



Success and Failure in Clinical Bioethics: Three Difficult Areas

Ruth Macklin

On the occasion of receiving the ASBH Lifetime Achievement Award at the October 2002 Annual Meeting, I reflected on some of the accomplishments of our field. In particular, what have been some of the successes and failures—or, at least, the lack of success?

What follows are three brief excerpts from my talk at the October meeting, addressing three topics in clinical ethics.

Advance directives

Attention to the desirability of making an advance directive arose out of interests promoted by bioethicists, among others. From the time of the first living-will statute—the California Natural Death Act in 1976—bioethicists looked hopefully at this development as a way of ensuring that patients could state their wishes about future treatment and that those wishes would be respected once patients lost their mental capacity. Today, all states have statutes and all healthcare institutions that receive Medicare or Medicaid funds must have policies, as required by the federal Patient Self-Determination Act.

These days we have a convenient way of finding out whether a topic has gotten people's attention: Do a search on the Web. I searched using the words *advance directives* and was surprised at the number of matching results: 224,000.

So much for the success of the movement to promote advance directives. There has also been a distinct failure: It remains the case that very few people have actually executed advance directives. Despite the state laws and the Patient Self-Determination Act, only a small minority of the population has availed themselves of the right to determine their future course of medical care. According to Post, Blustein, and Dubler (1999), "Studies demonstrate that only 10

to 25% of patients ever complete an advance directive of any sort and that these documents are regularly ignored." This is not encouraging.

Evidence reveals that a much higher percentage of older people than younger people have advance directives. I routinely ask the first-year medical students I teach whether they have an advance directive for health care. In a group of 15 students, one, or at most two, say they do. I inform the students that several of the leading cases in which courts were petitioned to permit life support to be removed at families' requests involved young patients.

Informed consent to treatment

Informed consent has enjoyed some success. Doctors know they are ethically and legally required to obtain it. Physicians now refer to the patient's autonomy as if it were as relevant to diagnosis and treatment as the patient's anatomy. Yet despite physicians' and patients' awareness of informed consent requirements in the therapeutic setting, misconceptions continue to abound. To mention only a few:

- Informed consent is the piece of paper on which words are written, rather than the process of informing patients and obtaining their understanding permission to intervene.
- Informed consent is required simply to protect doctors and hospitals. More genuine worries are that
- Informed consent is a meaningless ritual—patients don't listen and don't care.
- Patients trust their doctors, so they'll sign any piece of paper the doctor gives them.

Despite bioethicists' endless attention to informed consent in teaching, writing, continuing medical education, ward

rounds, and other clinical activities, the actual process of obtaining informed consent is up to the treating physician. Much in the culture of medicine appears to militate against even approaching an ideal informed-consent discussion. It exists only in bioethics heaven.

Do-not-resuscitate orders

This is a matter that continues to plague medical residents. In my experience, there has been absolutely no learning curve from one year to the next.

Perhaps the situation in New York State is unique. In the beginning—the early 1980s—hospital risk managers and legal departments told physicians and hospital ethics committees to deny that do-not-resuscitate (DNR) orders were being issued in the hospital. The fear of legal prosecution was great, especially because some county prosecutors threatened to bring murder charges against doctors if they discovered that DNR orders were being written without patients' express consent. Well, at least in New York City, DNR orders *were* being written without consent from patients or families. Montefiore Hospital in the Bronx had a blackboard on which residents on call at night placed an asterisk next to the names of patients who were to be DNR. La Guardia Hospital in

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Literature and Medicine

"Literature and Medicine" is devoted to the literature and history of bioethics and the medical humanities. Poetry, short stories, and short descriptions of important historical episodes are welcome. Please send submissions to Catherine Belling at cbelling@notes.cc.sunysb.edu or Hilde Nelson at hlnelson@msu.edu.

As the ASBH Task Force on Graduate Medical Education observes on its useful Web page, many of the general competencies recently defined by the Accreditation Council for Graduate Medical Education (ACGME) "pertain to the art of medicine." How do the texts and methodologies of disciplines in the humanities map onto teaching this "art"? A starting point: Narrative fictions can give life and practical meaning to abstract precepts like "communicate effectively," "create and sustain a therapeutic and ethically sound relationship with patients," and "demonstrate sensitivity and responsiveness to patients' culture...." (ACGME Outcomes Project). I went to the task force's syllabus-exchange page to see whether anyone was using literature in response to these new educational goals. I found Johanna Shapiro's syllabus and asked her to tell us more about her use of stories in residency teaching.

—Catherine Belling

New Points of View: Fiction in Residency Teaching

Johanna Shapiro

Fiction and poetry can be used to address hard-to-teach professional competencies like treating patients with compassion and coming to terms with the emotional demands of a medical career. The residency experience nonetheless presents challenges to using literature, including perceptions of irrelevance or insufficient practicality and straightforward dislike of reading fiction.

Literature-based teaching has been a required component of the behavioral sciences curriculum in the University of California-Irvine Department of Family Medicine since 1998. The goals are for residents to learn how reading fiction can supplement their understanding of common psychosocial aspects of primary care medicine; to learn about behavioral science topics from a particular, local, and subjective perspective; to develop skills of emotional self-exploration and self-disclosure; to develop increased empathy for patients in difficult or frustrating medical situations; and to link the insights of literature to clinical experience.

Approximately 15 residents participate in each 50-minute monthly conference. Short stories or poems are distributed on site and read aloud. One story that never fails to engage residents is "Fathering," by the Indian-American writer Bharati Mukherjee, from her collection *The Middleman* (1988, New York: Grove Press). Residents read the story aloud in readers' theater format. Jason, the first-person narrator, is a Vietnam veteran. He and his girlfriend Sharon have recently located his 10-year-old Amerasian daughter Eng and have brought her to the United States so they can be a family. Things do not go well. Sharon and Eng compete for Jason's attention, while he struggles with guilt over the war and the shambles of his life. When Eng becomes sick, she tries to heal herself as her grandmother had, through traditional "coining." Seeing the resulting bruises,

Sharon enlists the kindly but culturally insensitive family doctor to help her convince Jason that his daughter is "crazy." Jason, the classic person-in-the-middle, is forced to choose sides. He decides to remove his sick daughter from the physician's care: "My Saigon kid and me: we're a team. In five minutes we'll be safely away." This conclusion always provokes strong reactions.

Discussion begins by establishing a plot summary and airing initial interpretation. Residents typically start by looking for the "diagnosis" and analyzing the story from a medical perspective. Eng, they decide, appears to have posttraumatic stress disorder. Sharon probably has a prescription drug dependency. The family dynamics are triangulated and demonstrate inappropriate boundaries. The physician does a good job of providing brief counseling to the family and does not deserve to be bitten by the frantic child. The father is irresponsible and should probably be reported to social services.

None of these conclusions is necessarily wrong, but they all reflect an emphasis on professional labeling that seeks to find the pathology and treat it. This view sees all the family members "from the outside in," at a safe professional distance. The residents tend, understandably, to identify with the physician as expert authority and hero. They initially overlook an essential step in good doctoring—that of experiencing the patient, family, and physician as struggling, suffering people with strengths and limitations.

The residents are then asked to respond to the story from the points of view of various characters. This strategy helps break down the tendency to intellectualize about a particular clinical dilemma. Speaking about the story not in the third-person ("Eng needs psychiatric help"), but in the first ("I saw my grandma get shot by Yankee bastards"), residents suddenly discover more understanding, insight, and compassion for the characters' predicaments. From these new perspectives, they begin to see the family as admirable as well as "dysfunctional"; that Jason's decision, while medically questionable, provides important emotional support for his frightened daughter; and that the well-meaning Dr. Kearns makes largely unconscious assumptions about what constitutes normal behavior, shaped by his own background as a small-town New England doctor. Ultimately, residents are able to generate approaches to the family that offer additional possibilities and are embedded in a context of caring and concern. Finally, residents are asked to make specific links to their own work, such as patients or situations that remind them of people or events in the story.

At the beginning of literature sessions, residents often express polite skepticism. In particular, they are concerned that such sessions may waste their time, offering nothing directly useful in patient care. Informal feedback, however, suggests that the discussions often provide valuable insights. One resident commented, "These sessions always seem to come exactly when I need them." Another remarked, "The readings don't always make me feel comfortable, but they always make me think." Such reactions suggest that even limited exposure to prose and poetry may be useful in helping residents develop the professional competence that enables them to manage difficult patient situations and the stresses and strains of residency training.

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