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When you enter the hospital check your rights at the door

BY GEORGE ANNAS

Civil libertarians have little difficulty appreciating the plight of prisoners or mental patients. But tell the average civil libertarian that there are significant and unnecessary restrictions on the individual rights and liberties of patients in general hospitals, and you are likely to encounter a blank stare. There are a number of reasons for this lack of attention to hospitals. One is the general misconception that the problems are minor, or that certain temporary restrictions on individuals are essential if hospitals are to treat sick people properly. An unconscious desire not to perceive ourselves as being at risk may be another reason.

Civil rights lawyers seldom seriously think they will ever be either prisoners or mental patients. But almost all of them — and us — have been hospital patients at least once, however, and it is predictable that each of us will be a hospital patient an average of seven times during our lives. By not dealing with the issue, perhaps we are seeking to avoid thinking about our own future hospitalization — an event which is almost always traumatic and undesired.

Other than the fact that the average length of a hospital stay is about eight days, there are probably more similarities than differences among prisoners, mental patients and general hospital patients. While no social stigmatization attaches to admission, the patient,



PHOTO/ALFRED GESCHEIDT

for example, almost never comes to the hospital voluntarily. Some outside force, usually an illness or injury, has made admission mandatory. Unless the patient comes in through the emergency room, a doctor is likely to have ordered the admission and chosen the particular hospital.

Upon arriving the patient is made to sign a variety of forms which generally are explained only with the assurance that they are routine. The patient then is separated from accompanying friends or relatives and escorted to a preassigned room. The patient's clothes are replaced with a johnnie — a one-piece garment designed for the convenience of the hospital staff in testing and treating the patient. The patient is given a plastic wristband with a number written on it — a number that becomes more important than his or her name. The patient is confined to a bed and may even have to await permission to use the toilet. Medication and food may be prescribed without consulting the patient; and nurses, students, aides and physicians may enter the patient's room without knocking and submit the patient to all manner of examination and treatment without explanation. Moreover, all of this will be carefully recorded in a written record which the patient generally is not allowed to see, but which is available to all who see the patient and probably to anyone on the hospital staff, as well as

to medical researchers and insurance companies. Unless the patient is in an expensive private room, visiting hours are restricted, as is access to the outside by means of the telephone.

The experience tends to intimidate and disorient the patient and discourages any assertion of individual rights. While medical care in the past was a one-to-one relationship involving only the patient and physician, in the modern hospital it is one patient being treated by a team in a large, unfamiliar, institutional setting. Because of this, the patient-institution relationship becomes at least as important as the doctor-patient relationship.

Those interested in the rights of women, children and the poor should also be able to identify many problems in the hospital. Patients are asked to behave like children, investing in the physician and staff the faith they once had in their parents. Women are often treated as more neurotic and emotional than men, and thus frequently deprived of information concerning treatment alternatives and possible complications because it might "upset" them unduly. To suit their convenience, hospital staffs often separate children from their parents, ignoring their physical and emotional needs. Finally, the source of payment often may determine the quality and type of care, as well as the manner in which it is administered. And hospitals, which have become major

financial enterprises, may view their primary functions as research and education rather than patient care.

Why hasn't the voice of the consumer risen up in effective protest to demand changes in the more dehumanizing practices of hospitals? First, the average length of stay of about a week makes formation of an in-patient consumer group impossible. Second, most patients in hospitals are simply too sick to assert their personal rights. Indeed they may be more than willing to forego them if they believe that this will speed up their treatment and return home. Third, healthy individuals do not see the issue as one which is as vital to their lives as others which affect them daily, such as housing, education and racial discrimination. Finally, there is the great difficulty outsiders have in understanding what the institution called a hospital is all about.

ONE PATIENT TO A BED

Hospitals as we now know them are a product of only the past three or four decades. Before the turn of this century it was unlikely that going to a hospital (or almshouse or pesthouse as they were more often termed) would do one any good — most people went to them only because they were poor and dying or had an incurable condition. The only recorded hospital patients' rights measure before this century was instituted in France in 1793 by the National Convention of the French Revolution. It decreed that there should be only one patient in a bed (as opposed to the usual two to eight) and that beds should be at least three feet apart. A cynic could argue that we haven't come very far since 1793.

As drugs and surgery replaced the purging, pucking and bleeding of the nineteenth and early twentieth centuries, and as medical education and specialty medicine progressed, the hospital gradually became the center of medical research. States and localities set up hospitals for their citizens, following the lead of private charities and nonprofit corporations. Perhaps the most significant development was the teaching hospital. Usually a large, general hospital in which medical students, interns and residents are trained under the direction of experienced physicians on the faculty of a medical school, it is here that most medical research takes place, most medical advances are initiated, and where the best medical techniques available are most likely to be found.

The argument for enhanced patients' rights is based on two fundamental premises: first, the American medical consumer possesses certain interests, many of which may properly be described as rights, that are not automatically forfeited by entering into a relationship with a doctor or a health care facility; and second, most doctors and health care facilities fail to recognize the existence of these interests and rights, fail to provide for their protection or assertion and frequently limit their exercise without recourse.

THE EMERGENCY ROOM: HOW MUCH ARE YOU WORTH?

More than twice as many patients as are admitted to hospitals are seen in emergency rooms. As a consequence, emergency rooms have become the primary source of medical care for communities surrounding major hospitals, especially for the poor in those com-

munities. Since so many people depend on them for their health care, the type of treatment they afford patients is critical. Problems can arise from a refusal to examine and/or treat an individual, a requirement of a cash down payment prior to examination, long and harmful delays before examination, transfer to another institution, treatment and discussion of a patient in full view or hearing of others, or inability to understand the patient's language.

Probably not atypical is a case that occurred recently at Boston City Hospital. A psychiatrist was called to the emergency ward to see a Puerto Rican woman whose stomach had just been pumped out. He was the first person on the scene able to speak Spanish. The woman told him that she had received some very distressing news at home, had taken two Alka-Seltzers and had come to the hospital to talk with a doctor. The emergency ward staff had assumed that she was an overdose case because, they explained, "most Puerto Ricans who demonstrate symptoms like those shown by the woman have overdosed."

Though the woman's life was not endangered, the example is important because hospitals frequently fail to provide an interpreter despite the presence of a large, foreign-speaking population in their areas, and often make ethnically stereotyped diagnoses. Had this hospital been properly concerned with informed consent, it would have recognized its obligation to communicate to the patient the medical staff's assumptions about her condition, which she would then have promptly contradicted, refusing her consent to a stomach-pumping.

More serious are instances in which hospitals refuse even emergency treatment, in direct contravention of the law, to patients who have no cash or insurance. The father of a ten-year-old child related the following story to Senator Edward Kennedy's Subcommittee on Health. His son, Paul, had a seizure at home and passed out. He rushed the boy to the nearest hospital, a private institution (his son had been receiving treatment at the county hospital, a considerable distance away). When they arrived, he was subjected to an interview about his finances and insurance. The staff refused to examine his son until he had answered such questions as: "Do you own your own home?", "Who is your employer?" and "How long have you worked there?" The interviewer also refused to call the county hospital. In frustration the father left the emergency room and drove the long distance to the county hospital. In the course of his trip he passed several other private hospitals but was afraid to stop for fear of receiving another interrogation but no treatment. His son died within an hour after he arrived at the county hospital. Prompt attention would have saved the boy's life.

Cases abound of hospitals refusing to see emergency patients who have neither insurance nor cash with them, hospitals transferring emergency patients to county or municipal hospitals because of their apparent inability to pay, and patients dying in emergency rooms while they are waiting to be seen by a nurse or a physician.

There is some evidence that the emergency room situation is improving under pressure from the courts (which have required hospitals with emergency facilities to treat all emergency cases that present themselves for

treatment), new federal Hill-Burton regulations for providing funds to hospitals, Medicare and Medicaid regulations regarding emergency services, and the promulgation of emergency room standards by the Joint Commission on Accreditation of Hospitals. Few would disagree, however, that much remains to be done before patients needing immediate aid can present themselves confidently at any emergency ward.

CONSENT TO TREATMENT: DOCTOR KNOWS BEST

In his essay "On Liberty" John Stuart Mill wrote: "The only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant." This principle stands in sharp contrast to the aphorism that "The doctor knows best." The doctor might, but it is the doctor's legal duty to explain in lay terms the treatment he proposes, the risks of death and serious side effects, problems of recuperation, probabilities of success and alternatives, *and* to obtain the patient's informed, competent and voluntary consent before proceeding with the treatment. In order to preserve the patient's right of self-determination, it is essential that the patient make the decision regarding treatment, not the physician. As a leading law textbook expresses it: "Individual freedom here is guaranteed only if people are given the right to make choices which would generally be regarded as foolish."

This principle may seem almost self-evident, but apparently it is difficult for most physicians to comprehend. Many argue, for example, that they can get patients to consent to anything, depending on the way they phrase their description of it. Another way of saying this is that patients can be deceived by coloring or distorting the truth. In a recent California case, for example, an orthopedic surgeon, Dr. John Nork, admitted that he had persuaded over 30 patients to submit to laminectomies (removal of an intervertebral disc) that they did not need. Many of these patients were rendered worse off than before the surgery, and some were crippled for life because of the physician's ineptitude in performing the surgery. The power of the physician is illustrated by the fact that one of the patients he crippled even testified on his behalf at a malpractice trial.

Malpractice case law is filled with instances of physicians failing to disclose information concerning surgery to patients. Examples include doctors failing to mention the risk of paralysis in a laminectomy, failure to mention any risks in an ulcer operation, failure to mention any possible harmful effects of cobalt treatment for cancer, failure to explain a procedure in words the patient can understand, obtaining consent while the patient is under the influence of drugs or alcohol, and failure to explain to the patient that the recommended procedure can actually make the patient's condition worse.

Providing patients with complete and accurate information concerning their conditions and the treatment alternatives can, therefore, directly improve the quality of care by reducing the number of unnecessary opera-

tions performed. Insistence on consultation with a specialist in internal medicine would also significantly reduce this number. As to the hazards to patients from fully disclosing information about their illnesses, surveys have found that although some patients are upset at learning the risks of operations, most prefer to know and either are unaffected emotionally by the information or feel more comfortable after receiving it.

ACCESS TO MEDICAL RECORDS: OPENING UP A CAN OF "NUTS"?

It is fairly standard procedure for hospitals never to permit patients to see their records. While this is usually justified by the rationale that patients cannot understand records and will only be distressed by them, this paternalism is as misplaced as it is unjustifiable.

The record is about the patient, and while the hospital may own the paper on which it is printed, the patient has the most vital interest concerning its content. The real reasons that records are not routinely given to patients seem to be that: first, physicians do not wish to take the time to explain their contents to patients; and second, physicians often write impressions of the patient in the record which may be seen by them as useful, but which may have no basis in fact.

Both these records are illustrated by a recent case that arose at Boston's Beth Israel Hospital. Massachusetts has a statute that gives patients a legal right to see their records while they are in the hospital and after they are discharged, and to obtain a copy at "reasonable cost." A former patient on Medicaid made a request to the hospital to look at his lengthy medical record. The person in charge, who knew that the individual was indigent, said that a copy could be had at a cost of \$40.00. Unable to raise this much money, the former patient asked simply to see his records. This request was refused.

The patient then sought legal help, and an attorney obtained an agreement that the patient's former physician would sit down with him and go through his record. At this meeting the patient evidenced a desire to go through the entire record carefully — a procedure that could have taken six to eight hours. The hospital then decided to give him a copy of the record to study at home. As he read it he found a number of statements by physicians, unsupported by any data or psychiatric evaluation, to the effect that he was crazy or "nuts," or that his illnesses were psychosomatic.

It is essential that patients know what the record contains not only so they can decide where to go for future care (it is unlikely a patient would receive as serious attention in a hospital which had a record calling him "nuts" as in one which had not previously treated him), but also in deciding whether or not to permit copies of medical records to be examined by prospective employers or insurance companies. Moreover, knowledge of what one's medical record contains may well be a prerequisite to giving truly informed consent to any hospital treatment.

MEDICAL EXPERIMENTATION: "BETTER OFF NOT KNOWING"?

Whenever physicians depart from standard medical practice and seek in their treatment of a patient to

Hospitals teach medical students it is permissible to lie to patients

obtain new knowledge, they are engaging in human experimentation. Studies have shown that the "ignorant, the poor and the ethnically despised" are the most frequently used subjects in human experimentation [see "Human Guinea Pigs: the Law as Bad Medicine" by Frederic Melcher in the February *Student Lawyer*]. In the Tuskegee syphilis survey, to choose one egregious example, 600 black men with syphilis had treatment withheld from them in order to permit public health officials to study the disease. Nor did it surprise many familiar with hospital experimentation that of the first 100 heart transplants, over 60 donors were black, but there was only one black recipient.

Much experimentation simply involves going through all the medical records of patients who have a certain disease, doing additional tests on tissue that would have been removed from the patient in any event, or drawing an extra syringe of blood from a patient who would not otherwise have had it drawn. All these studies raise serious questions concerning confidentiality, privacy and self-determination. The medical profession in general also takes it for granted that in experiments involving minimal risks, there is no need to obtain a patient's express consent.

It was not until 1966 that the National Institutes of Health, which funds much of the research that goes on in this country, issued guidelines for researchers that included having the research design, the risks and benefits, and the informed consent procedure reviewed in advance and approved by a hospital-based review committee. Last May these guidelines were revised and reissued to insure limited multidisciplinary review.

More interesting than what these guidelines contain is what they do not contain. As an example, NIH makes no provisions to defray the medical bills or loss of earnings of someone injured in an experiment unless the injury resulted from negligence. Usually, the experimental subjects, those least able to bear the risk, are left to their own devices.

Reports on the research suggest that most patients do not understand in any clear way the distinction between treatment and experimentation, and that institutional review tends merely to be a rubber stamp for experimentation. Therefore, while not a legal requirement, the provision for indemnification for injury of the research subject should be a *sine qua non* of ethical research.

THE TERMINALLY ILL: OBJECTS DON'T HAVE RIGHTS

The patients perhaps most at risk of losing all their human rights in the hospital are those who are dying or terminally ill. The first right lost is the right to truth. Studies have indicated that most doctors never tell their patients they are dying, and over 90 percent seldom tell them. Instead doctors usually tell the family, depriving the patient simultaneously of another right: the right of confidentiality. In addition, dying patients are likely to receive less attention than other patients from medical personnel and are more likely than other patients to be used as subjects of medical experimentation. Since they are not told that they are considered terminal, truly informed consent is never obtained for their "treatments."

Many of the problems of the dying are related to society's discomfort with the elderly (nursing homes, for example, present most of the same problems as hospitals extended over an average length of stay of three years). While many of the elderly would prefer to die a "natural death," without the massive intervention of medical equipment and procedures that might prolong their agony for days or even months, hospitals are often very reluctant to follow their wishes. Some fear malpractice suits; others place the wishes of the surviving family above those of the patients; still others consider a patient who no longer desires to live incompetent to make treatment decisions or to refuse treatment.

A terminally ill college professor was so upset about the way he was treated while being diagnosed that he wrote an article about it. Here he relates his feelings after having been given a battery of tests by a neurologist and three medical students:

I got a reinforcement of the sense of not only am I a patient who is supposed to behave in a certain way, but I'm almost an object to demonstrate to people that I'm not really people any more, I'm something else. I'm a body that has some very interesting characteristics about it. . . . I began to feel not only the fear of this unknown, dread thing that I have, that nobody knows anything about — and if they know they're not going to tell me — but an anger and a resentment of "Goddamn it, I'm a human being and I want to be treated like one!" And feeling that if I expressed anger, I could be retaliated against, because I'm in a very vulnerable position.

THE TEACHING HOSPITAL: WHEN MEANS JUSTIFY ENDS

While some of the illustrations in this article highlight the horrible and ignore the routine, in many ways they do not begin to reach some of the fundamental problems in hospitals. The teaching problem, for example, has only been alluded to. In teaching hospitals the main mission is often viewed as education rather than patient care. Doctors argue both that medical students and interns need clinical experience to become good doctors, and that patients do not like to be treated or examined by students or operated on by interns or residents.

One result is that often medical students are introduced as "doctor" when they are not yet M.D.s. A dental student has related, for example, how while in training at a major teaching hospital he was asked into an examining room and, along with three medical students, introduced to a sixteen-year-old girl as a "young doctor." Each of the four then performed pelvic examinations on the mortified patient. While most physicians would probably justify this unjustifiable deception on the part of the medical students, there is absolutely no argument to make in favor of the dental student.

Another abuse is perpetrated by the doctor who assures the surgical patient that he will be performing the surgery, when in fact a resident performs the operation and the doctor observes and instructs. When the doctor is not in the operating room at all the practice is termed "ghost surgery."

George Annas is director of the Center for Law and Health Sciences at the Boston University School of Law. This article first appeared in The Civil Liberties Review, Vol. 1, No. 4, pages 9-29. Copyright © 1974 by the American Civil Liberties Union and reprinted by permission of the copyright holder and the publisher John Wiley & Sons, Inc.

Not only does this method of "teaching" involve the direct deception of the patient, it also teaches medical students that it is permissible to lie to patients if you have a "good reason." There are studies indicating that some operations are performed on Medicaid patients not because the operation is necessary, but because the intern or resident hasn't done enough of them to become proficient. When a student-investigator questioned a resident as to why a particular patient was having a hysterectomy instead of a tubal ligation, for example, he was told: "We like to do a hysterectomy, it's more of a challenge . . . you know a well-trained chimpanzee can do a tubal ligation . . . and it's good experience for the junior resident . . . good training."

HUMANIZING THE HOSPITAL

From the variety and extent of the potential infringements on human rights in the hospital it should be apparent that there are no simple solutions. Also, unlike most areas in which civil liberties attorneys work, litigation probably is of relatively little significance. Most of the situations discussed above become irrevocable before a hearing can be held. Furthermore, most of the law that has developed in the field has been based on malpractice litigation. While there certainly are some important principles to be established regarding standards of care and the elements of informed consent, most of the problems demand either new legislation or the promulgation of regulations under existing legislative authority. Even with these, however, the actions of individual patients may be of greater importance.

In late 1972 the American Hospital Association issued a twelve-point Patients' Bill of Rights and encouraged its 7,000 member hospitals to adopt it or a similar declaration. As one could probably guess from the source, the document's provisions were a vague restatement of the law involving such concepts as informed consent and the right to refuse treatment. One commentator likened it to the fox telling the chickens what their rights were.

In Minnesota a bill of rights similar to the AHA model has been enacted into law, and all health care institutions are required to post it in conspicuous places in their facilities. This trend toward publishing rights is important because it not only reminds people that they have rights, it also encourages them to assert them and to make further demands. To be really significant, however, such bills should deal with the fundamental problems that patients encounter in trying to retain self-determination and privacy in health care facilities. I offer the model bill on page 24 which contains a minimal listing of the rights that should be accorded all patients both as a matter of hospital policy and state law.

In talking about "rights" here, the term is used in

three senses: first, rights that a citizen clearly or probably can claim as a matter of law under the Constitution, existing statutes or judicial doctrines; second, rights that a person probably can claim as judicially enforceable because of his or her relationship with another party, such as a doctor or hospital administrator; and third, rights that a growing body of people believe should be recognized as the moral rights of individuals and the obligations of authorities, even though courts would probably not recognize them as such yet.

Though some would like to see the emphasis placed on enforceable legal rights only, at this stage in the development of the patients' rights concept such a limitation would be both conceptually and strategically unwise; humanizing the hospital will require a movement that joins the legal and moral aspects of the cause into one campaign, and buttresses the arguments from legal precedent and logic with the spirit of the moral cause. This was the manner of the civil rights and women's movements, and it would be useful for patients as well. Therefore, when the phrase "legal right" is used in the model bill, the right is one well recognized by case law or statute. The term "right" refers to one that probably would be recognized if the case were brought to court, and "we recognize the right" refers to a statement of what "ought to be."

Once these rights are recognized, some mechanism for hearing complaints and enforcing rules must also, of course, be established. If enacted into law in the future, all of the rights would then be legal rights.

The model bill is set out as it would apply to a patient in his or her chronological relations with the hospital: sections 1 through 4 for a person not hospitalized but a *potential* patient; 5 for emergency admission; 6 through 15 for in-patients; 16 through 22 for discharge and after discharge; and 23 relating back to all 22 rights.

As is apparent from the preamble of this document, it is my view that a statement of rights alone is insufficient. What is needed in addition is someone, whom I term an advocate, to assist patients in asserting their rights. As indicated previously, this advocate is necessary because a sick person's first concern is to regain health, and in pursuit of health patients are willing to give up rights that they otherwise would vigorously assert.

THE PATIENTS' RIGHTS ADVOCATE: PLACEBO OR PANACEA?

Many health care facilities view the problem of patients' rights and consumer demands as one of public relations. Some have therefore assigned members of their staffs to act as some form of "patient representative." In a recent survey, for example, 462 of the 1,000 hospitals with more than 200 beds that responded said that they had at least one employee whose primary job is "to serve as management's direct representative to patients." Their duties were almost always limited to nonmedical matters, and they would accordingly be more properly denoted "management representatives."

Boston's Beth Israel Hospital has just such a placebo system. The hospital's director, Dr. Mitchell T. Rabkin, describes the type of problems he thinks are most important to patients and those his representatives are

designed to meet: "... the burned-out lightbulb, the dirt in the corner, the afternoon nourishment missed while at X-ray, the allergy-free pillow, the patient's car left in front of the Emergency Unit, the airline tickets needed on discharge, and so forth." His representatives are specifically forbidden to deal with nursing or medical complaints patients may have.

The philosophy behind such a system is that what the patient really cares about are basic creature comforts, not the quality of health care, the medical alternatives and the likely outcome. While such a stance is in many ways ludicrous on its face, the rationale often given is that such "housekeeping" problems are in fact what patients complain about most. There *are* real "housekeeping" problems, requiring not a patient's representative, but a larger and more efficient hospital staff to solve them properly. But patients don't discuss or complain about the type of care they are getting because this is frowned on and almost always is met with the response: "Ask your doctor."

The average patient is lucky to see his or her doctor five minutes a day, and the doctor is likely to discourage any lengthy discussion about the patient's condition. Moreover, since most hospital bills are paid by third-party private or government insurance, patients may feel that they have nothing to bargain with because even if they were dissatisfied with the quality of care they receive, they know the bill will still be paid, and they know the hospital knows this also. Under these circumstances, to equate patients' rights with adequate housekeeping in the hospital is hypocritical at best, and does nothing to help the patient maintain either self-determination or privacy.

To refocus patients' concern on health care and to afford patients the opportunity to exercise the rights outlined in the bill of rights requires an advocate whose main concern is medical care and treatment and whose powers are the same as the legal powers of the patient. The advocate should be able to exercise at least the following unrestricted powers on behalf of individual patients and at their direction:

- complete access to all medical records;
- the ability to call in qualified consultants;
- ex-officio participation in all hospital committees responsible for monitoring the quality of health care;
- the power to lodge complaints directly with the hospital's director and executive committee;
- immediate access to all chiefs of service;
- access to all patient support services; and
- the ability to delay discharges.

There is no single set of qualifications for the advocate. The advocate must deal with people of varying degrees of education and ability to communicate, and of different ethnic, religious and social backgrounds. Some knowledge of law, medicine and psychology would appear essential, but the extent to which formal education would prepare a person for this position seems minimal. Knowledge of the community served and the language of its population will probably prove the most essential attributes of a successful advocate.

Ideally this person should be financially independent of the institution in which she or he will function.

(continued on page 49)

hospital

(continued from page 16)

Financing could come, for example, from a state's department of consumer affairs or attorney general's office or the U.S. Department of Health, Education and Welfare, which could establish a national patient advocacy office.

In the health maintenance organization (HMO) framework, funding could be included in the yearly premiums, and advocates hired by consumer-dominated boards of directors. In this regard, experimentation is probably in order. It already seems evident, however, that patients' representatives paid by the hospital in which they work would have divided loyalties and could not take too strong a stand in favor of patients' rights. Only patients should have the power to fire the advocate.

As far as I am aware, there are no advocate systems currently in existence that follow this model. Boston has applied for funding to initiate at Boston City Hospital a program similar to the one proposed in this article. The Massachusetts General Hospital is experimenting with this type of an approach to a very limited degree. Initiatives from hospitals, however, are unlikely — pressure must be put on governmental units to sponsor such programs in the hospitals under their jurisdictions. The goal is not to so disrupt the hospital routine as to make effective care impossible, but to improve patient care by making the recognition and exercise of patients' rights the rule rather than the exception.

LEGISLATING ACTION

Access to medical records. One way to have patients' rights legally recognized is to pass a law. Even if enacting a strong patients' bill of rights is not feasible, work can progress on a piecemeal basis. Access to medical records is one example. The only legal method by which hospital patients in more than 40 states currently may get to view and copy their medical records is by filing a medical malpractice suit. Indeed, the Malpractice Commission of HEW has reported that routine denial of access to records is a primary reason for the instigation of such suits: i.e., patients weren't sure if malpractice had occurred until they could view the records, but weren't allowed to view them until after they sued.

Such domination by hospitals of the agencies designed to regulate the industry is, of course, the rule rather than the exception. Consumers usually must rely on their own strength, backed up by legislation and legal assistance when necessary, to exercise their rights. The passage of laws will not perforce open up hospital records, but will make it extremely difficult for a doctor or hospital to deny access to patients as a routine matter and will encourage patients to make such demands. If enough patients put direct pressure on hospitals to see their records, hospitals will respond and policies will change.

Health insurance. Payment of hospital bills may be the most important health issue for the average American. Many of the problems faced in this area are directly attributable to hospital domination of the major health

care insurer, Blue Cross. The Blue Cross organizations, chartered nationwide as a group of non-profit corporations to work for the public good, are controlled by the hospitals to such an extent that in the absence of tough state regulations, Blue Cross routinely reimburses health care providers at whatever rates the hospitals tell them is "reasonable" for services the hospitals indicate are "necessary." The items that go into one's hospital bill often include such things as research and the teaching of medical students and nurses (it is not enough that the patients are practiced on without consenting; they must also pay for this learning experience).

Recently there has been much talk about legislation to monitor the quality of health care and reduce the length of a stay in the hospital. Professional Standards Review Organizations (PSRO) are currently being formed all over the country to monitor the quality of care. As they are composed entirely of physicians, however, it is extremely unlikely that much change will come from them, and even more unlikely that they will deal with the types of issues outlined in the proposed Patients' Bill of Rights. Much more sensible than all-physician review boards with a board of consumers to advise them would be consumer-physician review boards dominated by lay people, with a panel of medical experts to advise them on technical matters of which the physician members are uncertain.

It is possible that decreasing the length of a stay in the hospital may also improve the quality of care a patient receives, but the major reason for shortening the period of hospitalization would be to save the patient's money. However, many of our metropolitan areas now have numerous empty hospital beds; this puts tremendous pressures on hospitals to keep their occupancy rates up, regardless of the cost to the patient. Often, patients who are scheduled for surgery on Monday are hospitalized not on Sunday night — which usually is soon enough — but on Friday evening so that the bed can be filled over the weekend. Legislation that would set up procedures for careful monitoring by independent review boards could certainly eliminate this kind of abuse.

The national health insurance bills currently before the Congress won't do much for patients' rights. They incorporate the PSRO review structure in which patients' rights are not encouraged. They do not change the present system of delivering medical care. They are, as the rubric denotes, *insurance* bills — bills that make sure that doctors and hospitals will get paid for the services they render. They are not bills that either increase the amount of health care services available or guarantee to the poor or any other segment of society access to health care services. Most are also financed, at least in part, by the most regressive tax we have: the payroll tax. All of these bills would benefit the consumer-patient more if they incorporated a Patients' Bill of Rights, a patient advocacy system and a consumer-majority, quality-of-care review board.

Malpractice litigation. Some physicians and medical societies have begun to advocate the abolition of the malpractice suit, proposing that it be replaced by either binding arbitration or a no-fault insurance system. While binding arbitration is useful in the context of health

EDITORIAL POLICY

The *Student Lawyer* is the magazine of the Law Student Division of the ABA. Its purpose is to advance the goals of the Division and to facilitate communication among law students.

The *Student Lawyer* should stimulate law students to evaluate and assess their roles in society. It should challenge the values and opinions, the prejudices and presumptions of students. The publication will reflect the diversity of the thoughts and philosophies of the Division's membership and will seek to broaden awareness of our changing society, profession, and tradition.

The *Student Lawyer* will also present ideas and comments on law school admissions, legal education, and bar admissions. These are areas of particular concern to law students.

The *Student Lawyer* invites readers to contribute timely and imaginative articles, and over a period of time, a balanced view will be presented, with no restriction of free expression.

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maintenance organizations, in which payment is made and contracts are signed before the person is ill or injured, it is completely out of place in the more common office and hospital situations. No-fault, on the other hand, is an appropriate solution only for indemnifying the victims of medical experimentation, since most of the harm done, though foreseeable, is unavoidable.

As it happens, most malpractice claims are based on the failure of the doctor or hospital to conform to good medical practice or to obtain informed consent. It is therefore ironic that while they tout no-fault as a replacement for the litigation that arises in the course of ordinary medical practice, most doctors and hospitals are unwilling to provide for the indemnification of victims of experimentation.

The malpractice suit is currently the only way patients can successfully challenge the actions of doctors and hospitals and obtain some compensation for sub-standard care. As noted previously, it is also the only way in many states that patients can see their medical records. The major problems with the system from the consumer's point of view are that it is time-consuming and that few lawyers will take small claims. These arguments make both binding arbitration and no-fault attractive *supplements* as long as strict upper limits are placed on the applicability (e.g. \$25,000).

Computerization of medical records. Another development that patients should view with some alarm is the computerization of medical records. While there is some value in a doctor anywhere in the country or world being able to get your medical record upon making the proper query to a computer, the implications for invasion of privacy are enormous. Some have surfaced already in the corporate person of MIB, a Connecticut firm that keeps medical files, files which it has recently computerized for efficiency and which it makes available to insurance companies when subjects apply for insurance. Not only has this use of personal records not been authorized by the patient, the patient is probably completely unaware it is happening.

Erroneous medical records circulated without the patient's consent can have a devastating effect on his or her ability to get a job or life insurance; they also affect the quality of the patient's future health care. It has been estimated that at least 10 percent of computerized medical records contain errors and that it would be financially unfeasible to reduce this to below 3 percent. All other arguments for access to one's records aside, in the face of these figures it is imperative that patients be able to inspect and approve the entries in their medical records. When errors occur, patients should also have the right to have them corrected. Unfortunately, as important as they are, medical records generally are exempted from even the limited consumer credit information access statutes currently on the books.

The living will. The increasing use of drastic "heroic" measures to prolong the life of the terminally ill has generated increasing public awareness of the problems of dying. A 1973 Harris poll found that 62 percent of Americans favored allowing the terminally ill patient to direct the doctor to "let him die rather than extend his life when no cure is in sight," and only 28 percent thought this practice was wrong. Legally, of course,

physicians are free to follow the wishes of a patient in this matter. The problem is that many doctors continue to treat terminal cases because of their own beliefs and convictions or those of the patient's family.

One proposed solution is the "living will" (so-called because it takes effect while the patient is still alive) which instructs the physician to take no steps to prolong the dying process. To date most attempts to make such a request legally binding have not been successful. (A measure did pass the Florida House last year. The sponsor argued that old people used to be afraid to go to the hospital because it was a place where people went to die, but now they are afraid because it is a place where people are not allowed to die.)

A state statute is thought to be necessary by some to make a living will legally binding on doctors and hospitals, since otherwise, it is argued, such a document would violate public policy against suicide or euthanasia. I do not agree: the patient has a legal right to refuse treatment, and this clearly includes any treatment proposed by a physician who views restoration of health as an impossibility.


Much more difficult questions are raised at the beginning of life when it is proposed that treatment of severely deformed or retarded infants be suspended and they be "permitted" to die. At the least, such action on the part of a doctor is a violation of the equal protection guarantee of the Constitution; at worst, both doctors and consenting parents are committing criminal acts and should be prosecuted. The medical care system and the secrecy of the hospital must never be used to circumvent the criminal law to the detriment of a class of individuals completely unable to protect themselves.

ASSERTING YOUR RIGHTS

While I have argued that hospital patients are in many ways treated like prisoners and mental patients, I do not propose either abolishing hospitals or fundamentally altering their role in the delivery of health care. What I do propose is making them more responsive to human needs and human rights — something I believe can be accomplished without a decrease in the quality of patient care, and perhaps even with a significant increase in the quality of care. While that care is unlikely to be seriously affected by the patients' rights movement, the manner in which it is delivered and the role of the patient in its delivery is likely to be altered drastically.

The system of keeping relevant information from the patient will be eliminated. Open discussion will replace guarded comments and outright deception. Teaching and experimentation will be acknowledged (and undoubtedly accepted) as such and not presented to the patient as treatment. Patients who wish to die in the hospital without having their dying prolonged will be allowed to do so.

None of these changes will take place overnight, but they need not take long in an institution as young as the modern hospital. Development of a bill of rights backed by an effective patient advocate system would significantly speed up the process of change. Even without these, however, all of us — since we have frequent contacts with various parts of the health care system — can begin by encouraging change from outside.

In a society in which individual rights are compromised on all sides, the patients' rights movement provides all of us an opportunity to assert those civil rights we espouse so eloquently in other contexts. 



- Kissinger was there
- King David was there
- Napoleon was there
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