The preceding portions of this Report have set forth the Commission’s vision of the patient-professional relationship as a flexible arrangement, defined in substantial part by the desires of the parties and the demands of the situation. The obligation of the professional is to provide each patient with a basis for effective participation in decisionmaking about his or her own health care. This obligation entails providing information, answering questions, talking over options and doubts, and helping patients to clarify the values and goals relevant to the decision. Such discussion serves to enhance patients’ competence and hence the likelihood that the course of action selected represents the patient’s voluntary choice. In this portion of the Report, the Commission examines several ways to bring this vision closer to reality.

First, the Commission has examined several innovations in practice (all within the scope of existing law), including increased efforts in patient education to promote self-confidence and the ability to be an active participant in health care decisionmaking; broadened sources of information, such as hospital libraries and pharmacists; and appropriate efforts to engage patients’ families in these processes. The Commission finds that there are a number of techniques that could facilitate effective patient participation in health care decisionmaking.

Although the experience with most of these innovations is too slight to justify recommending them as standard practice, the Commission identifies in Chapter Five several that, on the basis of their inherent logic and early results, deserve further study and experimental application. The Federal government now spends many billions of dollars a year on health care, of which some $5 billion is allocated to health-related research, from basic laboratory science to large-scale studies with patients. The Commission believes that the effectiveness of health care—indeed, its true quality in terms of improving
patients’ well-being and satisfying their needs—would be enhanced by the support of behavioral research that shows promise of increasing professional-patient communications and shared decisionmaking. Great advances in medical technology deserve to be matched by improvements in the human side of health care, which has been the central concern of the Commission in this Report. The Commission recommends that the Department of Health and Human Services, and particularly the National Institutes of Health, develop appropriate initiatives and explicitly encourage the pursuit of scientifically sound studies in this field.

The Commission believes that what is ultimately needed to improve mutual respect and participation and shared decisionmaking in health care are changes in traditional attitudes toward the patient-professional relationship. To this end, Chapter Six examines current trends and innovations in medical and nursing education to assess what might be done to encourage and reinforce empathic qualities in health care professionals, to improve communication not only between professionals and patients but also among health care professionals, and to promote the basic values of health care by ensuring that patients are active, informed decisionmakers about their health care. Again, a number of promising avenues exist, and the Commission recommends that those involved in the education and training of health professionals, both within the Federal government and, more importantly, at academic institutions, systematically explore these avenues. At the very least, medical and nursing students should be better educated about the issues and objectives of informed consent that are explored in this Report.

Finally, in Chapter Seven the Commission considers whether changes in the existing law of informed consent might more effectively promote the objectives identified by the Commission and evaluates the costs associated with such changes. Although the law has a useful role in defining certain minimal standards and processes, the intimate and necessarily diverse nature of therapeutic relationships cannot be fully prescribed or enforced by law. The Commission does not believe that the law needs to be modified through new statutes on ordinary physician-patient interactions but regards the concepts developed in this Report as useful for judges in the resolution of cases and for clarification of the common law. Statutory law may be appropriate, however, as a means of ensuring patients greater adherence to their wishes—through “advance directives”—after they lose the capacity for personal participation in decisionmaking.
As discussed in Part Two of this Report, the goals of informed consent and the realities in practice often diverge. Many innovative and practical suggestions have been put forward on how to alter communications between patients and health care professionals to meet the goals of informed consent more fully. In addition to ideas taken from the existing literature, the Commission heard testimony from a number of witnesses concerning ways to improve communications generally and the informed consent process specifically. Suggestions included (1) preparing patients better for effective participation in health care decisionmaking; (2) providing patients with more sources of information; and (3) involving family members more fully in the decisionmaking process.

Preparing the Patient for Effective Participation

To achieve the goals of open communication and shared decisionmaking in medical care, not only must health professionals possess certain interpersonal skills and attitudes, but patients must be willing and able to participate. The Commission views communication between patient and professional, not simply the disclosure of risks, as essential to promoting the value of self-determination discussed in Part Two of this Report and ensuring that patients participate voluntarily, competently, and knowledgeably in decisionmaking about their care.

As discussed in Chapter Four, to participate effectively in the decisionmaking process patients need information. Some experts have argued that the more patients know about health in general, the better able they will be to participate meaningfully in any particular health care decision.1 Such general

1 Testimony of Donald Vickery, transcript of 15th meeting of the President's Commission (Dec. 11, 1981) at 21-25.
knowledge would help patients consider whether and when to seek care, realize what information was important to volunteer to health care providers and to ask about, and decide whether or not to consent to particular procedures. Furthermore, specific information about a patient’s particular condition may result in a better understanding of the patient’s own needs, better compliance with medical regimens, greater involvement in the care process, and improvements in health.²

A variety of techniques have been designed to help patients obtain information they need and want, thereby equipping them for a more active role in their care and for a more equitable partnership between professional and patient. Development of these techniques has been based on several important assumptions:

(1) patients can participate more in health care decisions³;
(2) such participation is of value both because it can promote greater commitment to the therapeutic process, thereby enhancing health, and because it promotes the value of self-determination⁴;
(3) education for health care decisionmaking is useful for all decisions, however minor, and is therefore best seen as a process, not as something to be done once at a moment of crisis⁵; and
(4) patients can effect changes in the relationship with their physician because health professionals respond to patient-initiated styles of interaction.⁶

The Commission recognizes that, as in all of life, a little knowledge can be a dangerous thing. Patients may be naive and overly optimistic about their situation; they may not

---

³ The entire field of health education as well as the underlying principles of informed consent rests on the assumption that patients can participate in health care decisionmaking.
⁴ Virtually every patient education intervention is designed to assist patients to care for themselves better, follow therapeutic regimens more closely, and enhance health.
⁵ Vickery, supra note 1.
⁶ See, e.g., Debra L. Roter, Patient Participation in the Patient-Provider Interaction: The Effects of Patient Question Asking on the Quality of Interaction, Satisfaction and Compliance, 5 HEALTH EDUC. MONOGRAPHS 281 (1977); Testimonies of Debra Roter, Donald Vickery, and Lawrence W. Green, transcript of 15th meeting of the President’s Commission (Dec. 11, 1981) at 21-25 and 79-96.
appreciate uncertainties and the probabilistic nature of medical knowledge. However, generally it has been found that having information and understanding its implications increases patients’ self-confidence. Educated patients tend to feel more competent about managing their illnesses and freer to interact with the medical staff. Given the numerous barriers to meaningful professional-patient communications discussed in Chapter Four, presenting information in a way that maximizes understanding is a prerequisite for more equal participation. Health care practitioners should endeavor to provide information to patients in language they can understand and under circumstances that will promote understanding. A layperson can understand medical information better when simple, nonjargon language is used and when important concepts and implications are stated explicitly. For the message to be understandable, health care professionals must be clear in their own minds about which information is most important. This process of self-scrutiny may have the additional benefit of causing them to rethink, or at least to review, their own diagnosis, prognosis, and recommendations.

Written and audiovisual materials can also aid the communication process. Pamphlets and numerous other aids, both written (stickers, charts, brochures) and audiovisual (tapes, films, computer-assisted instruction, slide shows) have been used to improve patient knowledge and to explain treatment options. Such aids are useful supplements to, but not replacements for, face-to-face discussion. In general the Commission believes that written materials, including preprinted consent forms, should only augment the continuing process of information exchange.

---

7 This was discussed by several witnesses who testified at the 15th meeting of the President’s Commission (Dec. 11, 1981) and is the rationale behind many of the self-care books in the popular market.


In addition to improving the quality of personal communication and written materials, health care professionals must provide patients with the proper time and setting to absorb the information. A step as simple as allowing patients to take written materials home to read before making a decision (or signing a consent form) can improve understanding.\textsuperscript{11} It removes the needless pressures of having to make a rapid decision not required by the medical circumstances and permits the patient to raise questions with, and hear questions from, family members on the information in the materials. Discussion with others is helpful not only in providing other sources of information but also in revealing issues the patient is unclear about and may wish to raise again with the health care professional.

Some efforts have been made to “test” patients at the conclusion of the consent process to ascertain whether they had absorbed the essential information.\textsuperscript{12} For certain patients and procedures, the Commission was impressed with the benefits of having patients write their own consent forms.\textsuperscript{13} As recounted by one medical witness, patients who have discussed with a physician a particular elective procedure under consideration, including its attendant risks and the alternative treatments and their risks, are asked to go home and write down what they have understood. When they return to the physician’s office with this “consent form,” specific areas of misunderstanding can be identified and discussed until the physician is sure that all pertinent information has been understood. The Commission believes that this approach deserves further exploration and urges that studies be conducted in a variety of medical specialties to assess the relative efficacy of such a consent process.

The timing of disclosures is also important, especially when the discussion or the medical setting is likely to provoke anxiety. For example, upon hearing a diagnosis of cancer, patients are typically so preoccupied with fear that detailed information is not heard or even desired.\textsuperscript{14} What little information is taken in is likely to be distorted. Similarly, a pregnant woman who has been told that her fetus is abnormal might very well fail to absorb other information unless the physician


\textsuperscript{12} See the discussion on p. 90 and note 25, Chapter Four supra.

\textsuperscript{13} This procedure was discussed by Dr. Arnold O. Roberts in his testimony before the Commission on Dec. 11, 1981. It appears particularly promising for elective procedures and other treatment decisions that are not urgent.

\textsuperscript{14} See, e.g., M.W. Eysenck, \textit{Anxiety, Learning and Memory: A Reconceptualization}, 13 J. OF RESEARCH IN PERSONALITY 363 (1979).
mentions the slight possibility of intervening successfully; a decision made at this point would be based on incomplete information because the woman would be unable to attend to the serious limitations and risks of such interventions.\textsuperscript{15} The Commission, therefore, encourages health care professionals, whenever possible, to discuss upsetting diagnoses, risks, uncertainties, and other threatening information over a period of time in several encounters rather than to rely on a single discussion.

A suggestion of this type is considered unrealistic by some.\textsuperscript{16} It calls for longer talks with patients by professionals who are often pressured to see many people each hour and who are not adequately reimbursed for discussion time. Given the projected oversupply of physicians (at least in some geographic locations and in some specialties)\textsuperscript{17} and the fact that health care services are increasingly being provided by nonphysicians,\textsuperscript{18} some of the time pressures that have so far militated against doctors spending more time talking with patients may be alleviated. From the viewpoint of the health care system as a whole, a physician’s saving time by failing to educate a patient may be a false economy. Even for the individual practitioner, improved initial communication may save time later by avoiding misinformation or misunderstandings, including those that lead to a malpractice action by a dissatisfied patient.

At the present time, health care professionals are generally reimbursed at higher rates for specific physical interventions (from diagnostic procedures to major surgeries) than they are for communication.\textsuperscript{19} Physicians and health planners have long

\textsuperscript{15} Robin Marantz Henig, Saving Babies Before Birth: The New Promise of Fetal Surgery, NEW YORK TIMES MAGAZINE 16 (Feb. 28, 1982).

\textsuperscript{16} Physicians often complain that time pressures are too great to allow a full discussion with every patient. However, in the Commission’s survey there was no relationship between reported disclosure behavior or attitudes toward disclosure and patient load (total number of patients seen divided by number of hours worked per week). Furthermore, physicians rarely reported time pressures as a factor they consider in determining how much information to give to patients.

\textsuperscript{17} Graduate Medical Education National Advisory Committee. FINAL REPORT, VOL. 1, Health Resources Administration, Hyattsville, Md. (Sept. 1980).

\textsuperscript{18} See, e.g., Loretta C. Ford, A Nurse for All Settings: The Nurse Practitioner, 27 NURSING OUTLOOK 516 (1979).

\textsuperscript{19} As recently noted:

Our current financing mechanisms peg personal physician-patient interactions as “loss leaders” and over-reward the use of tests, procedures, and devices. There are striking financial incentives that coax physicians to go with the technologies as
observed that the third-party reimbursement schedules provide incentives for laboratory tests and diagnostic procedures but disincentives for taking adequate histories. In fact, only by actually undertaking a reimbursable intervention does a practitioner even indirectly receive payment for ensuring that the patient has validly consented. When the time spent with the patient is billed to a third-party payor, its validity is judged only by a standard of therapeutic necessity, which has not traditionally included any independent obligation to help the patient participate in the decisionmaking process.

If the approach to informed consent proposed in this Report is to be implemented in practice, certain incentives in the reimbursement system may have to be readjusted. Notably, nearly 40% of the public in the Commission’s survey said they would be willing to pay more if their doctors spent more time explaining routine care. Presumably this proportion would be even higher in cases of serious illness. The Commission notes that changes in reimbursement could be an important element in achieving a pattern of medical practice where decisions are truly shared by patient and professional. It recommends that procedures—whether preventive, diagnostic, or therapeutic—be defined in such a way that appropriate communication and consent is regarded as a necessary part of good patient care, rather than that a separate reimbursable category of information-giving be created.

**Developing Other Sources of Information for Patients**

The health care professional providing treatment is typically the one to initiate discussions of patients’ conditions and possible remedies and in the end is responsible for ensuring that patients are informed decisionmakers. Yet this single professional is not the only source of information available to patients. When practitioners are committed to the goal of patient participation in health-related decisionmaking they may encourage patients to explore the implications of their illnesses and treatments by, for example, talking to other professionals and patients. To the extent that other informa-

---

the most economic use of their time. Our reimbursement system sends strong signals to physicians to maintain a high-technology practice within their chosen fields.

tion sources can assist the patient to understand, reinforce, and explain what the primary provider has said, patients may be able to make better decisions.

Patients may, of course, on their own initiative seek out other sources of information, including the professional literature, to translate jargon that a health care professional has not made understandable, to follow up on the latest account of a “miracle cure” reported in the press, or to discover alternatives to a treatment suggested by their practitioner. Although such excursions can at times create misunderstanding and confuse patients, they need not do so if they occur in the context of a relationship characterized by mutual respect and open communication. By encouraging patients to bring back any information they discover, health care professionals can correct any misunderstandings while encouraging and harnessing the active participation shown by the patient toward their joint objective—the maximum improvement in the patient’s well-being.

To illustrate the available sources of information outside the professional-patient relationship, this section of the Report looks at sources of information on the use of medicines and at hospital medical libraries as general resources for patients.

**Pharmacists and Pamphlets for Patients on Medication.** One of the areas where patients are most likely to need information is in the use of medication, since drugs are the most common treatment in all medical care. Most visits to the doctor result in a prescription being written; many patients with chronic diseases must take medications over long periods of time; and many patients take several drugs simultaneously, often on the basis of prescriptions written by different specialists. The educational aspect of the pharmacist’s role—providing basic drug information, reinforcing instructions about how to use drugs, and warning patients about possible side effects and drug interactions—has not been fully taken advantage of. Pharmacy students are trained in communication skills and patient education. As in medicine and nursing, the clinical roles of pharmacists have expanded greatly in recent years and now include patient drug monitoring, drug utilization reviews, consultations on pharmacotherapy, patient education, and other related pharmaceutical services. Pharmacists are trained to work with other health professionals and with patients on the appropriate use of medicines, although relative-

---

ly little attention has been paid to the formal establishment of an educational role for neighborhood pharmacists.\textsuperscript{21}

Substantial effort has been devoted, however, to the development of patient package inserts (PPIs) in recent years.\textsuperscript{22} These small pamphlets are designed to inform patients; they include information on when and how to take a drug, contraindications, side effects, and risks. To date, PPIs have been used by the Food and Drug Administration (FDA) only for a limited number of drugs on an experimental basis.\textsuperscript{23} Some physician groups have raised formal objections to PPIs because they fear patients will no longer take what is prescribed if they know all the side effects. Others worried that details on side effects would increase the frequency with which patients perceived them.\textsuperscript{24}

A recent evaluation of PPIs conducted by the Rand Corporation found that patients generally had read the information sheets; though increases in side effects were reported, it was not clear whether the information actually led to an increased perception of symptoms or merely to an increased and more accurate attribution of those symptoms to the drugs. Perhaps most importantly, the Rand study found that PPIs led some patients to discuss more fully with their physicians the reasons for taking a drug and its potential risks and benefits.\textsuperscript{25} Thus, providing specific information with drugs appears to have opened up avenues for more meaningful doctor-patient communication. Although the FDA recently shelved the PPI program, the American Medical Association has begun a voluntary system under which physicians can purchase information forms on 20 of the most widely prescribed drugs for

\textsuperscript{21} Letter to the Commission from Howard Ansel, Dean of the University of Georgia School of Pharmacy, April 1982; pamphlet from the American Association of Colleges of Pharmacy, Pharmacy Education: Responding to the Nation’s Health Care Needs, Bethesda, Md. (1980).

\textsuperscript{22} Following the introduction of H.R. 14289 by Paul Rogers and S. 1282 by Edward Kennedy requiring that patients be provided with written drug information, the FDA proposed to require that printed information be dispensed with prescription drugs concerning its nature, purpose, proper use, and risks. Under an FDA contract, the Institute of Medicine and the Rand Corporation evaluated the effects of drug leaflets. See also the report of a symposium on drug information sheets published as a special supplement to DRUG INFORMATION JOURNAL, Jan. 1977.


\textsuperscript{24} Institute of Medicine, EVALUATING PATIENT PACKAGE INSERTS, National Academy of Sciences, Washington, D.C. (1979).

\textsuperscript{25} Kanouse, supra note 23.
distribution to their patients. “Patient medication instructions” are also being developed for additional common drugs.  

**Opening Medical Libraries to the Public.** Lay witnesses at Commission hearings complained about the limited access to health information outside the medical setting and advocated opening more medical libraries to patients as a means of supplementing information provided by health care professionals.  

While the codes of such groups as the American Library Association do not deal specifically with the issue of access to medical materials, the Library Bill of Rights states that “libraries should provide materials and information presenting all points of view on current and historical issues. Materials

---

26 The AMA decision was approved by the House of Delegates during the annual meeting in June 1982.
27 Testimony of Martha Weinman Lear, transcript of 11th meeting of the President’s Commission (July 10, 1981) at 209-70; testimony of Minna Nathanson, transcript of 17th meeting of the President’s Commission (Feb. 12, 1982) at 114-91; testimony of Herbert Paris, representing the American Hospital Association, transcript of 7th meeting of the President’s Commission (March 14, 1981) at 392-93.
should not be proscribed or removed because of partisan or doctrinal disapproval." Librarians have argued that these statements should be applied not only in the literary and political spheres, but to medical information as well.29

Librarians have recognized a burgeoning demand for medical library services from patients.30 Some have identified this as an outgrowth of the consumer movement of the 1960s. They have linked this trend to phenomena such as the demystification of the professions generally, to the impact of the Freedom of Information Act, and to a desire by consumers to take greater responsibility for their own health through self-care.31 (Analogs have arisen for the legal profession with the advent of do-it-yourself divorce kits, small claims courts, and other legal self-help mechanisms.) Those at the forefront of the movement for patient access to medical records note that "[a] sophisticated patient might want to research the diagnosis himself and learn more about it while monitoring the physician."32

The professional responsibilities of librarians, as they have identified them, include providing access to materials, helping patients find the proper references, and putting these references "in context." They have recognized their duties to specify that some materials may be out of date, to note that there are a number of leading texts in a certain field, and to refrain from injecting personal biases or engaging in the "unauthorized practice of medicine" by giving armchair medical advice or making clinical referrals.33

Librarians have described a number of particularly problematic encounters with patients—the emotionally upset patient who wants the Physician’s Desk Reference to identify a

28 Library Bill of Rights, American Library Association, Chicago (1980). The bill was originally adopted in 1948 and was amended in 1961, 1967, and 1980. The American Hospital Association’s Patients’ Bill of Rights also includes the right to obtain information and speaks of health education as an integral part of health care, although it says nothing about access to libraries.
31 See, e.g., Norman Charney, Ethical and Legal Questions in Providing Health Information, 39 CALIF. LIBRARIAN 25 (1978); note 30 supra.
32 Budd N. Shenkin and David C. Warner, Giving the Patient His Medical Record: A Proposal to Improve the System, 289 NEW ENG. J. MED. 689 (1973).
33 Foster and Self, supra note 30; Charney, supra note 31; telephone conversation with Arthur A. Levin, Director, Center for Medical Consumers and Health Care Information, New York.
handful of pills, the patient wanting to confirm or deny a diagnosis of terminal illness, the client seeking information about a sensitive or embarrassing condition. Medical librarians have urged that professional standards or codes of ethics be developed to guide actions in such situations.\(^{34}\)

Neither the American Hospital Association nor the Joint Commission on the Accreditation of Hospitals has a policy on access to hospital libraries, although they do have policies that deal with questions of patient information generally. Many medical libraries receive support from the Federal government under the Medical Library Assistance Act of 1965,\(^{35}\) which was intended to make medical information available regardless of geographical location. Under this statute a number of regional libraries have been established so that “qualified persons and organizations shall be entitled to free loan services.” While this issue has not been tested in court, “any individual who can read and who has a desire to research a particular medical question is a ‘qualified’ user under the act” and ought to have access and loan privileges to at least these federally established regional libraries.\(^{36}\) In the Commission’s view, institutional arrangements should be made so that individuals can generally have access to whatever medical information is desired, and libraries should facilitate those information needs whenever possible within the constraints of resources.

Although the literature reveals a growing desire on the part of patients to use medical books, articles, and reference materials to improve their understanding of medical conditions and treatments, comprehensive information is not available to describe how this need is being met. The Commission has found that some hospitals and clinics have information centers designed specifically for patients. Furthermore, the library profession has established networks linking some medical school and professional libraries with local public libraries, and at least a few medical libraries for laypeople have been established.

One example is the Center for Medical Consumers in New York City, a reading library open to the public that contains scientific and medical texts and journals and a clipping file from professional and lay sources.\(^{37}\) The library is funded

---

34 Foster and Self, supra note 30, at 246, discuss the need for such standards or codes for legal and medical libraries. They note, for example, that the American Association of Law Libraries’ proposed code of ethics states that law librarians ought not engage in the practice of law or “create an attorney-client relationship,” but that it neglects to define these terms.
37 See note 33 supra.
through small foundation grants and subscriptions to a monthly newsletter that discusses issues and controversies surrounding specific diagnoses, prognoses, and treatments. The 10,000 subscribers include some physicians and institutions, but most are laypeople. Although staff at the Center will assist people in finding information and will make referrals to other sources of information, they are prohibited from providing clinical referrals even though they are sometimes pressured to do so. Establishing and maintaining separate libraries of this sort nationwide would be too expensive; in any case, such a service might be more efficiently performed by public libraries or, in some instances, by hospital libraries.

Involvement of Family in the Process

Another way to enhance patient-provider communications that was discussed by many of the Commission’s witnesses is to involve a patient’s family members more directly and deliberately in the information process. For example, one of the intended side effects of having patients go home to write their own “consent forms” is that it gives others in the family a chance to help the patient understand the situation. This issue has been extensively addressed at the Maternity Center Association in New York, whose director testified before the Commission on the importance of family involvement to promote understanding and support of a pregnant patient’s preferences regarding childbirth. At the Center, involvement is coupled with detailed and candid informational materials.

Several lay and professional witnesses indicated that when families are not included in the disclosure process they feel left out and helpless. A pilot study conducted at the NIH Clinical Center, described to the Commission, has begun to document the important effects of including families. Being involved in the process of discussion and decision allowed family members to feel they could be helpful and more actively

38 “Family” may be defined broadly to include closest relatives and intimate friends, since under some circumstances, particularly when immediate kin are absent, those with most concern for the patient may not be actual relatives.

39 See p. 118 supra.

40 Testimonies of Ruth Watson Lubic, transcript of 15th meeting of the President’s Commission (Dec. 11, 1981) at 7-11.

41 Testimony of Maxwell Boverman, transcript of 15th meeting of the President’s Commission (Dec. 11, 1981) at 15-20; testimonies of Minna Nathanson and Edwin Forman in panel discussion on the role of the family in biomedical decisions, transcript of 17th meeting of the President’s Commission (Feb. 12, 1982) at 114-91.

42 Testimony of Boverman, supra note 41, and preliminary report of the study by John C. Fletcher and Maxwell Boverman, Involving the Patient’s Family in Informed Consent, presented at American Psychological Association 88th Annual Convention, Montreal (Sept. 2, 1980).
involved with the patients. It also appeared to facilitate communication within the family generally by establishing a practice of talking openly even about matters that were unpleasant. Family involvement often gave physicians and other health care providers important information about the patient that they might otherwise not have received. Finally, family involvement seemed to help correct errors and omissions in communications, not only because family members remember things the patient has forgotten, but also because they ask for information the professional has neglected to discuss.

Beyond making the family feel more useful and aiding professional-patient communication, family involvement seems to be therapeutically desirable for two reasons. First, family members have an enormous influence on one another in terms of when and whether an individual actually gets sick, recognizing that someone is ill and deciding whether or not to seek care initially, facilitating or hindering adherence to medical regimens, and ultimately, at least in some instances, influencing treatment outcomes. Second, the interdependence of family members makes any particular individual’s illness a family problem. In some ways, therefore, the family may be viewed as the unit of care, which means it needs to be involved in medical decisionmaking because the effects of decisions about anyone member will affect the entire family.

The value of full and active involvement of patients’ families, like other strategies for improving patient-professional relations and communications, deserves further study. The Commission notes the importance of great care in this area,

---

44 Ronald A. Anderson, A BEHAVIORAL MODEL OF FAMILIES’ USE OF HEALTH SERVICES, Center for Health Administration Studies, Chicago (1968).
46 To the extent that family members influence one another to comply with medical regimens they may indirectly influence health outcomes.
47 It has long been recognized that the family is a social system whose overall functioning reflects the functioning of the individual members. Thus any member’s illness has an impact on the whole family, though the nature of the impact will depend on the particular roles played by the ill member. See, e.g., Talcott Parsons and Renee Fox, Illness, Therapy, and the Modern Urban American Family, 8 J. OF SOC. ISSUES 31 (1952); and Janis Lee Gogan et al., Impact of Childhood Cancer on Siblings, 1 HEALTH AND SOCIAL WORK 41 (1977).
however. Families are not always cooperative units. They may interfere, pressure, misinterpret, and misinform. What is in the patient’s best interest may not be congruent with the interests of all other family members. And, most important, any involvement of outsiders in the therapeutic relationship—even family members—depends upon the patient’s agreement. Even if the family has been involved, health professionals ought to make clear to the patient that he or she can insist upon privacy at any time and on any subject.