

Cancer, Culture, *and* **Communication**

Edited by

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and

David Spiegel

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Foreword

As a young man from time to time I found myself sitting with my left leg upon a hassock, for no obvious reason. One day, however, it came to me that quite unconsciously I had been imitating the posture of my grandfather who in his later years had had a bad leg. Now that I am older, there is reason enough, for that leg was the site of a vein that some years back short-circuited a block in my coronary vessels. Actions like mine as well as habits or codes of behavior can be inherited without the intervention of DNA, so to speak, and so can attitudes – from Republicanism to abhorrence of spiders, or a distaste for fatty foods. In the very same way, I am convinced, many symptoms – digestive ones high on my list – are passed on from one generation to another not by the genetic code, but as appropriate- or at least customary-ways to respond to stress, embarrassment, or other situations, just like voting for the Democratic Party.

Heartburn, recently promoted to the status of a disease by gastroenterologists and pharmaceutical manufacturers as GERD (*Gastroesophageal Reflux Disease*), offers a pertinent example. That new designation has turned heartburn into a thing, reified as the philosophers say, changed from a symptom that once was a badge of industry to a disease that must be guarded against and tamed. An often harmless symptom that could be ignored has been made into an icon of disease that must be treated forever, no matter the evidence that about half the people who complain show no evidence of its organic/structural basis. More than likely it seems to me, if your father or mother had heartburn when aggravated (mine did not), you will learn that complaint as a family/familiar response, and the ability of your lower esophageal sphincter to guard against acid reflux may not really matter.

If the family matters, culture has an even broader influence in the genesis of symptoms and the response to disease or disability. Long ago, Walter Alvarez of the Mayo Clinic wisely observed that symptoms, like

many other habits, were transmitted as a cultural/idiosyncratic reaction from one generation to the next. That seems self-evident once you think about it; it may have been easier in the innocently more homogeneous early 20th century for physicians to understand and empathize with the emotional responses of people much like them. The change in American society over the past century, however, has turned the founding British culture into a cosmopolitan Americanism that is still refining itself. That is certainly true of the medical scene. In the 1920s at Yale Medical School, Dean Milton Winternitz, though an early pioneer in social medicine, sympathetic to the new science of psychoanalysis, and himself a Jew, continued the racial restrictions on admission: "Five Jews, 2 Italians, no Negroes." At Harvard Medical School even in the early 1940s, we students were all white men, largely because of the conviction that after medical school women would get married and so be lost to the active care of patients. The change in these two medical bastions by the 21st century reflects the diversity that now has so improved America. More than half the students at Yale and Harvard are women, there are many blacks, Asian-Americans abound, gays are welcomed as faculty and students, and one can go on and on. The elderly, the aged, alone face prejudice that remains unremitting because, it is argued, everyone ages.

To the happy intermingling of cultures under the American flag there has been added the contributions of science to medical practice. Science and technology have let physicians cure diseases that in the past killed so many, and have led doctors to believe that medicine has turned into a science, that rules are everything and that medical practice can be modular and "evidence-based" with guidelines. Every patient resembles another and diseases are deemed concrete entities to be dealt with by the "best evidence." Doctors sometimes forget that much more of their time outside a hospital setting is spent caring for patients who feel and suffer and fear, and for that intuition and emotion are needed. The right hand of fellowship, the close relationship of physician and patient, and, in this existential crisis of cancer, faith in caretaker or Creator, all help to relieve pain and suffering and to reduce anxiety. A myriad of writers remind us that we "health care" professionals treat diseases, but we care for people.

Let me explain those quotation marks in the preceding. Nurses and physicians and other caretakers have been denominated by that new category, but one can wonder whether we confer good health or more likely simply eliminate disease some of the time. Health may be a gift from the Creator. Here let me also observe how much I prefer the word "person" to "patient," for the stereotypical patient does not exist, any more than the much-abused "case." Both are jargon terms, useful as shorthand but threatening to lose the person in his or her disease.

Indeed, people with cancer risk losing their identity in the overwhelming portentousness of that diagnosis, a label that changes everything. To call someone a “recovered cancer patient” affixes a label which ignores the person. It’s like the stamp of schizophrenia: one never shakes the adjective “schizophrenic” which arouses so much skepticism in caretakers. Once so labeled, a “cancer patient” – a doctor even cannot exchange that tag for a nicer one at “Lands’ End.” Physicians with cancer have complained that they are never again regarded as wholly healthy, always a suspicion that they may not be available in an emergency. Such opprobrium is rarely discussed, yet it adds to the burden of those who have survived cancer, the young woman with breast cancer far more than the elderly man with prostate cancer.

Such observations are not far from the idea which motivates this book, that culture plays a crucial role in the transactions of medicine, whether the doctor/patient relationship, the sick person’s response to therapy, or the cultivation of valetudinarianism. Thanks to our postmodern diversity, women now are free to prefer female gynecologists, African-Americans justly choose a physician of their own background, and as a physician looking at 80, I like to think that I have special understanding of the problems and opinions of sick people over 65. The powerful drugs with which cancer can be assailed should not blind physicians to the importance of cultural background, and individual experience, in the care of people with cancer. That is the focus of this book that you are about to read. Empathy counts. And it helps.

“God writes straight with crooked lines,” is the way Pope John 23 described the ebb and flow of customs and ideas. Over the past two centuries, mainstream medicine with its reliance on science and reason has gained sway, and rightly so because the nostrums of alternative ways could not challenge the very real cures of science. In the past few decades, however, even mainstream physicians have begun to confess that these triumphs conquer diseases but do not much relieve the disabilities and symptoms that come from sorrow, stress, or the daily events of life on earth. Our victories do not set straight passions gone awry. Antidepressants may cure sadness, but they do not relieve sorrow, nor is it likely that antioxidants can cure love. With newfound diversity has come the recognition that many people come to their practitioners for reassurance, the right hand of fellowship, advice and consolation from an experienced expert. They come for comfort and not always for cure.

It is sad that modern physicians have made so little use of their own powers of persuasion, the powers of comforting words to help their patients, the power of the placebo response in the patient–physician encounter. Here the editors and writers prefer the phrase “context effect”

as a stand-in for placebo, but they have much to say, explicit and implicit, about the importance of the placebo-response in people with cancer. Placebos do help, and sometimes in controlled trials almost as much as the agent under study. As the authors realize, more than pills, placebos are procedures, diagnostic studies, the routines of diagnosis that provide certainty. But they are also words of comfort, rhetoric as well as potions and pills.

Pain is part of life, and does not always rattle along the C-fibers to yield to anodynes. Pain may come from the wounds of cancer, but it has many other wellsprings, and among them are bitterness, tribulation, and anger. Medical measuring and counting and the ever-growing attention to statistics and to evidence – based medicine, run the risk of failing to give enough attention to that phenomenon, to teach it to our students. They need to learn how much culture as well as heredity, the mindset as well as the molecular disposition, play in the management of the sick. Such matters and more are brilliantly discussed in this powerful book that emphasizes the humanity of our patients and strengthens us as physicians, nurses, and – yes – as “health-care” workers.

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RHONDA J. MOORE
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