# Virtual Mentor

American Medical Association Journal of Ethics August 2013, Volume 15, Number 8: 672-676.

## **MEDICAL EDUCATION**

The Medical Student and Care at the End of Life Thomas P. Duffy, MD

Almost 20 years ago, care of the dying was described by Daniel Callahan as an "open moral wound" in the American health care system [1]. He attributed the continued festering of this lesion to the American veneration of self-mastery and self-realization that cannot submit to the inevitable reality of death. He also cited the secularization of death, with a religious/spiritual response replaced by a medicotechnical assault, as a contributor. Physicians exaggerated and prolonged this injury by the avoidance behavior generated in them by encounters with death and dying. There was a reticence to initiate discussions about advance health care planning, a failure to elicit patients' values in these matters, and a propensity to ignore directives even when they were in place.

The Patient Self-Determination Act, passed more than 2 decades ago to correct this situation by encouraging discussion of end-of-life (EOL) issues, saw only a modicum of success in reversing physicians' disinclination to make such discussions a priority. Even a multimillion-dollar interventional study (SUPPORT) to improve patient-physician communication with critically ill patients succeeded only in documenting the extent and frequency of this communication gap in modern medicine [2].

Physicians' reluctance to initiate and flesh-out patient preferences regarding EOL care has been defended (and excused) on the grounds that such discussions threaten the patient's ability to maintain hope. This long-adhered-to but now outmoded belief and practice resulted in "benevolent" deception being the primary communication style in EOL care of the past. Physicians' problems with a personal sense of failure in the face of death, a disproportionate belief in the mastery of science over disease, and unacknowledged anxiety over their own deaths all contributed to this physician-centered rather than patient-centered approach to end-of-life care. The shift from curing to the caring stance required during the dying process is not an easy transition for physicians trained in the ethos of delaying death at all costs. The financial and time constraints of modern-day practice have only accentuated the omission of end-of-life conversation from encounters with patients.

This serious oversight persisted even in the face of the expressed desires of their patients to be engaged in EOL conversation [2]. A major reason for this was the way in which physicians were educated throughout the last century. The Flexnerian biomedical model of medical education was strongly anchored in scientific ideas with less emphasis on or inclusion of professional ideals. Generations of physicians

were not schooled in the artful care of the dying; death and dying were absent from the medical curriculum as topics and almost nonexistent in medical texts. Communication skills were taken for granted. Death, which inhabits the halls of every hospital, was excluded from the discourse of physicians' daily lives. Physician interest and attention to patients appeared to dwindle as the battle against dying was lost. This twentieth-century professionalization of physicians determined a way of life that paradoxically failed our patients' expressed concerns and needs.

Healing of this wound has become the major moral responsibility of the medical profession in the twenty-first century, and major alterations and emphases in how students are trained are being implemented. Bioethics has played a huge role in the healing and has been a gadfly, energizing the profession to address and correct the omission. Palliative care teams, nonexistent until only a few years ago, now work alongside the health care team in a therapeutic and educational role. The dialogue on this subject has, to some degree, become mainstream. Popular TV programs such as Bill Moyer's PBS series in 2000 on dying "On One's Own Terms" and films specifically created to address this topic have helped put "power-of-attorney" and "advance directives" into most patients' vocabularies. The modern plague of AIDS made it impossible for anyone to escape confronting dying and death. The debate over the legality of physician assistance in dying and its approval in Oregon, Washington, Vermont, and Montana have catapulted "how we die" into the forefront of concerns for the medical profession and its patients.

A rapid correction to the problem, analogous to a surgical closure of a wound, is, however, not possible. The solution requires a departure from the type of professionalization in which many of the current ranks of physicians were schooled. It rests in training medical students to be more comfortable in the territory of death and dying and to be more skilled in discussing these topics with their patients. This is essential for cultivating the habit and skillful practice of "benevolent" disclosure. Such physicians will be better prepared to support their patients in living while dying and in helping to orchestrate a "good death." The movement is already well under way in most medical institutions in America, with attention and emphasis on this aspect of care across the curriculum. Initiatives such as the EPEC (Education in Palliative and End-of-life Care) project are serving to heighten physician awareness and engagement in EOL care [3].

The new importance EOL care is being accorded is emphasized by its introduction early on alongside the previously sacred terrain of basic science. The cadaver introduces students not only to anatomical detail but to the more complicated and awesome territory of dealing with death and dying. Studies have documented that student attitudes and adjustments to dealing with death begin early in medical school with students' encounters with the cadaver [4]. And integration of this material continues across the curriculum throughout the 4 years of training. Special emphasis is being placed on nurturing the development of effective communication skills; professional actors are portraying patients in clinical scenarios in which students acting as physicians deliver bad news or discuss EOL issues [5].

Medical school ethics courses contain a heavy concentration of EOL issues. Hospice visits are part of most medical clerkships. Clinical ethical reasoning proceeds hand-in-hand with classical clinical reasoning. Incorporating questions about patients' preferences concerning death and dying into student learning of routine history taking strongly dispels the tendency to avoid these subjects. Giving this information equal importance with other parts of the history makes both patients and physicians more at ease with such discussions. No longer should there be a need to introduce this essential dialogue at the bedside of a dying patient; knowledge of the patient's wishes should have evolved from conversation that has become a natural part of the patient-physician encounter.

The issues that must be considered in end-of-life care are multidimensional, and the skills physicians must possess are many. Ethical grounding for discussing end of life with patients is rooted in the principles of respect for patient autonomy, beneficence, nonmaleficence, and justice. Truth telling and informed consent are central to the task. The legal implications of living wills, advance directives, durable power of attorney, competency, and surrogacy must be understood. The use of agents to relieve pain must be mastered and skillfully employed to the patient's advantage.

# Patient Narratives and the Student's Role in End-of-Life Care

None of the many goals of end-of-life care can be met without what is often the medical students' most valuable contribution—elicitation of the story of the patient's life and the conversations that identify the values, wishes, needs, fears, and, most importantly, the goals of the patient. The importance of eliciting the patient's narrative in EOL care is a surprisingly recent realization. An ongoing conversation to understand where patients are coming from, where they now are in their illness, and to where they will return, depending on the outcome of the illness, was not recognized for its defining role in care decisions until, perhaps, 15 years ago. History taking had been taught as a distiller's art—the distillate of the disease was removed from the rich and oftentimes messy details of human life and illness.

This oversight is now being corrected. Courses in narrative medicine even have their own place in some medical schools [6]. The narrative not only promotes a more empathic understanding of patients, it is an essential resource for addressing and helping resolve moral issues in patient care [7]. This perspective has its origin in the belief that moral judgments cannot be properly made unless the circumstances of an individual's life are identified and considered.

It becomes easy to see that the student's role in EOL care is critical when one recognizes the value of eliciting the patient's story in its fullest detail. It is often the student's sympathetic and earnest listening that evokes the narrative that lays the groundwork for a team's understanding of the patient. The elicitation of the story identifies each patient's uniqueness and determines how each patient's management will be tailored to his or her needs. Engagement with the patient in the act of attentively listening incorporates the listener into the developing narrative and helps

cultivate trust in the relationship. Equipped with this knowledge, the student is better prepared to learn from and even question decisions about a patient's care. The opportunities to witness the delivery of bad news by members of the team become richer occasions for learning. The artful engagement of an attending physician in EOL discussions becomes embedded in the student's repertoire of clinical knowledge.

The term "personalized" medicine—referring to treatments that genomic analyses make possible—is evoking tremendous excitement. But the term is misapplied to genomic medicine. Treatments that arise from genomics will be "individualized" to the patient's cancer cells, but they will treat the cancer, the disease, the way medicine has long treated the disease. "Personalized" medicine treats the person with the disease—the illness experience. And true "personalized" medicine is the domain of narrative medicine and is the proper possession and pursuit of all physicians [8]. It is through the understanding of stories—not genomes—that personalized medicine is realized.

Medical students are equal players in that process and have the same access to the stories of patients' lives that William Carlos Williams claimed afforded him entrance to the "secret gardens of the self" [9]. This generation of medical students is fortunate in being able and encouraged to enter these gardens and use this training in all of their patient interactions, especially in the circumstances of EOL care.

When former trainees of the physician Paul Beeson were questioned about the source of his persisting influence on current generations, they opined that it was the fashion in which he encountered each patient that was the basis for their ongoing admiration [10]. His habit was always to draw a chair to the patient's bedside and listen attentively to the patient's story. It is that simple act that is the key to the gardens of our patient's lives, the entrance to the discovery of our patients' fears and apprehensions.

#### References

- 1. Callahan D. Frustrated mastery. The cultural context of death in America. West J Med. 1995;163(3):226-230.
- 2. Schroeder SA. The legacy of SUPPORT. Ann Int Med. 1999;131(10):780-
- 3. Education in Palliative and End-of-life Care (EPEC) web site. http://www.epec.net/. Accessed July 2, 2013.
- 4. Montross C. Body of Work: Meditations on Mortality from the Human Anatomy Lab. New York: Penguin Press; 2007.
- 5. Communication training provides healing touch [news release]. Chicago, IL: Northwestern Memorial Hospital; July 11, 2011. http://www.nmh.org/nm/communication-training. Accessed July 10, 2013.
- 6. Charon R. The patient-physician relationship. Narrative medicine: a model for empathy, reflection, profession, and trust. JAMA. 2001;286(15):1897-1902.

- 7. McCarthy J. Principlism or narrative ethics: Must we choose between them? *Med Hum.* 2003;29:65-71.
- 8. Shannon M. Giving pain a voice: narrative medicine and the doctor-patient relationship. *J Gen Intern Med*. 2011;26(10):1217-1218.
- 9. Williams WC. *The Autobiography of William Carlos Williams*. New York: New Directions; 1967:288.
- 10. Lee R. Collected letters of Paul Beeson. Yale University Library Manuscript and Archives.

Thomas P. Duffy, MD, is professor of medicine/hematology and director of the Program for Humanities in Medicine at Yale School of Medicine in New Haven, Connecticut. He is a graduate of Johns Hopkins Medical School, where he also completed his Osler Residency and Hematology training. He is a member of the bioethics group at Yale and a founding member of the ethics committee of the Yale New Haven Hospital.

### Related in VM

The Art of Writing Patient Record Notes, July 2011

End-of-Life Care and the Goals of Medicine, June 2007

<u>Planning End-of-Life Conversations: Hospitalist and Primary Care Physician Roles,</u> December 2008

<u>Medical Students Learn to Tell Stories about Their Patients and Themselves</u>, July 2011

Creative Training Opportunities in Pediatric Palliative Care, July 2010

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Copyright 2013 American Medical Association. All rights reserved.