# CONSUMER EALTH ERSPECTIVES



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# PATIENTS AND DOCTORS

### HISTORY OF THEIR ROLES AND RELATIONSHIPS

by Zita Fearon

### THE CHANGING PHYSICIAN-PATIENT RELATIONSHIP

by Diane Hundt

#### **Determining Factors**

Throughout history, all of human society has had a social organization to fight disease. This social organization has been determined primarily by the social and economic structure of society, and by the technical and scientific means available to medicine at the time. The role of the healer and his/her relationship with the sick or injured person(s) has also been determined by the structure of society and the level of its technical and scientific development.

The hierarchical aspect of the patient/doctor relationship, which is currently widely discussed in the media as well as in the accompanying article, is a fairly recent phenomenon in the history of man and medicine. The hierarchical aspect of many relationships today causes concern, conflict and litigation, but the media seldom gives attention to the historical development of relationships, or to the social and economic structure of society which causes the inequality in relationships, or to the tension which exists when scientific and technical developments have outgrown the social and economic structure of our society. This introduction to the main article will briefly discuss these issues.

### **Historical Development**

From earliest times, people have simply taken care of themselves medically, and even today, the vast majority of sickness is never seen by a doctor. As homosapiens formed tribes and groups, and tasks were divided rather than shared, the medicine man and woman came into existence. In some tribes the task of medicine was combined with being the priest, the bard, the storyteller or the sorcerer. In poor, agricultural tribes, the medicine man was a farmer too, practicing medicine only when called upon. The level of production of goods was very low, just continued on page 2

#### I. Inequality in the Traditional Roles Between Physician and Patient.

Doctor: Well, Ms. Reed, your GI series results show a gastric ulcer.

The best course of treatment for your condition is a subtotal

gastrectomy.

Ms. Reed: (looking puzzled) Oh? If that will really help...

Doctor: How soon can you be ready for admission into the hospital

Ms. Reed: Surgery? You didn't mention that . . .

Certainly, I did. I told you that you need a subtotal gastrec-Doctor:

tomy to cure your ulcer. Now how soon can you be ready? Ms. Reed: Well, I'm not sure . . . Do I really need to have surgery? It

seems so drastic.

The best way to correct your problem, as I see it, is to remove Doctor:

that part of your stomach which contains the ulcer.

Ms. Reed: Remove part of my stomach? That is drastic! Doctor:

It's the best way to treat you. There are several complications that may occur, but we'll handle them as they arise. You

really have nothing to worry about. Now sign this surgical

consent form.

Ms. Reed: Well, I guess you know best, doctor.

Traditionally, the sociological concept of the relationship between physicians and patients has been the sick role, in which the physicians are in charge, and the patients are obligated to cooperate with prescribed regimens. The practitioners define who is ill, as well as the nature and severity of the illnesses. This places seekers of health care in a vulnerable position, dependent upon the expertise of physicians to help them get well.

Talcott Parsons, a Harvard sociologist, views ill people as deviant from the accepted norm of good health and medical practitioners as agents of social control. Indeed, "the obligation of the sick to seek expert help in order to get well explicitly involves deferring to professional authority in receiving and accepting information and instructions on how to end a deviant status." Parsons defines the responsibilities and obligations of being a sick

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enough to provide subsistence and not enough to provide for any excess or accumulation; hence there were no rich tribe members, not even rich medicine men.

In ancient Babylonia, the physician was also a priest because that society held science subordinate to theology. The surgeon was liable for his acts, however, and if his surgery failed, his right hand was cut off so he would not practice surgery again.

The ancient Greeks believed that good health and health care was a privilege of the rich. The physician, however, was a craftsman like a shoemaker or a blacksmith, and was trained through an apprenticeship. Physicians worked for fees, and since Greek society despised people who worked for money, they had a somewhat low social standing. They were unlicensed, but gained their reputation based on their ability to predict the course of a disease, which people could check on.

In ancient Rome physicians were mostly slaves. They were not very skilled and when the Romans discovered Greek physicians they sought to entice them with Roman citizenship, and exemption from taxes and serving in the army. Certification and regulation were instituted to weed out the quacks.

In the Middle Ages, physicians were clerics and provided medical care as a form of charity, while the church provided them with a means of subsistence. The profession was viewed as a vocation, in which one expressed one's duty to God and man. Laymen did enter the profession by the 11th century, and were supported almost entirely through stipends and salary. What few fees there were, were very strictly regulated. From early times, being any kind of a professional meant that one received no fees because a profession, by definition, was practiced for its own good. (From that point of view, one could say today that fee-forservice medicine is unprofessional!) Professionals were supported by salaries and stipends, and by being kept on retainer. The remnants of this approach are still visible in the legal profession today.

As the medieval world gave way to a new economic order, the church lost its ascendancy and the middle class assumed a central role. A profession was no longer a vocation. It was simply a way to earn a living. Physicians now had to compete and sell their wares on the open market. However, only the rich and middle class could afford to purchase their wares. The private physician came into being. He was kept on a retainer as the private physician to a rich family. He needed only a few rich families to live comfortably. People sitting in a physician's waiting room to be seen would never have been considered private patients, since they were in a very public place, and not in their own homes, and were sharing the doctor. In any case, such a setting was not used by paying patients, but was more characteristic of charity clinics.

The poor, as always, relied on their own folk medicine and the local midwife and herbalist. As industrialization set in, most of this medicine went by the board. People were crowded into industrial towns to work, where their working and living conditions caused disease and death on an unprecedented scale. It soon became clear that physicians could do nothing to alleviate this problem.

Public health measures were taken and became increasingly effective through regulation and as the causes of disease became known. Many diseases were prevented through public health measures and immunization, but many others were not and physicians could offer little more than comfort until the discovery of sulfonamides in the 1930's and antibiotics in the 1940's.

Since that time there has been an incredible increase in our knowledge of the human body and its diseases. It is no longer possible for a physician to know it all. He has to specialize. It is also difficult for the layperson to know the boundary between what the physician knows and doesn't know. That would almost require a medical education.

Diagnosis and treatment are available to us for a vast number of diseases through advanced scientific research and technology. Most of this research has been financed by the public, but all the advances in medical technology have become the property of private enterprise. The pharmaceutical and medical technology industries, as well as the computer, upon which hospitals greatly depend, and energy industries, are among the most profitable in the country. The distribution of their goods is put in the hands of the most highly paid professional in the country, the physician. It is a partnership, where one member (industry) sells the goods to another member (doctor) who orders the goods for another (patient), who is not part of the partnership, and who cannot possibly afford to pay the two partners out of his own pocket. So an arrangement has been made with a third party, the insurance company, who will join the partnership and in effect take up a collection and distribute the money to the first two parties and himself on behalf of the person(s) excluded from the partnership.

Even this novel arrangement does not assure that everyone who needs health care will receive it. The right doctor in the right place at the right time, at a price anyone can afford, hardly exists in this country. This is due to a number of factors: medical specialization, which is the result of the knowledge explosion; the continued existence and growth of poor communities where no one really wants to live, least of all the doctors whom the community needs; the continued predominance of the private practice of medicine; and the provision of health care and health insurance primarily as a commodity like steak and patent leather shoes, instead of as a public service like education and fire protection.

The economic resources of our country and the technical development of medical care are such that everyone in our country could receive the basic preventive and primary care they need, and probably most, if not all of the specialty care they need, at no additional overall cost. This, however, would require having a National Health Service, with all personnel on salary, including doctors. Strict cost controls would be instituted, not in the market-place where the only impact is to reduce access, but in the place where costs originate, with the pharmaceutical and medical technology industries.

The patient's place in all this is pretty clear, based as it is on an impossible cash relationship. That relationship must change if the patient is to benefit from the medical care system and still retain his/her autonomy. Patients' rights bills, patient advocates, patient education, all this can be successful only if it is viewed as the prelude to changing that cash relationship. Those things in themselves will have little impact on the overall problem inherent in the patient/doctor relationship.

But what is the doctor's place in all this? The cash relationship means that he is a businessman, primarily, not the guardian of the people's health. This relationship, and his training, tell him that he is responsible only for those people who come to him, whom he is willing to treat. Due to his training, and to specialization, he is able to diagnose and treat a limited number of diseases. Most of the people he will see may have problems he is unable to deal with. He is not trained in communication, the single most important tool in his profession. He may be sued for malpractice or possibly even negligence. He is constrained in what he may do by the requirements of third party reimbursement, in that, for example, he will not be paid for providing any preventive services he might know about. His patients may not be able to afford the care he believes they need, and they may have inadequate insurance to cover it. Many of us often view the doctor as a villain. In a certain sense, however, he and the patient are both victims of the system. The accompanying article focuses on a very interesting aspect of this whole problem.

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person in society, and the "need to work toward the common goals of the system as a whole." The obligations of sick people involve a commitment to cooperate with the health care system. To achieve this cooperation, the sick, in seeking competent help, transfer their decision-making powers to the members of the health care team (usually the physician) while retaining the responsibility to cooperate unconditionally in order to get well again. Parsons argues that physicians are supposed to avoid emotional involvement with their patients' plights, to restrict their activities to those in which they are professionally competent, and to treat every patient in the same way irrespective of race, sex and socio-economic status.

How did physicians come upon their power and authority in the first place? "Authority classically is defined as the right to influence and direct behavior, such right having been accepted as valid and legitimate by others in the relationship. In the medical context, authority is defined as the patient's grant of legitimacy to the physician's exercise of power, on the assumption that it will be benevolent."4 Physicians' extensive education and training in the discipline coupled with the laypeople's ignorance and dependency in health matters afford physicians the power and authority to command patients. It is, in fact, professionals who dictate to patients what is good and bad for them; and patients have no choice but to accede to professional judgment. Because patients are usually not very knowledgeable about medicine, they cannot diagnose their own needs or discriminate among the range of possible solutions for meeting such needs. An unequal relationship is created in which physicians enjoy a superior position, and patients succumb to a position of dependency and cooperation.

Indeed, society has long accepted the "built-in institutionalized superiority of the professional roles grounded in responsibility, competence and occupational concern." To eliminate the inequality would "surely jeopardize the therapeutic benefits of the vast accumulation of medical knowledge and competence which our culture has pain-

fully built up over a very long period."6

Traditionally, trust in the complete competence of physicians and the desire "to be taken care of" by one's doctor have been considered essential aspects of a physicianpatient relationship. Any objections offered by patients regarding diagnosis or treatment were usually interpreted by physicians as being manifestations of illness, or as some kind of neurotic behavior. The clients do derive a sense of security from the professionals' assumptions of authority. The authoritative airs of practitioners cause clients to believe in the competency of their physicians and that as patients, they will be well provided for during their times of need. Although the degree of dependency and trust may vary with the individual patient's health condition, socio-economic status or ethnicity, both parties generally accept the unequal relationship as appropriate and desirable. "It is the knowledge difference, the 'competence gap,' between doctor and patient that justifies both the professional's assumption of authority and the client's trust, confidence, and norm of obedience."7

# II. The Changing Relationship Between the Health Care Provider and the Health Care Recipient.

Doctor: Well, Ms. Reed, your GI series results show a gastric ulcer. I

think the best way to treat it is by a subtotal gastrectomy.

Ms. Reed: The GI series are those special X-rays I had to take after

drinking that chalky stuff?

Doctor: That's correct. That chalky stuff, or barium, enabled us to

visualize that ulcer in your stomach.

Ms. Reed: What is this treatment, this "subtotal gastrectomy" you

mentioned?

**Doctor:** I feel the best way to cure your condition is to remove that part of your stomach which contains the ulcer. That pro-

cedure is known as a "subtotal gastrectomy." It's a relatively

simple procedure with few complications involved.

Ms. Reed: Oh? What are some of those complications?

Doctor: Well, you could develop a post-surgical pneumonia, or fluid

in the lungs, a post-operative infection at the site of incision, or poor feeding tolerance because of the missing part of your stomach which helps to absorb food. But these things can be

effectively handled as, they arise.

Ms. Reed: How?

Doctor: Antibiotics and breathing exercises will help prevent or cure any pneumonia that may develop, antibotics and careful

wound care will help prevent or treat any infection, and small frequent meals will help you retain or hold your feedings.

Ms. Reed: Gee, I don't know. Surgery seems a bit drastic. Isn't there

any other way to treat my problem?

**Doctor:** There is another approach. This involves allowing the ulcer to heal instead of removing it. This treatment utilizes

to heal instead of removing it. This treatment utilizes sedatives, antacids and a bland diet. However, this method is not always effective. The ulcer does not always heal itself.

I would advise surgery.

Ms. Reed: I think I'd prefer the less drastic approach first, and save the

surgery as a last resort. Perhaps I'll seek a second opinion

on this matter.

During the last decade, a new model of what the physician-patient relationship could be has begun to emergea model that challenges the physician's authority and is based on bargaining rather than on authority acceptance. This new model focuses on patients' rights and physicians obligations rather than on physicians' rights (to direct) and patients' obligations (to follow directions). It has resulted partly from the public's increased demands for health information and medical knowledge, which have, in turn, decreased the "competence gap" between physician and layperson. It centers on educated, informed decisionmaking by patients who have sought information from health care providers concerning when to seek medical care and how to handle illness situations. Physicians are no longer automatically in charge at all times and in all places.

Physicians bring to the encounter within the bargaining model their training and knowledge, and their "institution-alized role of gatekeeper to desired services and medications." Patients bring with them their own resources of knowledge and experience (however good or bad), the threat (overt or implied) to take their business elsewhere if unsatisfied and their legal right to informed consent before any invasive procedures are inaugurated. The outcome of such a relationship is more dependent now on the characteristics and personalities of the parties involved than on authority and dependency. Neither party is automatically in charge; a negotiated agreement concerning diagnosis and treatment is established prior to the delivery of medical care.

#### THE PATIENT'S RIGHT TO KNOW

Patients have the right to be adequately informed about their illnesses. They have the right to know what is wrong. why, and if it is treatable and the options for treatment. These rights are protected through the legal requirement of informed consent. Under the new model of physicianpatient relationships, informed consent is a physician's obligation to a patient. But, there is much controversy from physicians about how much information is considered adequate. Two authorities suggest that "concealment can lead to unfortunate consequences by promoting distrust in the physician and subsequent withdrawal from cooperation in . . . treatment procedures."9 Another authority further adds, "When those in the health professions and family join together in a pact of secrecy, they are removing from the patient the right to participate in making decisions about his future and denying him the opportunity to decide how he wants to live ... "10

Studies have shown that, in general, patients prefer far more detailed disclosures than physicians routinely offer, and that the two groups have widely different beliefs about the consequences of these disclosures. While patients prefer extensive information particularly regarding risks and alternative therapies, physicians usually talk about those risks which are most likely to occur and provide little information about alternative therapies. With detailed information, patients would know what to expect from treatment programs and be more prepared to deal with the consequences of such treatments. However, physicians claim insufficient time for this kind of patient education sessions in their "busy medical practices." 11

While patients believe they should make decisions concerning treatment, physicians strongly oppose this view. Physicians tend to underestimate patients' abilities to comprehend medical terminology and to make appropriate decisions concerning courses of treatment.<sup>12</sup>

Physicians often assume that detailed disclosures of risks may increase patient anxiety, treatment refusal and the incidence of side effects. Other studies have shown that limited disclosures and one-sided exchanges between physicians and patients result in noncompliance with instructions and poorer medical outcomes. 13,14,15 Results such as these indicate that physicians' failures to respect patients' rights to be adequately informed can, in certain circumstances, adversely affect patients' health. Communication is the essence of the physician-patient relationship.

#### **SELF-HELP MOVEMENT**

New patient consumerism implies that instead of relying on the idea that only physicians are qualified to make decisions regarding an individual's treatment choices, patients are qualified to become more involved in such decisions based on their knowledge acquired through past experiences and education. In recent years, there has been an upsurge in self-care and self-help publications, such as Our Bodies, Ourselves (Boston Women's Health Book Collective, 1973), How To Be Your Own Doctor (Sometimes) (Eisenberg, 1975), and Take Care of Yourself (Vickery and

Fries, 1976), in response to an increase in consumer awareness. This trend recognizes the appropriateness of self-care and demonstrates that physicians' services are not always necessary in handling common ailments. Some experts believe that consumers "should be able to evaluate their own health status, to seek outside sources as needed, and to provide important elements of primary care."

#### SECOND OPINION

While the use of "second opinions" has been promoted as an ethical means of reducing expensive and unnecessary surgery, the use of second opinions can also provide patients with options and a broader knowledge base for their decisions. Patients need not remain under the care of practitioners whose ideas concerning treatment do not agree with their ideas of how the case should be managed. In one case which I know well, a man went to a surgeon complaining of intense calf pain in his left leg after walking only two blocks. The surgeon, after performing a few tests, diagnosed the condition as arteriosclerosis, and, because of the patient's diabetes, informed him that there was no way to save his legs. The patient, disagreeing with the prescribed treatment for his condition, sought out another surgeon who recommended exercise, cessation of smoking and meticulous foot care. Today that man can walk over four miles with minimal discomfort, has not touched a cigar in a year and does not face the prospect of bilateral amputation of his legs because of his tremendous progress. The physician must take into consideration the ideas and wishes of his or her patients to the point where it is feasible to do so, or lose clients. Physicians still hold the monopoly on medical knowledge, however, and may influence the ideas of patients based on sound medical information.

Patients generally use two interlocking criteria when deciding on a regular practitioner: 1) the technical competence of the health care provider that will yield good medical care, and 2) the interest physicians will take in patients, so that not only emotional satisfaction is obtained, but also competence is exercised in more than a routine way. The first visit to a phycisian's office is generally a tryout. If patients' expectations are unmet, they will seek help elsewhere.

Receiving incorrect or inadequate information may also cause a patient to lose faith in the physician or to look elsewhere. (In the example cited above, the first surgeon originally said the patient would lose his left leg, then changed it to his right leg, then finished with the loss of both legs. He was not very forthright with information regarding the patient's condition, and skirted around any questions asked of him. The surgeon did not proffer alternative treatments. The second surgeon, however, was more than willing to explain the condition, showing x-rays and drawing diagrams of the blocked arteries.)

Using second opinions to seek out more information thus fits well into the bargaining model of the physician-patient relationship. As described earlier, agreements must be established between physicians and clients concerning diagnosis and therapy. Patients are not forced to remain under the care of physicians with whom they are unhappy.

#### MEDICAL MALPRACTICE

Medical malpractice is defined as ordinary negligence or carelessness on the part of a health professional. Medical malpractice suits have become a main means to challenge physicians' authority, and consumers are turning to their lawyers in increasing numbers. In fact, by the mid-1970's, malpractice litigation had become a matter of major concern in the United States. The volume of suits had increased, the magnitude of settlements had risen, and insurance premiums for physicians had jumped 300%.

Experts in the field agree that the main issues involved in malpractice suits are the following:

- The deterioration of the physician-patient relationship is seen as probably the number one factor in lawsuits. Generally, the patient is not out for financial gains, necessarily, but to punish the physician for lack of kindness, consideration and sensitivity in handling the case. Herman Somers, a health economist, points out that two out of three suits could be prevented if physicians discussed the cases with their patients in a plain and candid manner. He also points out that the vast majority of claims really have no merit.
- Poor results from treatment which may trigger a lawsuit. This problem, in great measure, is caused by the discrepancy between the patient's conception of what modern medicine should do, and what modern medicine actually can do. This is due, in part, to a lack of communication between the health professional and the client. Patients who are not fully informed about the nature of illnesses, the prescribed courses of treatment and what they can realistically expect as a result of treatment, will feel disappointed if their expectations are not met.
- The rapidly rising cost of medical care may lead some patients to try to recover some of their expenses through malpractice litigation.
- Physician misdiagnosis of the patient's medical problem occurs when he has made an incorrect assessment of the patient's condition, with the result that the wrong treatment or no treatment is prescribed. Physical harm may come to the patient: either a worsening of the condition, or an inducement of an iatrogenic condition (a physiciancaused disease or condition). Aside from the inability of some physicians to make a technical judgment (diagnosis) based on signs, symptoms, laboratory and radiological testing, the majority of misdiagnosis probably happens because the physician has not listened to the patient, or taken the patient's complaints seriously. Professional competence goes beyond mere technical competence and includes the ability to listen and hear what patients are saying, and to communicate to them effectively what they need to know.

Other causes of malpractice suits are the increased supply of attorneys, thus providing consumers with easy access to legal assistance, and physician incompetency in policing their own ranks for negligence and carelessness, thus causing consumers to "take matters into their own hands." Another cause of lawsuits is the active or smoldering resentment between the parties, again partially due to communication gaps or personality conflicts.

Yet there are ways of preventing the malpractice suits which arise from the physician-patient relationship. The

best method is for physicians to develop good rapport with their patients. In a climate of high technology and increased specialization, there is an emphasis on the more technical aspects of healing. This contributes to a disregard for the patients' need for information, explanation, understanding and assistance. Physicians need to take time to provide adquate information and support for their patients. Development of "good bedside manners" may eliminate the motivation for lawsuits.

Accurate medical notation in the patient's record is necessary so that the quality of the diagnostic work and the rationale for treatment are documented. The chart is often the first item subpoenaed in a court case for validation of some kind of negligence. It could make or break the case depending upon how clearly and specifically it documents the physician-patient exchange.

## III. What Impact is this New Model Having on Current Practice?

Although the reactions of physicians to the new roles are not always favorable, physicians are becoming increasingly aware of the changing model in physician-patient relationships through first-hand experience with their own clientele, the media and the literature. Articles are appearing in medical journals urging more patient participation in clinical decision-making, and criticizing "traditional physician paternalism and patient submission." Many physicians are beginning to realize that they are dealing with a more educated and less submissive public, thus affecting their professional relationship with clients.

Some studies have shown that physicians tend to underestimate patients' understanding of their care, and have little time to devote to patient education since "time is money" in their practice. Physicians will use technical terminology to increase patients' inferiority in health care matters so as to remain superior and ward off challenges to their medical judgments. Yet, further studies have demonstrated that patients do, indeed, understand more than they are given crdit for by physicians. One-third of the physicians in these studies saw the need for improved communication between themselves and patients since patients are demanding more technical and complete information on health issues. 18,19

Physicians still tend to withhold some information from their patients, believing that the knowledge would only be detrimental to the patients' welfare and recovery. There is a long tradition in medical practice which dictates that physicians need only to disclose selected pieces of information to patients. The tradition is supported both by various codes of medical ethics (which favor discretion in disclosure over a firm duty to tell the truth to patients) and by the legal doctrine of "therapeutic privilege" (the privilege of physicians to withhold relevant information from patients in cases where they predict that such information may harm the patient).<sup>20</sup>

These issues raise interesting questions. What gives physicians the right to decide what information patients can and cannot handle? Are physicians threatened by

knowledgeable patients? Are physicians worried that increased information may yield performance evaluations by patients and future lawsuits? Are physicians disturbed over not knowing all the answers themselves? Do physicians feel they must maintain the authoritative positions because to treat patients as equals would undermine the physicians' skills and training? Do physicians fear losing their "god-like" position and reverence from their patients? These are problems that must be addressed by the medical profession. What should be uppermost in physicians' minds is the welfare of the patients from the patients' point of view, and not their own.

It will take time and effort from sympathetic physicians and consumer activists to educate the public and the medical profession in accepting and exercising these new roles. A necessary place to begin would be the medical schools. In 1973, the Secretary's Commission on Medical Malpractice suggested that continuing programs of research and analysis should be aimed at increasing knowledge and understanding of patients' psychological and psychosocial needs; the findings of such research should be translated into specific action programs aimed at improving the training of health care personnel in the human aspects of medical care.

## PATIENT INITIATIVES IN DEVELOPING THE NEW ROLE

Patients can enhance a positive relationship with health care providers by:

- choosing a physician carefully based on referrals, personal values, academic affiliation with hospitals or medical schools, skills, honesty, quality of communication, flexibility, intellectual curiosity, ability to listen, and respect for the patient as a person;
- evaluating physicians' "bedside manners" by the quality of their interviews and the amount of interview time:
- becoming a partner in the plan of care by asking questions about anything that is not understood, reading carefully any consent form and inquiring about vague or technical terms; and
- obtaining second opinions from other health professionals when in doubt about certain prescribed treatment plans, or dissatisfied with the physician's care in general.

By exercising their rights, patients may expect:

- an accurate diagnosis of their condition, healthy or otherwise.
- results and interpretations of all diagnostic tests and examinations.
- indications for treatment as well as risks and complications, and the physician's reasons for such a course,
- answers to any questions regarding examinations or procedures, in advance of or at any time during such procedures, and stopping such an exam or procedure at any time at the patient's request,
- complete information about purpose, content and known side effects of all drugs prescribed,
- willingness to accept and wait for second medical opinion before having any elective surgery done which involves alteration or removal of any organ or body part, and

• answers to questions concerning general physical health in addition to any particular condition, or encouragement to seek answers from another source.<sup>21</sup>

Knowledge becomes an important factor in "negotiating" with physicians. The more knowledge patients have, the better is their position to "bargain" and participate with physicians in planning care. Many local hospitals do offer health information centers where people may stop in and receive information on just about any health matter. These centers also provide referrals as necessary or desired. There are numerous books written on diet, good health habits, and self-care as well as on how to select physicians and hospitals to obtain care; these materials can be found in bookstores or local libraries. Self-help groups are available for information and support to those people who have particular problems (e.g. Reach for Recovery and Alcoholics Anonymous).

Patients need not be the objects of health care any longer. They can, and should be, the co-participants in the maintenance of health and the treatment of disease.

#### **FOOTNOTES**

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# Diane Hundt is a graduate student in Health Care Administration at New York University.

NOTE: The Consumer Commission is preparing a series of guides for patients and consumers. Two of the early guides will be: "A Patient Guide to the Physician/Patient Encounter (A Visit to the Doctor)," and "A Guide for Patients: Keeping Your Own Medical Records."

### **BOOK REVIEW**

by Zita Fearon & Bertram Allan Weinert

THE RIGHTS OF HOSPITAL PATIENTS: THE BASIC ACLU GUIDE TO A HOSPITAL PATIENT'S RIGHTS (ACLU HANDBOOK, AVON, NEW YORK, 1975)

This is not a recently published book, but it is one that the Consumer Commission thinks prospective hospital patients, and most particularly, members of community boards of health care facilities should read. As people are losing their "entitlements" to health care and as federal legislation which provided rights to certain groups of people is being whittled away, the Consumer Commission receives many inquiries from people asking what their rights actually are to health care under this administration. Knowledge helps to empower people, of course, so that they are less helpless when they become hospital patients. Even more important, consumers on community boards of health care facilities either make or impact on the making of policy at the health facility level. This book will give consumers the information they need to help change incorrect policies and to cause the formulation of new policies consistent with the legal rights of patients.

Patients actually have three different kinds of rights, as described in the handbook: 1) legal rights, which are provided for under the Constitution and its Amendments, the laws of the fifty states, and court decisions; 2) probable legal rights, where it is expected that a court would act favorably given the opportunity to recognize a particular new legal right; and 3) human rights, which tend to be philosophical and political statements or concepts, and which frequently pre-exist recognition by positive law. The early days of the civil rights movement provided numerous examples of such assertion of human rights, some of which subsequently were enacted into positive law. The book deals primarily with legal rights and probable legal rights. In this context it is important to know that in the United States the citizenry has no legal right to health care. Many people have thought that holding a Medicare or Medicaid card gave one a legal right to health care. It does not. The card only means that if you obtain health care, it will be paid for to one degree or another.

Most patients' rights documents (a patient's bill of rights) are of limited utility in informing patients and consumers of actual legal rights which they have. In general, they are limited to discussing two kinds of things. The first is a description of etiquette and protocol for behavior between patients and providers which is nice-sounding but not a legal right and simply unenforceable by anyone. No one is likely to try to sue his/her doctor for being discourteous. The second is a very limited discussion of informed consent issues which arise from the legal right of patients to self-determination. The discussion is usually very inadequate to truly inform a patient of the full scope of matters about which s/he must be informed and give consent before they can be done to him/her.

The right of informed consent and the right to refuse treatment are of paramount importance to patients who have made it into the medical care system. By law, patients must be told everything in language they understand, which would materially impact on their decision to agree to having a diagnostic procedure or treatment performed on them. They must know the risks of any given procedure, the probability of risk, and any alternatives to the proposed treatment. Since the relationship between the patient and doctor is an unequal one, in which the doctor holds all the information, the doctor has a *legal duty* to provide the information which the patient needs in order to exercise his/her rights of self-determination.

Getting into and out of the hospital are other major problems for people. People only have a legal right to health care if they are in a medical emergency. Hospitals which receive Medicare reimbursement are required to provide emergency care and every hospital which provides emergency care must accept emergency patients. If the medical problem is not serious or emergent, the hospital may refuse to admit a patient who cannot pay a deposit or who does not have medical insurance coverage. Federal law prohibits hospitals from requiring a deposit from patients with Medicare or Medicaid coverage. To admit a patient to a hospital is to assume a duty to treat so a hospital may not discharge a patient it has admitted or initiated treatment on but subsequently discovered had no insurance coverage. The uninsured patient cannot be discharged until medically indicated, just like any other patient. Patients also cannot be refused admission on basis of race, color or national origin, and duration of residency requirements cannot usually be invoked as a reason to deny admission.

Once a patient is in a hospital, the hospital cannot pre-

vent him from leaving if he wishes to, even against medical advice and even if the bill has not been paid. The hospital would be guilty of false imprisonment. The only circumstances under which a patient could be restrained from leaving would be if his/her leaving would endanger the health and safety of others, such as if s/he had a seriously contagious disease. Then, however, the public health authorities would have to be brought into the case, since this is covered by public health law, and not hospital law.

Abandonment of a patient is both unethical and illegal but unfortunately, very common.

"Abandonment occurs when the physician severs the doctor-patient relationship without the consent of the patient. If injury results to the patient because of the abandoment, the patient may successfully sue the doctor for damages. If the treatment is in a critical stage at which abandonment might be harmful to the patient, non-payment of bills by the patient cannot be used as a justification for refusal by the physician to extend further aid. This rule, of course, should also apply to the hospital."

The above quote from this guide makes it clear that no patient should be without the guide in the event of being hospitalized or receiving emergency or other care from a hospital. Other chapters in this guide deal with, among other things, the rights of the terminally ill, of women and children, and the very important issue of patients' rights to their medical records. If you want to know more, and we hope you do, buy this book, in paperback for \$1.75.

Bertram Allan Weinert is the Director of Consumer Education, NY State Attorney General's Office.

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