

autonomy is, in fact, eroded by the practices of some managed-care organizations. I agree with Drs. Salmon and Middleton that there are HMOs that make quality and access to appropriate care dominant goals and thus do not constitute barriers to patients' rights.

I disagree with Dr. Balducci's view that scrutiny by accrediting bodies is an adequate substitute for making certain types of information available to members of the public about their doctors. Patient autonomy in the choice of doctors cannot be exercised meaningfully if patients are denied information that would influence that choice.

Dr. Peters states that I have confused autonomy with entitlement to care. My article gives examples to illustrate my point that limiting access to care with economic barriers can undermine patients' autonomy. Although I do believe that just societies should provide universal entitlement to medical care, this issue was not addressed in my article.

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1. Weston B, Lauria M. Patient advocacy in the 1990s. *N Engl J Med* 1996;334:543-4.

2. Woolhandler S, Himmelstein DU. Extreme risk — the new corporate proposition for physicians. *N Engl J Med* 1995;333:1706-8.

### Patient Advocacy in the 1990s

*To the Editor:* Perhaps the problems detailed in the article on patient advocacy by Weston and Lauria (Feb. 22 issue)<sup>1</sup> would not have occurred if the physicians involved had been more honest with the parents. The seriousness of the illness should have been impressed upon the parents by the physicians involved. The desire of the physicians to do something was the primary cause of all the subsequent social problems.

It is time for health care providers and the lay press to stop fostering unrealistic expectations about medical care in the minds of the public. Why were the parents not told that the child had a fatal illness and little could be done? The no-treatment option is an important component of true informed consent.

When are physicians and the public going to accept the fact that death is a normal part of human existence? Rather than blame the health maintenance organization (HMO), the involved physicians should shoulder some of the blame for perpetuating the belief that no one dies anymore and someone else always pays the bills.

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1. Weston B, Lauria M. Patient advocacy in the 1990s. *N Engl J Med* 1996;334:543-4.

*To the Editor:* The article by Weston and Lauria was particularly poignant. Their recommendations, however, that "we must speak out" and "we cannot allow national contracts and policies to harm the individual family and patients we serve" ring hollow because of their failure to dis-

close the responsible parties and participants in the case they related. They have a responsibility to identify the participants. They have a responsibility to employers who select HMOs, thereby entrusting the health of their employees to these providers, and to the HMO medical director, who might respond to the care policies that govern decision making. They also have a responsibility to identify the transplantation group that marketed itself as a center of quality yet lacked published reports that would certify its research productivity in the field. What incentives were there for the center to participate in this contract? The *Journal* should have insisted on this identification. Otherwise this report is just one more anecdote.

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The authors reply:

*To the Editor:* Dr. Hopefl raises a good point about the health care expectations of the U.S. public, but our particular case does not address that issue or its corresponding costs. Pediatric oncology has more than two decades of practical experience with informed consent. We are meticulously honest with families and often include no-treatment and palliative options in our discussions. All patients are treated according to therapeutic plans that include rigorous informed consent. These plans undergo institutional and multi-institutional scrutiny. Both of our patient's parents were fully informed of the situation when the transplant was recommended, and they understood the potential risks involved (including relapse and treatment-related complications) as well as the possible benefits. For infants with acute lymphoblastic leukemia, it is difficult to cite meaningful numbers, but our recommendation of allogeneic bone marrow transplantation reflects one common treatment approach.<sup>1</sup>

Dr. Goldberg is one of several people who have urged us to identify the participants in the case history. We have not done so, primarily out of consideration for the family's privacy. Our agreement to protect the confidentiality of the family, which could be identified through the identification of the other participants, was formalized as part of the written informed consent before publication. To identify specific individuals or groups involved in a patient's history, especially in a case that is "hardly unique,"<sup>2</sup> does not further the dialogue about the difficult choices we all face. Identification also misses the central point of the article, which is to encourage the use of subspecialty and psychosocial expertise in complex medical decision making, no matter who the gatekeeper is. The proper persons to choose treatment for a patient are the providers most involved in that patient's care. Many families and providers have responded to our article by telling us of similar case histories. We cannot ignore current trends in managed-care decision making and ethics.<sup>3,4</sup> These changes are pervasive and require the attention and reflection of all health care providers.

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