Being Mortal: Medicine and What Matters in the End
Atul Gawande
Reviewed by Dean Gianakos, MD

When Atul Gawande was recently asked what book he would most recommend to aspiring doctors today, he answered, Leo Tolstoy’s The Death of Ivan Ilych. The story and its themes figure prominently in Gawande’s new book, Being Mortal: Medicine and What Matters in the End. In the opening pages, Dr. Gawande recounts how Ivan Ilych, a Petersburg magistrate, strives to live a socially proper, pleasant, and comfortable life. He gets promotions at work. He lives in the right neighborhoods, and belongs to the right clubs. Everything goes pleasantly well for him until he develops a mysterious, deadly disease that confounds his doctors. During his illness, he asks himself serious questions: What is the meaning of my life? Is it possible I have focused on the wrong things?

In Being Mortal, Gawande asks similar questions of doctors: Is it possible we are focused on the wrong things, especially when it comes to delivering care at the end of life? Is it possible for older adults to find meaning in their lives as they suffer loss after loss? How can doctors help them to do that?

Not long ago, I admitted a stoic, eighty-year-old man to the hospital. His family said he had been vomiting for several days. The patient did not complain about it. He looked ill and wasted. There were dark, bilious stains on his hospital gown. His breaths were shallow; his pulse weak and rapid. One week earlier, he had been diagnosed with rectal cancer, and had extensive metastases to his liver, peritoneum, and lungs. He did not argue with the oncologist when she suggested a trial of chemotherapy. His children were all for it—“There’s always a chance, dad, right?” Not wanting to disappoint the doctor or his family, he consented. During this admission, the palliative care specialist declined to see the patient until the oncologist determined there was “nothing more to do.”

Here’s the dilemma, perfectly described by Gawande:

In all such cases, death is certain, but the timing isn’t. So everyone struggles with this uncertainty—with how, and when, to accept that the battle is lost. As for last words, they hardly seem to exist anymore. Technology can sustain our organs until we are well past the point of awareness and coherence. Besides, how do you attend to the thoughts and concerns of the dying when medicine has made it almost impossible to be sure who the dying even are? Is someone with terminal cancer, dementia, or inurable heart failure dying, exactly?

Gawande tells moving stories about older adults coping with illness and decline. The best one is about his father—an energetic surgeon like his son—who develops a life threatening spinal tumor. Gawande shares the difficulties of making decisions in the face of contrary medical opinions, his father’s conflicted values, and his own feelings about what should be done. Between the stories, he offers insightful commentaries on modern medicine’s inadequate attempts to help ageing and ill patients like his father find meaning in their lives. He also provides interesting histories of pauper houses, nursing homes, hospice, and the assisted living movement. He offers advice from palliative care experts and geriatricians. As an internist who sees primarily older adults, I learned another good question to ask patients: “If time becomes short, what is most important to you?”

If there is one shortcoming to this excellent book, it is this: Gawande offers few suggestions on how to slow the medical imperative. He acknowledges he is short on answers. His hope is the book will raise awareness of the problem, in the same way illness roused Ivan Ilych to question the meaning of his life:

This is a book about the modern experience of mortality—about what it’s like to be creatures who age and die, how medicine has changed the experience and how it hasn’t, where our ideas about how to deal with our
finitude have got the reality wrong. As I pass a decade in surgical practice and become middle-aged myself, I find neither I nor my patients find our current state tolerable. But I have also found it unclear what the answers should be, or even whether any adequate ones are possible. I have the writer’s and scientist’s faith, however, that by pulling back the veil and peering in close, a person can make sense of what is most confusing or strange or disturbing.99

Gawande successfully pulls back the veil, and leaves physicians with a vital question: if time becomes short, what is most important to your patient? It’s a question we hope our own doctors will ask us when our time comes.

Reference

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The Health Humanities Reader
Therese Jones, Delese Wear, and Lester Friedman, editors
Rutgers University Press, 2014, 603 pages
Reviewed by David A. Bennahum, MD (AΩA, University of New Mexico, 1984)

The Health Humanities Reader, edited by Therese Jones, Delese Wear, and Lester D. Friedman is a 600-page compendium of stories, poetry, and commentary that will be of most value to teachers of the social sciences and literature to students of the health sciences, rather than to the students themselves. While I found a number of interesting essays and stories, I particularly appreciated “What Is Sex For? Or, the Many Uses of the Vagina,” by Alice Dreger, which was simply hilarious, as well as sad and often scary. On first reading I found much of the volume heavy on the analysis. But I must admit that my bias is for the story, the poem, or the case rather than the theory. However, as I delved deeper into the collected essays I did find the theory intriguing and quite instructive.

Another exception to the rule that this is serious stuff was my colleague Jack Coulehan’s “Occupational Medicine,” a charming reminiscence of his time as a college student working in the Wheeling Steel plant in Steubenville, Ohio. Discovering that their greenhorn apprentice was premed instantly elevated him to the rank of physician in the estimation of his co-workers: “I turned into ‘Doc’ . . . ‘Hey, Doc, my wife’s gall bladder is acting up.’ ‘Hey, Doc, my youngest boy, he’s been coughing all night.’ ‘Listen, Doc, Brick’s got the clap again. He says penicillin doesn’t work. What do you think he should do?’ “5149–50

The text is divided into twelve parts, each part composed of three or four chapters. The editors and authors represent some of the most distinguished scholars of the medical humanities. The parts are: Disease and Illness, Disability, Death and Dying, Patient-Professional Relationships, the Body, Gender and Sexuality, Race and Class, Aging, Mental Illness, Spirituality and Religion, Science and Technology, and Health Professions Education.

In contrast to the analytical writing of a number of the authors, there are several graphic stories illustrating the value of images to narrative. In fact the importance of narrative is stressed throughout the volume, especially the insights of Arthur Kleinman and Howard Brody that have influenced many of the scholars and writers represented. Digging through the demanding analysis of the essays in this book, the reader can find much wisdom in the editors’ understanding of the importance of narrative to the encouragement of empathy and to the practice of listening to patients. In reality, if there is a fundamental problem in modern scientific medicine, it may be the too common failure of so many physicians—often pleading their lack of time—to listen for and elicit the patient’s story, the history.

As the grandfather of a young boy who is on the autistic spectrum, I was very interested in the essay “Teaching Autism Through Naturalized Narrative Ethics: Closing the Divide between Bioethics and Medical Humanities,” by Julie M. Aultman. She comments on the difference between medical ethicists and humanities scholars.

The often unspoken, but ever-present social divide between medical ethicists and medical/health humanities scholars is created in part from the ways illness, disability, and death are conceptually, descriptively, and normatively examined. Medical ethicists use theories, principles, and approaches to ethical decision making to recognize, resolve, and reflect on ethical problems. The humanities scholar, in contrast, is
not solely concerned with problem solving, per se, but seeks to understand the human condition—those who suffer, those who are disempowered by disease, those who want their children to be "normal." They also seek to understand the webs of relationships in which individuals are embedded, along with the meanings of those relationships. Edmund Pellegrino wrote that the good physician was both competent and compassionate. But that same physician and nurse are often wounded warriors. Long hours, the suffering and death of patients, work that separates the health care professional—especially young house officers—from family and friends, all exact their toll. A defense and a strategy for healing from the unavoidable deformation that is a consequence of caring for the sick is the search for meaning through images and literature, music and dance, and the other arts and humanities. Medicine is indeed an art, what the Greeks called techne, or the craft of medicine. And it is often indeed in the humanities where those of us who care for the sick can find meaning and healing.

This book will be very helpful to teachers of the humanities to medical students, physicians, nurses, and all other health professionals who wish to prepare themselves to use a variety of materials such as short stories, images, music, and the social sciences to encourage the natural empathic skills of their students, and to offer meaning and healing to those engaged in the privilege of caring for the sick. It belongs in every health sciences library and on the desk of many humanities and social science teachers.

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The Birth of the Pill: How Four Crusaders Reinvented Sex and Launched a Revolution
Johnathon Eig
New York, WW Norton, 2014
Reviewed by William P. Reed, MD

The history of the development of the birth control pill is remarkable for the low cost of the process and the simplicity of testing and marketing it, as told by Johnathon Eig in this detailed and readable book. The idea began with Margaret Sanger, the fiery and well known proponent of woman's rights. Mr. Eig summarizes her role in the first sentence of the book: "She was an old woman who loved sex and she had spent forty years seeking a way to make it better." Sanger fervently believed that there should be a way for a woman to take a scientifically designed pill in the morning and have sexual intercourse later in the day with no fear of pregnancy, while knowing that she could stop taking the pill and return to normal fertility. She had asked many medical scientists if such was possible, and had always received the answer that no, there was no way that such a pill could be developed.

At age seventy-one, still looking for a scientific way to fulfill her dream, Sanger visited forty-three-year-old Harvard scientist Gregory Goodwin Pincus, an expert in the hormonal aspects of pregnancy. Considered to be a brilliant scientist, his work on in vitro fertilization in animals was widely reported by the press, although misrepresented as an attempt to produce test tube or bottle babies. (He was in fact re-implanting fertilized eggs in experimental animals.) The notoriety led to Harvard’s refusal to renew his contract. After unsuccessfully applying for jobs at many universities, Pincus eventually gained a minor appointment at Clark University in Worcester, Massachusetts, where he established his laboratory in a dirty basement. Unlike other scientists Sanger had contacted, Pincus believed that it was possible to create a birth control pill. He immediately focused on progesterone and manmade progestins. Progesterone concentrations were known to be elevated during pregnancy and were presumed to be the reason that pregnant women did not ovulate. Some progestins were known to block ovulation at much lower concentrations than were required for progesterone itself. Over the next decade Pincus concentrated his experiments on the birth control problem and became the scientific brains behind the idea.

To pay for the experiments, Sanger relied on her friendship with Katherine Dexter McCormick, the daughter-in-law of the founder of International Harvester. Dexter had earned a BSc in biology at the Massachusetts Institute of Technology in 1904, and later that year married Stanley McCormick. In 1906, Stanley McCormick was diagnosed with schizophrenia, and he was declared legally incompetent some years later. After meeting Pincus, McCormick became interested in his experiments, and supported them until they were complete.

For the first part of his animal studies Pincus had worked on using progesterone or a progestin as an agent to prevent ovulation. Because he had no idea what dose to use in humans and what the toxicity of the drug would be, he needed a medical doctor to oversee that part
of the study and to run the subsequent clinical trials. That was John Rock, MD, the last major person to become involved in the development of the birth control pill. Rock was a Harvard professor of obstetrics and gynecology, one of the world’s leading experts in the treatment of infertility, and intensely interested in women being able to control their own reproduction. Rock had a sterling reputation and became the ethical standard bearer for the study. Before his participation, and even after he became involved, parts of the trial had ethical lapses that would be unlikely to be tolerated today. In one case, female Puerto Rican medical students were told in one class that they had to be subjects in an early study evaluating the safety of the drug, and that their grades would partly depend on their participation. While Pincus knew and approved of this attempt to force participation, Rock did not.

Even as the date approached on which the group had hoped to have the pill on the market, Pincus had not decided which progestin he would use. He finally settled on a 10 mg dose of norethynodrel, a G.D. Searle patented progestin. The drug choice may have been influenced by Searle’s willingness to provide the progestin and manufacture and market the drug, although the cost to the company was very low. The dose was chosen since Pincus knew that it would provide near 100 percent efficacy in preventing pregnancy; the side effects could be reduced later if necessary by reducing the dose.* One batch of the drug provided to Pincus was inadvertently contaminated by estrogen—when Pincus learned of this, he realized from the test data that the addition of estrogen had reduced the side effects, leading him to incorporate low-dose estrogen in the pill.

Application to the Federal Drug Administration (FDA) faced the problem that no criteria existed for approving a drug to be taken by healthy women for contraception, given the existence of non-drug options, as well as opposition by the Catholic Church. It was decided to apply for permission to market the drug for menstrual disorders (too much bleeding or painful periods), for which there was adequate experimental evidence that the pill had value when taken for several cycles. The FDA at the time was seriously understaffed and overworked, and sought outside advice. The drug was finally approved in 1957; there is no evidence that it could have been approved as a contraceptive. Pincus touted Enovid’s use as a contraceptive at conferences, noting that physicians could prescribe it off-label for that purpose. This was reported widely in the news media, leading to the drug being regularly prescribed for contraception. Enovid was approved for contraception in 1960 as an amendment to the original approval.

It would be difficult to think of another drug that has had a greater effect on human behavior than Enovid, initially marketed at about fifty cents a pill. And it is remarkable that only four people were primarily responsible for its development: Sanger with her dream, Rock with his clinical skills and reputation that made the drug successful, McCormick with his scientific knowledge and skill to develop the drug, McCormick with the funds and commitment to pay the majority of the costs, and Rock with his drive to make it happen. Pincus with his scientific knowledge and skill to develop the drug, McCormick with the groundwork, and Rock with his clinical skills and reputation that made the drug successful.

Reviews and reflections

*In a study of eighty patients, only five had no side effects. Common side effects were nipple swelling or discoloration, soreness of the breast, nausea or vomiting, vaginal discharge, changes in libido (usually an increase), and occasional subjects experienced lactation. In other studies there was breakthrough bleeding. Thrombophlebitis was later noted as a side effect.

References


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