

Keeping the Patient in the Equation — Humanism and Health Care Reform

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Over the past decade, two major movements have emerged in medicine, both intended to improve patient care. The medical humanism movement seeks to understand the patient as a person, focusing on individual values, goals, and preferences with respect to clinical decisions. The second movement is evidence-based practice, which aims to put medicine on a firm scientific footing; experts evaluate the best available data and develop clinical guidelines designed to standardize procedures and therapies. These two movements will now play out in the context of national health care reform, the goals of which are universal coverage and cost containment. Until now, the two trends have largely progressed in parallel, with mutual acknowledgment of the other's merits. But now, when it is most important for them to coalesce, they are poised to collide.

The World Health Organization (WHO), in its June 2000 assessment of medical care systems around the world, used "responsiveness" as one of its major criteria.¹ This concept encompasses the core principles of medical humanism — specifically, dignity for individuals and families and the autonomy for them to make decisions about their own health. In the United States, medical education has increasingly emphasized the importance of understanding patients' individual concerns and values. To this end, medical schools and residency programs now routinely teach and assess cultural competence, for example, and a

growing literature highlights the diversity of patients' experiences and ways for doctors to better individualize their care.

This approach represents a sharp shift from the traditional paternalistic role in which doctors simply told the patient what to do without factoring in his or her wishes. The new model incorporates "shared decision making," in which the physician attempts to provide the patient and family with the full range of information about the clinical problem so that they can assess potential risks and benefits and make an informed decision about how to proceed. Part of the ethical basis of shared decision making is medical professionalism — the notion that doctors should always align their interests with those of the ill person and be free of any self-serving motivation so that patients can trust their physician's advice.

At the same time, the application of scientific evidence rather than anecdote to clinical practice has extended to virtually every area of medicine. Principles of evidence-based medicine have become central to medical education and the development of clinical acumen. Patient safety has been markedly improved through the stringent implementation of infection-control measures and "cockpit rules," with validated checklists, for example, being used in operating rooms and intensive care units to prevent avoidable errors. Expert panels convened by professional societies and other organizations have promulgated guidelines for the prevention and treatment of

various illnesses. These guidelines are meant not only to make care more scientific, but also to even out regional variations in practice and potentially to cut costs.

As health care reform proceeds, the implementation of universal coverage will bring disadvantaged and underserved populations fully into the medical system. These groups, which often rely on emergency rooms and other acute care facilities for their medical care, are disproportionately composed of poor Americans, members of racial and ethnic minorities, recent immigrants, and young adults. Complex psychological, sociological, and cultural factors will challenge the successful integration of these groups into the health care system. The skills associated with medical humanism will become even more important in helping physicians understand these patients' values and needs, which will have to be taken into account if prevention and treatment guidelines are to be successful. Here, clearly, medical humanism and evidence-based medicine must coalesce.

Another essential goal of health care reform is cost containment. End-of-life care may be the most compelling example of an area of medicine in which efforts to achieve this goal will require a thoughtful collaboration between evidence-based practice and humanism. A substantial fraction of our current national health care costs are incurred for care of patients during their last 6 months of life.² As we develop scientific guidelines that reflect what will

surely be highly charged conclusions about which treatments are actually beneficial at this stage, we will need to draw on medical humanism to apply the information in ways that are compatible with the cultural and religious values of our diverse population.

As these examples suggest, outright collisions between medical humanism and evidence-based guidelines for standardized care can be avoided as long as clinical guidelines (beyond safety measures) remain recommendations rather than mandates. We believe it is essential to respect the ethical principle that any choice of treatment must ultimately be made by the patient who will benefit or suffer from it. Many patients have become aware of the scientific limitations of guidelines through reports in the media about recent reversals of expert advice on hormone-replacement therapy for postmenopausal women, low-fat diets for obesity, the use of erythropoietin for cancer-associated anemia, and tight regulation of glucose levels in various settings. Because guidelines are derived from clinical studies carried out in selected groups of patients and their statistical conclusions are based on study populations, they may not apply to an individual patient, especially if he or she has coexisting conditions. In many instances, the results of larger and better-designed clinical trials have contradicted what appeared to be firm conclusions from earlier research. Furthermore, there are frequently experts who dissent from the majority opinion on which guidelines are based, and their views are not routinely represented in the guidelines.

Mandated rather than recommended treatment guidelines are being considered as part of Medi-

care reform, within the context of “value-based purchasing” and “pay for performance,” but these guidelines will have the unintended consequence of misaligning the goals of doctors and patients. Physicians will face a new conflict of interest: they will be financially motivated to pressure patients into accepting a mandated treatment, regardless of whether it is compatible with their values or preferences, or to avoid caring for patients who refuse the mandated treatment. Such behavior is already reportedly occurring in pilot pay-for-performance programs.³ Moreover, given the scant evidence of meaningful cost savings from pay-for-performance or disease-management programs,² such reforms may end up pushing physicians and patients to adhere to rules that don’t even achieve their purported financial aims.

What is the remedy? We suggest that shared decision making be central to any changes resulting from current health care reform initiatives. All national guidelines should acknowledge the dissenting opinions of experts. Furthermore, these guidelines should indicate which specific populations were studied and which important coexisting conditions constituted criteria for exclusion from the trials, so that physicians can judge whether and how the guidelines apply to an individual patient. Currently, some guideline committees receive financial support from pharmaceutical and device companies, and there are indications that such support has influenced the recommendations.^{4,5} In order to assure the public that there is no potential for a conflict of interest that would taint the guidelines, an independent government body should be established to develop guidelines without industry sup-

port — analogous to the role of the Food and Drug Administration as an unbiased party for the approval of treatments. Funding could come instead from the federal monies already designated for comparative-effectiveness research.

In the debate over health care reform, much has been made of the WHO’s ranking of the United States as 37th in health care overall.¹ What is not emphasized is that we are rated first in responsiveness — that is, in providing patients with choices that are meaningful to them. We scored poorly on the variables related to economics and fairness in distribution of services, and these factors will be addressed through the reform measures that are now in the works. Retaining our hard-won advances in shared decision making will allow us to ethically combine the contributions of medical humanism and evidence-based guidelines while addressing the imperatives of cost containment and universal coverage.

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