the medical and philosophic literature, over the nature and scope of the information to be disclosed and discussed. Although the content and extent of the information to be discussed will inevitably depend on the circumstances of the particular case, the ethical standard for assessing the adequacy of discussion is constant. Professionals should discuss with patients the facts and associated uncertainties that will give patients a working understanding of their situation and of available treatment alternatives, so they can participate effectively in the decisionmaking process. This will include consideration of patients’ values and objectives, as well as their ability and desire to participate in the decisionmaking process.

To the extent these characteristics of an individual differ from those of the law’s hypothetical “reasonable person,” professionals should tailor the “standard” presentation. Obviously, for such tailoring to take place, practitioners must be aware of the special needs of particular patients. For legal purposes, an important question concerns whether the burden of communicating such special needs is placed squarely on patients (who typically are the best judges of their own values and objectives), or whether health care professionals should notice certain “apparent” special needs and try to elicit others through discussions with patients (or, in some cases, with members of their families). The professional’s responsibility may be especially compelling given that certain procedures are objectionable to identifiable population groups (such as blood

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3 See full discussion pp. 99-102 infra.
4 Many medical writers, see note 5 in Chapter Seven infra, assume that the law of informed consent requires that patients be given a detailed “mini-course in medical science,” Cobbs v. Grant, 8 Cal. 3rd 229, 104 Cal. Rptr. 505, 502 P.2d 1, 11 (1972), as the California Supreme Court characterized it in the course of rejecting such a view.
transfusions for Jehovah’s Witnesses) and that different patients assess the desirability of various medical procedures in very different ways (as with surgery for breast cancer, or “last ditch” therapies for cancers that are terminal). Whatever the legal resolution of this burden, from an ethical perspective professionals should in good faith try to elicit and discuss the values of their patients insofar as those values affect choices to be made among medical alternatives.

Professionals should recognize, and lawyers and courts should perhaps be reminded, that patients’ interests are not well served by detailed technical expositions of facts that are germane neither to patients’ understanding of their situations nor to any decisions that must be made. Such recitations are not legally required, nor should they be. Overwhelming patients with a mass of unintelligible technical data that they are ill-prepared to comprehend or use, particularly at what may be a stressful time, can be as destructive of the communication process and its goal of enhanced understanding as giving too little information is. Similarly, reciting “all the facts” in a blunt, insensitive fashion can also destroy the communication process, as well as the patient-professional relationship itself. The professional’s goal should be a tactful discussion, sensitive to the needs, intellectual capabilities, and emotional state of the particular patient at that time, in terms that the patient can understand, assimilate, and work with as part of the ongoing decisionmaking process. To be sure, translating medical jargon and discussing issues of concern to patients requires time and considerable intellectual and emotional effort. But those are the necessary costs of achieving the objective and are properly regarded as part of practitioners’ professional responsibility.

The current tendency toward excessively technical recitations of medical data may reflect, at least in part, the medical profession’s understandable reaction to the fear of lawsuits in
the event an undisclosed, remote risk should result in injury to a patient. This illustrates one important counterproductive effect of the law’s focus on the “duty to warn” aspect of informed consent. Reconciling the requirement that all material facts be disclosed with the objective of facilitating an intelligent discussion of the most salient issues is clearly no simple task, either for the law that must formulate disclosure standards or for practitioners who must apply those standards to the myriad individual circumstances that arise in medical practice. Nor is the conflict between full disclosure and intelligent discussion unique to the law of informed consent. Indeed, this conflict represents an important limitation on the law as an instrument of social control.

In the Commission’s survey, professionals and the public were asked several questions about disclosure in general and about who is responsible for making sure patients are adequately informed. Nearly all the public (97%) said that patients should have the right to all available information about their condition and treatment that they wish. Somewhat surprisingly (since patients report that they want virtually all information), when asked “Who do you think is the best judge of the amount of information that should be disclosed to the patient?,” 45% of the public said the patient and 44% said the physician. In addition, 56% of the public thought that some patients should be told less about their treatment than others. Few people (2%) complained that doctors tell patients too much about either routine care or serious illness. However, 38% felt that patients are told too little about routine care and 33% felt the same about serious illness.

Physicians were asked: “How often do you find yourself in a situation where you must make a conscious and deliberate evaluation of how much to tell a patient about his condition or treatment?” Far from being a rare occurrence, 27% said “several times a day,” 25% said “daily,” 20% said “weekly,” 25% said “rarely,” and 3% said “never.” In an open-ended

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5 People in poor health, the elderly, and those with little education or low income were most likely (up to 58%) to view the doctor as the best judge. People with a life-threatening illness, those in poor health, those over 35, those with high incomes, and college graduates were more likely (up to 65%) to feel that some people should have less information than others.

6 Young people, women, people without a usual source of medical care or health insurance, the college-educated, and those with high incomes were more likely than others to feel that doctors give too little information about routine care and serious illness. Overall, 11% of the public were uncertain whether doctors give the right amount of information about serious illness.

7 Internists were most likely and obstetricians/gynecologists least likely to deliberate frequently about how much to tell a patient. Among specialists and sub specialists, 9% reported they deliberate as
question, physicians were asked: “What are the primary factors that influence how much you tell a patient about his condition or treatment?” The patient’s ability to understand (56%) and to cope with the information (31%), the seriousness of the condition (30%), and the patient’s desire to know (25%) were the reasons given most frequently.\(^8\) Time constraints were mentioned by only 2% of the sample.

In terms of responsibility, physicians felt it is primarily their responsibility to make sure that the patient is fully informed (77%) rather than the patient’s responsibility to ask for information (3%), although 19% said the doctor and patient are equally responsible. The public, on the other hand, especially those in poor health and with little education, generally placed more of a burden of responsibility on the patient (20%). In general, however, the public agreed with the physicians that it is the latter’s responsibility to make sure patients are fully informed.

When asked whether their physicians keep them informed about questions and decisions relating to their medical care that they (the public) consider important, 37% said they are informed on all important issues and another 30% said they are informed on most issues.\(^9\)

seldom as weekly and 11% reported that they rarely evaluate the amount of information to disclose. Physicians who are hospital-based and those who treat a high percentage of patients with serious illness were more likely than office-based physicians or those who treat fewer seriously ill patients to report frequent conscious evaluations.

\(^8\) Some significant variations were found within subgroups of physicians concerning the factors that influence how much information is disclosed. Although the patient’s ability to understand was the factor most often cited by all physicians, those treating primarily poor patients were significantly more likely than those with few poor patients (71% versus 52%) to mention patient understanding. Foreign medical graduates were most likely to mention seriousness of the patient’s condition (37% versus only 14% of graduates of U.S. public medical schools with major research support). Foreign medical graduates and physicians treating primarily poor patients were the least likely to mention a patient’s desire for information as a factor that influenced disclosure (15% of foreign graduates compared with at least 25% of U.S. graduates, and 17% of those with a majority of their patients being poor compared with 27% of physicians treating few poor patients).

\(^9\) People without a usual source of care felt least well informed. Those in poor health, the elderly, the poor, nonwhites, those with no health insurance, and the poorly educated felt best informed, perhaps because their expectations were lower. Those most satisfied with their doctor’s willingness to answer questions about their condition and treatment were people who had had a life-threatening illness, who usually got their medical care in a doctor’s office, or who were in poor health, elderly, female, white, or with little education. These
What, then, are the substantive issues to be discussed by professional and patient? These have been variously formulated by courts and commentators, and one version has been incorporated in the federal regulations governing the conduct of research with human subjects. In addition, recent surveys have identified a number of elements as particularly important to patients. Without seeking to provide the last word on this much-discussed subject, the Commission believes the core elements 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.

Current Medical Status. Inaccurate or incomplete information about illness limits patients’ understanding of the effects and of what is at stake in any effort to alter the natural course of diseases. For patients to make effective use of available information, not only must it be understandable, but patients must recognize the uncertainties inherent in the information itself and in any effort to prognosticate on the basis of it.

In the Commission’s survey, 56% of physicians said they always discuss their diagnosis and prognosis with the patient and another 42% said they usually do. According to the public, 52% of their physicians always explain their diagnosis and prognosis; 26% report their physicians usually do. The frequency with which this is done differed in the various subgroups examined.

In a different version of this question, given to half the samples, 99% of physicians reported they initiate such

same groups were most likely to report high satisfaction with their doctor’s honesty in discussions.


11 See, e.g., Ruth Faden et al., Disclosure of Information to Patients in Medical Care, 19 MED. CARE 718 (1981).

12 Those who had had a life-threatening illness, who had high incomes, who received their care in a doctor’s office, or who were young, female, white, in excellent health, or college-educated were significantly more likely to report that their physicians always or usually explained such information (for example, 87% of the college-educated versus 64% of those with less than a high school education). Although almost none of the physicians reported they rarely or never discussed diagnosis and prognosis, up to 10% of the public with no usual source of care, the elderly, and the least well educated reported that their physicians rarely or never discussed these items.

13 Questions on specific items of information that could be disclosed
discussion as a matter of course, though only 75% of the public felt this was a professional obligation. Here, too, there were variations by subgroups in the population, with more than 80% of those with life-threatening illness, the young, the college-educated, and people in excellent health feeling that physicians should initiate discussion.

Since informed consent has, in terms of legal requirements, sometimes been equated with a duty to disclose according to the standards of the medical community, it is interesting to learn that on certain points physicians and the public are in substantial agreement. For example, 17% of physicians claimed that all their patients want candid assessments of their diagnosis and prognosis, even unfavorable ones, and an additional 69% perceived that most of their patients felt that way. Of the public, 94% reported that they would “want to know everything.” Indeed, the public displayed an unflinching desire for facts about their conditions, even dismal facts. When asked specifically whether they would want to know about a diagnosis of cancer, 96% of the public said yes (with almost no variation across subgroups). When asked “If you had a type of cancer that usually leads to death in less than a year, would you want your doctor to give you a realistic estimate of how long you had to live, or would you prefer that he not tell you?,” 85% (again, with little variation) said they would want a realistic estimate.

When, however, physicians were asked “If you had a patient with a fully confirmed diagnosis of lung cancer in an advanced stage, which of the following would you be most likely to tell your patient?,” they showed much less willingness to be candid. Only 13% said they would “give a straight statistical prognosis for his class of disease”; 33% said they would say they “couldn’t tell how long he might live, but would stress that it could be for a substantial period of time”; 28% would say they “couldn’t tell how long, but would stress that in most cases people live no longer than a year”; and 22% would “refuse to speculate on how long the patient might live.” Thus it would still appear that physicians are more reluctant to disclose a limited prognosis than patients would like. Nonetheless, the Commission’s survey indicates that physicians generally disclose information about patients’ diagnosis and prognosis, and that both physicians and the public feel this should be

were asked in two different ways in the Commission’s survey (by splitting the samples of physicians and the public) in order to determine not only the frequency with which physicians say they disclose certain information (and patients report such disclosures) but also whether physicians initiate discussion about various pieces of information as a matter of course or wait to be asked (and whether patients think physicians should initiate discussion).
done. These results are consistent with findings from other surveys that have demonstrated a recent trend toward more complete and frank disclosure and even toward more open discussion specifically regarding “bad news.”

_Treatment Alternatives and the Professional’s Recommendation._

In order for medical intervention to be warranted, the patient must stand to gain more from some intervention than if none were undertaken at all. As noted previously, the benefit to be gained must be assessed in terms of the patient’s own values and goals. Thus, a practitioner should be cautious not to rule out prematurely an alternative that might offer what a particular patient would perceive as a benefit even if the practitioner sees it differently.

The patient’s condition and the range of available alternatives will necessarily shape the course of the discussion. In some instances, there may be only one medically recognized treatment, so that the decision is primarily between that treatment and no treatment at all. In such cases, discussion will naturally focus on the benefits and risks associated with that treatment compared with the likely course of the untreated disease. Time is an important dimension here: can an intervention be put off, and with what consequences, to allow for greater diagnostic certainty and to permit the patient to reflect on the decision and to engage in any desired activities with which the intervention might interfere?

More commonly, there will be a range of medically acceptable responses to a given disease or health condition. The decision then has two components: whether to treat and how to treat. Here the discussion will typically require a comparison of several treatment options and an airing of the preferences of both professional and patient.

Since the judgment about which choice will best serve well-being properly belongs to the patient, a physician is obliged to mention all alternative treatments, including those he or she does not provide or favor, so long as they are supported by respectable medical opinion. For example, an internist has an obligation to discuss a surgical option with a patient who might benefit from it. In any case, the physician would ideally offer to refer the patient to a physician who does offer or favor the alternative treatment.

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Similarly, a physician ought not withhold information about a treatment from a patient simply because the physician judges its potential benefits not to be worth its costs.\(^\text{15}\) Increasingly, however, even when physicians fulfill their obligation to describe alternatives, the expense of some alternatives may make them unavailable to most patients. Ordinarily, alternatives should still be described, even though they would not be covered by a patient’s insurance plan (if any) or enrollment agreement with a health maintenance organization, lest the patient be deprived of the opportunity to seek other avenues for paying for the treatment or to look for treatment outside the insured or prepaid options.

Plainly, the special rules and expectations generated for the patient-professional relationship by the legal and ethical precepts summarized in the requirement of informed consent find no precise equivalent in commercial relationships in the insurance marketplace. Nonetheless, because of the close connection between health insurance (including prepaid group plans) and health care, both the sellers and the buyers of such insurance should make sure buyers receive a comprehensible explanation of the limitations in what they are purchasing. Otherwise, their subsequent decisions at the time of selecting among treatment alternatives may not in any real sense be either voluntary or informed.

The Commission does not believe that each alternative must be discussed in comprehensive detail. Rather, the professional should initially set forth, in a fairly general way, the nature and implications of the various options. Such a discussion can and should be used to “sound out” what is important to the patient and to identify the options likely to prove most satisfactory in light of the patient’s values and preferences. Once the options (including the possibility of no treatment) have been pared down to those that seem most promising to patient and professional, a more detailed evaluation of the risks and benefits is appropriate. Attention should be devoted as well to the time dimension and finality of the choice, and to the possibility of a sequential approach to various alternatives. In this process, the Commission views the discussion of risks and benefits as a step toward a sound decision among alternatives, not a supreme objective in itself.

This Report, like many discussions of informed consent, places considerable stress on the patient’s right of self-determination, including the right to choose among available treatments or to reject a particular treatment. Yet the Commission

\(^{15}\) Nothing in the obligations that arise within the patient-professional relationship precludes physicians, individually or collectively, from taking steps to make the health care system more efficient, including the elimination of treatment options that do not produce a favorable cost-benefit ratio in particular cases.
does not mean to suggest that professionals must take a neutral position among available alternatives. Physicians ordinarily do make recommendations to patients, and many patients would be quite disconcerted if they were rebuffed when they requested a “doctor’s opinion.” Indeed, a critical aspect of the professional’s role is to provide expert advice and judgment, and not solely technical diagnostic or curative skills. But the recommendation should neither be, nor appear to be, coercive; rather, it should function both as a yardstick against which patients can measure their own inclinations and as a stimulus to further questioning and discussion if the recommendation is not one the patient agrees with.16

_Treatment information in practice._ The public clearly feels that physicians _should_ discuss the nature, risks, and other consequences of the recommended treatment. Although physicians generally report that they do so, the Commission’s survey found that patients are less likely to perceive that this information is generally disclosed by their physicians (see Table 1). The greatest disparity was found on the question of discussion of costs associated with treatment. Whereas 70% of the public thought physicians should initiate such discussions, only 38% of doctors reported that they do so. When the expense of treatment is borne by the patient—and a substantial amount of expense _is_ borne by the patient, even when he or she is insured—differences in the cost of alternatives can be as important to the patient’s “pursuit of a life plan” as differences in risks or side effects. A number of proposals are currently being considered that would increase the amount of cost-sharing by patients; this would make cost information

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16 In making treatment recommendations the health care professional may indicate what his or her own values are. To the extent that a particular recommendation is based on the professional’s values, rather than the patient’s values, that should be made clear. For example, a physician may recommend that an athlete retire from competition because it is harming his or her health. The athlete, however, may want to remain in professional competition as long as possible. The physician may reply that the patient’s view is shortsighted and that health is more important than another year of professional sports. Once having stated the recommendation, however, and having made clear the values that led the physician to the recommendation, the choice remains the patient’s. When there are a number of medically appropriate treatment alternatives, the decision among them may also turn on value preferences. For example, a physician who feels strongly that kidney transplant is preferable to renal dialysis is likely to be stating a value preference rather than a purely medical conclusion. In such situations, physicians should recommend that the patient consult with another expert with opposite views before making a final decision. In both examples, clarification of the professional’s values is likely to provoke a useful discussion of the patient’s values. See, e.g., Robert M. Veatch, _Generalization of Expertise_, 1 THE HASTINGS CENTER STUDIES 29 (1973).
even more important. Even when the patient does not bear the expense directly, providing cost information would permit the patient to consider whether the personal benefit seems commensurate with the cost to society. (Although this may not cause a patient to alter his or her behavior, at least the person will have some idea of why insurance premiums are so high.)

Furthermore, although discussion of costs may, in the short run, be embarrassing to patients and physicians, in the long run

Table 1:

Public and Physicians’ Views on Initiation of Discussion and Explanation of Treatment

<table>
<thead>
<tr>
<th>Subject of Discussion</th>
<th>Public View: Doctors Should Initiate Discussion</th>
<th>Doctors’ Report: I Do Initiate Discussion</th>
<th>Public View: My Doctor Always or Usually Explains</th>
<th>Doctors’ Report: I Always or Usually Explain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nature and Purpose of Recommended Treatment</td>
<td>85%</td>
<td>96%</td>
<td>77%</td>
<td>96%</td>
</tr>
<tr>
<td>Pros &amp; Cons of Recommended Treatment vs. Alternatives</td>
<td>81%</td>
<td>84%</td>
<td>68%</td>
<td>83%</td>
</tr>
<tr>
<td>Likely Side Effects</td>
<td>88%</td>
<td>95%</td>
<td>68%</td>
<td>93%</td>
</tr>
<tr>
<td>Probable Impact on: Patient’s family life</td>
<td>79%</td>
<td>74%</td>
<td>*</td>
<td>78%</td>
</tr>
<tr>
<td>Patient’s job role</td>
<td>79%</td>
<td>79%</td>
<td>*</td>
<td>86%</td>
</tr>
<tr>
<td>Cost of Treatment</td>
<td>70%</td>
<td>38%</td>
<td>45%</td>
<td>47%</td>
</tr>
<tr>
<td>Risks of Death or Serious Disability that are: 1:100</td>
<td>75%</td>
<td>81%</td>
<td>*</td>
<td>82%</td>
</tr>
<tr>
<td></td>
<td>1:1000</td>
<td>64%</td>
<td>52%</td>
<td>59%</td>
</tr>
<tr>
<td>Risks of Temporary Disability that are:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1:1000</td>
<td>65%</td>
<td>43%</td>
<td>57%</td>
</tr>
</tbody>
</table>

* Not asked.

Source: Commission survey conducted by Louis Harris and Associates.
failure to discuss expenses could compromise health—a patient who is reluctant to explain that a prescribed medicine is unaffordable may fail to fill the prescription; an individual who fears that an expensive operation will be recommended may decide not to go to a specialist when referred to one. In the view of the Commission, health care professionals have an obligation to ensure that patients get the cost information that is relevant to the treatment options under consideration.

The observational studies conducted by the Commission are most striking in their findings that in hospital settings often little or nothing is actually discussed with patients regarding either alternative treatments or the recommended treatment. Instead, physicians commonly make decisions and proceed to treat the patient. Beyond this generalization, however, there was tremendous variation in the nature of disclosure and decisionmaking that was related to the structure of the medical care setting, the nature of the patient’s illness, and the treatment under consideration.

In the study of treatment refusals in medical, surgical, and specialty wards of a university teaching hospital and a community hospital, it was found that most of the treatment refusals were related to the nature and extent of information provided to patients. In many cases there was a total lack of information concerning diagnostic and therapeutic procedures. Typically these were ordered by physicians without patients being alerted to what was to be done, much less being asked. Although most people went along with these tests and procedures, the lack of information served as a trigger for refusals by patients already primed to resist treatment because of ambivalence about the primary procedure for which they had been hospitalized, delays, previous complications, etc. It was not always obvious to patients why something needed to be done and some refused to proceed until they were given some justification. Thus this lack of information was often a precipitating factor, but not generally the sole cause of refusals. In some cases, patients were told that a test or procedure would be performed, but they were not informed about the purpose or the risks. Patients who knew or discovered that certain procedures were potentially very risky refused treatment until reasonable justification and assurances were provided.

Another source of refusals of treatment was conflicting information given to patients by different health care professionals. This is especially likely to occur in hospitals, where patient care is divided among different people, many of whom are not in direct communication with each other. This resulted in patient uncertainty about who was making decisions about their care and whom, therefore, they should trust. In some cases patients questioned the capabilities of the house officers
and wanted their own primary physician’s endorsement before agreeing to a procedure.

Some refusals could be traced to a lack of communication on the part of both the doctor and the patient. For example, one patient refused to take a routinely prescribed laxative because she had severe diarrhea. The doctor had failed to ask the patient about her bowels and the patient was hesitant to volunteer the relevant information. Once the patient told the nurse responsible for dispensing medications why she did not want the laxative (which she had previously been taking despite her diarrhea), the medication was withdrawn.

In the Commission’s other observational study, the nature of the communication and decisionmaking process varied for cardiology versus surgery patients, for outpatients versus inpatients, and for acute versus chronic disorders. Differences in the nature of disclosures for surgery and cardiology patients derived from differences in the authority structures and daily routines in the two wards and from the nature of the interventions themselves. Surgery is a single event that is relatively easily described by staff and understood by patients. On the surgical ward, a single, readily identifiable physician was usually clearly in charge. Patients had a greater opportunity to ask questions than in cases where responsibility was more diffuse. Cardiology is organized around an organ malfunction, not around a particular treatment. Cardiac care is therefore more process-oriented and ambiguous and may involve numerous forms of treatment and diagnostic tests. The nature of disclosures for cardiology patients varied with the procedure. For example, patients undergoing exercise stress tests (who were usually outpatients referred to the hospital just for this procedure) were mailed a cover letter and consent form describing the test. Upon arrival at the hospital the nurse asked if they had read the form and had any questions. If they had no questions (which was usually the case), no discussion took place. Presumably the referring physicians had discussed the test somewhat with the patients previously, but those encounters were not observed.

Cardiac catheterization patients, on the other hand, got detailed explanations of the procedure and its risks. The following is a transcript of part of a typical conversation between one physician and patient. Having explained why the procedure should be done and what information it would provide, the physician went on to describe how it was done and what it would feel like, including that the patient would feel very hot for about 20 seconds.

Patient: Oh, seconds only, that’s all right. But I do want this explanation because I knew I would get this for 25 years. I guess I’ve heard a lot of
things about it. Friends of mine have had it and so forth.

Doctor: Yes, some people like it and some people say it’s the worse thing that happened to them in their lives. I think I ought to tell you that there’s some possibility that we may have to do a transeptum catheterization [and he explained what this consisted of]. There’s some potential risks. I think you will find they are terrifying, but I want you to remember we weigh the risks both of doing it and not doing it before we recommend it to you.

Patient: Maybe you shouldn’t tell me until tomorrow.

Doctor: Well, I could wait until tomorrow, but I do have to tell you this. I want you to know the risk is low. We are talking about a one in a thousand chance of a major risk. There’s some minor ones, too. But they can all be dealt with. Some of the major ones can, too, but they’re not very likely. Here are some of them. First of all we have to go into the vessel, and we can injure the vessel, and that can sometimes require surgery, which can be difficult in its own right. The second one is that you might have hardening of the arteries already, and some sort of blockage could result from pushing through them. This can require surgery also to make it better, and even so there’s a low risk of a heart attack or of stroke from it. Then another thing is that some people are allergic to the dye, and this can put somebody into shock, and usually we can treat that with medicine, but it’s quite serious. Another thing it can do is it can cause an irregular heartbeat, and you can even need an electric shock because it can cause your heart to stop. But of course you would be asleep then, and you wouldn’t feel it. Another thing is that if we need to do the transeptal catheterization, that can cause a puncture of the heart and bleeding. The blood can get between the heart and the sac around it, and then we would have to drain that. One of the minor risks is that you can have a hematoma around where we put in the catheter. That’s not much of a real problem, but you can get black and blue, and that happens because of the Heparin we put in to prevent the clotting I talked about earlier.
Patient: You know, I can’t remember any of that stuff.
Doctor: Well, I know it’s scary, but I want you to understand that it’s my feeling that it is a higher risk not to have it done. But of course ultimately it’s your decision, not mine.
Patient: Do you do this often?
Doctor: Yeah, this is a big center for that sort of thing, for valve replacements, and we see a lot of these.
Patient: You see it’s all new to me.
Doctor: And one other thing is that you’re going to have to sign a consent form. The nurse’ll bring that in later tonight.
Patient: Well, you have to do it because it’s the best procedure.

Several things are worth noting in this exchange. The patient was clearly ambivalent about learning all the details about risks; the doctor was clearly determined to enumerate them and tried to be reassuring. Given the sheer volume of information provided, coupled with the anxiety that probably pervaded the entire situation, it is not surprising that the patient stated immediately that he could not “remember any of that stuff” (though other patients following similar disclosures had actually been able to remember a good deal). The patient was more concerned about whether the procedure would hurt and about the physician’s experience with it than in knowing details about the risks. It was the patient who pointed out a key aspect in most of medical care, namely that these things may be routine for the staff but they are new to the patient. The ultimate decision to go ahead with the test was based on the patient’s assessment that it was the best procedure and that it was necessary.

The studies further indicated that the extent of disclosure was related both to the nature of the proposed treatment and to the risks involved. For courses of action perceived to constitute “procedures”—typically, surgical and invasive diagnostic interventions—substantial information was provided, particularly when the procedure was recognized to be a risky one. For more routine courses of action, not perceived as formal procedures, less information was provided. This was true even in the case of administration of potentially risky drugs, which might entail greater risks than minor surgical procedures for which more information was disclosed. These practices may reflect the origins of consent requirements in surgical practice. 17

17 Only a few jurisdictions have ever considered the applicability of informed consent to medications, see, e.g., Hamilton v. Hardy, 549 P.2d 1099 (Colo. App. 1976); Sharpe v. Pugh, 270 N.C. 598, 155 S.E.2d
In general it was found that surgical outpatients received less unprompted information than inpatients. On the other hand, they asked more questions and sought other sources of information, so that ultimately they may have ended up getting as much information as those in the hospital.

The nature of the disorder was found to affect the amount of information patients receive from physicians about treatments. Chronically ill patients are sometimes so well educated about their illness that they speak in the same jargon as the medical personnel. Their understanding of information relevant to their illness and treatment grows over time. The increase in both informing and understanding that time allows is most apparent in the case of chronic illness.

Furthermore, it was found that much of the information given to patients is not necessarily intended to assist them in participating in the decisionmaking process, though it sometimes

108 (1967); Marsh v. Arnold, 446 S.W.2d 949 (Tex. Civ. App. 1969), and none of them has ever explicitly rejected the applicability. In fact, one much-discussed recent case, Truman v. Thomas, 165 Cal. Rptr. 308, 27 Cal.3d 285, 611 P.2d 902 (1980), held that an informed consent claim could be founded on a physician’s failure to disclose the risks of not performing a procedure. One case holds that informed consent requirements do not apply to the dispensation of medications. In Malloy v. Shanahan, 421 A.2d 803 (Pa. Super. 1980), in an opinion that did not include an explanation of the court’s reasoning, the Pennsylvania Superior Court held that the administration of a drug, not involving any physical touching of the patient, could not constitute a battery and thus was outside the scope of the state’s informed consent requirements. The Pennsylvania approach is undesirable in that it substantially undercuts the goals of patient well-being and self-determination that informed consent is intended to serve. Since so much medical care involves the use of drugs, many of which have potentially serious or even lethal side effects, informed consent requirements should be applicable.
The Communication Process

has that consequence. People who are newly diagnosed as having a chronic disease are given a great deal of information to help them adjust to a new way of life and comply with the treatment recommendations of the attending medical personnel.

Ideally, information should help patients to cope with their illnesses and should produce better outcomes. It is thus a part of good care and goes beyond merely trying to improve compliance. However, it was found that patients suffering from an acute illness typically are given only enough information so they can agree to the therapeutic recommendation of the medical personnel and so they will not be too surprised by untoward results. According to the nurses in the observational study of informed consent, this is the main purpose of preoperative surgery education.^

Thus it would appear that in actual practice the nature and extent of information provided to patients regarding treatment alternatives, including the recommended treatment, risks, benefits, and other consequences, varies substantially depending on the nature of the patient’s condition and of the proposed treatment as well as on the preferences of the patient and providers.

**The Role of Uncertainty.** Underlying all three core elements of the professional-patient communication process is the dimension of uncertainty. Few would claim that medicine is an exact science, yet many commentators have remarked on the disinclination of medical professionals to discuss with their patients the uncertainties inherent in diagnosis, prognosis, and potential treatments. Explanations of this attitude range from an insistence on maintaining professional control and dominance to the potential therapeutic efficacy of unquestioning confidence in a treatment by patient and professional alike.^

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18 Certainly not all nurses would agree that the goals of preoperative education are so limited. The findings from this study may be peculiar to the particular health care providers in the institution studied or may be peculiar to university hospitals.

19 The significance of medical uncertainty for the doctor-patient relationship was first discussed by Talcott Parsons, THE SOCIAL SYSTEM, Free Press, Glencoe, Ill. (1951) at Chapter Ten and has been elaborated on by Renée C. Fox in many of her writings; see, e.g., Training for Uncertainty, in Renée C. Fox, ESSAYS IN MEDICAL SOCIOLOGY: JOURNEYS INTO THE FIELD, John Wiley and Sons, New York (1979) at 32-48, The Evolution of Medical Uncertainty, 58 MILBANK MEMORIAL QUARTERLY 1, 49 (1980), and, with Judith P. Swazey, THE COURAGE TO FAIL: A SOCIAL VIEW OF ORGAN TRANSPLANTS AND DIALYSIS, Univ. of Chicago Press, Chicago (1974) at 40. See also G. Honigfeld, Non-Specific Factors in Treatment II: Review of Social-Psychological Factors, 25 DISEASES OF THE NERVOUS SYSTEM 225 (1964).
universal acceptance of the randomized double-blind design in biomedical research to eliminate “placebo effects.”

Whatever the reasons, numerous studies have indicated that people respond differently to uncertainty, and it seems there may be systematic differences between physicians and patients in how uncertainty affects their decisions regarding medical interventions. The Commission’s view of informed consent includes as one facet patients being able to reflect their own attitudes toward uncertainty in their decisions. If they do not know of uncertainties in the diagnosis and treatment, their ability to be self-determining is limited.

**Types of uncertainty.** Uncertainties about medical decisions derive from a number of sources, some more intractable than others. First, of course, there are limitations in medical knowledge. While biomedical research continually pushes forward the frontiers of knowledge, much remains only imperfectly understood.

Second, there is what may be termed “empirical uncertainty”: that uncertainty inherent in any knowledge obtained through the scientific method. The reliability of information based on past experience with a defined, similar group of patients depends upon the determined error of statistical prediction, the adequacy of definition of the group, the accuracy of observations, and the constancy of natural history and medical care over time.

A particularly difficult uncertainty for both doctors and patients derives from the probabilistic nature of much health care. Most treatment recommendations are based on the physician’s view of what is most likely to be successful rather than on absolute certainty that a particular treatment will lead to a particular outcome. Implicit is some notion of probability—90% of the time this is successful. Yet most people, physicians and patients alike, see the results of diagnostic tests as completely reliable, even though they know that no test is 100% accurate. Patients especially may draw broad and unwarranted inferences from a similar case they know of, acting as if an example were proof.20

Uncertainty can also arise from limitations in the knowledge of particular health care providers about medical information. Obviously no practitioner can have instant command of the full range of medical knowledge. In some instances such gaps in knowledge may reflect a failure to keep up with fundamentals; in others they may simply indicate a regrettable but unavoidable limitation of human capacity.

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A fifth, somewhat different type of uncertainty may be termed “experiential”: the limits on an individual’s ability to imagine what life under very different circumstances would be like. A previously healthy individual contemplating life as an invalid, for example, or a pregnant woman anticipating her first labor and delivery faces certain inherent limitations in knowing how the new experience will feel.

Each of these areas of uncertainty is to some degree inevitable, but health care professionals can and should take steps to reduce them, where possible, and to help patients deal with those that remain. Continued biomedical research and efforts by professionals to remain informed will reduce the scope of the unknown, both for medicine as a whole and for individual practitioners. Patients can be given some indication of the extent of a professional’s knowledge—specialization, prior experience, scholarly inquiry—and of the availability of second opinions by expert consultants. Practitioners can also share the experience of other patients in similar circumstances (consistent with norms of confidentiality), help patients to meet others who faced similar decisions, and work with patients to understand their own resources for coping with and adapting to new situations.

**Attitudes toward uncertainty.** Both health care professionals and patients may have difficulty dealing with the concept of uncertainty as well as the substance. And for both, uncertainty can evoke uncomfortable emotions. Nonetheless, in the Commission’s view, where significant uncertainty exists health care professionals have an obligation to discuss it with patients.

Although there was variation among subgroups of those surveyed by the Commission, physicians on the average reported that they initiate discussion and always or usually discuss uncertainties, and the public feels physicians should raise such issues (see Figure 1). Interestingly, the public is generally less likely to feel that physicians should initiate discussion about uncertainties about diagnoses (75%) than physicians report they actually do (90%). On the other hand, the public is more likely to feel that uncertainties regarding the best course of treatment should be discussed (80%) than are physicians to report bringing up such discussions (66%).

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21 Of the various subgroups examined, those who had had a life-threatening illness, who received their care in a physician’s office, who had high incomes, whose current health was excellent, or who were young, white, or college-educated were more likely to feel that doctors should initiate discussion about these uncertainties. Those in poor health, the elderly, and the least well educated were most likely to say they were “not sure” whether such discussions should be initiated.
Not surprisingly, physicians who regard most (90-100%) of their patients as able to understand most aspects of their conditions and treatments were more likely to discuss uncertainties. Although there was some variation among physician subgroups, the differences were neither as regular nor as pronounced as those among the public. Generally physicians who graduated from medical school after 1972 were less likely than older physicians to report that they always or usually discussed uncertainties. Given the burgeoning interest in informed consent and in litigation during the last decade, this is somewhat surprising and serves as a reminder that the law may influence—but does not necessarily control—relationships that are subject to myriad other subtle influences. However, many commentators have noted that medical students and young physicians are themselves unable to deal with uncertainties.

Physicians in general or family practice were less likely than others to initiate discussion about most uncertainties, although the one exception was for uncertainty regarding diagnosis, for which obstetricians/gynecologists were least likely to initiate discussion. Surgeons were most likely to report that they always or usually discussed uncertainties with their patients. Office-based physicians were more likely than hospital-based ones to discuss uncertainties.
uncertainty, so much so that they are uncomfortable discussing it with patients.23 Only after being in practice for some period of time do physicians reconcile their sometimes overwhelming sense of responsibility to heal with the real limits and uncertainties inherent in medicine.

The observational study of informed consent found that when the nature of the patient’s problem is fairly certain and a professional consensus exists about the best approach for dealing with that problem (for example, general surgery), patients receive more information about their illness and its treatment than when the nature and etiology of the problem, and thus the best method for dealing with it, are more uncertain (for example, cardiology). Even when there is a high degree of uncertainty about a patient’s problem, it was found that medical personnel tried to convey a sense of certainty rather than subtle information about the illness and its treatment.

The study of treatment refusals found that even when physicians did discuss uncertainty, patients often had a difficult time understanding it. They sometimes even claimed to be unaware of information that study observers heard the physicians discuss with them. One patient, for example, who suffered from a “fever of unknown origin” kept refusing to have any more blood tests despite repeated explanations that they were necessary in order to discover the reason for her fever. The patient seemed unable to grasp the idea that her doctor really did not know why she had a fever and she wondered why he did not just prescribe an antibiotic. A similar example concerned a patient with pancreatitis whose physician told him honestly he did not know why he had it and what was causing pain even after an operation. Because “no one ever told me why I had it,” he said, he refused further diagnostic tests. Here, too, the patient seemed unable to believe that there was something the doctor did not know. It is perhaps not surprising that physicians may sometimes try to make things sound more certain than they really are in order to proceed with tests they consider necessary, to do something concrete for patients, and to avoid undermining people’s confidence in them, even though patients in such situations are denied full opportunity to participate meaningfully in decisionmaking.

Mode of Presentation and Barriers to Effective Communication.
The way information is presented can greatly affect understanding. Research has identified a number of influences on the success of the communication process and the nature of the message received. These include the particular words used, the structure and framing of the information, the timing of the

23 Fox, Training for Uncertainty, supra note 19.
disclosure, and the setting in which the discussion takes place. As already discussed, some kinds of information are inherently more difficult than others to describe and to understand.

The public was asked: “Do you usually come away from your doctor feeling that you have understood the important issues relating to your treatment?” Of all those surveyed, 38% said they felt they understood fully, 14% understood more than adequately, 36% said adequately, and only 10% said their understanding was usually less than adequate. The place of care and type of relationship had significant effects on the degree of self-reported understanding. In a follow-up question, when asked “When a patient doesn’t understand his medical treatment, how often is this because the doctor did not explain things well?,” 12% of the public said “always,” 32% said “often,” 37% said “sometimes,” 8% said “rarely,” 3% said “never,” and 7% were not sure. Thus, it would appear from the Commission’s survey that doctors believe most patients have the capacity to understand and that most patients feel they do understand most aspects of their medical care and regard promotion of this understanding as a task of the physician.

The amount of information that is actually understood is more difficult to establish empirically. A number of studies purport to have examined the extent to which patients understand medical information, but unfortunately they all suffer from several methodological shortcomings. The most serious flaw is that “knowledge” is usually equated with “comprehension.” The typical study tests patients after they have read consent forms or talked with physicians, in order to determine whether they can repeat information accurately. Some tests are multiple choice in nature, thereby assessing “recognition”; others are open-ended, thereby testing “recall.” While some tests are given immediately after disclosure, others are given after a substantial period of time has elapsed to test “retention” of information.

Those receiving care in a doctor’s office were more likely than others to feel they fully understood; those with no usual source of medical care were most likely to report inadequate understanding. People in poor health, the elderly, women, and those with less than a high school education were more likely than others to report either that they fully understood or that their understanding was inadequate, with fewer falling in the middle categories of “adequate understanding” on the scale.

The college-educated were significantly more likely than those with little education to say it was always or often the doctor’s fault (51% versus 31%). People in poor health and the elderly were less likely to blame the doctor for their lack of understanding and more likely to be unsure (up to 19%) whether it was the doctor’s fault.

See, e.g., the review article by Alan Meisel and Loren H. Roth, What We Do and Do Not Know About Informed Consent, 246 J.A.M.A. 2473.
Although knowledge is a necessary condition for comprehension it is not sufficient. True understanding involves the ability to use information rationally. Very few empirical studies have attempted to examine how information is used in the decisionmaking process. Little is known about variations in knowledge and understanding that are related to the nature of the patient or the condition for which treatment is being proposed.

For information to have been communicated successfully, it needs not only to have been disclosed, but also attended to, understood, accepted, remembered, and put to use. For patients to use information, they must pay attention to the physicians’ communications, select out the details important to them, interpret and integrate new knowledge with information they already have, and later recall and use the information to make decisions.

Not only are there finite limits on people’s ability to use information, but patients—anxious, frustrated, trying to understand unfamiliar yet threatening information—are at a serious disadvantage when it comes to absorbing what physicians say. At the very first step—paying attention to what is said—limitations of the patients’ ability to process information are probably most evident. It is difficult for patients to pay attention to details about their therapy when they are thinking, and probably worrying, about the diagnosis given earlier in the interview.

In addition to the limiting effects of the patient’s emotional state, the lack of familiarity with the topic being discussed constrains the patient’s ability to attend to essential messages. People cannot possibly remember every word they heard during discussions with health professionals. Rather, they extract what they consider to be the important points. Unfortunately, patients may not know which ideas are most important medically. They may not realize the implications of what is being said because they do not recognize the special meanings of medical phrases, especially ones that do not sound “medical.” For example, it has been found that the phrase “admitted
for a work-up” does not convey to some patients that they will be hospitalized.28

Under these circumstances, patients may direct their attention to the most familiar aspects of what the physician is saying, concentrating on old problems and failing to recognize the severity of new ones. Health care professionals can assist patients by indicating which information is medically important and the reasons why, by avoiding jargon, by timing discussions so as to minimize anxiety, and by holding discussions in a setting that will encourage patients to ask questions.

Practitioners should be particularly careful about how they present information concerning uncertainty. In some instances, there is no neutral or obviously correct formulation; however the information is conveyed, it will carry some distinctive bias that will affect how it is heard. An attempt to be neutral is quite different, however, from deliberately presenting or framing facts to induce a particular reaction. “You are very ill; but, even so, almost everyone survives this operation—only 17% die” is comprehended very differently from “You are not doing too well, and the only operation that might help kills nearly one in every five patients.” Such formulations are not necessarily deceptive, but they certainly can be manipulative in the sense of eliciting a different decision from that which might result from other professional-patient discussions.29 A more forthright recognition of these aspects of communication and an effort to present complex information about uncertainty in several ways could achieve a more well rounded understanding of what is at stake. Such an approach would do much to advance the values of patient welfare and self-determination.

Finally, health care practitioners often find their ability to inform patients severely constrained by the limited or nonexistent history of their relationship. Often professionals do not know patients before their current crises and may never have known them as reasonably healthy individuals. Furthermore, when people are ill, they are often frightened and in pain, which can compromise communication. These barriers may be an inevitable concomitant of modern, high-technology, acute-care medicine. Yet their absence in many chronic care situations suggests the real possibility of effective patient participation.

The detrimental effects of having little, if any, previous knowledge of hospitalized patients can be ameliorated by frequent contact, sincere concern, conversations with families, and limited change of professional responsible for the patients’

29 See pp. 66-68 supra.
care. Moreover, it is important for professionals to indicate not only an interest in learning about patients but also a willingness to provide information and respond to questions and concerns. This message can be conveyed—or contradicted—in subtle ways. Physicians who remain standing when they enter patients’ rooms create a different impression than those who sit down by patients’ beds to talk.

Justifications for Less Than Full Disclosure. Quite apart from these barriers to effective communication, there may be times when a full communication process is not desirable and should not be required. The law recognizes a number of such situations. These “exceptions to informed consent,” when properly invoked, shift all or part of the decisional authority from the patient to someone else. The exceptions fall under several headings:

1. Legal requirements;
2. Emergencies;
3. Incompetency;
4. Waiver; and
5. Therapeutic privilege.

Informed consent is not required in certain instances in which medical interventions are directed or authorized by law. These include certain tests performed pursuant to the authority of police officers or of public health officials, such as testing drivers for inebriation or immunizing school children against contagious diseases. Since consent need not be sought in such circumstances, “informed consent” is a misnomer. Nonetheless, it may still be appropriate to discuss with a person the nature of the procedure and the reasons for it, out of respect for that person, even though such discussion is not intended to assist the individual in making a choice.

The emergency exception applies when immediate treatment is required to preserve life or prevent a serious impairment to health but consent cannot be obtained from a patient (or from someone empowered to authorize treatment on the patient’s behalf) and there is no indication that the treatment would be refused were the patient then able to make his or her wishes known. It is sometimes said that consent in such situations is “implied by law,” by analogy to situations in which a patient by his or her conduct implies consent without explicitly giving it. This terminology is misleading. More accurately, in an emergency the law sets aside the requirement

30 See Alan Meisel, The “Exceptions” to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical Decisionmaking, 1979 WIS. L. REV. 413.
31 See Rosoff, supra note 14, at 19-24, 253.
of consent, based on the presumption that a reasonable person would want emergency aid to be rendered and that a particular patient has such wishes unless he or she has indicated otherwise.

The remaining three exceptions actually comprise modifications in, rather than eliminations of, the usual rules for informed consent. A patient’s informed consent is not required in cases of incapacity to make a particular decision. As discussed in Part Four, however, the requirement of consent is not eliminated; rather, a surrogate must exercise the authority on behalf of an incapacitated patient. It may still be appropriate to inform such patients of the nature of their situation and to seek to involve them in the decisionmaking process, even when they do not have the capacity to make legally binding decisions.

The modest attention paid to the fourth exception—waiver—in the courts and scholarly literature is regrettable given its interesting relationship to the value of self-determination that underlies the doctrine of informed consent. As observed in Chapter Two, self-determination encompasses both the moral right to formal control over a decision and the ideal of active participation in the decisionmaking process. Although these two senses of self-determination often go hand in hand, sometimes they do not, as in the case of a waiver, when a patient asks not to be informed of certain matters and/or delegates decisional authority to another person.

The impact of the waiver exception is that if a waiver is properly obtained the patient remains the ultimate decisionmaker, but the content of his decision is shifted from the decisional level to the meta decisional level from the equivalent of “I want this treatment (or that treatment or no treatment)” to “I don’t want any information about the treatment.”

The legal requirements for effective waiver in the context of informed consent have never been clearly articulated by the courts. There is substantial reason to believe that the courts would respect waivers of certain information (for example, the disclosure of particular risks) or the delegation of certain decisions to others. Yet it is questionable whether patients should be permitted to waive the professional’s obligation to disclose fundamental information about the nature and implications of certain procedures (such as, “when you wake up, you will learn that your limb has been amputated” or “that you are irreversibly sterile”). In the absence of explicit legal

33 Meisel, supra note 30, at 459.
guidance, health care professionals should be quite circumspect about allowing or disallowing, encouraging or discouraging, a patient’s use of waiver.

The final exception to informed consent, which has been the subject of substantial comment, is called therapeutic privilege and permits professionals to refrain from making a disclosure that could so seriously upset a patient that it would be countertherapeutic. The obvious danger with such an exception is the ease with which it can swallow the rule, thereby legitimating wholesale noncompliance with the general obligation of disclosure. Accordingly, some courts and commentators hold that the scope of therapeutic privilege should be severely circumscribed, and that, at the least, the privilege should not apply in situations when the potential harm to the patient from full disclosure would result not from the disclosure itself, but from a treatment decision the practitioner fears the patient might make as a result of the information disclosed. More plausible claims of therapeutic

34 Ironically, the “privilege” not to disclose was first recognized before there was a well-established legal duty to make disclosure. Alan Meisel, The Expansion of Liability for Medical Accidents: From Negligence to Strict Liability by Way of Informed Consent, 56 NEB. L. REV. 51, 99 n.140 (1977). The two earliest articles discussing the privilege—Charles C. Lund, The Doctor, the Patient, and the Truth, 19 TENN. LAW REV. 344 (1946); Hubert Winston Smith, Therapeutic Privilege to Withhold Specific Diagnosis from Patient Sick with Serious or Fatal Illness, 19 TENN. L. REV. 349 (1946)—appeared at a time when very few cases had imposed upon a physician an affirmative duty of disclosure, and almost a decade before a court first used the term “informed consent” Although one commentator has remarked that “[i]t is not clear where this privilege originated,” Note, Restructuring Informed Consent: Legal Therapy for the Doctor-Patient Relationship, 79 YALE L. J. 1533, 1564 n.95 (1970), something like the privilege was referred to in Twombly v. Leach, 65 Mass. (11 Cush.) 397, 405-06 (1853): “Upon the question whether it be good medical practice to withhold from a patient...a knowledge of the extent and danger of his disease, the testimony of educated and experienced medical practitioners is material and peculiarly appropriate.”

35 “The privilege does not accept the paternalistic notion that the physician may remain silent simply because divulgence might prompt the patient to forego therapy the physician feels the patient really needs.” Canterbury v. Spence, 464 F.2d 772, 789 (D.C.Cir. 1972). As is true of much of the Canterbury case, this language is taken from Jon R. Waltz and Thomas W. Scheuneman, Informed Consent to Therapy, 64 NW. U. L. REV. 628, 642 (1970). Other courts have not been as restrictive in their formulation of the privilege: “[A] physician may withhold disclosure of information regarding any untoward consequences of a treatment where full disclosure will be detrimental to the patient’s total care and best interest.” Nishi v. Hartwell, 52 Haw. 188, 191, 473 P.2d 116, 119 (1970).

36 See generally A. M. Capron, Informed Consent in Catastrophic Disease Treatment and Research, 123 U. PA. L. REV. 340, 387-92 (1974);
privilege might involve certain disclosures to patients previously known to be suicidal or those susceptible to serious physiological effects of stress, and in situations where there is strong reason to believe that a particular disclosure is likely to result in serious self-destructive behavior that could not be justified in terms of the patient’s own long-term values and goals.

Despite all the anecdotes about patients who committed suicide, suffered heart attacks, or plunged into prolonged depression upon being told “bad news,” little documentation exists for claims that informing patients is more dangerous to their health than not informing them, particularly when the informing is done in a sensitive and tactful fashion. On the contrary, as discussed further below, there is much to suggest that therapeutic privilege has been vastly overused as an excuse for not informing patients of facts they are entitled to know. In light of the values at stake, the burden of justification should fall upon those who allege that the informing process is dangerous to patient health, and information should be withheld on therapeutic grounds only when the harm of its disclosure is both highly probable and seriously disproportionate to the affront to self-determination.

**Attitudes toward less than full disclosure.** In the Commission’s survey an attempt was made to discover how often and why physicians withhold information from patients, the conditions under which the public considers this acceptable, and the justifications for providing information to families when it is not given to patients.

Although physicians reported that they frequently make a conscious and deliberate evaluation of how much to tell patients, relatively few reported that they ultimately withheld information (see Table 2). Physicians who judged that 90-100% of their patients are able to understand most information were generally less likely to withhold details. Interestingly, physicians who had graduated from medical school ten years ago or sooner were more likely than older physicians to withhold information about treatment risks and alternatives and about diagnosis and prognosis.

Physicians were also asked: “What are the most common reasons for you to withhold information about condition or treatment?” Patients’ inability to cope with the information


37 Obstetricians/gynecologists were less likely than other physicians, especially internists, to withhold information. Practice location and the proportion of patients with serious illness influenced the withholding of information in the same way they affected making conscious evaluations; see note 7 *supra*. 
Table 2:
Frequency With Which Physicians Report They Withhold Information

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Information Is Withheld About</th>
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<tr>
<td></td>
<td>Diagnosis or Treatment Risks</td>
<td></td>
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<tr>
<td></td>
<td>Prognosis</td>
<td></td>
</tr>
<tr>
<td>Once a Day</td>
<td>2%</td>
<td>4%</td>
</tr>
<tr>
<td>Once a Week</td>
<td>7%</td>
<td>6%</td>
</tr>
<tr>
<td>Once a Month</td>
<td>12%</td>
<td>9%</td>
</tr>
<tr>
<td>Few Times a Year</td>
<td>32%</td>
<td>24%</td>
</tr>
<tr>
<td>Almost Never</td>
<td>46%</td>
<td>57%</td>
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Source: Commission survey conducted by Louis Harris and Associates.

(34%), inability to understand it (28%), and the wishes of the patients’ families (21%) were the reasons given most frequently. Only 9% mentioned effects on the patient’s health.

Further questioning revealed that in nearly two-thirds of the cases in which physicians withhold “bad news” the decision to do so is rarely or never based upon the patients’ wishes. Moreover, when members of the public were asked “Have you ever asked a doctor not to tell you ‘bad news’?,” only 2% said yes, although 5% of those who had received care in a setting other than a doctor’s office, or who were in poor health, or who had less than a high school education said yes. These figures on the public’s request not to be told “bad news” are substantially lower than the physicians’ reports of such requests.

Nevertheless, physicians do believe in disclosing information to patients’ relatives—a step that may alert them to potential idiosyncratic objections to an intervention or other special facts but that still falls far short of shared decisionmaking with the patient. Of physicians surveyed, 80% said they “usually discussed the withheld information with another family member,” 10% said “sometimes,” 4% said “rarely,” and

38 Physicians were asked: “For those patients to whom you do not disclose ‘bad news,’ how often is this because they tell you directly they don’t want to know it?”; 12% of physicians said “always,” 11% said “often,” 13% said “sometimes,” 45% said “rarely,” and 16% said “never.” Not surprisingly, physicians treating high proportions of seriously ill patients were most likely to say “always” (17%). 39 The legal status of disclosure to patients’ relatives when the therapeutic privilege is invoked is uncertain. See Meisel, supra note 30, at 465-67.
40 Among specialists and subspecialists, 11% were not sure; among doctors who graduated between 1966 and 1972, 8% were not sure. Obstetricians were the least likely (68%) and surgeons the most likely (88%) to report that they usually did discuss with the family information they had withheld from a patient.

41 In general, older, less well-educated people and those in poor health were more likely to feel that withholding information was justifiable; these groups were also more likely to express uncertainty than others. There is no recognition in law for withholding information from

3% said “never.” In an unusual response 3% said they were “not sure.”

The responses of the public, when asked whether a physician would be justified in withholding information about a medical condition or treatment from a patient, more closely parallel existing law than do those in the physician sample (see Figure 2). A majority of the public only disapproved of physicians withholding information when the withholding occurs because the information might make the patient unwilling to undergo treatment believed to be medically necessary. However, more than two-thirds of those responding thought a physician would be justified in withholding information if the patient asked for it to be withheld or if the information might significantly harm the patient’s health. About half those in the public sample find nondisclosure acceptable if the patient’s family asked that the patient not be told (which 8% of the public reports having done) or if the information might make the patient upset or anxious.
Effects of disclosure and nondisclosure. Despite the fair amount of conceptual attention paid to the notion of therapeutic privilege, there is very little empirical evidence to indicate whether and in what ways information can be harmful.\textsuperscript{42} Clearly there is a need to define “harmful” or “negative” consequences better and to distinguish between situational anxiety (caused by illness or hospitalization) and anxiety resulting from information. In addition, the mere fact that some information may be “upsetting” in and of itself does not justify withholding information.\textsuperscript{43}

Early empirical studies sought to discover how patients would respond to certain kinds of information that might be provided. Now that the law requires information about risks to be disclosed, a number of studies have sought ways to reduce anxiety associated with such information. Potential as well as actual patients have been asked whether they would want to know about risks of treatment; some patients, after having been informed, have been asked whether the information was upsetting. A study of hypothetical situations found that people often said they would not want information about risks.\textsuperscript{44} However, studies with real patients indicate that although information is sometimes upsetting, virtually all patients went ahead with procedures and thought the information was useful.\textsuperscript{45}

Some people have argued that informing patients about therapy can reduce therapeutic effectiveness by undermining the placebo component of treatment.\textsuperscript{46} Clinicians have long realized that patients are cured not only by a specific treatment, but also by the knowledge that they have undergone a treatment and that relief is imminent. Thus the suggestion

\begin{footnotesize}
\footnote{\textsuperscript{42} Meisel and Roth, \textit{supra} note 26.}
\footnote{\textsuperscript{43} Testimonies of Debra L. Roter and Lawrence W. Green, transcript of the 15th meeting of the President’s Commission (Dec. 11, 1981) at 79-96.}
\footnote{\textsuperscript{44} Ralph J. Alfidi, \textit{Controversy, Alternatives, and Decisions in Complying with the Legal Doctrine of Informed Consent}, 114 \textit{RADIOLOGY} 231 (1975).}
\footnote{\textsuperscript{46} Honigfeld, \textit{supra} note 19.}
\end{footnotesize}
that treatment is efficacious can lead to improvement. Arguably, if a patient is more fully informed about the limitations and risks of treatment, credibility and belief in the therapy can be destroyed, thus losing the therapeutic effects of blind faith. Systematic investigations have found, however, that patients who are informed about the side effects of drugs, for example, are no more apt to report the effects than are patients who are uninformed, but they are more apt to attribute those effects to the drug.

Not only is there no evidence of significant negative psychological consequences of receiving information, but on the contrary some strong evidence indicates that disclosure is beneficial. Several studies have focused upon the effects of giving patients information about their surgery and its recovery period. Preoperative counseling appears to reduce anxiety and complications during convalescence. Fewer analgesic medicines and days in hospital are required by those who are counseled than by those who are not. Providing information has also proved useful in burn treatment, in stress experienced by blood donors, in childbirth, and in sigmoidoscopy.


examinations. A number of hypotheses have been advanced to explain the distress-reducing effects of preparatory information. Some people believe that giving people such counseling stimulates preparatory worry prior to surgery, thus providing an “emotional inoculation” that allows the patient to cope better with distress. Others point to the role of information in producing accurate expectations or in allowing patients to obtain some control, through predictability, of adverse postsurgical convalescence.

Although information may generally improve postoperative outcomes, people clearly differ in how they use information. For some, preparatory information may reduce their ability to deny the threat; for others, it may sensititize them to specific threats, rather than general fears; for still others, it may be a sign of social support or a way to divert attention, refocus cognitive effort, or elicit certain coping responses. Thus, the meaning of the information to the patient will be the primary determinant of whether it produces positive effects. Yet even for frightened, denying, or aggressive patients, preparatory information does not necessarily produce negative effects.

Along with claiming that information about risks of treatment may have negative psychological consequences for patients, some critics of informed consent argue that such information will result in the refusal of necessary treatment and in noncompliance with therapeutic regimens. But several studies have investigated the effect of providing information about risks and side effects; none found any change in behavioral compliance due to the disclosure of information.

56 See, e.g., S.M. Auerbach et al., Anxiety, Locus of Control, Type of Preparatory Information and Adjustment to Dental Surgery, 43 J. OF CONSULTING AND CLINICAL PSYCHOLOGY 809 (1976); J.R. Averill, Personal Control Over Adverse Stimuli and Its Relationship to Stress, 80 PSYCHOLOGICAL BULLETIN 286 (1973).
57 Andrew, supra note 49; Averill, supra note 56.
58 Wilson, supra note 49.