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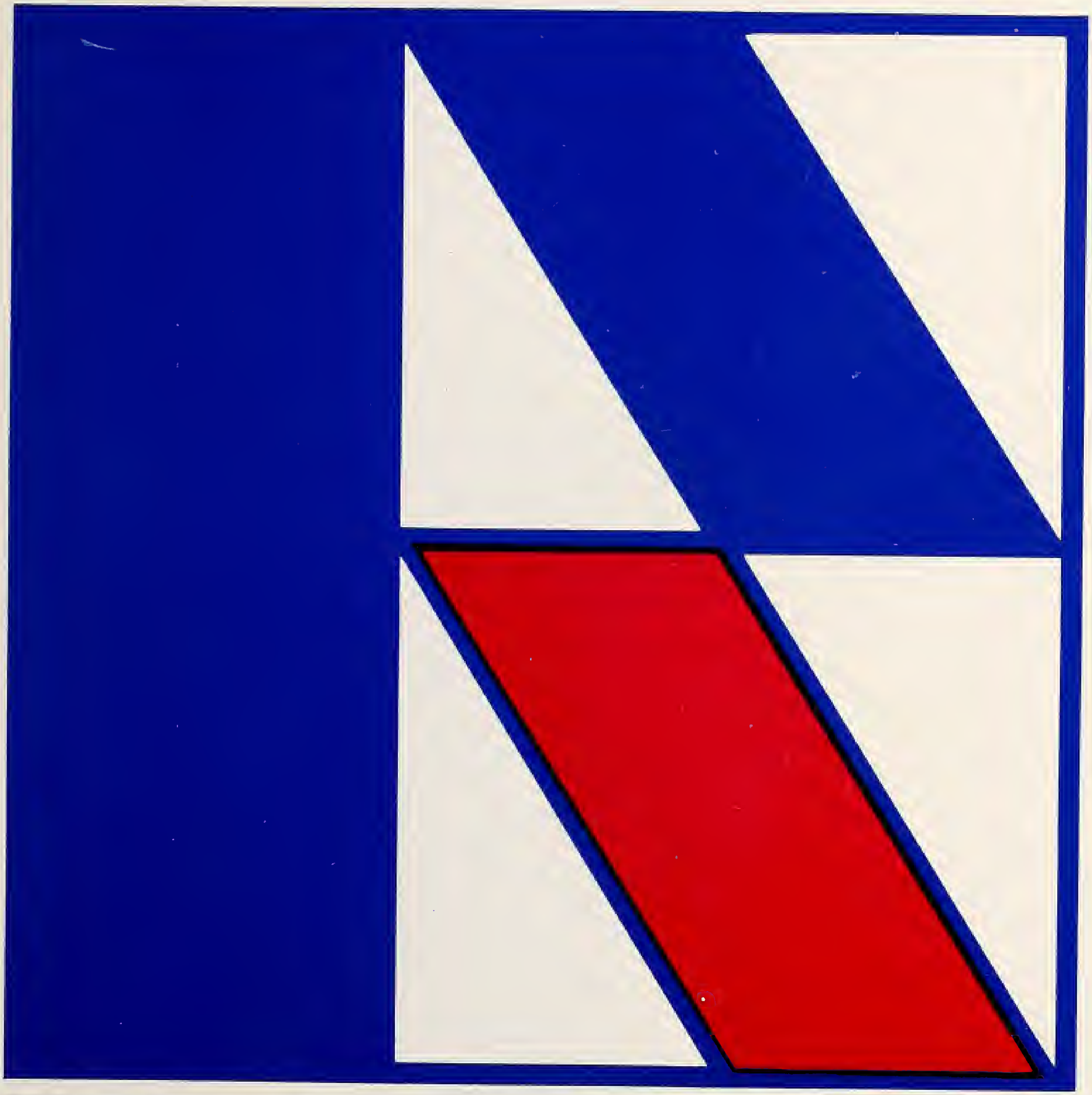
PROCEEDINGS

NATIONAL SYMPOSIUM ON PATIENTS' RIGHTS IN HEALTH CARE



17 and 18, 1976 INTERNATIONAL INN WASHINGTON, D.C.

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Public Health Service
Health Services Administration

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ON
PATIENTS' RIGHTS
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May 17-18, 1976

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
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INTRODUCTION

Since December 1974, Federal standards for facilities participating in the Medicare and Medicaid programs, such as skilled nursing facilities and intermediate care facilities, have included patients' bills of rights and other provisions designed to assure protection of the dignity and humanity of the patients served. Including these considerations in Federal standards was a new approach for a program that had previously been concerned with only such issues as the physical safety and staffing requirements of institutions.

The following year the Bureau of Quality Assurance, Health Services Administration, began to question how well the program was working. Were the standards on target to achieve the desired goal? Were facility personnel adequately trained to comply with the standards? Were government inspectors equipped to measure compliance with the requirements? Were patients benefitting?

The Bureau organized an interagency work group, comprised of the Social Security Administration, the Social and Rehabilitation Service, the Veterans Administration and the six Public Health Service agencies to assist it in developing a long-term program that would address the dual problems of safeguarding the rights of individual patients and involving the patient and the general public in the planning, development, and evaluation of health care programs.

The issues and approaches developed by the interagency work group provided the subject matter for the National Symposium on Patients' Rights in Health Care sponsored by the Health Services Administration on May 17-18, 1976, at the International Inn, Washington, D.C.

The Symposium was a two-day conference of representatives of the health professions, consumers, government agencies and private interests concerned in the provision of health care services.

The preliminary work of the interagency group, plus the feedback from the Symposium, will be used to plan and recommend methods of further defining and protecting patients' rights and involving the public in quality assurance.

Project Officer:
Marjorie A. Costa, M.P.H., D.M.A.
Assistant to the Administrator for
Community Affairs
Health Services Administration
Department of Health, Education, and Welfare

OPENING REMARKS

Marjorie A. Costa

This is an exciting day for me, and I think for all of those who have been involved in this project with me.

Without further ado, it is my privilege to introduce to you a senior officer in the Federal government, a lady who is committed to making consumer representation, involvement and rights, a reality.

I can't think of anyone better to start this auspicious occasion than Mrs. Virginia H. Knauer. She is Special Assistant to the President for Consumer Affairs, and Director of the Office of Consumer Affairs in the Office of the Secretary of the Department of Health, Education, and Welfare. Mrs. Knauer is a member of the Council on Wage and Price Stability; the Committee on the Rights of Privacy; the Energy Resources Council; and a former director of the Bureau of Consumer Protection.

We are grateful that she was able to come, and we welcome you, Mrs. Knauer.

* * *

WELCOME

Virginia H. Knauer

It is a privilege to welcome you to the National Symposium on Patients' Rights in Health Care. This is an issue which is growing in importance in the eyes of the public. Each of us here, as government officials or as providers of health services, has faced the question of what patients' rights does or should mean within the area of our special responsibility. Many of our questions are still unanswered.

The purpose of this symposium is to assess what has been done so far and to help each of us broaden our perspective on the rights of the individual patient.

In many areas we have already progressed from awareness of patients' rights to action. The American Hospital Association has produced a Patient's Bill of Rights and the Veterans Administration has a similar "Code of Patient Concern." Numerous Federal agencies have policies designed to protect human research subjects. The standards for skilled nursing facilities include a Patient's Bill of Rights.

I know these efforts to codify the patient's rights, and particularly the effort to incorporate them in Federal regulations, have caused concern in some professional circles. Regulations are criticized by those who say that they have been respecting the patient's rights all along. They have been equally criticized by those who say that such rights are virtually impossible to administer as required by the regulations.

This view of the patients' rights issue is a narrow one--a dangerously narrow one. The more one gets caught up in administrative details, the easier it is to lose sight of why we, as a society, are striving to do more to protect the rights of the individual.

Regulations on patients' rights are the product of a growing public concern for the rights of the consumer of health services. They are an integral part of much broader consumer issues. To understand the significance of patients' rights it is important to look beyond the questions of compliance with Federal regulations and to see them in the perspective of the consumer movement.

Throughout the early part of the century--and even into the 1960's--the consumer movement's main targets were specific abuses in a buyer-beware marketplace. Consumers tended to see business as the adversary--out to make a profit without consideration for the consumers' rights. Consumers looked to government for protection of their rights--the right to information on which to base purchasing decisions, the right to safety and the right of redress. They sought safety laws to protect them from unsanitary food, unsafe drugs, and other hazards in the marketplace from toys to automobiles. At the same time consumers sought laws, such as food labeling laws, that would give them more information about products. Armed with such information, consumers felt they could make decisions that would perfect the marketplace by stimulating business to respond to their needs.

Those times have passed. Consumers have found that dealing with individual consumer problems one-by-one is not enough. Simply forging the tools to defend themselves against specific abuses is inefficient. To ensure that their interests are heeded, consumers have learned that they must take an active part in shaping the system. After years of seeking legislation as the solution to consumer problems, it was clear that it was not just the laws on the books that determined government's role in protecting the consumer, but the attitude of the agencies administering them. Similarly, consumers discovered that in the business arena individual victories on issues such as labeling were not nearly as important as the willingness of business to seek out and respond to the broad range of consumer needs.

Thus, the main thrust of the consumer movement of the 1970's is to make the consumer a more active participant in the decisions that affect him. Government decisions, business decisions and professional decisions are being made every day which determine the consumer's environment. Consumers are asking that their needs and concerns, as they perceive them, be part of the decision-making process.

The Federal government has responded to consumer demands for involvement by searching for new ways to make the consumer a more active participant in the decisions that affect him. The Food and Drug Administration, for example, includes consumer representatives on many of its advisory committees. Some agencies now have a consumer spokesman within the structure of the agency. A year ago President Ford directed me to work with each of the executive departments and agencies on developing Consumer Representation Plans to ensure that consumers participate in the decision-making process from the earliest stages. The plans should be complete by early summer. Each of these plans represents a commitment from an agency to seek out consumer viewpoints before, not after, decisions affecting consumers are made.

Bills of rights for patients and the Federal patients' rights standards express a similar commitment to the individual's right to a voice in the decisions that affect him. They are a way of saying that it is not enough to set up endless regulations to protect the patient from every possible problem. We must first protect the patient's rights to protect his own interests by ensuring that he, or his guardian if need be, is an active participant in decisions on the course of his medical care or on his life in health care institutions.

It seems to have been a shock to some in the health field that consumerism would make demands of institutions created to serve the public. They question the need for statements of patients' rights. Underlying that question is the unspoken question--why is the consumer movement looking at us? Because consumerism began as a movement to protect consumers from exploitation in the profit-making marketplace, consumer rights have often been overlooked in non-profit, charitable or humanitarian service organizations--from schools to hospitals. Because the health community sees itself as professionals determining and serving the public's best interest, a "doctor knows best" philosophy has often unconsciously encouraged passivity on the part of patients.

The concept of patients' rights is relatively new as a formal Federal regulation but many of the basic principles are as old as our Constitution. Thus, for many of the better health care providers, the Federal regulations may seem to be nothing more than a statement of the obvious. But regulations, of course, are directed at those that have failed to live up to the public's expectations.

Whether health professionals and institutions are guided by mandatory Federal regulations or voluntary codes such as the American Hospital Association's or even simply by a general sense of obligation to the patient, they need to reexamine how they put the principles of patients' rights into practice.

Compliance with Federal patients' rights requirements has too often been treated as a matter of getting the patient to read and sign. This paper compliance is a failure to deal with the message of the patients' rights regulations. It's like Moses showing his people the Ten Commandments and reporting to the Lord, "We're in compliance."

Statistics are excellent on compliance with the Federal patients' rights regulations for skilled nursing facilities and intermediate care facilities. These good statistics are, in a way, bad news. According to reports of nursing home surveyors, the weakest areas of compliance are those that are easiest for the surveyor to measure, such as whether patients have signed a paper attesting that they have read their rights. It is much more difficult to determine whether the patient has been subjected to unnecessary use of chemical restraints, yet that is much more important to the patient's actual rights. The favorable statistics suggest that compliance is often a matter of adhering to the letter of the regulations and what surveyors can easily check, not the spirit or intent of the regulations.

There are positive signs, however, that the very existence of patients' rights regulations is forcing the issue into the arena of public discussion. Because the rights are defined on paper, and because the rights are in regulations that must be complied with, the concept of patients' rights can no longer be an abstraction. Professional groups and health providers are assessing the impact on their responsibilities. The regulations are a starting point for opening discussion of the relationship between the patient, the professional and the institution.

Traditionally, physicians have made most of the decisions about the nature and extent of the medical services provided and the patient has been the passive recipient. The lack of participation is a source of frustration for many consumers of medical services. Women's groups, in particular, have become very articulate in asking the medical profession to provide fuller explanations of procedures and alternative courses of treatment. The numerous articles in the press about death with dignity indicate the public concern that patients and their families are often denied the right to decide how much the patient is willing to go through in the hope of prolonging life.

The patient's right to be fully informed about the course of his treatment and to take part in decisions about it is gaining recognition. It is fundamental to Federal regulations governing institutional care and to those requiring the informed consent of patients who are participating in research projects. It is also the principle underlying the move towards patient labeling of prescription drugs. The Food and Drug Administration decided, in response to considerable public interest and pressure, that many women were not getting sufficient information from their physicians about oral contraceptives. Thus, it requires a patient package insert in each prescription describing the risks and potential side-effects. FDA is now considering requiring similar inserts in other drug packages to warn consumers of, for example, the dangers of mixing certain drugs with alcohol. At first, some doctors objected to more informative labeling as an interference with the doctor-patient relationship. But the pressure for labeling testitifies to the failure of that relationship. Too many consumers felt that their doctors were not providing them with the facts they needed to make informed decisions or to avoid certain hazards.

Patients are much more likely to be satisfied with the treatment they are offered if they understand both its benefits and its limitations. Perhaps the most important reason of all for respecting and fulfilling the patient's right to be involved in planning his care is that it is a statement of respect for the patient. It is a way of asking him to participate in deciding his medical fate as an adult rather than imposing a course of action on him as a child who must take instructions on faith.

The consumer also has an economic interest in participating in the decisions about his care. Decisions made by others are less likely to weigh the economic impact of the various options open to the patient. This is an important consideration at a time when everyone in the health field is worried about the rate of increase in health care costs.

The rights of a patient within an institution--whether hospital or nursing home--necessarily suffer limitations that would not exist outside. An institution, by its very nature, limits the individual's rights to make decisions about the way he lives his life. The patient is further limited by the disability that requires institutional care. And thus, every right the consumer can exercise becomes more precious to him.

Few of us are prepared by previous experience to live in a community as structured as an institution must be. In most cases, there is an inevitable strain between the needs of an individual to live a life without outside domination and the institution's needs to deliver its services efficiently. This is particularly true in long-term care facilities. Here, it is the institution's responsibility to try to minimize the inevitable strain by giving residents a voice in decisions about running the institution. This is often done through Patients' or Residents' Councils. It is not enough just to have such a Council. It is essential to look at how much of a voice that Council has. Is it used to decide where the next outing will be or does it have a role in making policy decisions which affect the quality of life in an institution? Does it function effectively in airing and resolving grievances?

This kind of patient involvement in the institutional community has therapeutic benefits for the patient. The more in control of his life a person feels, the less likely he is to be apathetic or resigned.

In addition to recognizing the principles of patients' rights within an institution, we have to recognize that in reality patients' rights depend to a significant degree on the attitude of the staff who cares for the patient's daily needs. The staff's view of its own rights and responsibilities within the institution and its sense of participation in the mission and in shaping policy will affect the way the patient is treated. The patients and the staff form a community, particularly in long-term care institutions. If it is a healthy community both parties take an active and significant part in determining how this community will function.

Some of the ways an institution promotes the patient's rights are obvious, others are subtle. For the patient who must enter an extended care institution and his family, making a choice can be traumatic. How can they know which institution will provide the care best suited to their particular needs? How can they judge which will show the greatest respect for the patient's rights?

Though there is a lot of information from surveyors' reports and other sources, it is not readily available to the public. I believe that if patients have access to this kind of information, they can make better choices for their needs and can help to ensure that long-term care facilities respect the rights of patients. The challenge is to find ways of pulling together information on extended care facilities and skilled nursing homes and presenting it in a way that is useful to consumers.

My office recently helped fund a pilot project that provides this kind of information for the Washington area and I hope we shall see it extended to other areas. The project is a quarterly magazine that evaluates consumer services in the same way that Consumer Reports evaluates products. The first area it investigated was health care services, including nursing homes. It used information from Government inspections and also surveyed clergymen who were familiar with the homes. Because services, unlike products, tend to be local rather than national, the evaluation of services is also best done locally. The part of the project my office funded was a report on how organizations in other cities could provide similar evaluations of the services in their communities. We have had over 100 requests for the report.

You have two very full days ahead. I am sure that they will be productive in helping all of us to explore how the general principles of patients' rights should be applied to the many different situations in which health care is provided.

In looking at the issues we must keep in mind that patients' rights are an expression of the same rights we seek in our daily lives as consumers and as citizens. We must help people to see that efforts to spell out patients' rights are not an imposition by the consumer or the Government. Our concern with patients' rights is part of our growing awareness that each of us needs to take part--as fully as possible--in the decisions that shape our lives.

* * *

INTRODUCTION OF MODERATOR

Marjorie A. Costa

We could not think of anybody better to keep this Symposium on direction than a former Federal officer, Ruth Knee. Mrs. Knee has agreed to be our chairperson and moderator, and I now present her to you.

Ruth Knee is presently a consultant in long-term mental health care in Fairfax, Virginia. She formerly was Acting Deputy Director of the Office of Nursing Home Affairs of DHEW, and Deputy Administrator of Health Services Delivery. She received an award from the American Public Health Association in 1975.

It is my privilege to present to you, Mrs. Ruth I. Knee.

* * *

PATIENTS' RIGHTS - WHAT ARE THEY?

Ruth I. Knee

We are embarked on a very important venture. A "happening"--that from an historical point of view may prove to be one of the most important events of the Bicentennial Year. Those of us attending the Symposium have an enormous challenge--to translate our concepts and ideas about patients' rights and consumer roles in health care into realistic approaches of implementation.

In her welcoming remarks, Virginia Knauer has given us a comprehensive overview of what patients' rights and patient (consumer) participation are all about in health care. A simplistic way of summarizing "What are Patients' Rights?" in my view, is that they are a combination of concepts that come from

- the time-honored medical mandate of "First, do the patient no harm;"
- the Golden Rule (and, as was suggested earlier this morning, the Ten Commandments); plus
- the Constitution and other basic documents, laws and court decisions that have established and supported the rights of individual citizens in this country.

Health care as a basic right of the individual has been a theme for the past decade or more. Many of the participants in this Symposium and the organizations they represent have been working very hard toward this goal. This has been done through many different approaches including:

- extending access through provision of or payment for health care services,
- improving quality of care,
- developing new techniques and strategies of health care including new approaches to service delivery, and
- establishing procedures to protect individuals against improper or inadequate care.

Although we can document many achievements in recent years, we still fall very short of the goal of Health Care as a Right. Actually, this Symposium expands that goal, because by its very theme, it is stating that not only does the individual have a right to health care, the individual must be a part of health care. The health care provider is not the only important dimension of the health care system. The health care consumer is an equally important component. And many times, following the concept of the "activated patient," the consumer becomes one and the same as the provider. Thus, the elements of consumer/provider form an equation that should be balanced and interacting. They become a partnership rather than a "we" - "they" proposition.

During these two days, we are going to be talking a lot about the definition of Patients' Rights. There are a number of factors that make precise definition difficult. Some of these are:

1. There is no single model of who the patient/consumer is. We must give consideration to persons of all ages, infants and children, as well as adults and the frail elderly. Persons who receive health care services have all degrees or levels of health and illness, rehabilitation capacity and life expectancy.
2. The consumer of health care may not always be an individual, but may be a family, a group, a community, or even a larger segment of society. (Many of the different health programs and organizations represented at the Symposium have very different definitions of "patient," "patient encounter" or "health care service.")
3. The role of health care consumer is only one of the many consumer roles that most individuals have as a part of daily living. It takes information

and understanding to be an informed consumer in any area, and to make responsible decisions in one's own self interest.

4. Consumer/patient rights imply consumer/patient responsibilities which means not only participating in decision making about one's health care, but also awareness of the consequences of not following healthful or therapeutic regimes and positive efforts to maintain or improve health status.

As we proceed to explore the many ramifications of consumer/patient rights in the health care partnership, we need to examine what are the policies and procedures that prevent an effective partnership, and what promote it. What changes occur in providers when they function as partners? What needs to be done by both providers and consumers to create a true partnership?

This Symposium has several important components. A major purpose is to share experiences, ideas, concepts, goals, constraints and concerns--around the central theme. The process is that of having the opportunity to hear from a variety of speakers, this morning and this evening, who will bring many points of view and experiences to the consideration of patients' rights--plus the opportunity for discussion both in the General Sessions and in the work groups. It is really through the work groups that the anticipated product of this Symposium will be accomplished.

Through your questions, comments, and interactions, the planners and sponsors of this Symposium hope to achieve:

- a better understanding of the current status and the potential of consumer roles and responsibilities in health care;

- a more definitive statement of what is needed in health care policy and delivery approaches or systems that can better support the concepts embodied in "consumerism;" and

- some guidelines on how we can "get from here to there" and how we can assess where we are and how much we have achieved at any one point.

A challenge that each of us can take back to the group or organization we represent is the need to examine how each of the many consumer-provider interests fits into the concept of partnership and common purpose.

* * *

KEYNOTE ADDRESS

John L.S. Holloman, Jr.

It is a real honor to follow Mrs. Virginia Knauer on this program. I am also very fortunate to arrive at the podium ahead of the group of distinguished program participants who are scheduled to follow. If I came at the conclusion of this symposium, tomorrow, I am sure that everything that can be said would have been said. I appreciate the opportunity to be first and to explore some truths that you all are aware of.

I'd like to pay a meaningful tribute, if I can, to all of you who are concerned with patients' rights, because these rights are not to be taken for granted and these rights do not happen automatically. They happen because people like you make them happen. The average person, as you know, does not plan to be in a position where he will have to exercise his patients' rights and, therefore, if he should take these rights for granted, he is frequently disappointed. I am reminded of the White House Conference, "To Fulfill These Rights," in the midst of the Civil Rights struggle in the 1960's. I think that human rights are indivisible and that Civil Rights, Women's Rights, Patients' Rights, etc., are all part and parcel of the same struggle for human dignity. This is what we are all about when we talk about patients' rights.

Patients' rights are part of a global struggle. They are one aspect of a broad struggle for the realization of our common humanity. When we talk about patients' rights, we are talking about something that has been talked about for a long time, perhaps throughout recorded history. Early on, it was Aristotle, I think, who said 333 years before the birth of Christ, talking about health care, "Health of mind and body is so fundamental to the good life that if we believe men have any personal rights at all as human beings, they have an absolute right to such a measure of good health as society, and society alone, is able to give them."

We've been talking about it in one way or another ever since. Many of the earlier pioneers were individuals who had very few tools except rhetoric. Nevertheless, they did use those tools as they attempted to put the sanctity and dignity of human life above all else. There are many organizations that have been involved in this struggle. In the memory of many of you here, there is an organization, the Physicians' Forum, which many years ago developed a Patient's Bill of Rights. This organization was coming from a rather peculiar position, because it was a group of "liberal" physicians who together were beginning to recognize their participation in the systematic denial of human dignity of patients, the denial of human rights, the denial of patients' rights.

There were other organizations which parallel this organization, but this particular organization has persisted throughout the years, and has given birth to other organizations and has inspired men and women who have participated more recently in such organizations as the National Medical Association, the Medical Committee for Human Rights, Physicians for Social Responsibility, and others.

It is important to remember, however, that victory has never been fully achieved; that victory will not be achieved until we achieve a fundamental change in our philosophy, until we develop a belief that will bring about the fulfillment of the pious promises and the political rhetoric which we have been given. I say that not in an accusatory fashion. I don't want anyone to feel guilty--unless of course, he happens to be guilty--that we lack a national health policy, and that we have a lack of commitment to the rhetoric that we often enunciate and pompously pronounce. It is so easy to spout rhetoric. We breeze through the words, as though with divine inspiration from Mount Olympus, yet when it comes to doing, we so often fall short. The rhetoric constantly exceeds the reality. When we talk about patients' rights, we are not necessarily talking only about patients' rights. We are really, as providers, many times talking about what <u>we</u> are <u>willing</u> to give to patients and I challenge whether or not it is our right to make those decisions. I challenge this because if we are going to change our fundamental philosophy to create important changes in the health care field, then we must enable patients' rights to become a reality.

This is a Bicentennial Year, as has been mentioned, to celebrate the 200th anniversary of the founding of this Republic, yet we see today more flaws, perhaps, than were seen by our founding fathers. Why are we celebrating, when we don't seem to be moving with the speed or the progression that so many of us would desire?

We hold these truths to be self-evident, that all men are entitled to life, liberty and the pursuit of happiness. Let's examine that. It is such an important thing. Do we mean that for our neighbors, or do we mean that for just ourselves? When we examine our neighbors, that means that in the final analysis we may have to share. Are we willing and are we ready, and in some instances, are we able to share with others? Are we able to really provide the wherewithal, for instance, to give liberty to our neighbors? To be able to say to them, "Free at last, free at last?" I wonder, are we willing to give life to a person who is perhaps different? I ask, "Are we willing to give life to a person, if we deny them an education, if we deny them a decent place to live, if we deny them a job?" If we deny them all these things, and then in the final analysis deny them health, deny them decent health care, are we entitled to celebrate life, liberty and the pursuit of happiness, or should we go back to try to find out why we do not have at this 200th birthday the "inalienable rights" that our founding fathers promised?

Until we can examine ourselves, our daily activities, and at least understand what we are all about, and until we can challenge those who make no pretense of doing anything other than operating a health care delivery system that works to the advantage of some, but to the disadvantage of most; until we come to grips with these problems, we will have great need for a solution that will not be there, and we will be in a state of turmoil.

In closing, let me say to you that the Health and Hospitals Corporation is in difficulty only because of a lack of commitment, by those who set priorities, to those who have been traditionally underserved and who depend upon the municipal hospital system for their health care.

It is in difficulty because those who profess to want to provide health care as a right are really not quite so concerned with the provision of health care as a right as their rhetoric would have you believe. In some instances, their commitment is to the voluntary sector only. So as we come to grips with the problem today, I challenge you to make health care a right for all, and to give to those patients all those rights that we are all entitled to as human beings.

* * *

PANEL ON PROTOTYPIC EXPERIENCES

Voluntary and Regulatory Bills of Patients' Rights - George Annas

My topic today is Patients' Bills of Rights--voluntary and regulatory: what their current status is and what kind of impact they are likely to have.

I'm thankful that the previous speakers have made some of the main points I wanted to make. I won't repeat those--I'll assume that they are ones you agree with.

One thing I think needs repeating however, is that bills of rights need to be different for different populations. They cannot be intelligently discussed generically. Each has its own unique parameters, for example, FDA warnings concerning prescription drugs, rights in the hospital setting, the nursing home setting, mental hospitals, prisons, etc. I'm going to confine my remarks almost solely to bills of rights in hospitals for two reasons. First, this is the area where they are most developed and, secondly, because 38 million of us every year will spend a week in a hospital and 200 million Americans will be treated in a hospital emergency ward or outpatient clinic. In short, the hospital is the area that has the most effect on most people.

Current bills of rights in hospitals have three characteristics: They're provider-generated, they are self-serving and vague, and they lack an effective enforcement mechanism. Those three characteristics seem to me to be the major problems with bills of rights in hospitals, and the three areas that we have to overcome if we want to develop adequate bills of rights.

I will illustrate this point with four bills of rights--the AHA Bill, the HMSHA Bill, the Bill of Rights that a major hospital in Boston has said was the first bill, and finally, one of the older documents on patients rights, the Nuremburg Code.

The AHA Bill of Rights was promulgated by the American Hospital Association in late 1972. That is the first problem--that it was promulgated by hospital administrators. You don't expect landlords to promulgate satisfactory bills of rights for tenants or automobile dealers to promulgate bills of rights for purchasers of automobiles, and we should not have expected the American Hospital Association to promulgate a satisfactory bill of rights for patients. The AHA's main concern seems to have been to respond to lawsuits naming hospitals as co-defendants with staff physicians and to try to get the patients on their side in their power struggle with medical staffs. They were trying to say, look patients, we're on your side, we're trying to monitor quality care and do other things that will protect your rights. I'm not going to say it's all bad however, because it is not. I think the statement of informed consent is relatively good, but most of the other sections are very vague and general, and do not add much concretely to patients' rights. The "right to respectful treatment," for example, is important, but not enforceable.

Even Johnny Carson, on his nightly TV show on January 9, 1973, the day the AHA Bill of Rights was published on the first page of the N.Y. Times, said that he thought there were some rights the AHA somehow overlooked--and he hoped they would include these in their next edition of the document. He listed, for example, the right of comatose patients not to be used as a doorjamb, the right of any patient who was to be given an autopsy to demand a second opinion, and the right of any patient to refuse a sponge bath with "Janitor-in-a-Drum."

I think Mr. Carson caught the spirit of the AHA Bill because it is in many ways a parody of a patient bill of rights. It is not complete, it is not specific, it has no enforcement mechanism, and all it is telling you is what it is convenient for hospitals, from an administrative viewpoint, to provide the patient.

In this regard, it is ironic that the hospitals haven't even accepted the AHA version. Only 30% of hospitals have adopted the AHA or a similar bill of rights. Why? Again, (ironically) they say the reason they haven't is almost the very reason I think the AHA adopted it in the first place. To avoid malpractice suits. As one hospital administrator put it, "It is an invitation to every shyster lawyer in town to come in and sue them for the rights they spell out." That is ridiculous. No hospital has ever been sued solely on the basis of the Bill of Rights, and the Bill could be introduced in evidence as custom whether the hospital had adopted it or not! The fact is, many hospitals simply don't want to adopt bills of rights.

The second example, HEW's Health Services Administration Guidelines for Ambulatory Care Centers. I have a couple of things to say about that. Of the 10 points in the Bill, three points talk about patients' responsibilities, making it a seven-point bill. Moreover, the things they don't include are more interesting than the things they do include. For example, they don't even mention informed consent in this bill, which I think is a patient's most important right. They talk about the rights to be fully informed of your medical condition--unless it is medically contra-indicated. So I don't think we have to say too much more about that except it's a provider-oriented bill of rights, obviously, not a patients' bill of rights--it tells patients that they shouldn't give too much trouble to doctors. It's in the tradition of the AHA Bill of Rights. I'm not sure what the theory is, unless it is that it is harder to deal with ambulatory patients because they are still walking. Maybe you can give patients more rights if they are flat on their backs.

The third bill of rights I want to talk about is the Bill of Rights of my "favorite" hospital in Boston, the Beth Israel Hospital. I want to make it clear I am not denigrating their medical care--I am talking about patients' rights. Beth Israel Hospital and its Director, Dr. Mitchell Rabkin, claim they had the first bill of rights in the country. They are very proud of that. That bill of rights is very similar to the AHA Bill of Rights, but in Massachusetts, that's not good enough. In Massachusetts--one of only a few states to have such a law--we have a law that says hospital patients have the legal right to see and copy their medical records, both when they are in the hospital and after discharge. The Beth Israel Bill of Rights neglects to mention this right. When questioned about this, Dr. Rabkin said, well yes, he understood this is the law in Massachusetts, but he didn't agree with it. He thought that patients shouldn't see their medical records unless the attending physician thought it was OK and so he didn't want to encourage patient access. Dr. Rabkin obviously has a right to his own views, but his views aren't the law. The omission of this legal right makes the bill incomplete and deceptive.

At this hospital, also, they have a system of patients' representatives. They are, in general, management representatives, hospital representatives. Their job at Beth Israel Hospital, and many other hospitals, is to represent the hospital administration to the patient. At Beth Israel they are limited as to what they can do to non-medical and non-nursing matters. In other words, they can't get involved in anything that is in the AHA Bill of Rights or other bills of rights. They can't get involved in informed consent, consults, delaying discharges, medical records, or anything else that is vital for you to know about your medical care. What can they get involved in? Did the flowers arrive? Has the linen been changed today? Housekeeping matters.

Studs Terkel in Working asked a "patient representative" what her job was. She said it was working for the collections department of the hospital, and that the way she got in a patient's room was to introduce herself as a patient representative. She said she "talked nice" to the patient for awhile, and then, wham, hit him with the bill.

Patient representatives in this country are based on the airline stewardess model--TWA even trains some of them--they are not concerned with medical care, what you came to the hospital for. These people are there to keep you happy in terms of creature comforts, not to get involved in and help you with your medical care, and not to upset the physician and hospital staff who are taking care of you.

The final example I want to talk about briefly is the Nuremburg Code. It is very interesting. It was written by three American Judges, after the doctors' trial in Nuremburg 1947. The question was the law of consent to human experimentation, specifically the Nazi doctors' experiments on prisoners of war in World War II. Were they violating the law? The doctors said they were only following orders under the laws of Germany. The court said there was a higher law called "natural" law or "international common" law, that said there were certain things everyone in the Western world agrees with and is bound by. The fundamental premise of that law was that you could not experiment on anyone without his voluntary, competent, informed, and understanding consent.

In the United States we have had various reactions to the "Nuremburg Code." The main reaction was initially to ignore it. In 1953, the U.S. Army became the first governmental agency to adopt the Nuremburg Code as official policy. That would be good for the Army except that they classified it Top Secret, and presumably none of the enlisted men who participated in medical experiments knew about it.

It wasn't until 1966 that HEW developed any regulations at all on human experimentation (although FDA had begun a few years earlier) and it wasn't until 1974 that HEW said that a token consumer (there only has to be one) has to sit on hospital review panels to review new research protocols before they are funded by the Federal government. Congress in 1974 passed legislation which set up a national commission to study this whole area and come up with new regulations on human experimentation which will probably be promulgated in a couple more years.

So our history in the U.S. dealing even with codes that we ourselves adopt as law in a criminal sense and apply to citizens of other countries has not been very good. Both the voluntary and the regulatory bills of rights, I would say, have been a failure in this country. They're not consumer-generated, they're not specific enough, and they don't have any built-in enforcement mechanism. So, I would urge that in any deliberations that are part of this conference, special attention be paid to consumers and what consumers want, and not to what administrators want or physicians want. Be sure that the patients' rights you want are very specifically spelled out, and are understandable by everybody so that consumers and providers both know what they are. And, finally, make sure that there is an enforcement mechanism, that there is some kind of person there, a patient advocate I would call it, who is responsible not to the hospital administrator, but to the patient, so that patients can exercise the rights set forth in your patients' bill of rights.

Judicial/Legal Aspects - Louis M. Thrasher

It strikes me that it is quite extraordinary that the medical profession would take it upon itself to promulgate bills of rights. I think that is an important thing to focus on. There is a Bill of Rights in the Constitution of the United States that applies to all citizens of the United States. It does not depend upon the medical profession for its efficacy. There are no special exclusionary clauses for people who are in hospitals.

There has been a substantial amount of constitutional litigation since 1970-71 on this subject. The Department of Justice has been involved in the field of patients' rights since its involvement in the right to treatment litigation concerning the mental health system in Alabama in 1971. Since that time we have increased our participation in such cases to approximately 20 lawsuits, most of which may generically be classified as right to treatment cases. The right to treatment cases stem from the deprivation of liberty of citizens of the United States pursuant to a civil process often accomplished by persons who are part of the medical profession. Such civil commitment procedures result in the placement of such citizens of the United States in State institutions, where they are not permitted to come and go as they will.

The Fourteenth Amendment to the Constitution provides, among other things, that no State can deny any person the right to liberty without due process of law. To concede that the medical profession, or anyone other than the People themselves, can be looked to to come up with a bill of rights is conceding an awful lot. The People, including the mentally handicapped, already have those rights. They are guaranteed by the Constitution.

Our litigation includes other people who are involuntarily confined pursuant to a civil process. These consist mostly of juvenile delinquents.

The mental retardation and mental health cases are, I believe, most analagous to what the people at this conference are concerned with. They stem, as I said, from the Fourteenth Amendment protection against deprivation of liberty without due process of law. Every State provides for involuntary hospitalization of mentally retarded and mentally ill persons. Normally, this statutory process provides that medical persons and in some cases other persons will attest to the fact that hospitalization is required. Typically, the hospitalization is involuntary on the part of the person whose liberty is being denied. We have seen many States where the parents and guardians of such persons "voluntarily" commit such handicapped persons to State-run institutions.

Clearly, since the right to liberty is the most protected right in the Constitution, giving up liberty is certainly not voluntary on the part of the person whose liberty is being deprived. Typically, the statutory commitment process gives the superintendent of such institutions the authority to release such patients when the conditions of those patients, in the judgment of the superintendent, have improved to such a degree that they may return and live independently in the community.

Such statutes promise in return for the giving up of liberty a right to treatment. That is, the justification provided in the statutory scheme of commitment is that we are denying your liberty for the purpose of giving you care and treatment. Obviously, if treatment is not then provided, or the treatment given does not meet the individualized needs of the person whose liberty is being denied, such a condition of improvement will never be attained. Since such a condition of improvement will never be attained under those conditions, the condition precedent for re-gaining liberty also will never be attained. All too often, therefore, what has happened is that civil commitment has become a life sentence to a state mental health system without one being accused of having committed a crime, without having been suspected of committing a crime, without having a listing of the offense supposedly committed against society which justifies deprivation of liberty, and without a trial by jury and a finding of fact of any act against society which would justify the involuntary deprivation of liberty.

Many people have recently criticized Federal courts in this area for exceeding their expertise and going into an area reserved for the medical profession. However, I believe the courts have frankly recognized that there is no exclusion in the Bill of Rights for the protection of the constitutional rights of the mentally handicapped citizens of the United States.

The conditions of the mental hospitals and the mental retardation facilities, and the treatment of patients who have been involuntarily committed to such facilities, have been atrocious and I'd like to describe to you rather briefly some of the conditions that have existed in cases we've been involved in.

Perhaps the most striking example of conditions to which citizens of the U.S. are being subjected are those which were established during the trial of Wyatt v. Stickney, in which Ruth Knee appeared as a witness for the United States. This litigation, as you may know, involved the Alabama Mental Health System. The legislature had (as is quite typical throughout the country) seriously under-funded the mental retardation center. Because the legislature had inadequately funded the facility, the facility was under-staffed. Because the facility was under-staffed, the staff found it too burdensome to provide care on an individual basis for the residents. Because they found it too burdensome, they did not pick up toys and they locked up toilet paper which residents would strew around the facilities on a daily basis. Therefore, the residents were dirty at the end of each day. Therefore, because they were under-staffed, they used residents to strip each other, and to line each other up, much as is done in a car-wash. Retarded residents were then handed high-pressure water hoses as other residents were walked through this car-wash system.

During this process, one resident died when the hose was inserted into his rectum. Another handicapped, mentally-retarded resident in a wheel chair was pushed through this car-wash system. The hot water was turned on and his testicles were scalded off and he died. Another resident died when he broke into a totally unlocked, unguarded, medicine cabinet. Children were strapped to their beds, in spread eagle fashion each night. The beds were shoved together and pushed up against the door so that in passing one staff person could look in the window and see all residents on the ward at a glance. From time to time when parents and guardians would come to take their children or wards home for a weekend, they would call the hospital and say that the resident was crying and lying on his bed in spread eagle fashion. Often the hospital had to instruct the parents to tie the patient to the bed; they were used to that system and that was what they were waiting for. If they would just tie them to their beds, they would stop crying.

I have set forth examples from Wyatt v. Stickney, because they are so striking. However, what we had there was not an arcane medical question. Rather, it is a legal question which is: Under what conditions may the personal liberty of citizens of the United States be denied?

Judge Johnson in the Wyatt case correctly held that if the purpose of commitment is to provide treatment (and clearly that was the stated purpose) and if the length of confinement was directly tied to recovery and improvement of condition, then it is a denial of due process if the confinement does not provide that degree of treatment which is individualized and which will give each individual a reasonable opportunity to improve his condition or to be cured so that the conditions of liberty will be attained at the earliest possible moment.

There have been a series of right to treatment cases that occurred since the Wyatt litigation. I don't want to imply by using Alabama as an example that this is a southern problem. It is not. The conditions that existed at the Partlow State Hospital, exist everywhere in the United States.

For example, Willowbrook on Staten Island was the largest facility in the country for the mentally retarded person. Parents who wanted to get their children on the waiting list for Willowbrook were told that in order to get on the waiting list, they would have to sign a waiver for their children which subjected them to experimentation. They were injected with viruses and the results systematically reported. The conditions at Willowbrook were even worse, we believe, than they were in Alabama. But you could examine a whole list of facilities located anywhere in the country and come up with the same or similar conditions: Pennhurst in Philadelphia; Rosewood in Maryland; Boulder River in Montana; the Beatrice State Home in Nebraska. The conditions pertain everywhere.

When we discuss the rights of patients, we are discussing rights that no one has the power to give. They were given 200 years ago. This may be a quite striking concept at this late date. I certainly hope not. Patients already have those rights. If it is necessary to now give constitutional rights to patients, then we have really slipped.

The United States is also involved in a series of cases that attack the processes of commitment in mental health cases. Let me give you an example. In Iowa it was possible for someone outside the State to pick up a phone, call a county clerk and tell the county clerk that they wanted so and so committed to a mental hospital. The county clerk would then write out a warrant and give it to the county sheriff. The county sheriff would then go to the home of the person to be committed, knock on the door and take him off--no hearing; no lawyer; no trial by jury; no assurance that the person was dangerous to the community and that involuntary treatment would be efficacious; no reason to believe that the person may have committed any crime. All of you know that the cases are legion in the Supreme Court that even the most heinous criminal is entitled to a lawyer; indictment by a grand jury, trial by jury, and a transcript of the proceedings against him upon which to base an appeal.

I would urge you all again to think in terms of patients not having to be given rights, but that patients, as all other citizens of the United States, have rights that may not be taken away from them.

Patients' Rights - What's in It for the Doctor? - Marvin S. Belsky

As a practicing family internist, participating in a panel discussion on patients' rights, I feel somewhat like the child who exclaimed: "The Emperor has no clothes." The only difference is that I too was once one of the silent, complacent crowd. However, I became increasingly aware that the medical mystique had created barriers to the utilization of my skills and kept me from reaching and better motivating my patients. Consequently, it was logical and natural for me to meet with five to eight patients informally after office hours twice a month as an approach to overcome barriers in communication. These meetings have enabled each of us to better understand and accept one another's rightful expectations.

As a result of more than three years' experience with such feedback sessions, I realized that the myths of the medical mystique are self-perpetuating and self-fulfilling. They are based on a minority attitude of patients that has been put forth erroneously as a majority viewpoint. The rationale has been that patients are not capable of knowing, emotionally or intellectually, the discipline of the medical expert. Further, they are not desirous of knowing or questioning. In addition, they do not need to know. As one physician stated: "My patients are my oysters." And, finally, according to the mystique, patients require infallibility, preferring a paternalistic, passive-dependent relationship. Therefore, patients are unable to make critical judgments or be involved in decision-making.

I have become aware, quite the contrary, from listening to hundreds of patients that as much as these myths are believed and supported by doctors and patients, to that degree the relationship is anti-therapeutic. I have relearned that what is good for the patient is good for the doctor; and, what is rightful for the patient is inevitably going to be right for the doctor. Patients' rights and interests are in the best interest of the medical profession and in accord with all we profess as physicians.

I do not intend to discuss today the social origins of the forces that have led HEW to sponsor this conference. They certainly encompass a Watergate era of accountability, the rise of the human rights movement, including women's, minority and consumer movements, the growing ethical dilemmas of the technological imperative in medicine, as well as the burgeoning malpractice crisis. What has been of immediate and profound concern for me has been the critical interaction between the individual patient and physician in the clinical setting.

By this gathering here today of people with diverse backgrounds, a democratic and representative government such as ours is beginning to respond to these social forces in the area of patients' rights, and, more important, to pay attention to the most significant unit of care--the one-to-one helping relationship between physician and patient. Since the best government is the one which governs least, wedding the best of the customs and traditions of the medical profession to the patients' rights movement will most likely guarantee the purposes and goals of both in a functional, non-coercive and therefore, harmonious manner.

For a few misguided doctors to oppose a general right to medical care or any other patient right is no more in accord with the democratic heritage of our country than with the real needs and interests as well as the traditions of the profession. My experience has taught me that physicians who incorporate into their practice the rightful expectations of patients will have a natural and powerful ally against bureaucratic intrusions and controls. In truth, patients' rights cannot be approached in an adversarial fashion as if one party in the helping relation takes from the other or limits the rights of the other. Rather, patients' rights are a bulwark to prevent whatever medical care form that might exist--free market, professional or socialized--from thwarting and dehumanizing the therapeutic goals of medicine.

Because of my role as a grassroots front-line family doctor, I cannot be accused of being an ivory tower social planner. And, because of my unique experience with feedback meetings with hundreds of patients I have learned not to reject the patient's ability, implicitly or explicitly, to help the doctor in innumerable and unforeseen ways. A skillful and open patient is required to fulfill the doctor's needs and expectations. Such a patient becomes a possibility only insofar as doctors themselves are open, willing to be questioned and share information.

Communication feedback is vital to the doctor and patients' rights are another technique, albeit a humanistic one, that permits the physician to reach his therapeutic goals. Therefore, my meetings with patients have linked information with rights. They have been filled with a warmth and gratitude and affection that patients have for the healing skills of doctors. They have been personal, direct and relevant and as a result, integrated to the needs and expectations of both patient and physician. A realistic basis for implementing the rights and responsibilities of both is provided not only for a three hour interlude, but by establishing a continuing and pervasive mood throughout our relationship. As a result, patients routinely participating in decisions are more likely to change their health behavior as they feel they are invested in the decision.

Patients discuss what they would like in a physician and more particularly in me. What they don't like. What's a good doctor? I regularly ask them: "How can you judge competence? How do you choose a physician? Which is more important, compassion or competence? What has upset you about my practice and what has been gratifying? How do you know if I am a good doctor? What's a good patient? What would change your health behavior? What about house calls? Or Emergencies? Where do you receive your health information? How does it affect you? Should you be told if you have cancer?" There are hardly any areas of our relationship that have not been explored, from the mechanics of the office setting to the mystery of the doctor's judgments.

Having learned from such feedback sessions, I routinely outline for all my patients at office visits their rights and consequently, their responsibilities. With warmth and camaraderie patients have shared experiences at these meetings with anecdotes illustrating how each of their rights can lead to better medical care--a goal also devoutly desired by physicians. As a result, their rightful expectations have been strengthened in a meaningful and relevant way.

Patients want to be fully informed. One patient who as an infant received radiation to her neck for thymus gland enlargement, was very anxious about secondary thyroid cancer and had consulted with numerous specialists. At the feedback, it was suggested that I provide her with any pertinent medical journals which she might peruse and question me about. Now she regularly reads such material and has even spoken to the authors and researchers, which has considerably alleviated her anxiety and lessened her frequent and redundant visits to specialists. Another patient who had had open heart surgery wondered if she could have been made more aware of the details. That feedback discussion brought out that patients might learn a good deal from fellow patients who had undergone similar clinical situations, particularly unusual ones, and that in the future it would be helpful if I might arrange to have such patients meet with others before the event.

Patients have felt that they could be better informed if they could learn about the side effects of drugs on their own and thus, feedback has encouraged me to print on my prescription blanks a request that the pharmacist enclose the drug brochure along with the medication. The vast majority of my patients have welcomed this and in fact they are now more compliant and less anxious about their medication.

A similar outcome has resulted from the feedback suggestion that changes on electrocardiograms and X-rays be shown to them. One patient responded after seeing changes in the T-wave on the electrocardiogram by giving up smoking. The right to question a doctor is highly valued by patients who feel that they are constrained by the medical mystique. One patient illustrated this by relating that when he asked his doctor how to take his medication, he was told the drug label would explain it. The label read: "Take as directed." Patients have a right to information without the confusion of jargon and lingo. A patient who had been told of a cerebral thrombosis and yet who continued her bon vivant lifestyle, behaved subsequently in a more sober fashion following a clearer delineation of "a clot on the brain" after the warm and informal give and take of a feedback session.

Even more important and subtle than the obfuscation of technical language is the emotional block that illness often brings. At my very first feedback, one patient revealed that following upsetting news she heard nothing else and that this was why she phoned so often after an office visit to question me. Other patients stressed the necessity and desirability of regularly bringing a friend or relative to overcome such a barrier. Despite the traditional denigration of "the patient with a list," I have been encouraged by feedback to welcome a statement of a patient's symptoms and history written at home in a more relaxed and less anxious environment.

In discussing the patient's right to confidentiality, we think of the traditional third party intrusion, but it was pointed out at a feedback that there is another more pervasive aspect of confidentiality that is forgotten. This was illustrated by a patient who noted that her mother learned of her cancer by overhearing a discussion between two residents in the hospital elevator. Another patient related how terror stricken she was when the patient in the next bed constantly warned her of the rate of flow of my patient's intravenous. Her roommate had overheard what the nurses had said about the remote possibility of heart failure.

Without the right to availability of medical care all else becomes less important. But the phone and medical assistants--"the gatekeepers"--and schedules can become effective barriers unless the patient and physician understand how to use them. At feedback we grapple with such problems together, sharing our special universes. We talk over how I may be reached on weekends and when necessary they should call me from the hospital as much as they would call me from home. "I'm as near to you as the phone," I tell them. One patient called from the hospital that she was scheduled for a kidney X-ray and was prepared to go except, she said, I had not informed her about it. I had not done so because the X-ray was scheduled for another patient with a similar name.

Suggestions have been made to patients to call ahead of their appointment time so that they won't have to wait. Patients have told me at feedback quite correctly that their time is as important as mine. My medical assistants receive feedback as well with regard to phone technique, privacy, and scheduling. The suggestion to identify themselves with their own names beyond the words "doctor's office" with each phone call has been warmly received. Patients have indicated when they find it acceptable for the medical assistants to give test results and when not, or when they should accept waiting and when not. And, yet, patients have expressed to one another different feelings and attitudes about a medical assistant; one feeling quite warmly about someone, and the other patient feeling the same assistant was distant. As a result of peer interaction, they begin to understand that their view may be singularly different from others and possibly should be changed.

Peer learning has been fundamental in outlining patients' rights and responsibilities. One man felt competence alone was sufficient--do the job and no need for hand holding. However, he learned from listening to another patient that that was not enough. She described how she had stayed away from doctors for ten years because they would examine her internally, in stirrups, without greeting her and talking to her. As a result of her withdrawal, a cancer of the cervix was discovered only after it had progressed to a symptomatic invasive stage.

Another patient who had had two coronary artery bypass operations felt I had been unavailable though he frequently called me on vacation and when I myself was hospitalized. As the evening progressed and the right of doctor's availability was explored, it was pointed out by his fellows that patient attitudes change and they can become quite sensitive when they have a chronic illness.

Feedback, as you can see, is a dialogue, an exchange, a mutual participation. Patients have the responsibility to utilize their rights. So too they have the responsibility to accept the physician's rightful expectations. At one meeting, after listening to one patient point out to another that a good patient doesn't obey the doctor's orders, but rather a skillful patient questions, understands and participates, a husband persuaded his wife to stop smoking and join the doctor's efforts and aspirations. Another patient, after hearing others reflect how their social conditioning contributed to ineffective health behavior, realized that taking after her mother's denial of health concerns and irrational disparaging attitudes towards physicians had led to her own cynicism towards doctors. She then understood that the skillful, dedicated physician had a right to <u>her</u> caring and <u>her</u> concern for her own health as much as she had a right to the physician's concern and caring.

My task here has been to reveal how patients' rights are linked with patient and physician expectations and how they can be met. Feedback meetings between patient and physician are not so much a method to delineate clearcut, firm guidelines as much as a mode to explore newer, therapeutic roles in a joint and creative manner. The lawyers here have defined legally the compelling state interest of a democratic, representative society in patients' rights. It has been for me to define the compelling therapeutic interest in patients' rights of the medical profession.

After an age where medical technology has reached the limits of its success in improving and extending the quality of life, we are entering a golden age of health communication and education where the obedient and passive patient--the slumbering giant--will become the involved and participating patient--the awakened giant. We can look forward to an exciting future where patients, truly practitioners of preventive medicine, will be able to write their own records together with their physicians and participate in clinical conferences. They will have the training and skills so that, with information fully shared, it will no longer be necessary to abdicate decision-making to others. As a physician I can only welcome this and say, "Long overdue."

A health educator has noted, "I feel obligated to tell the patient everything I can--it makes him a better patient." To which I would add: "I feel obligated to tell the patient everything I can--it makes me a better doctor." Patients' rights--what's in it for the doctor? Everything.

<u>Patient/Consumer Advocacy</u> - Linda Fay

Although I'm not a professional, I've worked as a volunteer with the National Paraplegic Foundation here in Washington and as a patient advocate. My interest in advocacy is a result of my own disability. I was injured when I was 16. I'm a spinal-cord-injured paraplegic, and spent about 14 months in the hospital initially after injury. I've been hospitalized since at different times, for two or three months at a time, so I have been an internal observer. I've been not sick enough to be incapacitated and well enough to see just what goes on inside.

Here in Washington, we have NPF programs in which we try to contact people with severe physical disabilities and stay with them through the process of acute care and rehabilitation. That is how I became involved in the rights of patients. We see many individuals in nursing homes who are being denied such rights.

The three people who have already spoken have said things which touched me deeply because I see people who are caught in similar situations and I know people, unlike Dr. Belsky's patients, who have no opportunity to interact with doctors, who are subject to doctors doing things to them that are grossly inappropriate for their condition.

We should realize that all of us potentially are consumers of health services. Any one of us can be injured or become ill at any moment, to enter the health care system as a patient. The word "patient" has certain implications and connotations. You automatically assume a dependent relationship to all the individuals providing services to you. You're no longer a person. You're somebody to be taken care of, somebody to have things done to. Your intelligence is immediately demoted to that of an infant or someone severely mentally retarded. The patient does not have the capability to comprehend anything written and he certainly has no right to contradict the medical profession. A very interesting situation to be in, and the "patient" who rebels is then subject to reprisal.

Mr. Thrasher said to me, "I have found in the medical profession a great resistance to patients' rights, to the promulgation of bills of patients' rights, and to consumers taking an active role because it's felt that all of the medical profession is defending the individual patient's rights." But that has not been my experience in my own hospitalization or in working with other individuals.

I think one of the major reasons for the "malpractice muddle" that we currently see is that this is consumerism rampant. Individuals who have found no other way to express their rights, to demand their rights, are resorting to litigation. I would suggest that, unless our health care delivery system makes some radical changes, this will continue because if there is no other recourse, people will take to the courts. I am just grateful to the Lord that we have a court system that has at least been somewhat willing to defend the rights of these individuals because there certainly has been no one else.

One of the specific rights I would like to address is the problem of medical records. Dr. Weed of Vermont has suggested that this record is the property of the patient and I would strongly agree with him.

I realize that this is close to heresy to the medical profession to suggest that those documents which specifically describe an individual should belong to him. Currently what happens is that someone is admitted to the hospital, all kinds of material about him are put in the record but he is never allowed to read it or correct it. This is then passed on from professional to professional. The patient is continually asked to sign releases of information when he has no idea of what is contained therein. I know that within my own medical records there have been derogatory remarks including some about my psychological condition. If you're in the hospital for a long time, don't you dare get depressed because the day you get depressed, boy, I'll tell you, you've got everybody on your back. It will be documented and immediately you're a candidate for a psychiatrist. It's a very dangerous thing. There's a promulgation of remarks and subjective judgments in the medical records that have no place there.

Many individuals are not told the diagnosis. I've seen patients where orders were written for treatment.... A specific example: an elderly lady who'd broken her hip and they'd ordered an intravenous pylogram. She had no idea of what was involved. They came and got her and said, "We're going to X-ray," with no explanation that this would involve an intravenous and an expensive series of X-rays, no explanation of the purpose of the treatment and no previous notification that it would take place. Now, I don't think that this is unusual. It may be unusual in teaching hospitals, but it's certainly not unusual in the county hospitals around the country, away from the large cities. I think--I know--that we have seen this repeatedly, particularly with individuals who have spinal cord injuries where the treatment is very complex. I intervened personally to prevent surgery that I knew was not necessary because it was being carried out by a physician who had no knowledge of spinal cord injury, had probably seen possibly one other individual with spinal cord injury and thought the only treatment of a neurogenic bladder was an ileostomy, which is totally unnecessary. We referred him to a decent urologist and were able to stop the wrong procedures. If I and other individuals hadn't intervened, this case would have had expensive surgery that could seriously endanger the kidneys.

Within a hospital setting, I have encountered great resistance on the part of professionals towards having any advocate present, particularly if it's not a family member. I have had the physician write notes on a chart that I'm not allowed to visit--I'm not allowed on the grounds of a hospital or nursing home because there's no desire to have someone come in who can tell patients what their rights are, to suggest to them that their doctor is not absolutely infallible, that he doesn't know exactly what he's doing and that they shouldn't just bow down.

In our experience, though, we have found that with individuals who have been hospitalized for long periods of time you have to begin to train people to assert their rights. This is one point where I would like to see more professional advocacy and government advocacy in terms of helping individuals who have been hospitalized or have been patients for a long time to stand up for their own rights and to begin to ask questions. Although it's very dangerous to ask questions if you happen to be in a nursing home. I've seen the quadriplegics shut in their rooms because their families were too aggressive--asked too many questions, caused too much trouble. So they just shut the doors and ignored them. They couldn't reach a call bell. I'm not kidding. I can document this. This happened in a nursing home in the Washington area.

I was very pleased to see, very surprised to see, actually, that now individuals who are in nursing homes on Medicare can go to their Social Security District Office and initiate complaints. But I'd like to know why that information was never handed out. Why isn't that attached to the Medicare bill of rights which is supposedly given to every patient? Why isn't there an address and a phone number and a contact person attached to that bill of rights? I'd also like to know if there's any extra funding paid to the overworked personnel in the Social Security offices to follow-up on these complaints, because I can tell you if this complaint mechanism is made available, there will be complaints. If this is publicized among those individuals who are currently consigned to nursing homes because there is no other alternative care, there will be complaints. The AHA Bill of Rights, as Mr. Annas said, is self-serving, is intended to quiet the rebellious patient. If you'll read through it, you'll note that four of the rights stated include the clause that this right can be withdrawn by a doctor. I don't know if you realize that those individuals on Medicaid and Medicare in nursing homes generally do not have a private physician. Few physicians will visit nursing homes. They are assigned to a physician who is generally the covering doctor and his job there is to sign orders that fit the convenience of the staff, not that fit the needs of the patient.

I realize that I was not supposed to discuss extensively the problems of individuals in nursing homes but these are what I'm most familiar with and this is where I feel that those abuses that occur in hospitals are exaggerated because of the lack of staff, the lack of supervision, and unqualified medical personnel. And also, in our particular situation, the fact that the most severely disabled are the people who are confined to nursing homes and the most severely disabled are the people who fear the reprisals that are built into the system. That's right. They not only fear them--they get them. Withholding of care, withholding of opportunities to get out.

When I was in a hospital here in the Washington area where I was rehabilitated, I wanted to take guitar lessons in the evening. I had arranged transportation. I had found an accessible place where I could go. My doctor decided that it would not fit in with the convenience of the staff to have me return after 9 o'clock, so, therefore, permission was denied. When a nursing home is your home, there are all these little things, these personal freedoms, rights of liberty, that are denied you. You are expected to conform, to fit in with the staff's convenience, and if you don't, and if you try to change things for yourself or for other patients, there are reprisals right down to the administration of heavy dosages of tranquilizers to the patient. This is going on now.

All these bills of rights, (and I've read quite a few, about, I would say, 15 or 17 over the last few weeks, mostly from the State of Massachusetts) are, as Mr. Annas has stated, for the convenience of the medical staff. They are to try to keep down the complaints. It astounds me that it has become necessary to codify such things as respect for the individual and the right to courtesy, the right to privacy. You should ask, what is actually happening in our health care institutions that we have to write a bill of rights and include such things, and I'll tell you, it's necessary. I'd like to see some court cases fought on the issues, the right to courtesy, the right not to be belittled. My son's pediatrician stood there and laughed at him because he cried when he was told that he would have to be confined at home for three days. "You're acting like a little girl," he said. This is the kind of thing that goes on in hospitals and health care situations continually. And I think it's a responsibility of each individual to speak out, to be a patient advocate, because at the moment hospitals and the medical profession will not incorporate the role of the patient advocate into their systems.

I consider myself an advocate. I intend to continue to stand up for the rights of people, but I'm not paid; I have to run a household; I have severe restrictions on my time because I don't get a salary.

It's my understanding that the Department of Health, Education, and Welfare has turned down grants that suggested programs with active patient advocates. They claim that they are willing to stand up for consumer rights, but there's no funding. It's fine that we have a conference that lets us all sit down and talk to each other, but how about some funding?

I get very angry, and I get very frustrated because I have so little outlet for this anger in a constructive way. I find when I go in and I try to be an advocate, my opinion is not respected because I'm not a professional; I have no M.D. or Ph.D. after my name.

I have had several doctors whom I know personally, whom I've called on in a particular situation when I knew that the treatment going on was wrong and I said, "Look, would you please intervene here?" The last time I tried to do this, one said, "I'm sorry, I can't do this any more. My malpractice insurance won't cover me in Maryland. I'm not willing to take a chance on this any more. I'm sorry. You're going to have to find somebody else. This really is not within my province."

I'm not a lawyer but I'm beginning to learn various aspects of law, but it's very expensive to push a malpractice case through. It's very difficult also, when records are destroyed by medical personnel, to prove malpractice.

I had a very good friend who almost died in a nursing home because the nursing home refused to get a doctor for him over a weekend. It was only because his mother went in and said, "If you don't get a doctor, I'm going to call an ambulance," that they finally did. When the doctor arrived, he discovered that this quadriplegic had a collapsed lung and severe pneumonia and it was just by the grace of God that he was still alive. We have now finally got him out of this institution where he was being psychologically and physically abused.

When I talked to a friend who's a doctor and told him where this happened, he said, "Oh, no, that couldn't have happened there. That's a good nursing home. That's one of the best in the area." And yet, we have the evidence that it happened.

I would strongly recommend that those special agencies that are able to (and I realize that this is consumer advocacy, but the consumers still do not have the power, the money and the pull within the government), establish a nationwide program of patient advocacy within every accredited hospital--patient advocates who are accountable only to the patients, whose salary and hiring and firing are not the responsibility of the hospital administration (or the hospital receives no government funding). Let's put some enforcement behind this. Patient advocates who can involve themselves in every aspect of the patient's care, with his permission, who have a right to read his records, who have a right to stop discharge, who have the right to demand a consultation or referral to other doctors. Patient advocates who understand both the medical and legal terminology and who can step in to make the patient's rights a reality.

OPEN DISCUSSION - QUESTIONS AND ANSWERS

MODERATOR: We have a little time now for some questions and discussion. The panel members may want to answer questions from each other or from you. Please let's have no speeches!

AUDIENCE QUESTIONER: I would like to know how many people here consider themselves consumers by the definition on page 12 of the Background Papers, which defines consumers as: "Members of the general public, persons who reside in a system's service area and who have no professional or financial interest in the provision of health care."

(Show of hands)

MODERATOR: Quite a few of those here evidently define themselves as consumers. We need both sides of the equation at this meeting.

AUDIENCE QUESTIONER: A number of name tags describe people here as directors of social services in hospitals. I'm wondering what the role is of the hospital social worker regarding the rights of patients.

MODERATOR: Anyone want to comment on that? (No response) That may be a subject to discuss in the workshops.

AUDIENCE QUESTIONER: I'm Doris Haire. I'm on the Consumer Advisory Committee for the FDA. We met with the heads of the pharmaceutical industry the other day and were quite interested to find that of all the proposals we made for patient package labeling, the one they resented and resisted and essentially refused to accept was a warning we feel is very important. No one knows the long-term effects of any drug and the FDA does not guarantee the safety of any drug it approves, and we felt that every patient should be advised, "Before you accept or refuse treatment with the drug blank, it's important that you understand that no long-term scientific followup, examinations, or evaluations have been made to determine whether this drug may have adverse, delayed effects which are unpredictable at this time." It was interesting to note that this warning was what the pharmaceutical industry resisted and I, for one, feel that in respect to patients' rights, there is an illusion in this country that if a person can afford good care, he gets it, and that is really just an illusion.

MODERATOR: Would a panelist want to comment on that?

DR. BELSKY: It is an interesting question how useful package inserts, which contain the complicated information used by doctors, are to patients. It's also interesting how many skillful patients can get hold of the PDR (Physician's Drug Reference) and, unfortunately, when the PDR is gotten hold of, there are some doctors who think they're going to be in a fight. I know--I received one in my mail--that there is one private concern which is sending out, for the most commonly prescribed brand-name drugs, a very simplified list of what the side effects would be, not with the statement you just enunciated, but in some detail.

MS. HAIRE: That's important.

DR. BELSKY: It probably is. We are in a drug-oriented society. For example, there are additives in everything we eat. Part of it is as much the patients' involvement with the mystique as the doctors'. Patients say, "Can you give me a drug?" or they take antibiotics left over from four weeks or three months ago or obtained from a neighbor. So, both in patient and physician, we have throughout this country a pervasive drug-oriented approach where both the doctor and the patient seem to feel that drugs have to be taken.

MS. HAIRE: I think the audience should know that there is no State in the country which has any law or regulation which precludes the druggist from giving the patient a package insert. All druggists will tell you that.

AUDIENCE QUESTIONER: Mr. Annas, you indicated that there were three States which allowed the patient to read his own records and you named Massachusetts as one. What are the other two States? Does this apply to all medical records?

MR. ANNAS: It only applies to hospital records in Massachusetts. Connecticut is one of the other ones and I'll have to look the other up. I don't know it off the top of my head. And in Massachusetts and Connecticut, I believe this applies only to hospital records. It does not apply to physicians' records or to all records in a mental institution.

AUDIENCE QUESTIONER: In activating a patient's bill of rights giving patients sufficient information with which to make informed consent, my assumption is that this takes more time for the health care providers. If that assumption is correct, my second assumption would be that the people who already have the least health care are going to suffer. The middle and upper classes in this country will have time devoted to them for greater education--not the lower--and I'm wondering if that price is worth it.

MODERATOR: I wish Dr. Holloman were still here to react to that from his standpoint.

MS. FAY: I'd like to react to that. This is a real problem and we really have a doctor shortage, only it doesn't seem that way. I mean a doctor shortage for rural and poor. I think that this is one of the functions that patient advocates could fill--when a doctor doesn't have time in a clinic setting for discussing in detail the treatment proposed with the patient so that he can make an informed consent.

MODERATOR: Historically, that used to be the job of medical social service departments in the hospitals and the public health nursing groups, so I don't know what's happened to some of those other roles that have gone into teamwork.

AUDIENCE QUESTIONER: My question is directed to Mr. Annas. He said one of the most important things is enforcement of patients' bills of rights. Could you enlarge upon that and describe what you think would be an effective enforcement mechanism?

MODERATOR: That will be part of the workshop deliberations. There are some on regulations and enforcement. Five and six, I believe.

SAME QUESTIONER: I'm signed up for five.

MODERATOR: You're signed up right.

MR. ANNAS: Very briefly, in Massachusetts the law on hospital records had been on the books for 20 years and it wasn't until two years ago that it began to be publicized, that people knew about it, and it wasn't until last month that the Attorney General finally said that he would sue or bring any hospital into court that failed to give people their medical record. That's the kind of enforcement mechanism we need. Any mechanism that requires patients to go and hire a lawyer doesn't work; number one, because it's expensive, and number two, because it takes so much time to get to court. Your problem is immediate. You need something that works right away, in 10 minutes or half an hour. That's why you want someone on the premises, it seems to me. And you need somebody that doesn't cost the patient money. I said nine states have various types of legislation on records. California, Vermont and Utah limit access to the patient's attorney; Massachusetts, Wisconsin and Connecticut are the three that give the widest access; three others, New Jersey, Louisiana and Mississippi, provide access under certain circumstances.

AUDIENCE QUESTIONER: I was glad to hear Mrs. Fay, particularly, talk about the nursing homes. And I think that, in general, I would like to see more of the Symposium focus on the accountability of all kinds of health providers, particularly nursing home administrators because the nursing home is concerned with the patient's care. I think we need to be looking at the director of nurses and the nursing home administrators and holding them accountable and I'd like the panel to address that issue.

MR. THRASHER: If I can say something about that, when the Department of Justice gets involved, it is usually on constitutional issues which require State action in order to fall within the parameters of the Constitution. However, we do have a lawsuit against the State of Pennsylvania to enforce on a contract theory the life safety standards which are associated with Medicaid and Medicare in 400 private nursing homes throughout the State. So, we are moving into that area and we have found that the conditions in nursing homes across the country are very similar to the large institutions that are operated by State governments. We are aware, for example, of a nursing home in Iowa which keeps its patients in cages. There are an astounding number of nursing homes throughout the United States that are operated by county and local governments.

We have also finished a trial in March in New Orleans which attacked the practice of Louisiana's referring its mentally retarded, emotionally disturbed, juvenile delinquent, dependent, neglected, abused children to private nursing homes located primarily in East Texas, almost entirely funded by various forms of Federal assistance. Louisiana was referring its children there because the private nursing homes and child care facilities within the State of Texas /sic/, for one, wouldn't accept black children. And two, they had gotten into a situation where they had invested so much money in contracts with the nursing homes in Texas that they really couldn't get out of the contracts. And we found that the conditions there were, if you just changed the nursing home's title and called it the State hospital for whatever it was, you could notice no difference. The primary problem we found there was massive over-drugging of residents, the use of drugs to make up for the lack of staff, and the use of drugs to insure that persons who were residing therein would not present any problem to an overworked staff.

So, there are theories developing which will bring more litigation in that area. That may not be totally responsive to your concern.

MODERATOR: I think it's an important point that throughout this session we're not just talking about the doctor/patient relationship, although that's a very fundamental element as Dr. Belsky said. But we are talking about the relationship between the consumer and all elements of the health care system, and that includes a number of different kinds of people and policy makers and providers and taxpayers, etc. So that it's a very complex network of interaction and relationships that we're talking about and we must address.

AUDIENCE QUESTIONER: We've been speaking about the problem of enforcement and saying how important it was. I was wondering if perhaps that's really the only problem here. When we've been talking about the rights of patients, they all, in a way, if you consider a right as something, the violation of which entails legal sanction, all these rights seem to be based on very general principles of common law or constitutional law. Informed consent is the right to be free of battery, the right of confidentiality fits in with the right of privacy, and even the right to see your medical records, which doesn't exist in many States, is part of a very broad right people are fighting for involving the right to see FBI records, credit records and other things. They really aren't patients' rights, per se, they are just general human rights. What makes patients' rights special is that the patient is flat on his back and seen by authority figures. And when you get right down to it, enforcement is the only thing we're talking about.

MODERATOR: Again, I think that's going to be one of the things that we're really going to have to spell out in the various approaches in the workshops.

DR. BELSKY: Well, I would just like to make a general comment as a physician. If each one of you could, one at a time, sit in an audience of doctors or nursing home administrators, you would think you are on two different planets. I'm serious about it. It's a very, very big problem but it doesn't have to be approached only in an adversarial way. If you're going to come on in terms of taking up the cudgels--which I think have to be taken up in a very creative, very innovative way of bridge-building--the response you will get will be every kind of legal action that's going to delay the kind of things that could be achieved much sooner. I think that what should pervade this Symposium is what innovative approaches we might use to get to the many physicians and other health providers and maybe even a few nursing home administrators who want to get out of the attitudes in which they've been so ensconced. I think that what we have to have is a whole new perspective on how we look at health. Instead of looking for good guys and bad guys, we may have to speak more about attitudes, beliefs and institutions.

MODERATOR: I've seldom seen such competition for the last question in the day.

AUDIENCE QUESTIONER: I have a specific question for Mr. Thrasher. I'm Marjorie Guthrie from the Committee to Combat Huntington's Disease. We have patients who are refused the right to be a patient. For instance, in the Veterans Administration, we have patients who have been refused admittance to Veterans Hospitals supposedly because there are no beds. I want to ask you, do you think that's a possible subject for the Department of Justice?

MR. THRASHER: Given the recent history of the Department of Justice, anything is possible. I'm not sure I understand when you say "a right to become a patient." I presume what you're talking about is a veteran who has some statutory right to medical care because he was a veteran. I don't know if it's a matter for the Department of Justice. You see, the Department of Justice is a litigating agency. The Veterans Administration is the United States. The Justice Department is the United

States. You can't very well, in civil litigation, have the United States suing the United States.

However, we often do receive complaints about various Federal facilities and we have received complaints about several Veterans Hospitals around the country and our practice has been to refer such matters to the VA after we do an investigation. If the allegation sounds like it's a criminal violation--for example, a charge against police for police brutality--if there are such things which occur in Veterans Hospitals, the Civil Rights Division would have jurisdiction to investigate and if the facts warranted, to criminally prosecute. If it appears only to be a civil matter, not a criminal matter, we would refer the investigation to the Veterans Administration.

MODERATOR: I know a number of you have questions and you've just been frustrated because you haven't been able to bring them out. Be sure that you go on record in your workgroup on what's really hurting you and what you're concerned about.

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IMPLEMENTATION OF PATIENTS' RIGHTS

Theodore Cooper

We are here to talk about patients' rights. But the fact that there is a necessity to hold a meeting such as this raises two issues. The first, I suspect, is that a meeting like this is a tribute to the health care system. It is a tribute to all the health professionals who have developed the ability to diagnose illness and prevent disease in ways that people a few years ago would have considered impossible. At the same time, it is an indictment of the by-product of this progress which is usually categorized as the health care system's capacity to convey, at least to the patients, a sense of the lack of personal concern.

This is not a 1976 concern. It has been generating for several years, and a couple of years ago it resulted in a law which has in its preamble a proclamation that every citizen, essentially, should have access to quality care at reasonable cost. That idea can be translated into another kind of statement--that every citizen has a right to good medical care. To some people, good medical practice has come to mean specialization. To some, it means getting service when you want it, not necessarily when you need it. And to many it means being able to set aside any financial barrier as a consideration for the services sought. To some it means everyone should have access to the same care as everyone else.

The perception over several years now has been that people consider that good medicine goes beyond technical excellence in diagnosis or treatment. It should include the feeling of satisfaction, of knowing, of understanding and of being understood.

A lot of people, with some reservations, want to know what their medical complaints or condition mean. Those of us who work in the field should not ignore this aspect. People want to know how the health provider knows what he is going to do. What happens next? Is it going to hurt? How long does it take? And, really to a lesser extent, how much does it cost?

Some people are reluctant to ask these questions. They are often reluctant to ask because they are intimidated by the setting, by doctors, nurses, hospitals, the smell, the aura, by instruments and so forth. And in that reticence which is generated, a busy provider will often, by sheer lack of time or for the sake of efficiency or by lack of perception of what the patient's problem is, contribute to a gap in communication.

Poor communication contributes in that way to what is called the mystique of medicine. The dehumanization of medicine. From such a beginning, the patient can well enter into an experience which leaves him dissatisfied with the total experience even if the clinical outcome was technically satisfactory. The capability for insensitivity exists in our system, and as we employ more machines, more drugs, and yes, more people as well, the potential for greater insensitivity increases. Medicine has in the last 20 years unfolded a great deal of science and technology. This has generated a new language. The practitioners tend to lose the ability to talk to patients about diseases in so-called lay terms and this often gets interpreted as "they don't understand" or "they can't understand," or indeed "they don't need to understand."

We must take time as health professionals to remind ourselves that patients are people, that they can understand, but more than that they want to understand. I would like to be sure that not only do they want to understand but they want to participate, and they want to be responsible for what they are supposed to be responsible for as well. One reason why the physician and other health professionals slip into poor communication, in my opinion, is that the patient comes to expect too much from the provider. Now, it is true that the provider has made this kind of dependency easy in many respects. The media has made this kind of dependency easy and the academic establishment has made this kind of dependency easy. It is also true that the people have abrogated their responsibility not only to participate in the decisions of how local and national systems should run, but even as to what they can and should do for themselves--for their own health care. They have come to believe that it is their right to have everything cured by the doctor or taken care of in the hospital. Participation in that way is destructive.

There are many Federal programs in which statements have been developed about what patients should have and should not have. We can write regulations saying that patients' rights and protections and such things are required for reimbursement or for some sort of certification. To some extent such prodding is helpful--I think it is useful as an awareness tool, to remind us of what we are supposed to be doing--but it cannot substitute for concern for human attention and for understanding.

It was necessary to have a National Commission mandated by Congress at a cost of several million dollars to study human experimentation. Why? Are our scientists so lacking in human values that they go off and do goulish things? I don't think so.

It has been necessary for the American Hospital Association to develop and promulgate a bill of rights for patients. Why should this be? Are the administrators or the staffs or the boards of hospitals composed of people who themselves do not get sick and therefore do not have to suffer the same thing--this dehumanized treatment we talk about? I don't think so.

Is it necessary for the Department to have a bill of rights for patients in nursing homes? Are people who take care of the elderly and disabled particularly callous? Again, I don't think so.

I believe that medicine is a part and parcel of the fabric of society, not a thing apart. It is a particularly human part and more is and should be expected from the medical profession with respect to leadership in performing in ways that are consistent with our values of human dignity and human kindness.

As we reaffirm our commitment to a humanistic form of medicine, we need to make sure that we look at ourselves as a society for all the answers. We have to look at ourselves and see what we are doing to create an atmosphere in which we are developing people who seem to be vulnerable to the loss of these values. We cannot make the health system the only scapegoat for a troubled society. But we need to be more specific--and that's not a cop-out for what the health professionals themselves need to do as participants--about what is the real requirement for what patients need most?

As I go around the country and talk to people in all different settings, the thing that patients complain about most is time. They do not seem to be able to get anyone's time, to make a meaningful communication with what is going on. Good medicine requires time to establish meaningful communication. The other thing they want most is information. I believe that the capacity of our public for learning is great and their curiosity, like in all of us, is great. There is rarely any reason not to tell someone what is known or not known about himself and his condition. I support the idea of disclosure in that regard.

The third thing the patient wants or what at least they feel is lacking in our current activity is not technological answers but attention, concern. It is my perception that the American public still wants attention as well as technology, and love as well as liberty.

The Federal government has recognized the desire and right of the public to participate in health policy decisions which affect them. Not everybody would agree that we have recognized it to the extent that it should be. Nearly all our advisory committees now meet in public and now provide advance information about the agenda and time on the agenda for public input.

We have established a Freedom of Information program...I don't take credit for the idea and I suspect it was the public and the Congress that mandated our requirement to do this--but the fact is that it is being done...which gives the public legal access to information which in the past was denied them or was very difficult for them to get. We have decentralized dozens of programs, placing our decision-making power with regional officials who are closer to the needs and desires of people at the grassroots. This is often in contravention to the wishes of our program administrators here in Washington. As I talk to several of our program leaders, they assure me how difficult program administration is--how less efficient it is--when it is decentralized. But one of the great functions of government is not to focus only on efficiency but on service to the people. I am willing for decentralization--for participation in the decision-making process--to be a fact of our programs, even at the cost of efficiency.

Secretary Mathews is making a concerted effort as Departmental policy to simplify the regulations process, to make it more comprehensible, and to ensure that input from the public can be had at an early stage in the regulations development process.

There are other things, but they cannot substitute for an attitude and behavioral change about who the patient is and how the provider deals with him. From what we can do we shall accept our responsibility to participate. We recognize the great power which the Federal government has over the care of people, and we are attempting to use that capability with an increasing degree of sensitivity and compassion.

I believe that if we in government, and you who are providers of care and consumers of care, acknowledge this basic right of the individual citizen to participate, and if we grant it without reservation, then the people will be more likely to respond as active participants to regain the ability to have confidence not only in each other but in their government. Then they will have the confidence and the courage to take the responsibility in medical care, and they will be more active in maintaining personal health, and will accept and exercise the responsibility for all those areas that a right implies. It is fine to talk about patients' rights, but the patient has to recognize that when he has the right, he has to be responsible also. The two--patient rights and patient responsibility--go together. You can't have one without the other.

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CONSTRAINTS AND LIMITATIONS
IN IMPLEMENTING PATIENTS' RIGHTS

Planning and Regulatory Processes - Leonard Bachman

It's very pleasant to be here this evening, at an event of this importance.

The question of patients' rights is a fascinating one for me. I've had an idealized romantic notion of my profession for the 24 years I've practiced it. That we can really, seriously, believe today that we do have such a need for patients' rights, and we do, is a kind of tremendously shocking thing to me personally. When I think of the medical profession and the health profession generally, I can remember a picture that was very popular around doctors' offices at the time I was a little boy. I saw this described recently and I remembered the picture so vividly. It was called, I think, "The Crisis," and there's a young girl, lying on a bed, with the doctor sitting on a chair beside her, watching. She is obviously flushed and going through a crisis, probably pneumonia. The parents are in the background, and the whole focus of the picture is this very distinguished old physician sitting there watching that child, full of compassion and concern and, of course, completely powerless to do anything about the situation except to be concerned. In fact, before about 50 or 75 years ago, the medical profession really did not cure anyone and what we call the non-curing activities were the key aspects of the medical profession. I believe the non-curing aspects of the medical profession have been described by a number of people. They are compassion, caring, and concern, some of the things that Secretary Cooper talked about a few minutes ago. I think that the fact that we need to have such a meeting as this, and the fact that I'm going to tell you in a few minutes some of the problems that a government agency has in guaranteeing patients' rights show how far we have gone in elimination of the non-curing functions and how far we've gone toward the industrialization of medicine and health.

I don't know whether we should or can reverse that trend, but the fact is that it is far along. We need constantly be reminded that the health system exists for only one purpose and that is to take care of the individual human being who is diseased or has pain or misery. If the system doesn't do this, then all of this vast structure need not exist at all. It seems silly that we have to continue to remind ourselves, and to have elaborate mechanisms to remind ourselves, of the health system's ultimate purpose but my experience of the last few years convinces me that we do.

The responsibility for ensuring patients' rights falls to a number of institutions in our society and we must be clear as to who is accountable and responsible for what, particularly we must be clear as to governmental responsibility. As I look at the system that we have, the main responsibility to protect the health of citizens, to promote the public health, and to assure citizens that the health services available to them meet standards is the States' responsibility under the reserve clause of the Constitution. The Federal entrance into this area, as commendable as it is, has been in a very indirect fashion, usually through their control of certain funding mechanisms, and these attempts have been rather tortured and convoluted. I applaud the Federal concern and attention but those techniques have been a constraint because there is a tremendous confusion about who's accountable. This confusion and inability to assign a role to different branches of government confuses the consumer and provider publics and acts as a strong constraint against actually realizing rights for people.

The second constraint that government agencies or regulatory agencies have in guaranteeing rights is that although now we are at least giving lip service to these rights by including them in our State and Federal regulations, they frequently exist only as empty letters because we do not have the resources to enforce these regulations. Government agencies need the proper monetary and staff resources to carry out these programs in patients' rights effectively. A related problem is that we do not know the proper programs, methods, and techniques to insure patients' rights. I spent most of the morning today on a budget hearing in my department to decide on our 1977 budget and that hearing was in the Office of Quality Assurance. We were trying to decide what we should seek in the way of new resources, and we got into a very interesting argument as to whether we should invest more money in personal complaint investigators or inspectors. One of the things that we have found, for example, is that individuals who inspect institutions and see that an institution lives up to certain written regulations do not have the experience and the point of view to deal with personal complaint investigations very well. We have to decide what would better serve the public; to invest more resources in complaint investigators or more resources in inspectors and I didn't have any really good way of making that decision at this time, with the data and information now available. So there is a tremendous amount that we don't know about the state of the art. Even with a real commitment to patients' rights and even if we have a modicum of resources, how to best use the resources to ensure patients' rights still must be decided.

Now, one of the sad and final things that I am going to say about the constraints, one that is saddening to me, is the attitude of the provider element in this heavily industrialized health system. The health industry perceives that any attempts on the part of government agencies or other advocates to improve patients' rights are in some way, somehow, at the cost of the rights of the providers. The providers, hospitals, physicians, etc., look upon this drive for patients' rights in an adversary situation. It is very saddening considering the romantic view of the profession that I hold myself. But it is a fact of life that one of the strongest constraints I had in Pennsylvania against the drive to improve patients' rights has been the providers of health care who have very effectively blocked legislation, regulation, and resources, and have put on an extremely effective campaign against patients' rights.

They do this as an institution. Although the individuals involved may be concerned about patients' rights, they are responding to their institutional needs. They are a tremendously strong force against patients' rights and represent, unfortunately, the largest constraint we face today.

Now, I have mentioned some of the problems. I hope at some of the discussions throughout the conference we can talk about how to reduce some of these constraints so we can more effectively guarantee patients' rights in the health field.

Consumers' Responsibilities and Involvement - Joan Claybrook

Public Citizen is an organization founded by Ralph Nader to represent consumer interests in governmental and corporate decision-making. Congress Watch is a part of Public Citizen. It is a public interest lobby group. We work on Capitol Hill on energy and consumer legislation.

My interest tonight is not exactly represented by the title of the speech. I think that the most important thing to say, from the consumer's point of view, is that a right without an instrument is no right at all. This is very important. Dr. Cooper said, "What is the responsibility of the patient of health care services?" We have to remember that in most cases patients are not in the emotional or physical condition necessary to assert their rights and thereby assume responsibility for determining their own course of treatment. Their incapacitation automatically places them in a position subservient to doctors and other health care personnel with whom they must deal. A systematic program for the recognition and assertion of patients' rights must be designed to accommodate this gap so that patients can even begin to assume their so-called "responsibility" in deciding their own medical destinies.

We have been involved in trying to design tools for citizens--for consumers--which will allow them to adequately protect their rights and to do so in an organized way so that they don't involve themselves in useless gestures. These tools must practically take into account the powerlessness of the individual consumer. One example of a consumer tool is the class action lawsuit. In the past few years the Supreme Court has ruled in several cases making it impossible for citizens to bring Federal class action lawsuits because they are not allowed to aggregate small claims. This means that if you are the user or purchaser of a product that is defective and you suffer a small amount of damage, it's not possible for you to file a lawsuit against the multinational corporation that manufactured that product. It's simply not worth the effort. If you could combine with a million other people or even 500 other people who purchased that product and join together in a lawsuit, you would at least have the chance--the means--to achieve a remedy. That is an example of a systematic tool which facilitates the assertion of a right and, in doing so, gives that right real meaning.

The same principle applies in the case of patients' rights. There <u>are</u> rights that exist today for patients. Some have been elaborated by the courts. Some have not. Patients have the right to control their bodies. They have the right to informed consent. They certainly have a right to choice of doctor, a right to privacy, a right of confidentiality. But the problem with these rights is that there has been no systematic effort made to help patients achieve these rights, patients who are ill and many times don't know who to rely on for advice.

I think another analogy is appropriate here. One of the grievance procedures that's been devised for consumers of products is small claims courts. These are courts that are easy to go in to. You don't need a lawyer. Your claim has to be relatively small, $500 or $1,000 or under, and while small claims courts haven't been used by consumers as they should have, there's been a recent increase in their use. They are an available mechanism for consumers of products to routinely go to when they want to recover damages for harm they have experienced.

The same kind of grievance procedure needs to be conceived for patients but exactly how to do this is a very complicated question. We've been working on a piece of legislation which hasn't seen the light of day because it is a very difficult one to draft. It would apply to all health care facilities which receive Federal funds. This is an angle which I think you have to use--it gives the legislation enforceability.

I differ with Assistant Secretary Cooper in saying that he's not sure of the next step that the Federal government could take. I think that any institution which receives Federal funds should create some kind of a grievance procedure. Obviously, if it's a complicated procedure, the patient is not going to be able to use it. Also, if it is complicated, the cost is going to be heavy and beyond the means of some facilities, so that a balance between effectiveness and practicality has to be struck. But I think that there clearly needs to be some kind of independent grievance procedure within health care facilities so that the very minimal rights of the American Hospital Association--they are probably no greater than the rights that any businessman would give to his customer, and I think that the patient deserves more than that--so that these rights can be elaborated and a mechanism provided which tells the patient exactly what to do if his or her rights are denied. I think also that patients ought to receive on entering into any health care facility an immediate statement of the rights of the patients, as well as instruments on how the patient can go about enforcing those rights.

Additionally, I think that there is another kind of tool that needs to be provided for patients. Without it, there's really no balance in power between the facility, the providers of health care, and the recipients. This tool is authority to use the courts of the United States. If there is a dispute between the recipient of health care and the provider of health care in a facility that's receiving Federal funds, both parties should have access to the Federal courts in deciding the dispute. This is a controversial proposal but I don't think it is an inappropriate one at all. The ultimate authority of the democracy is to have some objective review of disputes. This privilege should not be denied to cases involving patients rights.

A lawyer cannot place too much emphasis on legal enforcement procedures and on the review of the courts. If there is this kind of ultimate authority to objective review, then there's going to be the kind of respect given to patients that they deserve and should possess. The medical business, whether it's the doctors or the hospitals, respect power, they respect authority, and the only way they're going to respect patients is if the patients have some access to that authority.

Professional Vested Interests - John Alexander McMahon

At the outset, I should make it clear that I do not know what "professional vested interests" are. In a legal sense, a "vested interest" is a right, or a thing, or a property that can be sold or transferred. But a "professional vested interest" seems not to be a precise term but is rather possibly a term of opprobrium. At any rate, what I'm going to talk about are the constraints and limitations in implementing patients' rights from the provider point of view. And I mean "provider" in a very narrow sense, referring specifically to hospitals. I would like to describe how we got to where we are in the American Hospital Association.

The patients' rights issue, as seen by hospitals, has grown out of a recognition that with hospital growth and increasing sophistication of services and facilities, there has been a tendency toward depersonalization of care.

Where some have dismissed this trend toward sophistication and depersonalization as the price of progress, hospitals and the American Hospital Association have not. Our Patient's Bill of Rights was, and is, an indication of our industry-wide concern for reversing that trend. Moreover, it is only one of several indications of our concern for patients' rights, all of which grow out of the recognition that the world of health care delivery has changed.

I'd like to focus on three points this evening.

First, I'd like to tell you about our experience with implementation of the AHA Patient's Bill of Rights. Second, the reasons for nonimplementation, which is not the same thing as lack of concern for patients' rights. I don't think anyone who understands hospitals and doctors doesn't understand that they are concerned with only one interest--to take care of patients. And third, I'd like to tell you about some of our other programs, besides the Bill of Rights, which indicate a responsiveness to patients' concerns.

Let me first address the first point, the implementation of the AHA Bill of Rights.

It was approved by our House of Delegates, February 6, 1973, and was an attempt to identify and publicly state what a patient has a right to expect from the hospital, its physicians, its personnel, and others connected with the hospital. It is a device to say to hospitals, "Here is what we think you ought to be concentrating on."

It is certainly not a legal document, although certain items are consistent with generally accorded legal rights. It is a set of guidelines, a statement of principle if you like, for hospitals to follow in providing the quality of care their patients expect. We tried to state intentions and goals, recognizing that affirmative action is a hard thing to achieve.

Hospitals were free to adopt the Bill, endorse it, modify it, or use it in any way they deemed appropriate. The AHA does not have, and does not seek, any enforcement power over its member institutions.

Recently, we conducted a special survey asking hospitals what they thought about the Bill of Rights because we had gotten a good many questions and, in fact, criticisms, about it. We sent out a questionnaire, about 6,000 hospitals responded, and we are pleased with the positive results the responses revealed.

Eighty-six percent said their response to the Bill was positive. Fifty-six percent accepted the Bill in principle, but they had not specifically taken action to implement it. Some 30% responded that they had taken some specific action. Over 10% of the hospitals had posted the Bill in a central location. About 10% had made the Bill available to employees as a training device, to indicate how their employees should deal with patients. A substantial number made the Bill available to patients, as, for example, a reprint in patient admission booklets. Some hospitals adopted their own versions of the Bill.

Let me now address the second point, the problems of implementation.

There were, of course, some concerns about the document. Some hospitals felt the Bill was unnecessary because the hospital was already responsive to patients' rights. They felt the Bill would be interpreted as negating their past history. Some felt that implementation implied that they hadn't been doing enough, when in fact they had. According to the survey, the hospitals that took it most to heart were the larger hospitals, those with problems of growing sophistication, increased size, a large staff of some three or four employees to every patient, and so on. These were the hospitals most actively engaged in implementation. The smaller hospitals, those with less of a problem, were less inclined to formally implement the Bill.

In addition, one of the roadblocks to implementation of the Bill of Rights was legal interpretation. Some questioned its enforceability. Some were concerned that adoption would be misconstrued as meaning the Bill was a legally binding document.

Three of the rights in particular raised problems. Real questions were asked about what the "right to informed consent" really meant. One can have informed consent if he buys a radio or an automobile, but can he have it if his wife or child is sick, and he himself is worried, distraught, fearful, and so on. Can he really be informed in that situation?

There were questions about the meaning of the "right to refuse treatment," particularly, again, in a situation where the mental state of a patient presents grave problems of dealing with him on a reasonable basis.

Regarding the right to "a reasonable response to requests for care," there were ethical considerations for some of our institutions.

It was the opinion of many hospitals that these three rights, 1) were ambiguous, and 2) could not be assured by the hospital alone.

Let me come to my third point--what hospitals are doing in other areas.

Implementation of patients' rights goes beyond the adoption of a bill of rights. That statement we call a "bill" is only a document and a set of guidelines. Hospitals, some which adopted the Bill and some which didn't, are implementing patients' rights through a number of similar programs.

For example, there is a growing development of patient representation programs. After developing the Bill of Rights, we founded under the AHA umbrella a Society for Patient Representatives, in order to provide those people with some further discussion of patient problems of all kinds. The Society now has a membership of 500 persons actively working in hospitals as patient representatives. Over 1,400 hospitals have indicated to us that they have established patient representation programs in departments of social service, and some elsewhere in the administrative structure. Nearly half the community hospitals in the country (2,742) have social work departments which include among their responsibilities patients' rights issues. That number has been growing every year.

Developing hospital medical staff sensitivity to patients' rights is one of the objectives of our malpractice prevention program for hospitals. I'm very much concerned about the malpractice aspect, because I'm convinced that some of our malpractice problems stem from lack of communication between patients and patients' physicians, as Dr. Cooper illustrated so well.

I've tried to show you our experience with the AHA Patient's Bill of Rights and to point out some of the issues surrounding it. But more than that, I hope I've made it clear that as important as a bill of rights per se may be, it is the follow-up programs, and the spirit with which those programs are followed up, that determine whether implementation will be effective.

Hospitals, I believe, have been acutely aware of the patients' rights issue in recent years, and by their actions have shown a determination to solve the problems that still exist.

OPEN DISCUSSION - QUESTIONS AND ANSWERS

AUDIENCE QUESTIONER: I have a slightly unfair question for Mr. McMahon. You gave us the impression that there was probably very little the AHA could do to implement the AHA Bill of Rights as it stands now. Is there more that could be done in the nature of workshops or this kind of thing?

The second part of the question is the unfair part. What do you personally think is wrong with the guidelines as they stand in the Patient's Bill of Rights? Is there more that could be written in? Could it be written differently to improve the document?

MR. McMAHON: The first part of your question is, what can we do to implement it? What I said was, we couldn't enforce it. We're doing everything we can to encourage its appropriate use through workshops, through the development of the Society for Patient Representatives, and in other ways.

What would we like to do to improve the Patient's Bill of Rights itself and what do I think ought to be done? I don't know. We did the best job that we knew how to, and I assure you, it is not a provider protection document of any kind. All you need do is read it and note that we addressed ourselves to all of the things we could think of. There was a substantial amount of nonhospital-person activity in the development of it. It grew out of what we call the Committee on Health Care for the Disadvantaged, which is consumer dominated, of people not in the business of providing health care.

I frankly do not understand the attacks that are made on it. It is said that it lacks specifics, lacks specificity. I agree with that. Read the

Bill of Rights in the Constitution of the United States and you will understand how to get specific. You get specific by negatives, you prohibit things. For example, the Bill of Rights prohibited legislation abridging freedom of speech. It didn't guarantee equality of speech because we know that is absurd...it's never going to happen. But we certainly can and have lived up to a prohibition against legislation abridging freedom of speech. Now, we could have written the AHA Bill in negative terms but we thought of it more as a spiritual document that deals with the kinds of problems that we know about. I wouldn't for a minute say that we dealt with all of the possible problems.

SAME QUESTIONER: Would you feel that permitting a patient access to his medical records is a reasonable request?

MR. McMAHON: Yes, except that if you ever looked at a medical record, you would know that it needs a good deal of explanation to be understandable. In terms of information, it seems to me that what the patient has a right to receive from his physician is information necessary to give informed consent to his treatment. If you grant that the medical record generally needs some interpretation and many of the problems grow out of this, we speak more in terms of explanation to the patient of his condition, of the treatment planned for him, the implication of the treatment, informed consent to the treatment, and so on, thinking that is much better than an involved statement about access to a record that was not designed for his use in the first place.

MS. CLAYBROOK: I think a very serious, crucial question has just been answered and one which shouldn't be dismissed. The only way that citizens are ever going to be able to have any kind of oversight of, or make an evaluation of, a health care facility is if they're able to make some evaluations from the records in their own cases. The common defense to non-disclosure is the records will be misinterpreted. I think that's a right the individual has--to make a mistake--although he can always ask a doctor for an explanation of it. But I don't think that argument is a defense of non-disclosure of information that a patient has a right to have.

DR. BACHMAN: I thought that patients have legal rights to their own records, but I'm not a lawyer. Do they have that right?

SAME QUESTIONER: No.

DR. BACHMAN: Do you mean to tell me that (a patient's) lawyers can't ....

SAME QUESTIONER: True, in most jurisdictions a patient has rights, by introducing a suit, but usually it is only through a lawyer which for practical reasons is very expensive.

AUDIENCE QUESTIONER: I'm extremely disturbed about this. We have done a national survey of State regulations regarding the preservation of hospital medical records and we find that almost every State in the country is reducing the time it requires hospitals to preserve patients' medical records. I can see absolutely no value to the patient or to the continuity of care by allowing these records to be destroyed.

I would like to see the American Hospital Association (I realize it would be a hot issue) suggest to hospitals that they microfilm the records at the end of the patient's stay and send the records home with the patient. This is done in many hospitals now. At the University of Vermont they have been giving the patient complete access to his hospital medical records and have had no difficulties. It's done with obstetric patients and several others.

In some States, I think Delaware is one, they keep the records only two years. How can anyone pretend that's good for the patient?

DR. BACHMAN: Two years seems awfully short.

AUDIENCE COMMENT: Even 10 years is short.

DR. BACHMAN: I don't know what our regulations are specifically on that, but I know that many of our hospitals keep the records continuously--all of their records. I know several hospitals that I've been associated with have every record of every patient that ever came into the hospital, going back to 1855, in one case. Microfilming has been done but it is expensive. How many hospitals can afford it?

MR. McMAHON: As for microfilming and preservation, some time back we addressed ourselves to the question of the length of time records should be preserved. I'm sure it wasn't two--I don't think it was even 10--years. I think it was longer than that, especially in cases where there was continuous treatment. My recollection is that we addressed ourselves to the issue, with the thought uppermost in mind that if a hospital hadn't seen a patient for a substantial number of years--I think it was more than 10--then it was appropriate from the cost point of view, cost of space and cost of microfilming, to get rid of the record. Discussion was addressed more to the length of time than to the appropriateness of maintaining records. Discussion started with the premise that the records ought to be kept, rather than how quickly can you get rid of them.

AUDIENCE COMMENT: We say, give them to the patient.

AUDIENCE QUESTIONER: Is there a Federal regulation or Joint Commission regulation on the length of time records must be kept?

MODERATOR: I think we should get off the question of how long you keep a record. The point is, who keeps it? Can't the patient be the repository of the record to keep in his health jacket? I think that is the issue here.

AUDIENCE QUESTIONER: I am Ann Cohen, from the South Brooklyn Health Center. Mr. McMahon made a very important point. Members of the American Hospital Association are considering training programs for staff. I, as a consumer, hope that there will be consumer input in designing such programs, as we know where the sensitive areas are. Considered as staff, perhaps, should be the man who sweeps, the nurse, the aide, the administrator, the doctor. Nobody too high or too low to be included. We will then perhaps make a beginning.

So, will you tell exactly what AHA is planning in this area?

MR. McMAHON: I agree with you completely. All should be included. This is the kind of advice we welcome. Clearly, from the hospital's view, we don't see all the problems. Therefore, training programs ought to have contributions from the people that are affected, as well as those in the institution.

AUDIENCE QUESTIONER: This is a question to Ms. Claybrook about the bill which I guess is not out of committee yet. What kinds of procedures are you thinking of (damages, etc.)? What are the constitutional problems? In simple language, what kinds of sanctions might be applied? Would it be patients against individuals or, in some way, against the institution?

MS. CLAYBROOK: I think the right of the patient ought to be against individuals in the hospital, as well as the institution itself. Secondly, I think there ought to be a variety of remedies because the variety of harm is so great. You want a remedy that fits the harm to try to match the two.

AUDIENCE COMMENT: I am Dorothy Evans of the South Brooklyn Health Center. I think instead of fighting, we should institute some really good community relations practices and try to educate consumers. You don't gain anything by fighting.

The other thing I want to say is--we have great numbers of students who periodically get transcripts on the kind of work they are doing. Perhaps we can adopt this idea. These transcripts don't cost very much money to develop. Maybe a patient's record could be a transcript. Perhaps that's one of the answers. I think a transcript would be easier to keep track of than the "medical libraries" I've seen.

AUDIENCE QUESTIONER: We pay for health care, and part of the cost of health care is medical records. I wonder if payment could be refused: if one pays for something, one has a right to receive it. This might be a useful tool in terms of getting some kinds of information.

MS. CLAYBROOK: Sounds like a good idea.

Maybe what we ought to do is, before a patient goes into a hospital, there should be a contract between the hospital and patient. That contract ought to elaborate the patient's rights and the hospital's obligations, and the medical records should be part of the contract.

I would like to make one other comment on the concept of evaluation of hospitals and evaluating personnel. One of the things that Dr. Sidney Wolfe of the Health Research Group is trying to do is develop a directory for evaluation of dentists, another one for doctors. It has become tremendously controversial because doctors, dentists and others don't like to be evaluated by the consumer. They assume he is not competent to do that kind of evaluation. This is another aspect of patients' rights that shouldn't be ignored. It is an obligation of consumer health care to do these kinds of evaluations, though it is very difficult.

MODERATOR: Does anyone else want to comment on this idea of a contract?

DR. BACHMAN: I'll just say this. I personally believe that the medical record is something that belongs to a patient. He pays for it and he ought to receive it. I was enlightened today to find out he didn't have a right to it--he had to get a lawyer.

The comment I would like to make--the type of thing that has concerned me for the four to five years that I have been involved in this--is that the industrialization of medicine, especially the industrialization of medicine in a free enterprise society like ours, has engendered a kind of adversary situation between the providers of health care and the consumers. I think that this has necessitated the need for the kind of referee and kind of legal process we're talking about. The increase in malpractice suits, the setting up of grievance committees, are moving us even further toward an adversary stance between the provider and the consumer. I don't know when this particular thing can be stopped or whether it can be stopped, nor whether this industrialization has gone too far. But I think the trend is irreversible. It is a pity. I'm personally very pessimistic.

AUDIENCE QUESTIONER: I'm Beverly McGoin from Candlelighters, which is parents of children with cancer. I have a question for Dr. Bachman. How can patients organize around specific problems or deal with specific issues, when their doctors will not get them together? Patients have very little chance to know each other or get lists of patients in an area concerned with this problem. For example, in your State of Pennsylvania, in the Reading area, children with cancer go to several institutions, most of them out of the area, in Philadelphia, New York, or down here to NIH. They go to many different places. But they would like to try to organize and get together to talk about their common problems, to give each other psychological support or emotional support. But the doctors in the Reading area will not get the patients together.

DR. BACHMAN: I would say--if you want to get together, why do you depend on the doctors? The patients are going to lots of different doctors. Why the patients can't get together is beyond me. They could go to the newspapers, radio and TV to get people together.

In fact, there is one example of a very militant patients' rights group right in Reading. That is the kidney-dialysis people. There are 25 people in the Reading area who are on dialysis and have the strongest patients' group I've ever come across. It's a very strong group and they didn't have any doctors get them together.

MS. McGOIN: That's because they were together in one area. In this case, it's the frontline pediatricians or GP's who originally diagnosed the kids, who know who the kids and parents are. But the parents don't know each other, because they go to different places.

AUDIENCE COMMENT: In my organization, the Committee to Combat Huntington's Disease, a disease which requires great confidentiality, it was the doctors who helped us organize. In our instance, we could not ask the doctors who the patients were--we had no right to ask. What we did do was ask the doctors if they would give out our literature, to give those families an opportunity to meet with us. We have done this all across the country, and with the help of doctors, we were able to reach the families and they were able to get together.

MR. McMAHON: You've made this point much better than I could have, including the point about confidentiality. I think if you go about it the right way, you find a way to solve a problem by cooperation, because everybody understands how group support can help.

MS. McGOIN: Most of the people do, but there have been some doctors in some parts of the country who don't and won't! It's up to the parents to get together.

MODERATOR: There are three more questioners or commenters at the mike. We'll say that they must be the cutoff point for the evening, because we have been working almost 12 hours.

AUDIENCE COMMENT: I wrote a letter that has been extremely effective in getting people's medical records for them, and I would like to share it with you. The first letter is a friendly letter telling why you want the records, the second is a more threatening letter. It has never failed to work and I will be glad to supply copies.

The other thing I would like to say is that the doctors should be alerted to the fact that if they have personal opinions on a patient, they should put them on a colored sheet of paper that will not be part of the patient's record. The doctor can say nasty things about a patient--that's his privilege--but that's no excuse not to give a patient his record. I've heard this over and over again--you can't let the patient know I called her a hypochondriac, and that sort of thing.

Another thing, I called a hospital and asked how much it would cost to get a patient's records. I was told, "If you're not a doctor, it's a dollar a sheet; but if you're a physician, it's 10¢ a sheet." Why the discrepancy, I asked. The answer, "We consider if we give copies of the patient's record to a doctor, it adds to the continuity of the care." I contend it would add to the continuity of the care if the patient had a copy of his own medical records. There is no justification for charging 10 times as much to the patient.

The last thing I would like to say is that the hospital board of trustees of any hospital receiving Federal funds should have one-half of its board of trustees, women.

AUDIENCE QUESTIONER: I would like to ask a certain question--the American Hospital Association has a committee of accreditation. Is that correct?

MODERATOR: No.

SAME QUESTIONER: Well, who accredits hospitals?

MODERATOR: The Joint Commission on Accreditation.

SAME QUESTIONER: In terms of its standards, the Commission has until recently been concerned with fire exits, sanitation, how often things are washed. It has been, from what I gather, an auditing performance. Now, it appears to me that if we find it important for the quality of care to implement the Patient's Bill of Rights, why would that not become a criterion for accreditation of a hospital?

MR. McMAHON: Because of its nonenforceability, because it's a document of spirit, a document of guidelines, rather than a clear standard that is easily interpreted.

SAME QUESTIONER: One could not say how it could be enforced, but why couldn't one state that a bill of rights should be given to the patient, posted, or implemented by having patients' representatives as part of the standards of accreditation? I, as a physician, think that a patients' representative is as important to quality medical care as a proper fire exit.

SAME QUESTIONER: Another question refers to the right to receive certain information. Many in this room may be aware of the fact that there was a hospital near Boston in which the mortality of open-heart surgery was 50%. It led to the fact that the next chairman of the American College of Cardiology did not assume that position because of the fact that embarrassing questions were raised--and raised by the Boston Globe because the information was given only through a cardiac catheterization technician.

Patients are very concerned with outcome data. Doctors and possibly the American Hospital Association are concerned with process data. In other words, peer review is only process review. If you do the right things to work up the patient, the operation may be a success though the patient died. This illustrates what patients are concerned about. Process is not so important (to them) as outcome. There is data, I presume, that the government has, city governments have, and State departments have, on which hospitals have a higher degree of infection, which hospitals have certain mortality and morbidity (rates). Why cannot this data be accumulated, as to which hospital has more staph infections and which hospital has less? Why is this not public information? If the government knows it, and the city and State departments of health know it, I consider it a travesty that the information is being withheld from patients.

DR. BACHMAN: You've hit on an extremely important problem.

We deal with 300 hospitals in Pennsylvania. We have a data committee that each year works with them and tries to get rid of their opposition to our collecting information. As a qualification for certification or licensure, we have these report forms for them to report information to us about what happens in the hospital. They're very jealous of this information and fight this every step of the way. To get the simplest kind of information, and I would say the Hospital Association of Pennsylvania is a fine organization, probably one of the finest in the country, I have to tease and cajole to get them to approve the most simple piece of reporting. And when one of the members of my staff may send out a questionnaire to one of the hospitals in the State, and for some reason, didn't talk to them first, zoom, the very next day a newsletter goes out to all the hospitals saying, "The State Department of Health has asked you to report XYZ and didn't get our permission, and we don't endorse their request for this information, etc., etc."

Now, it is true that we probably have a legal right to ask for a lot of the information we are talking about, and it is true that more and more the government and we in Pennsylvania are going to ask for that information so that we can give it to the public. But believe me, you have to understand the power of 300 hospitals to send off letters to the legislature stating, "The Department of Health is at it again, those bureaucrats are at it again, trying to get information from us, taking up vital time." (But) you're quite right, we must continue the battle to get that information. It's a key to quality decisions.

AUDIENCE QUESTIONER: My name is Kathleen Ittig of the National Center for Health Services Research. I'd like to address my question to Joan Claybrook. My question bounces off a study I did last year in New York. I wonder why you are talking about a new model (for implementing patients' rights) when you could be using the Small Claims Court model which was used quite a bit by low-income and minority members because it has been used against them and so they have turned it around to use in the opposite direction. Particularly since physicians use the Small Claims Court to get their bills paid, I would think that low-income consumers particularly would be familiar with that system. I am wondering whether you thought of that in designing your own consumer redress ....

MS. CLAYBROOK: I didn't mean to suggest that Small Claims Courts couldn't be used. Rather, I was addressing myself to design of a grievance procedure within each health care facility, so that once a patient enters a health care facility, he would be given a list of his rights. He would have an individual not hired by the hospital whom he could go to for adjustment of any grievances for immediate consideration.

AUDIENCE QUESTIONER: I am the Consumer Counsel at the Columbia Medical Center. I would like to talk about patients' records. I think it's a very rare consumer who could read and understand the hospital record if he got it. Hospital records are put together in medical terms, etc., and there are very few patients able to follow them. I think they could follow and have a need for a comprehensive synopsis in lay language which they could understand and pass along to the next physician, if necessary.

MR. McMAHON: I agree with you precisely and that's exactly what we try to say in the Patient's Bill of Rights.

COMMENT: What I would like to propose is that the patients be given the complete records along with the summary so they have everything.

AUDIENCE QUESTIONER: I am Allan Forman of the Bureau of Quality Assurance in HEW. Dr. Bachman, you referred to the inspection process and how to enforce Federal regulations and State licensure laws. Do you have any thoughts on the appropriate role of citizens, the potential consumers of hospital and nursing care--in the process of inspecting facilities and implementing standards?

DR. BACHMAN: There is a place for consumers in this process. In Pennsylvania, we are working on trying to figure out what that place is. There are some unanswered questions. Most importantly, consumers, by their complaints, can alert the inspector as to what to look at. After all, we have only so many inspectors. They don't know what to concentrate on in a given institution. I can give you examples of where consumer complaints have directed us to make inspection in a certain way. Some consumer advocates have talked about making inspections with the inspector. I'm not sure how you qualify a person to do this, nor whether there is any legal right for this.

Of course, the results of inspection must be available to the public. The biggest problem I find, though, is the way the inspector and the inspection force suddenly become identified with the hospital. After they make their inspection and give out their results, they have a vested interest in the results. I don't know how to overcome this, except to have some other level review the first. In other words, the reviewer needs to be reviewed.

AUDIENCE COMMENT: Perhaps you could inaugurate a program such as one recently developed for utilities, using a voluntary checkoff and donation system. This would require hospitals to give patients a checkoff form on which to record their comments and to contribute $1 to support an ombudsman.

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CONCURRENT WORKSHOPS ON ASPECTS OF IMPLEMENTING PATIENTS' RIGHTS IN HEALTH CARE

Patient/Consumer Education
Leader: Keith Sehnert
Resource: Annie Phillips
Joan Hartwell

Professional/Patient Relationships
Leader: Bernice C. Harper
Resource: Marvin Belsky
Allan Forman

Subsidizing and Organizing Patient/Consumer Input
Leader: Danny K. Davis
Resource: Art Thomas

Access to and Use of Information
Leader: Alice G. Gosfield
Resource: Theodore O. Cron
Rachelle Hollander

Mechanisms for Implementation (Regulations, Policies, etc.)
Leader: Claire Ryder
Resource: Frances O. Kelsey

Techniques of Direct Program Implementation: Changing Attitudes
Leader: Muriel Shurr
Resource: Eleanor Friedenberg

Techniques of Direct Program Implementation: Advocacy and Enforcement
Leader: Cernoria D. Johnson
Resource: Sidney S. Robbins
Alvira Brands
Sharon Barrett

WORKSHOP REPORTS

MRS. KNEE: In respect to the following workshop reports, we have had to give the workshop leaders some rather strict time constraints in order to keep within the time available for this summary session. This has been a very productive group of symposium participants; all that has been said cannot be distilled into the brief reports for which we have time. The workshop leaders, therefore, will try to highlight the essential contributions from their groups.

Now, we shall have reports from each workshop.

Patient/Consumer Education - Reporter: Keith Sehnert

First of all, we felt that statements had to be made to clarify what is meant by consumer health education/patient education.

It was agreed in our deliberations that patient education is mainly sickness-oriented and consumer health education, wellness-oriented.

With this in mind, we created what we call a Declaration of Patient/Consumer Responsibilities. In the area of consumer health, these are:

1. Learn to recognize state of wellness through an understanding of physical, mental and environmental systems that affect individuals (such as housing, economics, food, stress, and so on).

2. Understand traditional and non-traditional health practices that foster wellness throughout the entire life.

3. Recognize the need to participate in activities that lead to wellness (such as learning self-care practices and medical self-help skills).

4. Understand health care system and resources.

5. Study the consumer activism movement.

In the area of patient education, the areas of responsibility are:

1. Participation in the decision-making process regarding treatments (such as alternatives, risks and consequences; right of consent and refusal of treatment; appropriateness of treatment).

2. Increased knowledge of appropriate medications both over the counter and prescription.

3. Increased knowledge of health care system, resources and their limitations.

4. Increased understanding of quality of health care resources (including manpower organizations, etc.).

We then reached areas of three recommendations:

1. Establishment of an advisory council on the level of the 10 HEW regional offices and an advisory council at the level of the Assistant Secretary for Health. The purpose of these advisory councils will be to encourage _all_ Federal agencies to have representation of 51% of consumer voters on Federal agency councils; that is, the National Institutes of Health, Health Services Administration, Health Resources Administration, Veterans Administration, Food and Drug Administration, and so on.

2. Seek all possible ways to get greater visibility for the Bureau of Health Education of the Center for Disease Control. We feel that its visibility now and the priority in Atlanta is rather low. We encourage a higher visibility, and propose that there should be a White House conference on consumer health and patient education at the earliest possible date.

3. We believe that an up-to-date directory/information bank should be established listing who is doing what, when and where in consumer health and patient education around the country.

Professional/Patient Relationships - Reporter: Allan Forman

Our group was given the responsibility for defining patient/professional relationships* and how these relationships might be better managed for the benefit of both parties.

The group recognized that the patient/professional relationship is usually characterized by ambivalence, unrealistic or unattained

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*In the popular view of the patient/professional relationship, the professional is a physician. It should be noted that our group viewed the professional more broadly; i.e., to include all those who provide patient care.

expectations, unrealistic images of the other person, unequal distribution of knowledge (seen on the part of the consumer as "power"), and a lack of a clear definition of responsibilities. Obviously, this is a relationship from which both individuals can benefit if both are made aware of their proper roles, or realistic, attainable expections, and of responsibilities, obligations and accountability. The ever-increasing tendency toward a polarization must be redirected toward mutual cooperation and trust. The key to solving these problems lies in education and advocacy, and these are the areas on which we focused. Our overlap into areas assigned to other work groups was unavoidable because these areas are an integral part of the patient/professional relationship.

The first recommendation toward creating this reciprocal relationship would be to establish an agreement of "rightful expectations" between every patient and health care professional. That is, when they enter into a relationship, there should be established an agreement on the plan for patient care which indicates what the individual patient and the professional agree to do to reach the mutual goal of health care. Such an agreement will give proper, healthful definition to the role (expectations and responsibilities) of each party, thus alleviating much of the adversity.

This agreement should include provisions for ongoing assessment; for example: (1) periodic, scheduled patient/professional feedback conferences; (2) consumer-developed rating scales based on outcomes achievement; (3) patient comment cards; (4) questionnaires that patients might fill out on their third-party reimbursement forms, indicating their ratings of the services received.

It was also pointed out that it would be necessary in some cases to have family or significant others involved in the development and assessment of such an agreement.

The second approach would be to bring about a much-needed change in attitudes of professionals, to increase their sensitivity, motivation and awareness of the patient as a person--to make each professional an advocate for the patient. This could be accomplished through a program of basic and <u>continuing</u> education.

Some of the problems related to the education of health professionals are: (1) professionals are often taught to be "with" the system rather than "for" the patient; (2) communication is often obfuscated through a tendency to use "medicalese;" (3) individuals are treated differently because of age, sex, profession, income, ethnicity; (4) professionals consider themselves "protectors," thus becoming paternalistic and autocratic and creating dependency.

To eliminate these and other problems, it is specifically recommended that, as a condition for Federal funding, health professionals schools require experiential and didactic courses in human relations, communication skills, geriatrics, community resources and involvement, nutrition and ethics.

Further, it is recommended that the existing inservice training requirements for federally funded health care facilities be strengthened to insure ongoing training for all facility personnel at all levels in the humanistic care of patients, with an emphasis on the team approach, to insure an involved, caring staff.

Also, it was pointed out that the licensing of nursing home administrators should be expanded to include these kinds of educational requirements plus ongoing training in their role and responsibilities to patients, with particular emphasis on the importance of their being an advocate for those in their care.

Thirdly, the importance of education for the patient, the family and for significant others must be addressed. People should enter the health care system in a competent and participatory way, including the assistance of their families and significant others as indicated.

Therefore, it is proposed that all public school curricula include health education taught by a professional health educator. With an emphasis on prevention of disease and illness and disability, content should include: healthful living, nutrition, body systems, anatomy and physiology, factors affecting health, diseases and populations at risk--taught at elementary and secondary levels. Also, in social studies, teaching should include the role and impact of health professionals, how the system works and how to use it, the rights and responsibilities of a consumer in a health care system, and community resources. This content should also be offered through hospital and community-based adult education programs.

Obviously, no one can presume to know what is best for someone else. In teaching a person to know his/her own body, to be more self-reliant and self-confident (and thus less dependent on the provider--the medical/social professional), the next generation would be a new kind of patient. Each person would be taught to be his/her own advocate. Passivity and nonassertiveness would be replaced by one's ability to help one's self.

And finally, every health care facility receiving Federal funds should have a formal health education and advocacy department to teach patient competency skills.

And last, but certainly not the least of our recommendations, is the immediate need for patient advocacy--and accessibility for those advocates to the system and the people within the system.

Obviously, every health care professional and family member or friend should act informally as a patient's advocate, so as not to place the whole load on a formal advocate. However, there must be such a person in the health system.

Within an institution, there should be a patient advocate who is clearly identified with and responsible to the patient. Outside of the institution there are various possibilities. Federal, State and local regulatory agencies clearly have a responsibility to advocate for quality care and should also be receptive to advocating on behalf of individual patients. We do not wish to create a whole new bureaucracy for advocacy, but there are some programs already in place such as the Administration on Aging's ombudsmen, and some programs with potential, such as the health systems agencies. These and others could serve the required advocacy function. Also, outside of the institution there are various community-based advocacy programs which need to be a part of the advocacy network and must be allowed access to patients in facilities.

In addition to these specific recommendations, we talked about several other areas of concern, such as:

1. The common practice of denying patients direct access to their own medical records--to see them in full and to have them explained. Inaccessibility leads to thoughts of a cover-up. The argument that access is a nuisance and that misinterpretation and misunderstanding will result is a "cop-out." Doctors and administrators must realize that "telling all" will not cause them a loss of power.

2. The need to view care in terms of continuity of care (including discharge planning), and the need for the patient to be an ongoing participant in that care plan.

3. The understaffing and maldistribution of staff in areas where patient/professional relationships are probably most important, such as working with geriatric patients and the chronically and terminally ill. It is in precisely these areas where health care personnel are unlikely to go because of low pay, low esteem, and probably most particularly, because of the lack of "reward" for people seeking, if not cure, at least rehabilitation for those they serve. An awareness that there are rewards and a potential for rehabilitation in the long-term care setting must be created.

4. The lack of commitment of professionals when they may see a patient only once or twice, as in a clinic--and the lack of follow-through by a patient in a situation where he has no private physician to relate to.

5. The patchwork nature of a system which, though set up for the convenience of the professional, often makes no sense to him and even less sense to the consumer.

6. The emphasis, through program funding and development and in clinical practice, on treatment and cure of a disease or condition at the expense of the psychological and social needs of patients.

7. The priority of a system attuned to acute rather than long-term care.

8. The need for resident councils and other mechanisms for sharing experiences.

9. The need for more research and especially for dissemination of information about factors affecting the patient/professional relationship.

10. The need for a DHEW clearinghouse, newsletter, information network, as one way to pull together and disseminate all the information available.

In conclusion the group emphasized two thrusts--first, that none of these changes or any other change can occur without adequate funding and authority; and second, that a profession is a "calling" and that responsible professionals will respond to that call by dedicating themselves to the assurance of not only patients' rights, but human rights, for all individuals.

Subsidizing and Organizing Patient/Consumer Input - Reporters: Danny K. Davis and Bea Miller

MR. DAVIS: We will have a two-part report, illustrating that we may have found how to solve the problem of the inability of consumers and providers to work together. The answer is--give the consumers most of the time and let them go first! Therefore, I wish to present Mrs. Bea Miller, a consumer who will give the first part of our report.

MRS. MILLER: In our workshop sessions there was a great deal of discussion on subsidizing and organizing, so much that I will not try to read it all. I will discuss our resolutions and then turn the microphone back to Mr. Davis. I would like to emphasize one statement that our leader, Danny Davis, made when he opened the workshop. "This country has grown out of people feeling that they have a right to be free. They had to fight for this. If we believe that patients should have rights, then we must fight for them."

Our resolutions are as follows:

1. We believe that Federal tax dollars should be spent to support patient advocacy programs and personnel.
2. We feel that there should be a national health insurance program which guarantees all residents of America quality, comprehensive health care with dignity, regardless of income or ability to pay.
3. There should definitely be "grassroots" consumers who are receivers of care on the planning boards.
4. A patient's bill of rights should be promulgated and enforced in hospital licensure regulations.
5. All members of Congress should receive copies of the proceedings from this Symposium on Patients' Right held in Washington, D.C. on May 17 and 18, 1976.
6. For future workshops of this nature, we should have a representative to explain the system, how it works and who should receive information for direct action.
7. We feel that there should be an amendment to the Constitution of the United States whereby the taxpaying public can vote for where their tax dollars are going.
8. We propose that P.L. 93-641 be amended to have inherent, legal, enforceable protection of human beings from being used as victims of genocide or psychosurgery, and to prohobit the use of patients' organs after death without their knowledge and consent.
9. We propose that DHEW accept and endorse the definition of the word "health" as defined by the World Health Organization which embodies the total needs and supportive needs of a person.
10. We propose that DHEW allocate funds (operational or otherwise) only to health systems agencies who have a proven record of advocating preventive health care as a priority, and who have an integrated membership on their boards of directors in significant meaningful numbers to promote the community's best interest.
11. We feel that "consumer" for health purposes and for input in government decision-making and representation should mean in any given situation, those

persons who are close to, work with, understand and experience the problems and the people being affected.

We have many more, but I suspect that my time is up and I will not be able to present them.

MR. DAVIS: I think that Bea Miller has done an excellent job of presenting the findings of our workshop and I will take just a minute or two to try to tie things together and wrap them up.

We tried to focus on the "how to" as opposed to just dealing with what ought to be or should be. Recognizing that much of our discussion was also taking place in other workshops, we tried to analyze why there is such a high failure rate amongst individuals and groups who profess some desire to promote change. We looked at many different types of organizations and groups and decided that one problem or one reason is that many people who have special interest and/or problems find themselves spending too much time with issues and not enough with organizing.

Therefore, we advocate that consumers groups should perhaps spend as much time becoming an organization as they do dealing with issues, if they are seeking to be effective.

There are many people with a lot of good ideas who never get any place. One of the reasons they never get any place is that they do not understand well enough the concept of moving to a point where a group decision can be made. If we are serious, once again, about promoting change, chances are it cannot be done in an ad hoc kind of way. A systematized approach is needed. Then we shall have patients' rights and the rest of the things that we want.

<u>Access to and Use of Information</u> - Reporter: Alice G. Gosfield

Consumer groups made up the large majority of participants in workshop number 4. Federal agencies were also represented, but there were few providers. After each participant introduced himself or herself and his or her individual and specific interest in the workshop topic, we discussed access to medical records. The difficulties perceived in access to records led to a discussion of the difficulties perceived in access to the Federal health care bureaucracy generally, especially with regard to information about its activities.

While Federal agency representatives believed that considerable information was available and that individuals were accessible, a significant number of participants felt information is not centrally available and is not reaching its consumer targets, and that the sheer volume of information leads to confusion.

Because of the perceived gap between expressed consumer information needs and Federal information programs, any expectations that consumers could start a comprehensive program for action on these issues for HEW remained unfulfilled. On the basis of the Background Papers, HRA was seen as the only agency recognizing some consumer mandate in its mission, and it was discussed as a potential focus for consumer access. Other agencies were perceived as having special constituencies that do not speak to general consumer concerns.

Two major kinds of needs with regard to information were expressed: 1) that information be consumer-oriented, and 2) that it be disseminated widely through an effective consumer network. Consumer-oriented information was stated to be information that is, 1) accurate, 2) accessible, 3) timely, 4) intelligible, and 5) jargon free.

With regard to access to information, two concerns were expressed: 1) how can Federal agencies help consumers get access to information, and 2) how can consumers help the Federal agencies get access to information which they currently do not have but which would help consumers choose medical options and determine policy positions.

Consumers were interested in getting access to the following types of information:

- personal records
- costs (personal and systemic)
- information on other consumer groups
- quality information including comparative data on institutions, services and providers, information on alternative modes of care, information on norms, criteria and standards of care, and information that can help consumers evaluate options
- technical information and specifically information on who can provide independent analysis of technical data, and
- information on Federal legislation and regulations, especially information that is timely prior to adoption, during the development process and after adoption.

Another part of the issue of access was the desire for personal confidentiality. With regard to confidentiality of personal information, two issues were raised: 1) what are appropriate Federal roles in preserving confidentiality of personal information; and 2) what consumer input would be helpful in establishing policies on confidentiality? Consumers are interested in having available to them information which can help them in individual health care encounters, such as what to ask in an encounter with a provider and what the consequences will be of a refusal to accept treatment or to give information? Consumers need information to know where they have rights with clout and how such rights can be developed if they do not presently exist.

In this workshop, at least, consumers did not expect they would be asked to offer recommendations for HEW. From the workshop title, they expected they would be provided with resource material. That was, without question, their strongest need. Besides such general needs as those I've just summarized, consumers said they needed a variety of lists of resources, and they expected such help would come from the workshop. Examples include the following:

- a toll-free hot line to provide information on cancer centers around the country

- information on training resources so consumers can organize themselves into vocal and effective constituencies to impact on the system

- summaries of consumer resources on legal rights in the health care area

- sources of consumer-oriented information on the various national health insurance proposals

- information on where and whom to go to for care, especially for the middle class which is not eligible for government benefits

- information on library resources, and

- information on what national centers and professional organizations can assist consumers in their needs.

Two specific suggestions were offered:

1. That out of today's Symposium as a starting point, come a published list, widely disseminated, of consumer resources, with special attention to specific Federal program offices with responsibilities in consumer relevant areas--in effect a consumer guide to HEW, as well as other resources, and

2. That the Federal Government sponsor local or regional consumer resource and educational sessions on all types of information relevant to the problems just articulated.

Based on these detailed discussions, two major conclusions emerged:

1. The Federal government has a responsibility to recognize the many wide-ranging consumer interest groups working in these areas. Many of them presently have no access to the bureaucracy. The present failure of Federal consumer health information programs is a reflection of the failure of that recognition, and

2. Consequently there is a need for a properly financed, trained consumer network with the mandate and ability to: 1) articulate consumer needs effectively, and 2) to help to create consumer responsive development and changes in Federal health policies and programs.

<u>Mechanisms for Implementation (Regulations, Policies, etc.)</u> - Reporter: Claire Ryder

I would first like to thank the entire group for a joint effort not only in terms of our excellent discussion but also for help in producing this report.

Our goal was to discuss and thoroughly explore the mechanisms for implementation of patients' rights through regulation and policy. We decided that a backdrop to our discussion is needed to know from which direction we came and also in which direction we are recommending change. We want you to assume that we are dealing with three trilogies. The first trilogy is the <u>dimension</u> of the approach and that means that whenever I say that something is to be done, we want you to consider this to include activities not only at the Federal level but also at the State and local levels as well. The second trilogy is <u>level of responsibility</u> where we want you to understand that all recommendations are a shared responsibility between the person or patient, the provider or providers, and the government. Finally, we have identified a trilogy relating to <u>kinds of levels of patients' rights</u>:

1. The right to a safe and adequate environment. Although we spent most of our time talking about hospitals and nursing homes as the environment, we felt that the same things apply equally as well to the individual's own home, to a boarding home or to the physician's office or clinic.

2. The right to health and to participate in one's own medical destiny.

3. Human rights, or the right to control one's life style.

Two and three above are particularly difficult to separate but we did feel that questions such as the right to die, or the right to refuse treatment, are part of both the determination of one's medical destiny, as well as of how one wants to continue or to end his life. It is clear these rights are interwoven, complex and changing. Some are more easily enforced than others.

A moment of insight came to us, I think, when we realized that when we referred to some rights that are enforceable and some that are not, what we really were saying is that some are measurable and lend themselves to enforcement more readily than others. Still, we did not deny the fact that we need to look for additional ways of testing and measuring the outcomes of regulations or policies relating to presently ill-defined or unmeasurable areas. This left us with some unresolved areas, not because we did not want to face them but because we did not have enough time. We felt that although some of these areas are not measurable at present, we need to seek measuring tools to determine whether or not compliance has been met. These measuring tools can vary from the very scientific to the very informal measurements, including activities of ombudsman and advocacy programs. Another of the unresolved areas was the question of who is finally accountable for assuring actual compliance with the regulation or policies? For example, the patient reads a list of patients' rights and signs a statement to that effect. Who must then see that he truly understands their intent and implications to him?

With these concerns or definitions as a backdrop, we began to identify criteria for developing sound and responsive regulations or policies. These are, in a sense, recommendations for action:

1. As repeated time and time again, there must be consumer input in the development of policies; as the Secretary of HEW has recently advised, even before the first draft of a proposed policy or regulation has been prepared.

2. In like manner, the provider should also be involved in the development of such regulation or policy, that is, early in the stage of development, even before first drafts are developed.

3. One of the interesting concepts that was presented to us that needs to be explored further, is that research can assist regulatory approach. As an example, the Food and Drug Administration is looking into the need for patient education materials on anti-hypertensive drugs, explaining the risks or complications in taking these drugs, and they are planning for a reputable clinic to conduct a field study of what it is the patient needs to know about taking anti-hypertensive drugs--what are the signs and symptoms they should look

for? This kind of early study should give us a better base for performance instead of the usual ivory tower that expects answers to questions without prior experience.

4. We believe that there should be even more emphasis placed on the open comment period that is required between the development of a proposed regulation and its finalization. By this we meant not only in terms of time, but more in terms of soliciting responses on the proposed rules from a wider audience. For example, recently the Intermediate Care Facility regulation on resident's rights drew forth only 27 comments from the public. A similar regulation for skilled nursing facilities drew forth 600 comments. Perhaps the lassitude evidenced in responding to the former was because they were essentially the same as the latter. On the other hand, the disappointing response to this regulation may also have been due to a failure to circularize to and solicit responses from everyone we can think of who has a stake in the regulation.

5. We also recognize that when the regulation is finalized, there must be wide dissemination to consumers, providers and third party payers alike.

6. We would add to this dissemination--training and orientation in the interpretation of the regulation, including the surveyor, the provider, and even the patient/resident if this is pertinent.

7. Reinforcement is a continuing process. These regulations are not going to work unless they are continually reinforced through training and further education, through discussion, through comments, through whatever means that can be devised, so that there will be consistency and coordination in their implementation.

8. We recommend that the survey/certification process be modified as well as the regulations to measure adherence to standards in terms of patient outcome, not in terms of paper compliance.

9. One more comment we would like to add relates to ongoing review and revision of existing policies. In the SNF and ICF requirements for patient or resident rights, we all agreed on the regulation that deals with confidentiality of information in medical records where the patient must sign a release

to such information before it may be given to a legitimate party. We could not agree, however, on the interpretation of the regulation that states: ... the patient is fully informed by a physician about his health and medical condition. The interpretations ranged from having the attending physician explain what information in the medical record he feels that the patient needs to know, to a patient keeping his own record, asking questions or getting laboratory results to include in his own diary or record. A third interpretation was that the patient should have free access to look at and copy any or all of his medical, hospital or nursing home record. Despite this wide variation, we were all agreed on the principle that the patient has a right to know his diagnosis, his treatments, and the options in treatments, his prognosis and risks. This is necessary for good care, continuity of care and taking a share in the responsibility for his own medical destiny. We came to no conclusion as to how this is to be achieved but I think this is an example of where we have to go in the future.

10. Finally, in terms of implementation of policies and regulations, we felt the word "enforcement" has a negative connotation, that it included such terms as "regimentation" or cutting off of funds or reducing patient case load if the person or the provider did not perform properly. We felt a broader interpretation was necessary and that this required education of the public as to its responsibilities, as well as its rights, education of the non-patient, as well as the patient, basic education of all professions to make them caring professions, involvement of the consumers in decision-making boards, development of councils of consumers advisory to provider groups and to the government, advocacy and ombudsman programs and adequate grievance procedures all the way to legal interventions where necessary.

Techniques of Direct Program Implementation: Changing Attitudes - Reporter: Muriel Shurr

First, I want to discuss mechanisms for implementation. We suggest that existing mechanisms be utilized to implement programs of patients' rights and consumer education. For example, the Joint Commission on Accreditation of Hospitals and the Professional Standard Review Organizations (PSRO's) should include evaluation and assessment of adherence to patient advocacy programs. Other mechanisms would be the health systems agencies and statewide health coordinating councils and ombudsman programs.

In implementing the National Health Planning and Resource Development Act (P.L. 93-641) and other legislation, programs should be established which will insure human, clinical and legal rights of patients in the delivery of physical and mental health care and health related services. Such programs will reflect representation by government, consumers, providers, the legal profession, and third party payers. While we are concerned about implementing patients' rights through attitude changes, we find that there is a substantive lack of knowledge as to how attitudes can be changed.

Second, techniques for positively influencing attitudes towards patients' rights:

1. Education
    a. Interdisciplinary team approach to maximize utilization of available health manpower
    b. Education on the roles of each profession and para-profession
    c. Integration of patients' rights into
        (1) Existing in-service training programs, and
        (2) Basic education preparation programs in all the health professions/disciplines
    d. Health education is a fundamental right of every person and should be included in all curricula on an on-going basis. For example, definition of patients' rights, general education at all levels in the school system and community outreach to teach people how to be their own advocate, to know their rights and to understand their own health status and needs.

We also have some suggestions on:

1. Consumer involvement
    a. Patients have a right of access to their medical records, and it was suggested that a patient-oriented record system be developed for continuity of care.
    b. Governing bodies of health service facilities and programs should include equal representation from providers and consumers.
    c. Reaching out into the community with information about available services.

d. Building community support for health care facilities and services. The target audience should include the consumer, the provider, government agencies, third party payers and the legal profession. Incidentally, we should be training our lawyers in patients' rights--that is, training the legal profession in human and clinical rights.

In order for attitudes to be changed, there seems to be a need for both educational and regulatory processes to take place.

And finally, our charge to the Symposium planners: That people who attend symposiums such as this one have a responsibility to assume leadership in changing attitudes on patients' rights when they return to their own communities.

Techniques of Direct Program Implementation: Advocacy and Enforcement - Reporter: Bobbi Granger

Our work group was charged with discussing advocacy and implementation in the area of patients' rights. The group was composed largely of persons interested in nursing homes for the elderly. In spite of this experiential bias, the deliberations encompassed the broader health care community as related to patients' rights. A majority of the participants expressed "a sense of anger and frustration over having been down this long road many times before."

Realizing that many of the suggestions have been heard many times before, the group proposed:

1. That the residents' rights regulations be revised to include a requirement that every nursing home establish active resident councils and a resident-controlled grievance procedure with appropriate remedies and powers set forth and including appropriate appeal mechanisms. Where patients' rights regulations don't exist, they must be promulgated throughout the health care system.

2. That evaluation and communication procedures must be developed between the health care facilities and agencies, such as ombudsman offices, surveyor offices and related offices. And that provision of such resources as pre-addressed and stamped post cards, and hot lines, be made readily available for use by the patients, visitors and other interested persons.

3. That the nursing home ombudsman concept as relates to advocacy and patients' rights being developed by the Administration on Aging be expanded and adapted to cover all other components of the health care delivery system.

4. That DHEW provide for the identification, recruitment and training of patient advocates/representatives of local health care delivery programs.

5. That DHEW take on sincere responsibility in developing the necessary consumer/patient advocate participation mechanisms and that they voluntarily make available all information and reports, such as the report of this Symposium, to this patient/consumer community. In making the patient/consumer advocate involvement a reality, these advocates should be involved at all levels throughout the decision-making process and in the planning and designing of programs and regulations.

It is further recommended:

1. That regular working forums should be made available for the patient care advocate community to participate with the public sector. The patient care advocate community should be made aware of all appropriate meetings before and not after the event. Moreover, transportation and per diem should be provided those patient/consumer advocates involved in decision making and program planning, if and where necessary.

2. The DHEW/ONHA plan for increased consumer participation in the decision-making process be rewritten to omit reference to the provider community--and where included, do not define as "consumer."

Finally, that DHEW sponsor a continuance of this Symposium, expanding and facilitating the attendance of the consumer advocate community in this process.

* * *

SUMMATION

Ruth I. Knee

The past two days have been a very intense experience for all of us. The richness and depth of the experience has been reflected in the excellent and challenging reports of the workshop discussions. The workshop leaders and reporters deserve special thanks for covering so many provocative issues and recommendations in such a short period of time. And we all know that their reports represent only the "top of the iceberg"--because discussion, thought and interaction have gone on at many levels during the Symposium.

We have gone through a rather interesting progression, yesterday and today. First, there was the exhilaration of hearing a remarkable group of speakers who were very knowledgeable about issues related to patients' rights, and who presented us with both broad and specialized viewpoints. They articulated our feelings and interests and communicated their visions of what was needed to improve the present situation, as well as concerns about problems and constraints or roadblocks in achieving change. Then, we had the opportunity to get our individual views, indignations and hopes "on the record," beginning with the many questions that were raised in the Plenary Session on Monday morning, and continuing into the workshop sessions. In visiting each of the workshops today, and in listening to the reports, it was clear to me that you have worked very diligently--not always with unanimity, but with a lot of mutual respect--to try to reach some concensus on what are meaningful expectations, what are short-range and long-range strategies, and what are the individual and collective responsibilities of each of the groups, organizations or interests represented here. We owe special gratitude to the planning committee for seeing to it that such a wide range of interests have been represented, both by the speakers as well as the participants.

Just as the workshop leaders could not cover all aspects of your discussions in their reports, I find it impossible to summarize all of the significant facets of the ideas that have been generated or discussed during the Symposium--but I would like to highlight several major themes that have emerged:

1. Health care as such is very diverse and includes many types of providers and infinite variations in the purpose, intensity and length of episodes of care. Patients' rights in health care are not an absolute or a constant, but vary in terms of these and other factors. Special attention needs to be given to the protection of patients' rights when:

    a. The patient/consumer is the most helpless. (This may be because of his condition or capacity, i.e. the mentally retarded, the severely disabled, the terminally ill and the elderly.)

  b. The consumer--for a variety of reasons--is unable to obtain (gain) access to the kind of care he needs.

  c. Care has been provided in a way which has left the consumer (patient) confused, angry, feeling belittled and helpless or unable to understand treatment procedures or the consequences of his illness or disability.

2. Much of health care is provided in complex and large organizational structures which have taken on a "life of their own" and have become "self-protecting of vested interests" even though their original and basic purpose is to "serve the sick."

3. The doctor-patient relationship itself often minimizes the patient's right "to know" or to participate in decisions which affect his well-being and destiny. The potential effectiveness of this relationship is often hampered by poor communication and power and status differences.

4. Many inequities in health care resources and inhumane or callous approaches by health care institutions and personnel reflect problems in the total society.

5. A starting point in the protection of patients' rights in health care is through the protection of basic Constitutional rights. Next comes protection against the criminal offenses of abuse, neglect and fraud. There must be opportunity for the consumer to achieve redress against any such grievances he may experience.

6. Even if the serious offenses and violation of rights mentioned above are prevented or remedied, there is much, much more that needs to be done to achieve a viable partnership between consumers and providers of health care. Improved communications, professional education, consumer information, consumer advocacy, more effective regulatory activities, broad community involvement in health care concerns and continuous staff training were all seen as places to start.

Much of our discussions have focused around the questions: "Whose job is it to see that patients' rights are respected and protected?" "How fast can change take place and where can we put pressure to achieve the most improvements?" "Must we settle for an incremental approach?" Many suggestions and recommendations were made concerning the legislative base, structure, standards, regulations and procedures of the Federal health programs represented in the Symposium. But the considerations of the past two days have gone far beyond the dimensions of federally funded health care and have looked at the roles of voluntary organizations and citizen groups, as well as other levels of government. Attention was given to the need for better enforcement procedures and for more involvement of the courts. Many persons expressed concern that unless special efforts are made, consumer interests will not be adequately represented in the new health planning organizations. Others indicated that unless there are adequate funding levels for health services--and for enforcement of regulations and quality assurance mechanisms--there can be no hope of an enhancement of consumer status, or improvement in health care.

A different set of priorities was stressed by a number of participants. These had to do with approaches or methods by which the consumer can become more responsible for his own care. Special emphasis was placed on the importance of the consumer (patient) having access to his own medical record and of the need for removal of legal and policy or procedural barriers to this access. The achievements of consumer or family groups concerned about specific diseases or disabilities (mental retardation, cerebral palsy, etc.) in bringing about change were also highlighted.

So where do we go from here? The Symposium has certainly accomplished its purpose of raising issues and eliciting concerns. None of us can feel complacent about the current status of patients' rights in any aspect of health care. Yet, we have identified many positive forces. Although the various statements of "Patient's Bill of Rights" were seen as unenforceable rhetoric, for example, at least they have been expressed in formal statements and people are talking about them--and this level of specification and concern did not exist five years ago. So, while no one wants to have all talk and no substance or action, talk can be important, too. All of you will need to do some talking about the ideas you have heard here. Each of you represent some group or organization--and we hope that you will share with your colleagues the things you have learned here. And, it may be that you have found some new allies or resources in the other groups represented here. We hope you will keep in touch with them and begin the creation of a communication network that can lead to exchange of information, better understanding, and more effective action.

The Federal agencies participating in the Symposium will have the opportunity to study the reports and recommendations as they apply to specific programs. Hopefully, the staff people who were responsible for planning the Symposium and others who have been here will be able to find ways to implement many of your suggestions. Dr. Costa will serve the important role of focal point for the continued involvement of the HEW health programs and will see to it that your ideas are communicated to them. I am sure that with her interests and energies, this Symposium will be but the beginning of a new appreciation of the consumer role in health care.

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