Correspondence

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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 unresearched 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."

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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."[1] *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 offended 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 Cote 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

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