Abstract
A historian of aging, privileged to work with an interdisciplinary team of caregivers and researchers in a division of geriatric and palliative care of a major medical school and teaching hospital, discovers that his history of chronic illnesses secures him a useful role as a humanistic patient who helps clinicians to respond to the concerns, fears, and needs of aging Boomers. J Pain Symptom Manage 2012;44:784–788. © 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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Humanities, humanistic patient

I finally fulfilled my parents’ dream for me. I became a doctor in a major medical center. True to form, I did not quite follow their script. I have a PhD in history not an MD. Despite a couple of diplomas, I am not licensed to do anything. So, an adjunct professorship in a medical center’s consortium on aging suits me well. I get to help colleagues prepare articles and proposals. (In return, I sometimes am listed as a coauthor.) I lecture interns and residents on either humanistic gerontology or on spirituality and aging. Best of all, the chair of geriatric and palliative medicine insists that I speak frankly when the executive committee deliberates division priorities and making faculty appointments.

Before writing this article, I was not terribly reflexive about the fundamental role I played in an interdisciplinary team of biostatisticians, cardiologists, dentists, epidemiologists, family care physicians, geriatricians, neurologists, nurses, psychiatrists, social workers, and therapists of all manner. Having written histories of notable people and about developments in gerontology and geriatrics, I offer big-picture perspectives to health care specialists. For more than two decades, I have been sensitizing professionals to the prevalence of ageism in medical settings and urging them to practice self-care for the sake of their well-being. Performing these services entitles me to be called “doctor” or “professor,” but I am not a clinician. Nor do I claim to be a “humanistic clinician” who can “fully integrate the biopsychosocial-spiritual model of care with his/her patients.”

I am a humanistic patient who facilitates “the mysterious dynamic of the interpersonal space between givers and receivers of care (Charles G. Sasser and Christina M. Puchalski, personal communication, April 4, 2011).” It is a liminal role that I am well qualified to play. Old enough to have a Medicare card, colleagues in the Center turn to me for a patient’s
perspective on receiving care from physicians and providers. “Every being cries out to be read differently,” declared Simone Weil. No Everyman, my particular medical history diverges from stories other elders tell. My account nonetheless resonates with people in white coats who want to hear how sentient, scared individuals (like me) struggle to make sense of what is happening inside our bodies. They want to know what patients assume about the likely impact of illnesses, especially chronic ones, on our lives.

My narrative serves as a touchstone. It helps caregivers and recipients find common ground in dealing with medical problems and fears that older people often encounter. Patients worry when maladies mushroom into life-threatening conditions. Sufferers pray for a magic bullet, a therapeutic regimen, something to mitigate wounds (emotional and physical) after the immediate crisis. Patients’ faith in beneficence usually is not enough to sustain the healing process.

Basic research as well as new technologies and interventions over the past century have dramatically increased professionals’ capacity to understand and deal with biological abnormalities. Diagnosing and treating chronic illness have improved. Medical educators nowadays stress “treating the patient as a person.” Meanwhile, the patient pool has changed. Gains in life expectancy, at birth and in adulthood, generally afford people longer lives. Extra years also expose them to greater risk from accidents, sickness, and unhealthful habits. Chronic woes afflict older women more than men.

Population aging alters the tenor of doctor-patient relationships. Baby Boomers like me are less compliant and deferential than were our parents at the age of 50 or 60 years. Boomers presume that our time is as precious a commodity as medical personnel’s. We dislike feeling pressured by constraints dictated by reimbursement policies. We want to know information that might influence our decision to undergo treatment.

More than our elders, Boomers are inclined to ask impertinent questions and demand immediate results. We recognize that health care professionals rely on probabilities and statistics to render a diagnosis but, thanks to MEDLINE® and Dr. Oz, Boomers often appear unduly entitled to offer material we deem relevant in the course of taking a medical history. We revert to bad habits when we do not get our way. Suspicious about relying exclusively on “scientific” patterns of problem solving, many Boomers feel that blinders and biases often cause experts to underestimate the value of personal knowledge in decision making.

Boomers for the next several decades will dominate the patient pool, presenting with acute illnesses and a concatenation of chronic ailments. Health care professionals must come to terms with the new-old’s personality traits. Members of my age group are as likely to rely on over-the-counter medications and remedies touted by alternative medicine as to adhere to preventive measures and annual physicals recommended by primary care physicians (if we have them). Few Boomers, including humanistic patients like me, comprehend how physicians are trained to think medically. We lack insights derived from healing countless others. Nor do we fully appreciate recent trends in the norms and economics of medical practice.

I hope that my experiences illuminate how Boomer patients perceive and process care delivery. Subjective memories are as important as detailed histories, I contend. Past trauma, sometimes even trivial incidents, affect older peoples’ confidence that they will be treated with dignity. It behooves all parties to review lines of communication that influence health care encounters. “Care is inseparable from understanding, and like understanding, it must be symmetrical,” medical sociologist Arthur W. Frank cautions. “Listening to another, we hear ourselves. Caring for another, we either care for ourselves as well or we end in burnout and frustration.”

At the age of 40, I was at the top of my game. I had just returned to my alma mater as a professor of history and research scientist in an internationally renowned gerontology institute. My wife and I had bought a home on the river, a few miles from campus, a perfect place where our two daughters could thrive.

Then, misfortune struck without warning. “In the middle of the journey of our life,” as
Dante put it, “I came to myself within a dark wood where the straightway was lost.” Over the course of four months, my brother died, followed by the deaths of a mentor and a dear friend. Intense grief gripped me; I showed up for work but accomplished little. Feeling suicidal, I reluctantly decided to go to the psychiatry department—despite sharing my mother’s opinion that lack of will and grit were at the root of my melancholy.

Duly screened and observed overnight, I was assigned to a research protocol testing a new drug for unipolar depression. Only after an iatrogenic psychosis, which resulted in hospitalization, did an accurate diagnosis ensue and were my mood swings controlled. I have been extremely lucky: except for making my poor handwriting more illegible, I have suffered no adverse effects from lithium.

But things did patently change when I went home and returned to work. My wife questioned my nascent interest in spirituality. Colleagues acted warily. I felt stigmatized by mental illness. For the most part, psychiatrists ask little about my emotional health, rarely seeking or permitting much response. Instead, they focus on results from blood tests. I am rebuked whenever I propose taking a drug holiday (hoping that it is all a bad dream). Why take the risk; I am doing fine. I sometimes feel like a leper; I miss the highs not the lows. Truth be told, this first bout with chronic illness was oddly liberating. I no longer had to exceed people’s high expectations nor surpass my relentlessly ambitious pursuit of busyness. Having little to lose, I could slow down, take stock, and finally seek to discover my true self, warts and all. My disorder sensitized me to potential health problems in others. Besides helping to save two students’ lives because I recognized telltale signs in their words and deeds, I slowly went public with my condition, as a way of sharing solidarity with others with the same disorder. I better understood how alcohol and overmedication exacerbate late-life depression.

Ironically, my firsthand experience with chronic illness lulled me into complacency. Neither taking pills twice per diem nor undergoing quarterly tests limits daily activities. I still have to address the complex, often ambivalent, range of pleasures, pain, anxiety, and boredom that are part of living. It was not until my second bout with chronic illness that I realized how debilitating bodily malfunctions can be.

About a dozen years ago, having successfully recovered from two hernia operations and knee surgery, my primary care physician observed a steady rise in my PSA level. He sent me to the best urologist in town, who performed a biopsy. I joined that unfortunate 2% of men at the time who contracted an Escherichia coli infection from the procedure. For the next three years, I went from clinic to clinic, drank lots of cranberry juice and vitamin supplements recommended by friends, had infections that looked like pseudo-penis removed from my groin, and took ciprofloxacin along with other medications that made me perpetually drowsy, nauseous, and weak. One day, after a brief examination, I complained to the urologist’s chief assistant that I was sick and tired of it all. “Well dear,” she replied wryly, “that is why they call it chronic prostatitis.” I fumed at being called “dear,” and I had read enough Jerome Groopman to know that health care professionals should not dampen patients’ hope. I was barely out of the clinic before I was on my cell phone, demanding that my primary care physician refer me to the second best urologist in Houston. This specialist handled me better. Trouble was brewing after a second biopsy, I knew, when I was invited to bring my daughter along for a consultation the next day. The Gleason score was high, and there was an increase in the level of PSA. I knew from studies about prostate cancer published by the Dartmouth Medical School that there were gruesome outcomes associated with every intervention. Given my age, opting for a radical prostatectomy seemed the least worst choice. Finding the organ nearly disintegrated, the urologist spent an extra couple of hours in the OR scraping remains to prevent the spread of cancer. My gratefulness was genuine, as was my disappointment that spared nerve cells and Kegel exercises barely mitigated undesirable consequences.

Thirty months after routine follow-ups, the surgeon’s office summoned me for another meeting. My PSA level increased unexpectedly. The urologist wanted to begin radiation and
chemotherapy the next day. I balked, protesting that I had endured enough compromises. Without missing a beat, the doctor retorted: “Professor, what do you think your quality of life will be when you are dead?” When I requested additional PSA tests, the urologist told me that insurance would not cover the costs. I asked my caregiver whether he thought these tests would be more expensive than his prescribed course of treatment. Happily for both of us, the PSAs yielded false positives.

Recently, I ran into the first urologist at a fundraiser. He asked me what had happened. I declined to tell him; I did not want his assistant fired. That might have been a mistake.

However one numbers my days, I am no longer young as I pen these words. I do not feel “old,” however. Someday, I may retire from my adjunct professorship and full-time job, but as long as I have health to complete various writing projects, I plan to stay meaningfully employed. So what does this humanistic patient have to offer health care professionals? This narrative offers three lessons.

First, I am troubled by the disparities in health care between my rights as a consumer and the access provided to peers less fortunate than me. I have been able to select caregivers and obtain information necessary to participate in making informed decisions about treatment plans. Not everybody is so privileged. White-collar employees of major corporations often have to fight with insurance carriers over reimbursements. Reluctant to treat older patients, some doctors refuse to accept Medicare. Each year, the smartest medical students I teach head to dermatology or some other high-paying specialty with manageable hours. Who can blame them: young doctors have debts to pay and families to raise.

The irony, of course, is that most people, like me, have ordinary bodies beset with treatable garden-variety maladies. I am glad that there are teaching hospitals, but my primary care physician deals well with most symptoms I present; he sends me to specialists when appropriate. We Boomers, accustomed to Dr. Welby reruns, will need a cadre of health care experts trained and committed to geriatric and palliative care, who are in short supply.

Second, there are limitations to vouchsafing personal autonomy in late life. On the one hand, relationships between caregivers and care recipients are asymmetrical. Health care professionals know more about the aims and practice of the healing arts than educated laypersons, even patients like me who can navigate through multidisciplinary centers that evaluate age-specific symptoms and integrate services. Specialists are hardly infallible. They make mistakes, miss symptoms, and have other things on their mind. But trained professionals are better equipped than their patients in recognizing patterns and prescribing the least invasive, potentially most efficacious interventions.

On the other hand, caregivers of geriatric patients usually recognize that older patients, except in serious cases of self-neglect and isolation, belong to a convoy that worries about them, cares for them. “To have hope is still to feel a connection to the social group,” Dr. Eric Cassell reminds us, “for in that joining we are whole.” My support group of experts, friends, and allied health professionals will keep me in Houston. And I have two daughters over 30 with whom I have shared repeatedly my wishes for optimal end-of-life care, duly codified in accordance with Texas law. My grandchildren provide incentives for me to exercise, watch my weight, monitor my moods, and do legacy work. This self-caregiver is not the only person with a stake in my well-being.

Third, I strive (as I have for most of my adult life) to be healthful. I am not as fit as I was four decades ago. Nor am I persuaded by definitions of health that are antonyms for the absence of diseases as identified in laboratory tests or defined in manuals. Healthfulness in late life differs from that homeostatic balance typically found in youth. It is a condition attainable and sustainable even in the process of dying.

Above all, healthfulness in later years extends the biomedical model of health by George Libman Engel. “The central assumptions on which 20th century medicine is founded provide no basis for an understanding of suffering,” observes Dr. Cassell. “Modern medicine is too devoted to its science and technology and has lost touch with the personal side of sickness.” Responding effectively to Boomer sensibilities requires health care providers to communicate with patients such that the
promise of relief from suffering is integral in treatment plans.

Boomers, meanwhile, have a distinctive contribution of our own to make. Although most of us were raised in the faith traditions of our grandparents and parents, many members of my cohort have insinuated spirituality into their lives. Whatever our specific practices, Boomers share several qualities in common. We see ourselves enmeshed in nature, in all its complexity and chaos. Many Boomers have come to terms with finitude with equanimity, although like me, most dread the prospect of losing our minds or enduring a prolonged existence on machines. My generation does celebrate life’s ripening qualities—meaningfulness, laughter, intimacy, hope. Sustaining these values opens possibilities for revisiting the ethical and efficacious bases for geriatric care. It puts a premium on the dignity of individuals, but not at any price.

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References


