

## Patient Rights

Dear Editors:

I have been forwarded a copy of an article by George Annas, J.D., M.P.H., *How to Make the Massachusetts Patients' Bill of Rights Work*, published in the February, 1980 issue of MEDICOLEGAL NEWS.

As responsible and enjoyable as I have found Professor Annas' writing in the past, it is with great disappointment that I must write a critique of this example. Specifically, I find great fault with his comment regarding the integrity and applicability of patient representative programs. As a former patient representative, it was my job not only to advocate but equally to educate, and who could miss the chance of educating, or attempting to educate, the "father of patient rights." Alas, my humble attempt.

In his article, Mr. Annas states that "patient representative programs are usually little more than public relations ploys," with limited job descriptions. While this statement could be indicative of the performance level of some patient representative programs, to make the statement that "current programs usually" reflect this approach is totally unfair and, quite possibly, an un-researched premise.

It has become apparent in New York State (if for no other reason than unrest among their own ranks), that the "professional" patient representative program, with its flexible institutional advocacy style, has come into its own. As an example, I know of few patient representatives who do not deal with quality of care issues within their organizational frameworks. This can be directly attributed to an upsurge of patient/community identification with the patient representative function and a realization by administrators and the medical community of the value of using a "professional communicator." Many patient representatives now report to top administration and have become important catalysts for change in their individual hospitals.

Additionally, the JCAH Standards on Quality Assurance, as well as self-administered hospital based risk management programs, have given a new impetus to including the patient's voice, through the patient representative, in major hospital decision making and planning.

Without challenging Mr. Annas unduly concerning the formulation of his opinions, let me end by asking him to take a more conscientious look at the role of the hospital based patient rep/advocate. If you desire, I would be most pleased to provide the names of numerous individuals who, as professional patient representatives, are truly responsive to the multiple and complex needs of their patients, physicians, hospitals, and communities.

Having just come back from a difficult physician/patient confrontation (dealing with the patient's right to receive medical information), I found our new patient representative victorious, but not unscathed. I asked him to take a few minutes to read your article and, if he would, to comment on it. He did, and laughed, and moved on to the next "public relations ploy."

**Bruce E. Payton**  
Quality Assurance Coordination  
Ellis Hospital  
Schenectady, New York

*Professor Annas responds:*

Mr. Payton's reaction to my single sentence about patient representatives in a 2,500 word article about the Massachusetts Patients' Bill of Rights is instructive for two reasons. First, it again indicates the type of anecdotal evidence that is relied upon in this field. The last formal study of patient representatives, which Mr. Payton must be aware of, was commissioned by HEW's Malpractice Commission. That study of 2,200 major health care institutions found that of the 1,000 that responded, 462 had a "patient representative." Their typical job description was: "a patient representative's primary assignment is to serve as management's direct representative to patients."<sup>1</sup> The point is not that such a person can never get involved in patient care issues on an institutional level, but that they are not representatives of patients — they are the administration's representatives to patients. Individuals generally get to choose their own representatives (e.g., lawyers, Congressmen). If the purpose of patient representatives (or advocates, the term I prefer) is to help the patient exercise his or her rights in the hospital setting, the representatives must be responsible to the patients they serve, not to "top administration."

Secondly, Mr. Payton and his laughing friend seem to be personally of-

fended at my characterization of the majority of patient representative programs as "usually little more than public relations ploys." This was not the point of the sentence. There are a number of extraordinary individuals who can function with some degree of success in this mode. A few superstars come immediately to mind: Anne Cole of New York, Lydia Espinoza of California, and Kathleen Countryman of Minnesota. I have nothing but respect and admiration for a person who can work for hospital administration and yet effectively help patients exercise their rights. But this is asking too much. Patient representatives should have significant individual authority to help patients exercise their rights, and should have sufficient job security and independence to enable them to help patients without risking their own jobs. As a rule, current models simply do not permit this.

I accept Mr. Payton's invitation and look forward to receiving his list of "responsive" patient representatives; I want to write them all and learn of their experiences. I am in the process of revising and updating THE RIGHTS OF HOSPITAL PATIENTS (Avon, 1975), and an important part of that revision concerns the growth and development of patient representative programs over the past decade. Readers are encouraged to send me their own experiences as patient representatives, or their experiences with patient representatives. Perhaps it is time for another national survey.

### Reference

1. Thompson et al., *Patient Grievance Mechanisms in Health Care Institutions*, Appendix to the Report of the Secretary's Commission on Medical Malpractice, (Washington, D.C., DHEW Pub. No. (OS) (73-89) (1973) at 758, 760 (emphasis added).

## Comments on Terminally Ill Patient Conference

Dear Editors:

At the Society's recent conference in Chicago, *Legal and Ethical Aspects of Treatment for Critically and Terminally Ill Patients*, the principal discussion surrounded identification of the decision maker. It was the general consensus that personal autonomy should prevail completely as long as the patient was competent. Only in decisions involving the incompetent or the never

competent does the diversity of opinion begin. As expected, the several solutions presented little unanimity and varied from the reasonable to the ridiculous.

Perhaps the most ludicrous comments of the day were advanced by Professor Charles Baron, who thinks that every difficult problem should be brought to the court room. This addition to the already overcrowded dockets surely would bring the entire judicial system to a grinding halt. Afraid to leave any decision to the solitary physician or to the immediate family, he would apparently leave everything to the judgment of the court — seldom utilizing a jury and presided over by a solitary judge.

His apparent belief that the purpose of the court is "to establish principles — ethical principles" makes me more than a little uneasy. The purpose of the court, especially in ethical issues, is to reflect the mood of society, to sense the will of the people, and to mirror already established societal values. The courts then should be lagging behind, awaiting decisions by the public, not vice versa. Courts would do well to articulate society's decision and to restrain their own limited and necessarily prejudiced opinions.

The alternate suggestion, that all these thorny decisions should be left to the physician, fails equally to address the issue. Certainly, the provider of health care needs to be intimately involved, but should not have such decisions "dumped" in his lap.

Both of these legal opinions show an ingrained distrust for the immediate family. Perhaps this arises from seeing so many families in an adversary situation and in dealing primarily with families where there is dissent, distrust, and dissatisfaction. Quite frankly, usually the opposite situation prevails. The immediate family is loving and caring, with the best interests of the patient being foremost in their concern.

The family appears to be in the strongest ethical position, although this may not be recognized legally. The family is closest to the patient, and therefore most likely to be able to recognize what his wishes would have been were he in possession of his faculties. This position was articulated by Professor Robert Veatch, specifically pointing out that patient's values are most usually a reflection of the family values. Furthermore, he clarifies the obvious, that family value systems are sufficiently variable that different answers

to the same ethical dilemma will be reached in accordance with the patient's heritage and religious convictions.

Ideally, with input from the patient's physician, the immediate family, and an ethical advisor — usually the family clergyman, the hospital chaplain, a counselor, or other trusted professional — a reasonable and sound decision can be reached that is within the moral framework that would be considered acceptable to the patient.

By all means the last resort should be the courts as is evidenced by the recent long drawn out decisions.

Carl W. Liebert, Jr., M.D., F.A.C.S.  
Louisville, Kentucky

*The following letter was solicited by the editors:*

Dear Editors:

Although I cannot in good conscience call Dr. Liebert's solution "ludicrous," it does seem to me to have a fatal flaw. In my experience, giving decision-making power for the incompetent patient to the immediate family really means giving it to the attending physician.

Even in this day, a family is unlikely to face such a decision more than once. The quandary is likely to find the family members feeling unprepared and uneasy. They may not be unanimous. They will certainly be grief-stricken, confused, and anxious to avoid the sequelae of guilt. Under the circumstances, they are usually eager to pass the decision-making burden to the doctor whom they see as an "expert" in dealing with all aspects of the problem. Unlike Dr. Liebert, many doctors feel the power to decide should reside with them anyway. When they approach the family with their own minds made up, they are capable of presenting the problem in a light which guides the family to the "correct" decision even where the family is willing to decide.

If these decisions are to be made by anyone other than a court-appointed guardian, they should, as Relman has suggested, see *The Saikewicz Decision: A Medical Viewpoint*, AMERICAN JOURNAL OF LAW & MEDICINE 4(2): 233-42, be made by someone who was earlier picked for that purpose by the now incompetent patient. Such a "ward-selected" guardian, who consents in advance to play such a role and who has discussed with the ward the

decision he or she would want, stands some chance of playing a meaningful "informed consent" role with the attending physician. In default of such a formal selection, resort should continue to be made to the courts for the reasons I have discussed elsewhere.

Charles H. Baron, LL.B., Ph.D.  
Professor of Law  
Boston College  
Newton Centre, Mass.

Dear Editors:

I simply could not send my evaluation form without expressing appreciation for the quality of the conference in Chicago. Living in a conservative mid-American city, where ethical issues are unlikely to be directly addressed, where meetings of doctors and lawyers are generally mutually patronizing and placating, where nurses and administrators for the most part allow themselves to be locked into traditional roles and ideas, may have contributed to my enthusiasm. However, I do not feel that these circumstances and my needs have entirely distorted my perception. I had a definite sense that I was in the presence of committed professionals and thinking persons. Some were clearly more open and in touch with the complexity of the issues, some more intellectually honest, some more visionary; still, overall the process of exchange worked.

What I learned and what I realized I did not know has inspired me in both my personal endeavors and professional goals. As a hospice nurse, the printed material, along with the taping I was able to do, will serve as the basis for an inservice program. I am convinced that at the very least this process will raise the necessary questions.

Susan Spanel, R.N.  
Eau Claire, Wisconsin

**Editor's Note:** The conference referred to above was held in Chicago in October 1980. Similar programs were held earlier in Detroit, Los Angeles, and Minneapolis. ASLM and the Health Administration Press of the University of Michigan will publish a book based on the proceedings of these conferences. Entitled *TERMINALLY ILL PATIENTS: LEGAL AND ETHICAL VIEWS ON THEIR TREATMENT*, the book should be available in the Spring of 1981. It is being edited by A. Edward Doudera, J.D., and J. Douglas Peters, J.D., co-chairperson of the Detroit conference.