Social Determinants of Health

- Education
- Nutrition
- Obesity
- Mental Health
- Neglect
- Complacency
- Food Deserts
- Environment
- Employment
- Finance
- Access to Medical Care
- Vaccinations
- Addictions
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Social determinants of health:
Reforming education and public health to improve health in the United States

By Richard L. Byyny, MD, FACP

The determinants of health that are most focused on by physicians, and the general public, include diseases, genes, biology, and pathogens. While these are important, health and associated outcomes are determined by social factors that are often unrecognized and unappreciated.

Social determinants of health (SDH) include early life experiences; socioeconomic conditions (income and poverty); quality and level of education; access to employment, work/life balance, and work environment; social and physical infrastructure and living conditions; community and environmental factors; behaviors, social networks, and public safety. The World Health Organization’s Commission on the Social Determinants of Health uses the definition “…the conditions in which people are born, grow, live, work and age,” with complex interactions among lifestyle, socioeconomic, biological, environmental, and social factors that affect people’s health and well-being. Physicians often learn about SDH through experiences caring for patients and families, and in clinical and community settings with diverse patient populations.

The cost of health care

The United States spends more than $3.4 trillion a year on health care. This is more than $10,000 per person, and more per person than any other country. The average life expectancy in the U.S. is 79.3 years, or 31st among developed countries. Most European and Asian countries, along with Greece, Slovenia, Cyprus, and Chile are all ahead of the U.S.1 Infant mortality in the U.S. is 29th at 6.5 deaths per 1,000 live births, which is also behind most European and Asian countries.2

Most of the improvements in lifespan, quality of life, infant mortality, and other indicators of public health occurred prior to the discovery of the causative factors of diseases, and preceded the widespread use of vaccines, antibiotics, modern medical treatments, and other scientific discoveries. It has been estimated that only about five years of the almost 30 years of increase in life expectancy in the U.S. has been due to preventive and therapeutic medicine. Eighty percent of improvement in life expectancy and health outcomes has been attributed to improvements in SDH, including income, sanitation, nutrition, clean water, education, living conditions, and public health measures to prevent disease. As dramatic and consequential as medical care is for some patients, it is not the major determinant of overall levels of the population’s health.

Influences on health

One of the most important contributors to poor health is poverty. Adult life expectancy increases with increasing income, and men and women in the highest income group can expect to live at least 6.5 years longer than poor men and women. Poverty leads to unhealthy behaviors, chronic stress, and few resources for improved health and access to preventive and primary health care.3 Education is also a significant determinant of health. Adult health status improves as educational attainment increases. Babies born to mothers who did not finish high school are nearly twice as likely to die before their
first birthday as babies born to college graduates. Adult life expectancy also increases with education. On average, 25-year-old college graduates can expect to live eight to nine years longer than those who have not completed high school.4

Higher levels of education prepare people with the skills to cope with day-to-day challenges, and enable them to participate more fully in work, employment, economic markets, social and family support systems, and local communities. The all-cause mortality, and coronary heart disease mortality, has been reported to be related to level of education. People who are more educated are less likely to smoke, drink to excess, be obese, or use illegal drugs. These associations remain after controlling for job characteristics, income, and family history and background.

In addition, location and associated environment within the U.S. can influence health and life expectancy. In New Orleans, a person born in one area can expect to live 25 years longer than one born just a few miles away, and this has been observed in other cities and towns throughout the U.S.

In 1854, before the germ theory and discovery of infectious disease pathogens that created epidemics, there was an epidemic of cholera in London. Dr. John Snow, a physician, often referred to as the father of epidemiology, evaluated patients with cholera manifestations and those ill with other non-cholera symptoms. He drew a map to illustrate the cluster of cholera cases around the Broad Street Water Pump where drinking water was provided by the waterworks company from sewage-polluted sections of the River Thames. He persuaded the local council to disable the pump by removing the handle, which ended the cholera outbreak.5

Snow utilized the evidence and his reasoning to perform an important and successful intervention for waterborne cholera epidemics.

There is now evidence that social determinants influence disease development and ill health, but as Snow faced in the London cholera epidemic, we don’t yet understand all the factors related to causation.

**SDH and adverse health effects**

Many social factors are associated with unhealthy behaviors that contribute to disease and ill-health. Evidence indicates that many social determinants are associated with “chronic stress” resulting in biologic and physiologic influences on the regulatory systems. These include perturbations in the hypothalamic-pituitary-adrenal axis; sympathetic autonomic nervous system; immune and inflammatory responses; metabolic systems; cardiovascular system; central and peripheral nervous system, and brain.

Since the discovery of the structure of DNA by Watson and Crick, scientists have identified how the materials of life are made. Humans have about 20,000 different genes, all of which are transcribed into mRNA in various cells. The mRNA is translated into proteins in gene expression that can be regulated in different ways. DNA can be chemically modified and made more or less active for specific genes by the process of epigenetics. Transcription is regulated by chromosome access and a variety of regulatory proteins. Proteins are often chemically modified by things being added to them, such as phosphates, thiols, or sugars, thereby changing their activities. The proteins that result from regulated gene expression have enzymatic activities that are regulated, both up and down, by the things added to them, and by further regulatory components. The chemical foods of life—the nutrients—are synthesized by enzymes, or made available from foods using different enzymes; the microbiome plays a large role in these processes.

The entire flux, from genes to metabolites, is regulated precisely by extraordinary complexity, some of which we understand, most of which we don’t. Evidence is accumulating that social determinants influence steps and processes in these complex pathways, including epigenetic processes, that regulate gene expression or suppression, and proteins in response to aging, environment, and other factors over time.

The constantly changing levels of proteins provides meaningful insight into a person’s state of health, and wellness. Monitoring arrays of proteins over time, and response to social and other events, can potentially provide ongoing evaluation of changes in health, well-being, and quality of life, much like blood counts, chemistry panels, lipids, and blood pressure.

**Omics, social media, and SDH**

Understanding mechanisms of social determinants of disease may provide new interventions to prevent adverse health effects, or treat outcomes differently. The impact of the influence of SDH on health and illness has not been fully studied using modern technologies. Despite all the evidence, the world of health maintenance has been influenced only slightly, if at all by, “modern omics.” Nonetheless, corporate entities have decided to choose an omic and make it broadly and inexpensively available, hoping that the one chosen for development and introduction to health systems will be actionable and useful.
For instance, 23andMe chose genomics, SomaLogic chose proteomics, and Metabolon chose metabolomics. Each of these entities has made an expensive venture that their chosen omic will be useful.

Social media may be used to potentially improve health outcomes, motivate patients, educate professionals and patients, provide health information to individuals and communities, and increase awareness of news and advances. More than 75 percent of adults use social media, and it is prevalent across all ages and professions. Evidence is beginning to show that the use of social media in patient care can improve care and health outcomes, and increase patient satisfaction.

Social media is also used to improve patient access to health care information and educational resources. It can influence health behaviors and goals, and may be used to improve or enhance professional networking in education, patient care, patient monitoring, and public health programs.

Although potentially useful, social media also presents potential risks to patients and professionals due to poor-quality information, damage to professional image, and lack of privacy and professionalism. Eventually, social media will gravitate toward providing insights through omics to people so health and wellness has a chance of being democratized, especially as the cost for the measurements comes down. If used wisely and responsibly, social media offers the potential to promote individual and public health, professional education and development, and possibly even improve SDH.

Studying SDH, omics, and causation is a vital research agenda, but there is already sufficient evidence to work to mitigate the adverse effects of SDH. Waiting for more than 50 years, like with tobacco, is not an option.

Now that we have accumulated a huge amount of knowledge and evidence that SDH can adversely effect health, quality of life, survival, and well-being, we need to be documenting associations, exploring pathways, and mapping biologic and pathologic mechanisms. A high priority must be the development and implementation of interventions to improve health. We need to contemplate the questions:

- How can we give every child the best start in life?
- How can we help everyone to have the best health and life?
- How can we provide important educational opportunities for everyone?
- How can we strive for an adequate standard of living that supports health and sustainable communities?
- How can we prevent disease and disabilities, and provide medical and health care for all?

**Time for change, and action**

We should strongly support universal medical and health care for all, while recognizing the compelling need to develop interventions in SDH that are likely to improve the overall health of the nation. Physicians and other health professionals must take an active role in helping their patients become, and stay, healthy by recognizing their nonmedical needs, emphasizing their overall well-being, and connecting patients and families to local community supports. Care providers should assess whether patients have access to food and healthy meal choices, safe housing, educational opportunities, and jobs and training. They should recommend services in the community that can help address patient needs.

We should make interventions in SDH a national priority and integrate it into national, state, and city planning processes. SDH can no longer be viewed as peripheral environmental issues. They are the determinants of the health and well-being of our entire society.

We should develop, implement, and fund SDH research and investigation by initiating a major new longitudinal cohort study—similar to the Framingham Study—to investigate the SDH, and health outcomes, including mortality, illness, disease, and poor quality of life.

We should make education the most important intervention. Education means a longer and healthier life. We have an extensive educational system and corresponding supports that can be utilized for a national program in education and learning. We need societal incentives to influence staying in school and obtaining at least a high school education, if not completion of a college or technical school degree.

Some countries, like Peru, have a secondary school graduation requirement to obtain a driver’s license. This results in an almost 100 percent high school completion rate. In the U.S., 27 states have “No Pass, No Drive” policies to counter truancy and dropout rates. With abysmal graduation rates in many states, these regulations tend to increase student retention and graduation. Given the importance of education to the health of people, this would seem to be a reasonable universal requirement to improve the population’s health.
**Teaching healthy living from the beginning**

We should begin teaching about SDH in preschool, if not earlier. The science and teaching of parenting has made important advances, and is critically important during the early childhood development years. Parenting is essentially experiential learning while developing one's parent identity. Role models have traditionally been limited to one's own parent(s), but we can now develop curricula on learning to be a parent supported by coaches, physicians, and others in the local school system and community. This should start with parents during pregnancy and continue throughout childhood. It can be integrated into the ongoing well-child visits. Pediatricians, family physicians, child health professionals, and health care teams can incorporate ongoing parenting and pursuit of healthy living into well-child visits and health plans.

We should ensure an earlier educational start with pre-school for all. The curriculum would be appropriate for the child, but would have a core curriculum for early childhood development and healthy living. This would include learning to learn, socialization, health behaviors, physical activity, self-care, life-long learning skills, thinking skills, problem solving, reasoning, use and understanding of language, and social support.

Full-day kindergarten should develop a daily curriculum that would progress in the healthy living core curriculum component. K-12 would have a required healthy living core curriculum for each school year that supports and progresses with age and experience. The healthy living curriculum would emphasize and support efforts to improve education, and retain students through postgraduate education or training.

We should update and revise our medical student, residency, and health professions curriculum, once again. Medical education continues to focus on the biomedical model with emphasis on biology, pathology, microbiology, and psychology. It is still largely focused on diseases and treatment. While this is certainly essential to development as a healer, becoming a healer and professional is more complex and occurs largely through experiential learning attained from those accomplished in caring for patients. Medical education must develop physicians who care for their patients, relieve suffering, and improve the health of communities. As Sir William Osler said, “The good physician treats the disease; the great physician treats the patient who has the disease.”

He also said, “The practice of medicine is an art, not a trade; a calling, not a business; a calling in which your heart will be exercised equally with your head.” Physicians need to think about health and medical care from a new, different perspective. We need to recognize that nonmedical factors play a significant role in our patients’ health. We need to learn and understand more about the SDH that adversely affect communities, families, and patients.

During periodic patient visits we should continue to evaluate our patients’ symptoms, physical findings, and test results to make appropriate medical decisions and provide counseling. But, we should also include preventive medicine assessments and interventions appropriate for the patient. We should broadly adopt a measure of health status and quality of life. The SF-36 Health Survey is available, and has been broadly evaluated. It is the primary
health outcomes measure in the Medical Outcomes Study, and was designed for use in clinical practice.

The SF-36 includes one multi-item scale that assesses eight health concepts (there is a short form):

1. Limitations in physical activities because of health problems;
2. Limitations in social activities because of physical or emotional problems;
3. Limitations in usual role activities because of physical health problems;
4. Bodily pain;
5. General mental health (psychological distress and well-being);
6. Limitations in usual role activities because of emotional problems;
7. Vitality (energy and fatigue); and
8. General health perceptions.

The use of this tool provides an ongoing regular standardized evaluation of a patient’s health, and any changes. It could be correlated with changes in the SDH for the patient. This could be completed electronically before the patient arrives, and the score could be available to the physician and team.

**Promoting interventions**

Physicians often have limited opportunity to change the social determinants for individual patients and their families, but we should strive to work in our communities as leaders to promote interventions that will have a positive influence. We can use our positions and expertise to advocate for change in areas outside of traditional medical care to promote research, and to identify social and other measures that promote good health. As physicians, we can make a difference by working to control the rising health care expenditures. As Harold L. May, MD, has stated, “all of the systems of society—health care, education, economic, political, justice—should work in harmony, as do the systems of our bodies.”

We must influence how we reinvest our societal resources wisely, and in a way that complements and supplements what we are doing to improve patients’ and society’s health, well-being, and quality of life.

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By Jack Coulehan, MD

Dr. Coulehan (AΩA, University of Pittsburgh, 1969), is an Emeritus Professor, Department of Preventive Medicine, and Senior Fellow, Center for Medical Humanities, Compassionate Care, and Bioethics, Health Sciences Center, School of Medicine, Stony Brook University in New York. He is a member of The Pharos Editorial Board, and Coeditor for the Book Reviews.

In “Transplant,” cardiologist-poet John Stone (AΩA, Emory University, 1974, Faculty) evokes the scene of a medical miracle. As a recipient lies waiting in an operating room, a donor heart arrives by helicopter. Surgeons remove the recipient’s diseased heart and insert the silent, motionless replacement:

Within the green purpose of the room
there were ten beating hearts, but now are nine

The poem concludes with the miraculous moment when the patient’s transplanted heart comes alive:

And then the shock, the charmed expectant start
the last astonished harvest of the heart.¹

The rapid progress of medicine has indeed yielded an astonishing harvest of improvements in our patients’ health. But, I believe Stone also had another harvest in mind, a continuing astonishment at his own experience as a healer. Medical practice provides a rich opportunity to experience empathy, hope, solidarity, compassion, and self-healing. Our profession gives us privileged access to deep bonds of humanity we share with our patients. Traditionally, physicians have considered this fulfillment one of the chief rewards of our profession. As Sir William Osler wrote, “Nothing will sustain you more potently than the power to recognize in your humdrum routine... the poetry of the ordinary man, of the plain, toil-worn woman, with their loves and their joys, their sorrows and their griefs.”²

These moving moments constitute an astonished harvest of the heart. The way some physicians evoke, record, and reflect on these moments is through poetry, though in a larger sense, clinical encounters can themselves be poetry—at least if we slow down and pay attention. In recent decades, as medical technology has rapidly improved diagnosis and treatment, more and more physicians report dissatisfaction with their profession, an irony that recalls John Knowles’ (AΩA, Washington University in St. Louis School of Medicine, 1951) well-known 1977 book about health care in the United States, Doing Better and Feeling Worse: Health in the United States.³ Technology itself is not to blame for this, except in the sense that its dazzle has distracted medical educators and clinicians from maintaining a focus on caring for the patient. They have tended to withdraw from the poetry of medicine.
William Carlos Williams (AΩA, University of Illinois, 1908) was a family doctor in Rutherford, New Jersey, for more than 40 years, until his retirement after a stroke in 1951. While devoting his days to medical practice, in the evenings he created the plain-language style of poetry that ultimately made him one of the most influential American poets of the 20th century. His neighbors and patients considered his poetry a strange, but harmless, hobby. In “Patterson” Williams gives voice to their sentiments:

We’re so proud of you!
A wonderful gift! How do you find the time for it in your busy life? It must be a great thing to have such a pastime. But you were always a strange boy. How’s your mother?  

Williams’ response came in another poem, “Asphodel, That Greeny Flower,” where he wrote:

It is difficult to get the news from poems yet men die miserably every day for lack of what is found there.

It is true we can’t get the news from poetry, we can’t learn about the latest antibiotics or immune modulators, or about the latest health insurance arrangements, so what does Williams think is so important that we might die if we don’t find it?

As a junior faculty member in Pittsburgh, I worked at a community health center in Terrace Village, the city’s largest public housing project. With its institutional buildings and drab, cracked streets, the place was nothing like a village. The clinic was one of the few safe places for people to socialize. I remember one woman who had lived in the projects since President Roosevelt cut the ribbon opening it in 1943. This lonely widow had multiple medical problems, and lived in constant fear of the “hoodlums” who had taken over Terrace Village. I hated to see her name on my office schedule because her symptoms never improved, her medications always caused side effects, and, according to her, I was “too young to know what I was doing.” I wrote a poem that illustrates what happened when she appeared in my office just before Easter, wearing an incongruous white lace dress.

The Act of Love
How foolish Celia must look to the Haitian cab driver on the Medicaid run!

She wears a white communion dress the week before Easter, a sign she brings me something more pressing than the pain in her shoulder and the son who doesn’t talk to her because his wife is embarrassed. Her hips creak in conversation, her knees grind, but even crepitant joints are modestly silent and stand aside when Celia hands me a potted plant for my office—an act of Christian love, she says, not a sign of being personal.

As for me, I’m stunned out of the ordinary anger at failing to help her by the waxy-leaves of her gesture and I receive this wafer of the season, heartbroken for no reason.
I was caught short by the unexpected gesture of gratitude from this chronically dissatisfied woman. I tried to use the language of poetry as a lens through which to glimpse the deeper meaning of my work as a doctor, and my relationship with Celia. Plenty of days I’ve been tired and distracted, angry with myself, and my patients. I’ve often consciously distanced myself from people like Celia. Nonetheless, somehow, on that occasion, empathy poured in, and we connected.

When I say medicine needs poetry, I’m speaking of these moments of insight, and awareness. I’m not suggesting that all physicians should write, or even read, poetry. Rather, I’m saying we need to pay attention to those “aha” moments that sustain us and make us better healers, if we respond appropriately to them.

Many years ago, I received an urgent Friday afternoon consult from the general surgery service. The patient, an irascible middle-aged man, 24 hours post-cholecystectomy, had become agitated and combative. The patient was paraplegic secondary to polio as a child, and a heavy smoker with chronic obstructive pulmonary disease (COPD). The surgeons thought he had incipient delirium tremens (DTs) so they snowed him with Serax and thiamine, even though the patient repeatedly complained, in no uncertain terms, that he didn’t drink. I wasn’t enthusiastic about managing this difficult patient over the weekend.

The patient was restrained in his bedside chair. He had a pockmarked face, long, greasy hair, a big red nose, tattoos on both arms, and a foul mouth. At first he seemed delirious and paranoid. However, when he yelled for me to leave him alone because his mouth was too dry to talk, I went down the hall and got him a carton of apple juice. The man was so flabbergasted that I had responded to his implied request, he began to talk sense. A more thorough evaluation revealed that his agitation and disorientation was caused by an anesthetic reaction, rather than alcohol withdrawal.

Subsequently, I became this patient’s internist. Aside from COPD and hypertension, he suffered from a festering case of anger. Every time he’d come to the office he’d ruminate about how badly he was treated in the hospital. “I haven’t had a drink in years,” he’d grouse. “They thought I was a drunk just because I have a big nose and ain’t been educated at Harvard.” (He had rosacea.) “Those slick bastards wouldn’t listen to me!”

One night I sat down and wrote a poem from his perspective, giving him the voice he needed to express his frustration and rage. This wasn’t difficult because I could tap into my own emotional memories of being insulted, ignored, misunderstood, and condescended to—memories I suspect we all have. Thus, the poem “I’m Gonna Slap Those Doctors” turned into a diatribe arising from the speaker’s sense of vulnerability and alienation.

I’m Gonna Slap Those Doctors

Because the rosy condition makes my nose bumpy and big, and I give them the crap they deserve, they write me off as a boozer and snow me with drugs. Like I’m gonna go wild and green bugs are gonna crawl on me and I’m gonna tear out their goddamn precious IV.

I haven’t had a drink in a year but those slick bastards cross their arms and talk about sodium. They come with their noses crunched up like my room is purgatory and they’re the goddamn angels doing a bit of social work. Listen, I might not have much of a body left, but I’ve got good arms—the polio left me that—and the skin on my hands is about an inch thick. And when I used to drink I could hit with the best in Braddock. Listen, one more shot of the crap that makes my tongue stop and they’ll have something on their hands they didn’t know existed. They’ll have time on their hands. They’ll be spinning around drunk as skunks, heads screwed on backwards, and then Doctor Big Nose is gonna smell their breaths, wrinkle his forehead, and spin down the hall in his wheelchair on the way to the goddamn heavenly choir.

When I showed the poem to the patient, he literally bounced up and down in his wheelchair, although managing to disguise any hint of softness behind a gruff, “Damn right, doc!” In retrospect, the gift of this poem was probably the single most therapeutic act I ever did for this patient. By helping to heal the memories that obsessed him, it created a bond between us. To his further delight, the poem appeared months later in Annals of Internal Medicine. For years he carried a crumpled copy of that page in his wallet, never failing to brag about it to his friends.
The moral qualities of a physician
For at least 250 years, medical writers have agreed that physicians need to work to counteract the tendency of medical practice to pervert humane values and virtue. In 1772, John Gregory, Professor of Medicine at the University of Edinburgh, wrote, of the moral qualities of a physician “the chief of these is humanity, that sensibility of heart that makes us feel for the distress of our fellow-creatures...” Thus, he warned his students to maintain “a gentle and humane temper” despite “being daily conversant with scenes of distress.”

In 1889, Osler told the medical graduating class at the University of Pennsylvania that they should face “the exigencies of practice with firmness and courage (but) without, at the same time, hardening the human heart by which we live.”

In 1927, Francis Peabody (AΩΑ, Harvard Medical School, 1906) warned that hospitals create a hostile environment for humanism, and urged his students to consciously commit “time, sympathy, and understanding” to creating a “personal bond” with their patients.

And, Thomas Inui (AΩΑ, Johns Hopkins University, 1988, Alumni), in a 2003 report to the American Association of Medical Colleges (AAMC) wrote, “What the literature and rhetoric of medicine lacks is a clear recognition of the gap between these widely recognized manifestations of virtue in action and what we actually do in the circumstances in which we live.”

All of these physicians viewed medical education as a lifelong process of character formation, rather than just an accumulation of facts and technical skills.

Over the last 40 years, medical educators have responded to our diminishing astonished harvest in many ways. George Engel (AΩΑ, Johns Hopkins University, 1938) proposed one of the first remedies in 1972 with his biopsychosocial model. He conceptualized a conflict between biomedicine—which was developing rapidly and effectively—and biopsychosocial medicine, a new model, or paradigm, based on understanding of the patient as a whole person, including the psychosocial context of illness and patient care. There was a great deal of talk, and some curricular activity in this direction, but it was unclear what the new model meant in practical terms.

After a few years, a new remedy swept through the halls of academe: communication skills, medical interviewing, and the clinical encounter. Its purportedly radical idea that the medical interview was not just a template filled with questions and answers, but rather an interactive process. The term “poor historian,” with which clinicians are still apt to label some of their patients, was perhaps more appropriately applied to the clinician. In fact, the doctor, not the patient, was the poor historian. Medical interviewing courses sprang up throughout the country. Standardized patient programs appeared, and textbooks devoted to clinical interviewing and the physician-patient relationship were written. The new approach—active listening, open-ended questions, facilitative responses—wasn’t difficult to learn. Yet, the hospital environment tended to devalue these skills, and students were rarely encouraged to develop them once they entered the clinical setting.

Around the same time, Lawrence Weed argued that medicine had come to devalue the patient’s subjective experience. He attempted to remedy this situation by developing the problem oriented medical record (POMR). By creating a structural category called “problems” to replace the narrower “diagnoses,” Weed believed the patient’s subjectivity—symptoms, dysfunctions, anxieties, and other concerns—could be brought to the forefront and attended to. Henceforth, subjective and objective would be given equal weight. The educational establishment latched onto the structure of Weed’s system, and POMR became de rigeur throughout medicine. However, in the process, its driving spirit was abandoned: subjective comments became progressively rushed and cursory, while objective data metastasized everywhere.

As the decades progressed, the sense of frustration and personal loss among physicians grew, and the internal satisfactions of medicine continued to diminish. Many attributed this to mounting external pressures, like insurance arrangements, malpractice crises, and endlessly increasing regulations. Physicians began to advise their children to avoid a career in medicine. Medical educators kept trying to capture the lost spirit of doctoring with new concepts, new models, new approaches. Some of the most prominent are:

1. The medical professionalism movement, endorsed by the American College of Physicians, the AAMC, the American Council of Graduate Medical Education, and other professional organizations, which seeks to revive traditional medical virtue in the 21st century context.

2. The narrative medicine movement, most eloquently articulated by Dr. Rita Charon, which teaches physicians...
to develop the ability to hear “the narratives of the patient, grasp and honor their meanings, and be moved to act on the patient’s behalf.”

3. The mindfulness and reflective practice movement, which seeks to teach physicians to listen attentively and reflect on their feelings and behavior.

4. The systems-based concept of patient-centered medicine, which makes the simple, and hopefully obvious, point that medical care is about caring for the patient, and not primarily about doctors, procedures, and diagnoses.

5. The medical humanities movement, which seeks to preserve and enhance our sensibility as physicians by introducing literature, creative writing, philosophy, history, art, and other disciplines into medical education.

Each of these seems to be reaching for the same goal, although their cognitive frameworks and intermediate endpoints are different. What narrative medicine, reflective practice, medical humanities, and patient-centered care all seek is to make us better healers. However, an underlying requirement for this is that we develop our ability to experience “the poetry of the commonplace... the loves and joys and sorrows and griefs” of our patients.

**Medical humanities**

The term “medical humanities” is often used to reflect the general concept that knowledge of history, literature, religious studies, art, and creative writing can help students increase clinical skills, like empathy, reflectivity, and cultural competence. The label is admittedly vague. Rafael Campo wrote that, as a specific concept, medical humanities seems “utterly exhausted, attenuated by decades of trying to encompass all that the invincible biomedical model of medicine actively ignores; it even risks sounding petty and adversarial, as if medicine were unmittingly inhumane.” Nonetheless, Campo states, “Many of us find ourselves looking instinctively to the humanities as a source of renewal, reconnection, and meaning.”

A liberal arts education constitutes far better preparation for medical school, and a life in medicine, than does today’s typical pre-med science degree. Abraham Flexner (AΩA, Raymond and Ruth Perelman School of Medicine at the University of Pennsylvania, 1946, Honorary), the man who created the modern medical school curriculum, shared the same perspective. He wrote that a physician should have a liberal educational experience requiring ethical valuation in the social context. He said, medicine “is today sadly deficient in its cultural and philosophic background.”

Some educators believe this can be remedied by introducing more humanities teaching into the medical curriculum. David Doukas and his colleagues in the Prime Project wrote, “such education should become an essential component of the curriculum because it would equip medical students with the conceptual and clinical tools of professionalism and humane care.”

Medical humanities (including poetry!) can provide tools, insights, and directions to follow. The same is true of narrative medicine and other forms of educational and institutional renewal. However, humanism, not new disciplines or techniques, is the goal, and humanism develops from within.

In 1986 I took care of an elderly patient, a former coal miner, who was dying of metastatic lung cancer. He had developed pneumonia, and was hospitalized for terminal care. We had started a morphine drip to ameliorate his air hunger and severe pain. I remember standing by his bedside, and for some reason, his chest X-ray was there in the room, and I held it up to the light to read. The patient reached out, pulled my hand to his lips, and kissed it. He died shortly thereafter. Some weeks later, I wrote a poem about this patient and gave it to his two daughters, who had taken remarkably good care of him during the preceding several months.

**The Man With Stars Inside**

Deep in this old man’s chest, a shadow of pneumonia grows.
I watch Antonio shake with a cough that traveled here from the beginning of life.
As he pulls my hand to his lips and kisses my hand, Antonio tells me for a man whose death is gnawing at his spine, pneumonia is a welcome friend, a friend who reaches deep between his ribs without a sound and puff! a cloud begins to squeeze so delicately the great white image of his heart.

The shadow on his X-ray grows each time Antonio moves, each time a nurse smooths lotion on his back or puts a fleece between his limbs. Each time he takes a sip of ice and moist chest shakes with cough, the shadow grows.
In that delicate shadow
is a cloud of gas
at the galaxy’s center,
a cloud of cold stunned nuclei
beginning to spin,
spinning and shooting
a hundred thousand embryos of stars.
I listen to Antonio’s chest
where stars crackle from the past
and hear the boom
of blue giants, newly caught,
and the snap of white dwarfs
coughing, spinning.
The second time
Antonio kisses my hand
I feel his dusky lips
reach out from everywhere in space.
I look at the place
his body was,
and see inside, the stars.?

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In the era of the first African-American United States president, African-Americans remain under-represented among physicians, and especially among medical faculty and researchers. The long career of Harold L. May, MD, MPH, FACS, provides insight into the two-century-long process by which African-Americans struggled to gain improved access to quality education, and strove to alleviate suffering among the poorest and most neglected in the world.

May was born in 1926 in Peekskill, New York. Son of a Methodist minister from Jamaica, his family moved to Poughkeepsie where he attended high school. Encouraged by his parents to aim high, he applied to Harvard College and was admitted in 1944.

Tuskegee University

During World War II, May volunteered for military service and was selected for the famous Army experiment in training African-Americans as combat pilots at Tuskegee University in Alabama. Founded in 1881 by the State of Alabama as Tuskegee Normal School for Colored Teachers, Tuskegee Institute (now University) is located in Macon County, about 40 miles east of Montgomery.

A 25-year-old African-American teacher from Hampton Institute in Virginia, Booker T. Washington, was hired as principal. Idolized by many African-Americans including May’s father, Washington energetically worked to expand
the school from one room in a church to an institution with a $1.5 million endowment in 1915. He emphasized self-reliance through agriculture and the trades—many campus buildings were constructed by students.

May was still in pilot training when WWII ended in 1945, yet his experience of the Tuskegee concept of self-help and community development remained a life-long influence.

Harvard Medical School

After the war, May finished premedical preparation at Harvard College, and in 1947 entered Harvard Medical School (HMS), graduating in 1951, one of only two African-Americans among the 144 HMS graduates that year.

HMS was founded in 1782 as the third U.S. medical school. Although HMS admitted three African-Americans in 1850, they were soon expelled by Dean Oliver Wendell Holmes in response to protests of the other students. It was not until 1869 that an African-American graduated from Harvard Medical School.²

Having overcome obstacles to education posed by race, May faced a new personal challenge that began in his second year of medical school with the emergence of progressive visual impairment caused by keratoconus. He was attracted to surgery but doubtful of the wisdom of pursuing it because of his diagnosis. Instead, with his vision improved by the use of hard contact lenses, he did a medical internship at the University of Minnesota Hospital. He followed that with a year of medical residency on the Harvard Service at Boston City Hospital. While there, having felt a call to become a medical missionary to the poor in Africa or India, and anticipating the need for surgical skills in an isolated outpost, he applied for a general surgery residency at Massachusetts General Hospital (MGH), despite having been rejected there earlier for a medical internship. Thanks to Chief of Surgery Edward D. Churchill (ΩA, Harvard Medical School, 1919), in 1953 May became the first African-American surgical resident since the hospital’s founding in 1811.

Midway through his third year of surgical residency, both of May’s eyes developed corneal ulcers caused by prolonged use of hard contact lenses. With the ulcers, he was nearly blind. He offered to resign his residency, but Churchill instead gave him an unlimited leave of absence to provide time for his eyes to heal.

During the healing process, May went to his parents’ residence, a historic site in Auburn, New York. May’s parents lived in the Harriet Tubman Home, which had been willed to the African Methodist Episcopal Zion Church in 1913.

Although he prayed for healing, May was fully resigned to a future as a blind pastor. Of the many articles that his
father read to him during their months spent together, one caught his interest in a special way, although he could not envision any specific relevance of the article to his personal future at that time. It described a hospital that would soon be opening in Haiti. The Albert Schweitzer Hospital was being built by William Larimer “Larry” Mellon (AΩA, Tulane University, 1982, Alumni), a son of the founder of Gulf Oil.

Although corneal transplantation was not widely available at the time, Churchill called May back to MGH in the spring of 1956 to receive a corneal transplant. The operation was a success, and May’s vision was restored in one eye!

During convalescence May accompanied his parents to their birthplace in Jamaica. While there, serving in the Montego Bay Hospital for six months to learn tropical medicine practice, he was deeply moved when he learned of the desperate poverty and lack of health care prevailing in nearby Haiti. He felt an irresistible call to visit Haiti before returning to Boston for his second corneal transplant.

May arrived in Haiti in December 1956, two days after a coup d’état had deposed its president.

**The history of Haiti**

The island known as Hispaniola was inhabited by the Taino people who called it Haiti (“land of high mountains”) when Columbus ran aground there in 1492 and claimed it for Spain. Later, France claimed the island and Spain ceded the western portion in 1697. The French imported tens of thousands of African slaves who came to outnumber whites ten to one. Triggered by ideas of the French Revolution, the slaves revolted in 1791, forcing the abolition of slavery in Haiti in 1792. However, the revolt continued. After losing 50,000 troops to war and disease the French withdrew in 1803, and the more than 700,000 blacks declared independence on January 1, 1804, restoring the name Haiti.

In the 19th century, France threatened invasion to extract costly reparations paid until 1947. In the 20th century, the U.S. invaded Haiti, occupying the country from 1915 to 1934. By 1950, Haiti had a population of 3.1 million. In 1957, Francois “Papa Doc” Duvalier was elected president, using dictatorial means to remain in power until his death in 1971.

Exploited by rich countries, bankers, corrupt governments, and a small Haitian elite, Haitians have long suffered from poverty, and Haiti is the poorest nation in the western hemisphere. Malnutrition, lack of access to potable water and latrines, high infant and child mortality, malaria, typhoid, and tuberculosis have been endemic. In 1983, life expectancy at birth was 48 years, and the literacy rate was less than 40 percent.

**A new Haitian hospital**

May arrived at the Albert Schweitzer Hospital (Hôpital Albert Schweitzer/HAS) early in January 1957, six months after its opening. The medical staff of the hospital was almost exclusively made up of short-term physicians, with the exception of Mellon. On the day following May’s arrival, three of the five-member medical staff left. When they met, Mellon, with great urgency, asked May to stay and help staff the young hospital. Able to do basic surgery...
with monocular vision, May welcomed the opportunity to join the HAS staff.

He had fallen in love with Haiti and with its people.

After six busy months, May returned to MGH for his second corneal transplant. With his binocular vision restored, he returned to Haiti for six months, then completed his surgical residency at MGH in December 1959.

May returned to HAS in January 1960, to assume the role of Chief of Surgery. He soon met and married Agnes Martens, a Canadian nurse, who had joined the HAS staff in 1959.

Situated in central Haiti in the Artibonite Valley, HAS was a modern, well-equipped hospital where May could perform any operation that he had done at MGH, and more. Since HAS was the last hope for many patients who could not receive the treatment they needed from any other hospital in Haiti, he treated many patients for conditions that he had never seen before. Such was the case with a young patient who had a tumor growing, for many years, on the left side of her face. May was able to perform the long operation that removed the tumor and brought the patient great relief.

May was pleased when Frank Lepreau, an experienced surgeon, joined the HAS staff in 1964. May and Lepreau worked as a team, with Lepreau working as the Medical Director. By 1970, the facility had grown from 80 beds to 133 beds, with an average daily census of 160, providing 60,000 outpatient visits, 3,500 admissions, and 2,500 operations annually. One surgeon wrote, “It is like those old open wards at Hopkins, Cincinnati, and the Brigham—no insurance forms, no committee work, just surgery.”

In 1960, when May began work at HAS, the world’s population was about three billion. Today, an estimated five billion of the world’s seven billion people lack access to the basic surgical care May and his team provided at HAS.

**A community elementary school**

In 1962, May took on an additional role as the lay pastor of the small non-denominational church, primarily made up of HAS employees and members of the local Haitian community. Fully realizing that Haiti’s hopes for its future depended on educating its children and preparing them for leadership roles in Haiti’s development, the church members opened an elementary school, Ecole La Providence. The school started with a kindergarten and first grade, with room for 75 children, but 750 children registered! Plans were made for children who were accepted to help those who were not.

The school added one grade every year, with its curriculum expanded from academic subjects to include active engagement in agricultural development on a 55-acre plot of land. Parents were included in the agricultural learning process.

May hoped that as the yearly growth and development of the school continued, it would become an integral part of the hospital’s growing public health and community...
development programs. He envisioned the school and hospital jointly serving as a center for Haiti’s sustainable development—a preparatory school for some of Haiti’s teachers, doctors, agricultural extension agents, nurses, and future leaders. The Tuskegee Institute was his model, but The Haiti Institute would be uniquely Haitian.

In July 1969, when the first students completed their primary school years, and the school was ready to grow to the next level, Mellon decided that the hospital’s charter would not permit the school to grow beyond the primary school level because the hospital’s mission focused on health care, not education. The school was moved to a nearby town, and its ownership transferred to a Haitian organization that incorporated Ecole La Providence and its mission as part of their own.

Going home to Boston

With the well-being of Ecole La Providence and the continuity of care of the surgical patients secure, May turned his attention back to America. In July 1970, he was recruited to serve as the director of the newly formed Peter Bent Brigham Hospital (PBBH) Division of Community Medical Care.

Since the new division was PBBH’s prime connection to the community, May learned much about Boston’s health care system, from preventive care to emergency care. He spent equal time supporting the development of the city’s newly organized health centers, and focusing attention on Boston’s Emergency Medical System.

May was appointed chairman of the Emergency Services Committee of Region VI, including Boston and a number of its neighboring communities. One of his responsibilities was to lead the development and testing of the regionwide medical disaster plan—the forerunner of the disaster plan that was mobilized decades later in the citywide response to the Boston Marathon bombing in 2013. He was the leader of a citywide disaster drill, a simulated plane crash at Logan airport, that took place on Saturday, June 21, 1974—the same day that Judge Arthur Garrity announced his decision to order school busing to desegregate Boston’s schools, a decision that unleashed a firestorm reaction in Boston.

He developed and taught an emergency medicine course for fourth year students for which he received the Faculty Prize for Excellence in Teaching twice. He also edited a textbook of emergency medicine.

Facilitating his work in the health care system, May obtained a Master of Public Health degree at Harvard School of Public Health in 1974.

Another calling to care for the disenfranchised

In 1975, May unexpectedly received a call to serve
individuals institutionalized with developmental disabilities. A member of the Home Care Service invited May to rounds at the Wrentham State School.

Opened in 1910, the state facility for the residential care of persons with developmental disabilities had a population of 1,250. In the 1970s, litigation over poor conditions at Wrentham and other facilities in Massachusetts led to a court order for improvement.

From 1975 to 1994, while maintaining his HMS and PBBH (later Brigham and Women’s Hospital/ BWH) affiliations, May served as Wrentham’s Director of Medical Services, shifting the culture from “warehousing” residents to valuing each individual. He discovered the importance of providing support that helps each individual to achieve his/her potential via individual support plans, and the need for interdisciplinary teamwork to develop and fulfill each individual’s plan.

May’s advocacy made the Wrentham residents welcome at PBBH.

By 1994, many Wrentham residents had been moved into the community, and the resident population had shrunk to 500.

**Transforming social services**

After 19 years of service at Wrentham, May retired on September 1, 1994. The next week, he read a one-page article in the September 12th issue of *Newsweek* reporting the death of an 11-year-old boy who had allegedly been shot and killed by fellow members of the Black Disciples gang in Chicago, several days after the boy had shot and killed a 14-year-old girl. The story was also featured in *Time Magazine*, with the boy’s face on the cover.

The first paragraph of the *Newsweek* article captured May’s attention:

In 1986, a child-abuse worker at a Chicago hospital said something that made Robert Sandifer (Yummy) snap. “F--- you, you bitch!” the boy shot back. He then grabbed a toy knife and put its blade to the women’s arm. “I’m gonna cut you,” he warned. At the time, Robert was less than three years old.

As May read the article, and the *Time Magazine* article one week later, he learned about Yummy’s drug-addicted mother, his father who was jailed on drug and weapons charges, and about Yummy’s troubled life of petty crime. The articles indicated that Chicago’s human services, justice, and education systems struggled to provide the supports that Yummy and his family needed, and many didn’t start soon enough. When the hospital care-givers learned that the teenage mother already had two sons, the first of whom was born when she was 15-years-old, did this information not serve as a red flag? What is society’s role in protecting innocent babies by assuring the development of support systems?

The answers came to May: all of the systems of society—health care, education, economic, political, justice, —should work in harmony, as do the systems of our bodies. The way to align all of these systems is to surround each of society’s babies and their families with the support systems they need for healthy development. And these supports should start for each baby at the beginning of life.

Since May had no expertise in child development, he met with T. Barry Brazelton (AΩA, Columbia University, 1943, Alumni), a pediatrician, and one of the world’s foremost authorities on child development. Brazelton provided May with some of his writings on family systems and child development—articles in which he points out that from the moment of birth human life is a progression from one level of development to another. As it is with each baby, so it should be with society.

**We are FAMILY**

Several months later, May realized the biological fact that we are one family, the organizing system of all healthy societies.

FAMILY (Fathers And Mothers Infants eLders and
Youth) was incorporated in 1997. In 2000, a FAMILY Liaison to establish supports for children and their families, starting with the kindergarten class, was established in the Lucy Stone School, an elementary school in the Codman Square section of Boston.

The program grew, working in close partnership with Wheelock College. A Family and Community Coordinator position was developed and subsequently adopted by 15 elementary schools.

When the Lucy Stone School was closed five years later because of its small size, the senior FAMILY liaison, who was working for the city program, was promoted to a senior position of leadership in a large nearby elementary school, which accepted all of the Lucy Stone School students.

During this time, May also established the FAMILY Global Positioning System as the organizing system for all healthy societies—from the smallest to the largest—based on the maxim:

Always act as though we are all members of one family—because we are. FAMILY’s mission is to create an environment in which all children and families can thrive.

**A life of commitment to the underserved**

May overcame the tremendous barriers posed to an African-American seeking top-quality higher education in the 1940s and 1950s. He graduated from Harvard Medical School, and became the first African-American surgical house staff member at Massachusetts General Hospital.

His desire has never been to achieve wealth or fame, but to serve the human family in Haiti, Boston, the Wrentham Developmental Center, and all communities.

A lifelong learner, May believes that the poor, the mentally challenged, and all families deserve the best care and life opportunities available regardless of their socioeconomic status. At the age of 91, May continues to serve the underserved, working as the volunteer director of FAMILY.

His is a passion that knows no bounds.

**Acknowledgment**

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**References**


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Do students lose empathy in medical school?

By Robert S. Brown, MD

Dr. Brown (AΩA, Columbia University, 1962), is Associate Chief for Academic Affairs, Nephrology Division, Director of Regulatory Affairs in the Department of Medicine at Beth Israel Deaconess Medical Center; and Associate Professor of Medicine at Harvard Medical School in Boston.

“There but for the grace of God, go I.”
—John Bradford (circa 1510–1555)
referring to prisoners facing execution

Empathy, defined as “the vicarious awareness of the experiences or emotions of another,” is a desirable quality for physicians as “empathic communication skills promote patient satisfaction and adherence to treatment plans while decreasing the likelihood of malpractice suits.” Yet, in their article “Vanquishing Virtue: The Impact of Medical Education,” John Coulehan (AΩA, University of Pittsburgh, 1969) and Paul Williams (AΩA, Stanford University School of Medicine, 1973) quote a fourth-year medical student before graduation:

“When I arrived in medical school...I was excited about addressing important issues because, as medical students, I was sure that we would have some clout and certainly a commitment to the well-being of others....However, medical school is an utter drain....And then during the clinical years, life is brutal. People are rude, the hours are long...physicians must regain their humanity after completing their training. For my part, I tried not to lose it, or at least to hold onto it as long as possible....Furthermore, I’ve become numb...I just try to get through school in the hope that I will move on to bigger and better things when I have more control over my circumstances.”

The authors then ask, “How does professional socialization alter the student’s beliefs and value system so that a ‘commitment to the well-being of others’ either withers or turns into something barely recognizable?”

That medical students lose empathy, most prominently during the clinical training of the third year, seems to be an accepted conclusion by most experts. Changes in teaching, particularly addressing what has been termed the “hidden curriculum,” have been promulgated to respond to this issue. However, what is the evidence that empathy is really diminished during medical school?

Various attempts to quantitatively measure empathy in medical students have generally confirmed a decline in empathy during medical school. This was noted in nine of 11 studies, including eight from the United States, and reported in a recent review covering studies from 1990 to 2010. The authors found similar declines in empathy in seven studies during residencies in the U.S. However, in three studies from the United Kingdom, empathy was either unchanged or increased significantly by the final year. And, in other countries, longitudinal results of
medical students have reported empathy to be increased, as in Portugal\textsuperscript{9} and Ethiopia\textsuperscript{10} or decreased, as in Canada\textsuperscript{11} and Poland.\textsuperscript{4}

Since empathy seems difficult to assess objectively, what is the validity of tests measuring its decline in medical students? In a study of 50 relevant papers utilizing 36 different instruments to measure empathy\textemdash20 in medical students alone\textemdashonly eight demonstrated reliability and validity, and none had “sufficient evidence of predictive validity for use as selection measures for medical school.”\textsuperscript{12} Similar results of low, or only marginal, predictive reliability and validity have been found by others.\textsuperscript{13}

The most commonly cited measure of empathy has been the Jefferson Scale of Physician Empathy.\textsuperscript{14,15} This tool has found higher empathy scores in women, and cognitive specialties\textemdashpsychiatry and internal medicine\textemdashwhen compared to technical specialties\textemdashanesthesia, radiology, and surgical specialties.\textsuperscript{3,8,14,16} When a longitudinal study done yearly using the Jefferson Scale\textsuperscript{3} showed a significant decline of scores after the third year, the authors concluded that empathy erodes in the clinical years of medical school. The questions of the Jefferson Scale student version are shown for readers to assess for themselves whether this scale will yield an accurate measure of student empathy, or may be assessing sensitivity and even beliefs, as well. Some studies have shown a disparity between lower test scores of empathy and self-reported empathy,\textsuperscript{16} or have reported an increase in empathy by observed behavior despite a decrease by the Jefferson Scale after the third year.\textsuperscript{17}

Another study using a similar survey tool, the Balanced Emotional Empathy Scale,\textsuperscript{1} also found that medical students appear to lose empathy after the first year and third

\textbf{The Jefferson Scale of Physician Empathy Student Version}

1. Physicians’ understanding of their patients’ feelings and the feelings of their patients’ families does not influence medical or surgical treatment.
2. Patients feel better when their physicians understand their feelings.
3. It is difficult for a physician to view things from patients’ perspectives.
4. Understanding body language is as important as verbal communication in physician-patient relationships.
5. A physician’s sense of humor contributes to a better clinical outcome.
6. Because people are different, it is difficult to see things from patients’ perspectives.
7. Attention to patients’ emotions is not important in the history taking.
8. Attentiveness to patients’ personal experiences does not influence treatment outcomes.
9. Physicians should try to stand in their patients’ shoes when providing care to them.
10. Patients value a physician’s understanding of their feelings which is therapeutic in its own right.
11. Patients’ illnesses can be cured only by medical or surgical treatment; therefore, physicians’ emotional ties with their patients do not have a significant influence in medical or surgical treatment.
12. Asking patients about what is happening in their personal lives is not helpful in understanding their physical complaints.
13. Physicians should try to understand what is going on in their patients’ minds by paying attention to their nonverbal cues and body language.
14. I believe that emotion has no place in the treatment of medical illness.
15. Empathy is a therapeutic skill without which the physician’s success is limited.
16. Physicians’ understanding of the emotional status of their patients, as well as that of their families, is one important component of the physician-patient relationship.
17. Physicians should try to think like their patients in order to render better care.
18. Physicians should not allow themselves to be influenced by strong personal bonds between their patients and their family members.
19. I do not enjoy reading nonmedical literature or the arts.
20. I believe that empathy is an important therapeutic factor in the medical treatment.

Source: Academic Medicine, Vol. 84, No. 9/September 2009, page 1194.
The impression that there is at least a blunting of students’ empathy during medical school seems apparent, even if the evidence is less than compelling.

This loss of empathy, noted concomitantly with the initiation to clinical medicine in the third year, is surprising. In individuals motivated to learn the healing arts, we would suspect that exposure to patients who are ill or incapacitated would provoke exactly the opposite response. And, if readers think back to the first few patients that they saw in medical school, a memorable sense of empathy persists to this day.

Hence, rather than exposure to patients at the bedside, much of the blame for loss of empathy has fallen on shortcomings in teaching, and the effect of the hidden curriculum, described by Hafferty and Franks, as:

…”what students learn about core values of medicine and medical work takes place not so much in the content of formal lectures (i.e., the curriculum-formal)...but via its more insidious and evil twin, “the corridor” (i.e., the curriculum-hidden).7

The experiences of students that take place in the hospital halls or conference rooms may counteract the formal teaching of medical ethics and humanism in the classroom. The stress of training that leads to student and resident distress is generally accepted to thwart professionalism and facilitate the hidden curriculum,4,18,19 fostering expressions, attitudes, and jargon disrespectful of patients and antithetical to ethical behavior. However, the medical humor and slang that develops under stress, euphemistically called “gallows humor,” appears to serve a useful purpose,20 and moreover, it appears that medical students recognize quite well its inappropriate and derogatory perspective.21,22

In a moving article,5 Neal Chatterjee writes that as a third-year medical student:

I have seen entirely too many people naked. I have seen 350 pounds of flesh, dead: dried red blood streaked across nude adipose, gauze, and useless EKG paper strips. I have met someone for the second time and seen them anesthetized, splayed, and filleted across an OR table within 10 minutes...I have sawed off a man’s leg and dropped it into a metal bucket. I have seen three patients die from cancer in one night.5

How can anyone go through such experiences without a desensitization process? Who cannot, in a sense, “become numb?” There isn’t enough empathy in one physician to go around for all the sadness we experience. Desensitization is an essential occurrence in medical school, whether good or bad. If loss of sensitivity is construed as loss of empathy too, those characteristics are replaced with experiential objectivity, required knowledge for any good physician. Even recognizing that the evaluation of empathy is a subjective area, the evidence supporting a general loss of empathy by medical students is weak at best. And, to extrapolate that data to conclude that we are graduating physicians with diminished humanistic motivation seems unfair to medical schools and their faculties.

Vicarious empathy may not be exactly what the physician needs to retain. Smajdor, et al., argue “that ‘empathy,’ as it is commonly understood, is neither necessary nor sufficient to guarantee good medical or ethical practice.”23 So what is necessary? Compassion, “the awareness and acknowledgement of the suffering of another and the desire to relieve it” is the quality we must strive to inculcate or maintain in our medical students.24

If empathy has withered in medical school, has compassion diminished as well? The anecdotal data supporting such a conclusion actually suggests the opposite. Neither of the medical students quoted above have lost their compassion, or their empathy. Both have experienced the desensitizing effects of observing illness and death, but their concern for patients, and their distaste for poor ethical behaviors, confirm that their emotional compassion remains intact. And, I’m sure that neither medical student would suggest that their classmates have less compassion than they do.

A review of the literature yielded no controlled studies evaluating compassion among medical students, but an essay study of 52 graduating fourth-year medical students (46 percent of the class) at Northeastern Ohio University College of Medicine indicated that their compassion remained intact, nurtured by their role models and self-reflection.25

As a physician attending on the medical service with medical students, interns, and residents each year for more than 50 years, I can attest that the current professionals in training care for their patients as deeply as my contemporaries did in the past, likely more so. Perhaps the formal teaching of humanism and interpersonal communication skills25–27 has helped students deal with the intrinsic desensitizing process of medical school. Either way, in the end, they appear to have converted some vicarious empathy to real compassion, and that’s what we really want!
References


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The fork trembles as if moved by some unseen force oscillating with increasing intensity as portions of pancake and fried egg fly off into space, missing their intended destination.

Eyes opened wide with frustration show the distress of lost skills acquired long ago, now relegating their owner to sitting in anticipation.

Bending to this need I pick up a spoon perhaps the more useful implement in directing transit of the desired pablum and begin.

Reminded of feeding my own offspring in decades past a familiar process of scooping and aiming to the target, their response triggering my hand to repeat this cycle again and again.

Lips open and tongue extends like an eager nestling to receive sustenance with gratitude, with necessity and the expectation of completing our task together.

This we must all engage in with intention and regularity cloaking animal need in the finery of linen and silver separating us from this primal instinct of snarling gnashing teeth with only a thin veneer.

There is humanity in feeding one another the gift returned to the elder from those to whom he has provided the same without the thought that he might return to this place once again.

David True, MD, PhD
Fin de siècle SCIENCE INTERSECTING THE ARTS:

Puccini, Debussy, and radium therapy

By Gregory W. Rutecki, MD

Dr. Rutecki (AΩA, University of Illinois, 1973), is a physician in the Division of Internal Medicine, National Consultant Service, Cleveland Clinic in Ohio.

“It can be thought that radium could become very dangerous in criminal hands, and here the question can be raised whether mankind benefits from knowing the secrets of Nature. The example of Nobel is characteristic as powerful explosives have enabled man to do wonderful work. They are also a terrible means of destruction...I am one of those who believe with Nobel that mankind will derive more good than harm from the new discoveries.”

The early 20th century was truly a “best of times” for science. At the fin de siècle, in 1900, Max Planck awakened scientific thought from dogmatic slumbers with the Quantum Theory. Shortly thereafter, Einstein—with his Theories of Special and General Relativity—shattered long-held perceptions of how the universe, time, and energy are ordered. Space, time, and light would now be filtered through a remarkable, and at times, counterintuitive prism.

There would also be the work of Niels Bohr on electrons, their orbits, and complementarity. Marie and Pierre Curie discovered radioactivity emanating from the heretofore undiscovered elements of radium and polonium. But, not all discoveries would emerge from physics. The science of medicine would begin in parallel during this period. There would be Roentgen’s X-rays; Landsteiner discovered the blood groups in 1901; the germ theory of disease opened a door into microbiology and nascent vaccines; and Paul Ehrlich’s “magic bullet” would result in a scientific treatment for syphilis.

The time from “bench to bedside” in this era was

Above, pitchblende is a brownish-black rock consisting mainly of uranium chemically combined with oxygen. It forms crystals called uraninite. Once considered useless, it is now the main source of uranium and radium.
unusually brief. The progression of X-rays from Roentgen’s discovery in 1895 to their therapeutic application was rapid, and would be a first salvo in an unfinished war against cancer, the “Emperor of all Maladies.” As early as 1896 medical student Emil Grubbe tried to harness X-rays as therapy for breast cancer.

The arts were concurrently exploding with radically novel ways of presenting music. A sampling of early 20th century composers—Schoenberg, Stravinsky, Sibelius, Bartek, and Holst—reveals a revolution in compositional technique. Two contemporaries, Claude Debussy in France, and Giacomo Puccini in Italy, figure prominently in the history of classical music and opera.

Puccini and Debussy’s experiences with cancer reflect a historical intersection between early 20th century medical science in the form of radium, and their terminal malignancies. Debussy had rectal cancer and was treated with radium, while Puccini suffered from laryngeal cancer and died during radium therapy. Their stories open a window into an intellectually vibrant era when major discoveries ushered in medicine’s scientific age.

**Radium’s evolution to therapeutic agent**

Three radioactive substances were discovered between 1898 and 1900—polonium, radium, and actinium. Radium, the archetypal radioactive element, rapidly went from scientific curiosity to internationally accepted therapy for cancer.

Twenty-three cases of X-ray injury to tissue were published prior to January 1897. Leopold Freund successfully irradiated a hairy nevus in November 1896 in Vienna. Although the child who was treated was cured of the nevus, it took six years for her X-ray-induced ulcer to completely heal.

In 1900, the Friedrich Otto Walkhoff wrote, “...radium owns astonishing physiologic properties, an exposure of the arm to two 20-minute sessions has produced an inflammation of the skin." As early as 1903, Curie suggested that radium’s ability to induce flesh burns might presage the element’s potential in cancer therapy. In 1904, Robert Abbe demonstrated that varied lengths of exposure to radium positively correlated with the degree of tissue erythema and necrosis. Around the same time, French physicist Henri Becquerel found that he had an inflammatory lesion on the left side of his body which he attributed to a tube of radium carried in his waistcoat pocket, and Pierre Curie burned his forearm from exposure to radium.

Exposure to radium by chance damaged human skin. The longer the exposure, the greater the harmful effects on living tissue. Deliberate exposure to radium killed bacteria on a medium where it was known to reproduce rapidly. Curie, Becquerel, and Abbe saw a connection between radium-induced cellular damage and the dividing cells of malignancy.

One hurdle remained. How to get radium to internal, solid tumors such as cancer of the prostate, larynx, or anus? When in contact with exposed skin erythema would follow, but the tissue damage did not penetrate into deeper organs. “Afterloading,” or the technique by which a delivery system is established and then filled with radioactive medicine, was introduced. In 1903 in Munich, Hermann Strebel said, “I am now in a position to increase the effectiveness for radium for deeper seated pathological conditions...intra-tumoral application is carried out by inserting the radium, which is enclosed in the drilled tip of a small aluminum rod, directly into the center of the tumor.”

Multiple variations on this theme quickly followed. There would be “cystoscopic” radium instruments, and mechanical hands to hold the radium in place against the tumor. Treating tumors with radium was on the rise. As early as 1922, a series of 217 prostate cancer patients treated with radium was compared to an untreated group of 363.

**Puccini and Debussy undergo radium treatment**

The composers Puccini and Debussy were treated with radium via brachytherapy and afterloading, respectively. As they were just two of many who were receiving such treatment, patient records and accounts of the treatment were prevalent:

When the patient opened his mouth...a large septic mass, obviously inoperable, was seen to occupy the position of the tongue...(which was) displaced to the left. Nine days ago, six radium needles, 10 cm. long, the radium occupying 1.5 cm. at the pointed end, were pushed 5 cm. through this mass....They were pulled out 1.5 cm. after 8 hours, further in 12 hours, and removed 7 hours later, so that the tumor was radiated systematically from back to front during 27 hours by radium in 18 different positions....Two days later, one at once saw the tongue, and had to look for the tumor, the anterior part of which had almost disappeared.

Puccini, the composer of Manon Lescaut, La Boheme, Tosca, and Madame Butterfly was working on what would be his final opera, Turandot, in August 1921, when he complained, “I have a sore throat. Several otolaryngologists have examined me, some recommend one treatment, others...
another. I have been suffering from tonsillitis and pharyngitis for seven months."12 Over the following months, he exhibited hoarseness, weight loss, and cervical adenopathy that interfered with buttoning his collar.12 Finally, the sore throat had an explanation, a supraglottic mass was biopsied and diagnosed as cancer.12

In the early 20th century, palliative treatment was typically indicated for Puccini’s dire situation. The surgical option was a dangerous one. The first laryngectomy was performed in 1873 by Christian Albert Theodor Billroth on a 36-year-old theology teacher with laryngeal cancer.13 Billroth stated that the surgery was necessary in an effort to “tear this still young man from the arms of a certain and tortuous death.”14 During surgery, the pharynx and trachea were not separated.14 However, the surgery was both a success and a failure. The patient survived for seven months, but the Billroth approach led to fatal aspiration pneumonia.13,14

In 1909, D. Bryson Delevan observed, “I am compelled to believe that operations in general for the cure of
carcinoma of the larynx have...lessened the sum total of the duration of human life.”

Billroth’s reputation was such that no one dared to alter his surgical approach for years. As a result, Puccini was referred to Brussels for radium therapy under the care of Dr. Ledoux, an expert in the field of cancer therapy with radiation. Puccini’s radium treatment was prescribed via two disparate techniques.

First, in November 1924, a radium collar was placed externally over Puccini’s neck. Puccini described the treatment as:

“I am being crucified like Christ! I have a collar around my throat that is like torture. I have external X-ray treatment at the present, and then they will put crystal needles into my neck and make a hole, again in my neck so that I can breathe...the thought of that hole, with a rubber or silver tube in it terrifies me....What an ordeal! God help me....They assure me I will be cured.”

Bleeding was the initial complication, but it ceased, and Puccini’s appetite began to improve. The external treatment was followed by radium needle implants or brachytherapy on November 24. Seven radioactive needles were placed directly in the mass, and the procedure, accompanied by tracheostomy and nasogastric tube, took three hours and 40 minutes. Puccini explained, “I feel as though I have bayonets in my throat.”

Unfortunately, the maestro died November 29, presumably of a heart attack.

His untimely death had profound effects on his last creation, the opera Turandot. Despite Puccini’s physical deterioration, he did not expect to die. On September 6, 1924, Puccini met with Toscanini to discuss how he intended to finish the opera:

“Toscanini has just left here and all of the clouds have evaporated...I am sure that in his hands Turandot will have an ideal performance...I will have all the time required to finish the little that I still have to do....My throat seems better. Smoking does not bother me.”

All that was left was 36 pages of preliminary Puccini sketches. The responsibility of completing Turandot fell to Franco Alfano. A full year passed without a premier, and then Alfano presented his work to Toscanini. The conductor sent it back for extensive revisions. The ending is that second revision.

At the La Scala premier of Turandot, Toscanini put his baton down when Puccini’s text was halted by his death. He told the audience that at this specific point in the composition, Maestro Puccini died. He then left the stage without conducting Alfano’s revised ending. Toscanini never conducted the opera again.

Claude Debussy

“Nature alone has all the time in the world; mine is beginning to run out....mother nature is usually deaf to her children's suffering...I was at a point...of finishing 'La Chute de la Maison Usher' ('The Fall of the House of Usher' by Edgar Allan Poe), but the illness has quashed my hopes...I am suffering like a condemned man!”

Much less is known of Debussy’s symptoms at his presentation with rectal cancer. There is scant information on the manner in which his initial diagnosis was made. Much more is known about his struggle with the fatal disease as he communicated his personal ordeal through letters to friends.

Debussy first saw a physician in November 1915. He was apprised that he had rectal cancer and that it could be fatal. On December 15, he developed an intestinal obstruction and was treated with a colostomy, drained by an animal skin drainage bag.

Radium therapy was a choice available to Debussy in 1915:

Inoperable cases of cancer of the rectum have certainly found in radium a palliative and useful treatment....Thus in two cases which before the radium treatment were in a cachectic condition, we were afterwards able without colostomy to prolong their existence and enable them to resume their occupations for twelve and fifteen months respectively....The most favorable cases are those where the rectoscope can determine the exact site of the cancer...a tube of radium is fixed into the end of a catheter, and inserted either directly into the rectum or into a rectoscope...(for) 1-2 hours.

Debussy’s postoperative and radium therapy periods were painful:

“I've just started a new treatment. It is all shrouded in mystery and I'm asked to be patient...Good god!...After 60 days of various torture. I'm still cultivating my rectal flora...the disease is always one step ahead of me.”
Debussy noted the side effects from morphine hampered his composing:

...there was something broken in this curious mechanism that is my brain...this illness had to come at the end of a spell of good work...and in addition to all of this misery, there were four months of those morphine injections that turn you into a walking corpse and completely annihilate your will...was preparing to write that violin and piano sonata...but now, I do not know when the impulse to write will return. There are times when I feel as if I had never known anything about music."  

After radium treatment, Debussy was described as “very emaciated, his complexion sallow and ashen.” The composer’s subjective descriptions match those of his friends, “I don’t take this tattered body for walks anymore in case I frighten little children and tram conductors.”

From December 1915 on, Debussy was a very sick man in the hands of doctors and surgeons. In spite of operations and radium treatments he was in constant pain, and growing ever weaker. Nearly the whole of 1916 passed without his writing a single note of music. Life had become unbearably hard. “Since Claude Debussy is no longer writing music, he has no excuse for being alive,” he wrote.

There were moments of rally interspersed by despair,
“I cannot say that I feel any better, but I have made up my mind to ignore my health, to get back to work, and to be no longer a slave of this over-tyrannical disease.”18 But these moments would be short lived, “a terrible fatigue, a disinclination for all exertion, overwhelmed him. The lightest work exhausted him...there are mornings when the effort of dressing seems like one of the twelve labors of Hercules...'I have to fight against both disease and myself,' he added.”18

Alas, his pen was stilled, “Claude Debussy lived his last sorrowful days to the sound of the bombardment of Paris by airships and long-distance guns. He had not even the strength to allow himself to be carried down to the cellar of his house when warning was given of the approach of the enemy,” wrote one of his friends.18

The first generation war on cancer in retrospect

...there is a wave of enthusiasm for this line of treatment (radium) which threatens to be overwhelming, and will inevitably be followed by a reaction and much disappointment... (The) public are already obsessed with the idea that radium will cure any case of cancer however far advanced...They think that thousands of people are dying simply because they cannot afford radium...As a palliative measure...radium is by far the best agent we have ever had...so long as we entirely neglect to educate the public so that they will consult their doctors on the onset of the earliest symptoms.19

The luminaries of the fin de siècle in science, medicine, and music continue to impact thought and art.

Despite the untimely deaths of two musical giants, Puccini and Debussy, their extant creations are frequently played, and enjoyed, today. “Nessun Dorma” is one of the most popular arias in the history of opera. The same can be said for “Che gelida manina” from La Boheme. Among the many works from Debussy’s opus, “La Mer” continues as a crowning achievement of the Age of Impressionism.

Although the medicine of today has come a long way from the primitive use of radiation, the scientific discoveries of the early 20th century, and the patients who endured the treatments, were models for today’s physicians.

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I
n 1974, not long after an antenna was implanted in his skull, the British artist Neil Harbisson became the first person in history to be officially recognized as a cyborg. A cyborg—short for cybernetic organism—is a living thing formed from the integration of organic and mechanical parts.

Before becoming a cyborg, Harbisson struggled as an art student afflicted with achromatopsia, an extremely rare, congenital form of color blindness that allowed him to see only black, white, and shades of gray. After an antenna was implanted in his occipital bone, Harbisson, at age 22, acquired the ability to receive electromagnetic waves from the surrounding air, and transform them using an implanted computer chip into carefully programmed tones. Harbisson is able to hear colors, including those that people with normal vision cannot see.

Harbisson regards his antenna as no less a body part than any bone or tendon. When he was caught up in a public demonstration during which jostling by the police caused damage to his antenna, he felt manhandled, the victim of a particularly grievous form of personal injury.

Harbisson's success as a highly innovative color blind artist is meritorious, not only in its own right, but for the way it illuminates the under-appreciated nature of color

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By Rebecca M. Shulman
Ms. Shulman is a fourth-year medical student at the Lewis Katz School of Medicine at Temple University in Philadelphia, PA. Her essay tied for First Place in the Alpha Omega Alpha Honor Medical Society 2017 Helen H. Glaser Student Essay Competition.

Color blindness and its illuminations

By Rebecca M. Shulman
Ms. Shulman is a fourth-year medical student at the Lewis Katz School of Medicine at Temple University in Philadelphia, PA. Her essay tied for First Place in the Alpha Omega Alpha Honor Medical Society 2017 Helen H. Glaser Student Essay Competition.
blindness. Harbisson has spearheaded a highly visible campaign to prove that color blindness is no obstacle to achievement in the arts. His efforts are just the latest example of a long struggle to prove that its reputation as a disability, that squelches careers and shrinks the lives of its victims, is a grave oversimplification of a complex reality.

200 years of understanding color blindness

If color blindness is indeed a serious disability, it is curious that its existence was not suspected, or at least not commented upon, until 200 years ago, when the disorder struck John Dalton. In his youth, Dalton, a student of nature, had great difficulty identifying wildflowers, especially reddish ones. He described his defect to the Manchester Literary and Philosophical Society in 1794, at age 28, hypothesizing that his vitreous humor contained an abnormal blue pigment. But with the exception of his youthful botanical blundering (which was duplicated in his brother), Dalton's color blindness seems to have posed very few impediments. Dalton was a genius who regarded his visual defect as a mere curiosity, a bit of impersonal exotica, like a rare plant.

A devout Quaker who had taken a vow of sartorial modesty, Dalton at first declined the honorary Doctorate bestowed on him in 1832 by Oxford University, raising a religious objection to the ostentatious scarlet of the graduation gown. But the hectoring of his conscience was, in the end, forced to yield to the testimony of his vision. The gown was not scarlet. To his eye, it was the color of dried mud.

Dalton's theory of color blindness—that it arises from tinting of the vitreous humor—was met with general skepticism. It was soon replaced by what became known as the Young-Helmholtz theory, which today remains integral to the understanding of human perception. The ability to see color depends on the presence in the retina of cone cells, photoreceptors that contain pigments responding to different frequencies along the spectrum of visible light. The three types of cone cells can be described as red, green, and blue. These color descriptions are based on peak sensitivities that correspond to light of long, middle, and short wavelength, respectively. However, the sensitivities of the cones overlap significantly—red and green are particularly close, their peaks just 30 nanometers apart (a difference largely accounted for by a difference of 2 amino acids). The range of spectral response for each photoreceptor is broad, although somewhat less so for the blue cone.

The science of seeing color

Photoreceptors do not pipeline encoded wavelength information directly to the visual cortex. Every photoreceptor acting alone is, in a sense, color blind, capable of signaling only the rate at which it absorbs photons. Any change in the output of an isolated cone that is induced by varying stimulus wavelength can also be induced by a suitable variation in intensity. This is the principle of univariance, which implies that diverse wavelength-intensity combinations that produce an identical response from all three photoreceptor types will be perceived in the same way. Colored stimuli producing only a two-receptor match will be perceived by a person with normal vision to be of distinguishable hues.

These observations are summarized by indicating that normal human vision is trichromatic. Those afflicted by color blindness are almost always dichromatic, although as the number of functioning cone types is reduced, they will become monochromatic, or like Harbisson, achromatic. The dichromat relies on the contributions of only two photoreceptors—with perhaps an overlapping or weakly functioning third—and matches colors that most observers perceive to be different.

The principle of univariance is the basis of trichromacy, but it does not explain certain critical aspects of human vision: spectral colors as we perceive them form antagonistic pairs. For example, there is no color stimulus that is
perceived as a combination of red and green hues. The same is true for blue and yellow. This tendency of spectral colors to arrange themselves along either a red-green or a blue-yellow axis is accounted for by the principle of opponency. The physiologic basis of this principle resides in post-receptor processing. To single out one such process, midget ganglion cells behind the retina subtract the signals relayed by green cones from those of red cones before passing the encoded information to the lateral geniculate nucleus, a relay center in the thalamus. The brain simultaneously receives the information that a stimulus is red and that it is not green. This explains why a defect in the red photoreceptor—the most common variety of color blindness—is expressed as a failure to discriminate red and green.

The similar profiles of the red and green photoreceptors, their adjacent location on the X chromosome, and their nearly identical nucleotide sequences suggest that they arose from a phylogenically recent duplication of a single gene. The duplication made possible the red-green discrimination required to forage small ripened berries amidst the abundant backdrop of leaves.

But there were also negative consequences. The proximity and similarity of the genes for the red and green photoreceptors predispose during meiosis to misalignments and crossovers of the maternal and paternal X chromosomes. These, in turn, produce hybrid photoreceptors that discriminate red and green stimuli poorly.

Because it is usually X-linked, color blindness is predominantly a disorder of males. The gene encoding the short wavelength (blue) photoreceptor, dwells remotely on autosomal chromosome 7 in, relatively speaking, a genomic safe space. It is of much earlier provenance than its longer wavelength cousins by a billion years, and only about 45 percent homologous to them.

Blue-yellow color blindness does occur, but rarely. It can be inherited as an incomplete autosomal dominant, sometimes the result of poisoning or illness.

Dalton was thought to have been a protanope, the word for those with a defect of the first red, long wavelength photoreceptor. This is now known to be in error. The evidence was hidden in plain sight for decades, in a glass jar where Dalton's eyes, removed postmortem at his request, lay entombed, awaiting the technical advances that might unravel their secret.

After successfullylobbying the curators of the Manchester Literary and Philosophical Society, in 1995 researchers were given a portion of one of Dalton's eyes for study. At last, the surmising of the 19th century could be supplanted by the verdict of 21st century laboratory science.

DNA isolated from the retina of Dalton's left eye was shown to contain the gene corresponding to the long-wavelength (red), but not the middle-wavelength (green) photoreceptor. Dalton was a deuteranope. His diagnosis had been firmly and correctly made, even if delayed by 223 years.

**Daltonism**

The ease with which “daltonism,” as it came to be known, escaped notice for so many centuries is remarkable, and instructive. Dalton's many-faceted career, which included chemistry, meteorology, and the grammatical use of participles, provides dubiety as to whether color blindness need be a disadvantage in any domain. There is a great deal of discontent with the way color blindness has been categorized, and stigmatized.

Elizabeth Green Musselman argues that Dalton's color blindness was taken by his liberal contemporaries—the inheritors of the Age of Enlightenment—as a metaphor for parochialism and deference to discredited classical teaching. To his peers, Dalton's scientific achievements proved...
that his origin in the provinces (he received his earliest education in the village of Pardshaw Hall, County Cumberland) need not be an obstacle to acceptance of scientific universalism, and therefore, that color blindness need not be an obstacle either.

Oliver Sacks (AΩA, Albert Einstein College of Medicine of Yeshiva University, 1970, Faculty), the British neurologist, portrayed by Robin Williams in the movie Awakenings, wrote a book describing an island in Micronesia with an unusually large population of achromatopes. In his description of the color blind, he describes their superior sense of “tonalities, shapes, and textures,” and their preternatural ability to live in a world of “heightened reality.”

These accounts of color blindness are informative, but the political or sentimental motives overarching them cast a long shadow. What kind of professional success might be enjoyed by those whose sense of color is profoundly altered?

Charles Meryon

The French artist Charles Meryon entered life inauspiciously, facing poverty and abandonment. He was born in 1821 to a Parisian ballet dancer and an English physician who returned to his wife in London months before. As a young man, Meryon’s ambition was to be a naval officer. Officer candidates in that era were not subjected to vision tests. Thus, Meryon had a clear path to the naval academy, which he entered in 1837. Upon completing his training, he embarked on several worldwide voyages, discovering during his travels that he had a talent for sketching the landscapes and the indigenous people he encountered. At age 25, Meryon left the navy to dedicate his life to art.

After serving an artistic apprenticeship rendering landscapes strictly in sepia tones, Meryon took up watercolor. Within months, he was writing to his father confessing a “color defect” that drove him to give up painting. He turned to etchings depicting the medieval neighborhoods soon to be demolished by Napoleon III.

Only one of Meryon’s oil paintings survives, hanging in the Louvre. “The Ghost Ship” is recognizably the work of a red-green dichromat. Both red and green tints are eschewed, since they were indistinguishable to the artist. In their place is a streaky surfeit of whipped up blues and yellows.

“The Ghost Ship” gives a vivid sense of the world as Meryon must have seen it, less softly hued, more phantasmal, more imbued with turbid and bilious grays. In its idiosyncratic fashion, Meryon’s rendering of the blackish sea with its bleached crests of spume, its pallid ship seems to disappear into an expanse of ochre sky—a fitting tribute to his vision of the world.

In 2009, the article “Colour blindness does not preclude
fame as an artist: celebrated Australian artist Clifton Pugh was a protanope," makes the case that color blindness among male artists is as common as it is in the general population, affecting roughly nine percent of both groups.\textsuperscript{10} It also notes that color blindness has been detected in works of art where it demonstrably did not exist. For example, Eugene Carriere, the French artist who came under suspicion for his striking monochromatic style, submitted to a formal examination which found conclusively that his color vision was normal.\textsuperscript{10}

**Discerning the colors in works of art**

If critics cannot discern between the artwork of a dichromat and the work of a stylist adopting a comparable technique, that may be because dichromacy has its own aesthetic legitimacy.

The centerpiece of the article is a case study that supports the authors’ claim that color blindness does not “preclude fame as an artist.” The Australian artist Clifton Pugh won the Archibald Prize for portraiture on three occasions, and placed 24 paintings in the Australian National Gallery. Pugh underwent formal testing of his color vision once, in 1942, when he reportedly applied to the navy and was rejected. He died in 1990 after waging a lifelong struggle with color; however, a few of his relatives were examined. An older brother and the brother’s grandson were shown to be protanopes, suffering defects of the red photoreceptor. The conclusion that Pugh was a protanope, while not airtight, is convincing.

Allowing themselves a bit of free rein, the authors used Photoshop to digitally alter several of Pugh’s original paintings. They reproduced the effect of red-green color blindness. The intent was to nullify the color choices Pugh appeared to have made visually, but as a protanope, must have made using non-visual cues. The altered paintings were shown to a group of known protanopes, most of whom could not tell the altered pieces from the original artwork.

Somehow, Pugh was able to circumnavigate, disguise, and/or exploit his abnormal color vision while turning out a succession of masterpieces.

**The disadvantages, and advantages, of color blindness**

It no longer is sufficient to claim that color blindness is a handicap that might, under favorable conditions, be compensated. Rather, it seems possible that color blindness, in the proper domain, might bestow some advantage. For instance, in a camouflaged setting the color blind possess the gift of enhanced sight. Camouflage relies on the fact that certain stimuli, metamers, are visually indistinguishable despite being composed of light of different wavelengths.\textsuperscript{11} Faint objects that fall on the blue-yellow axis can be disguised by placing them against a dappled background of variegated reds and greens. U.S. army combat uniforms were designed on this principle.\textsuperscript{12}

A small blue foreground object placed against such a background is swallowed up. To the color blind observer, however, a dappled red-green background appears a uniform gray, and a daub of blue placed against it stands out like a pearl on velvet.

This was used by the Japanese ophthalmologist Shinobu Ishihara who hand painted the color plates used for testing color blindness. These plates rely on the failure of the color blind to discriminate red and green, but a few of them take advantage of the camouflage principle.\textsuperscript{13} In 1917, given the task of devising a screening test for Japanese military recruits, Ishihara developed plates to identify camouflage-immune combatants.

**Color blind mothers**

Some mothers of sons with anomalous trichromacy, the most common form of color blindness, are mildly color blind. The Lyon hypothesis, named for Mary Lyon (AΩA, Emory University, 1965), states that the retinal cells of such mothers contain two X chromosomes, only one of which bears the gene for the anomalous red or green photoreceptor received by her color blind son. It is an anomalous photoreceptor because its spectral sensitivity is shifted. The Lyon hypothesis suggests that one of the X chromosomes is inactivated in a strictly random process. It proposes that the maternal retina contains a mosaic of normal and abnormal cones, potentially giving rise to a form fruste of color blindness.

However, another outcome is possible. The process gives rise in the affected mother to four types of cones, three of the usual kind, and one with anomalous properties. But, four distinct functioning cones might provide an entree to color discriminations of a superhuman kind. An analogous process of upward chromatic mobility is known to occur in New World monkeys. Heterozygous females become trichromatic by virtue of possessing an abnormal gene, as well as two normal ones, while the males of the species remain strictly dichromatic.\textsuperscript{5}

There are not many tetrachromatic women, because humans will be permanently a trichromat if they are wired for only three photoreceptors, no matter that they have four actual photoreceptors. This is for the same reason

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\textsuperscript{10} The Pharos/Autumn 2017
that you will be viewing black-and-white television if you own a 1950 Motorola, even if you are watching this year’s Tournament of Roses Parade. Tetrachromacy may begin in the retina, but it must be preserved in the post-retinal ganglion cells, as well as in their immediate connections, all the way to the visual cortex. Perhaps this is why the true human tetrachromat has proven so frustratingly elusive. Looking back, trichromacy may be viewed not as the terminus of a journey that the color blind never complete, but as a stopover en route to something better.

**Hearing colors**

Harbisson has declared his mission as persuading the chromatic world that something better has arrived. A microchip under his skin translates electromagnetic waves into vibrations that travel by bone conduction to his ear. In this way, he can “see” not only the entire visual spectrum, but spectral signals extending into the infrared and ultraviolet. He hears ultraviolet as an F minor chord.

Pointing his antenna at a deeply saturated color has the effect of turning up its volume. Harbisson is also Wi-Fi ready, which means that when his cranium is aligned with an orbiting satellite, he can receive phone calls from cyberspace without using a phone.

Harbisson’s claim that he is the first officially recognized cyborg is based on the fact that his antenna is clearly visible in his official passport photo, where it arcs from the back of his skull like an inverted fish hook.

With the aid of his enhanced “vision,” Harbisson has produced works that dwarf the accomplishments of many normal-sighted artists. This is exemplified in his sound portraits, where Harbisson first approaches his subject and pauses. With his antenna he scans the face he wishes to paint, generating tones that can be transcribed and performed on an electronic keyboard.

The artistic process also works in reverse. A speech by Martin Luther King, Jr., can be transferred to canvas by imagining the colors that would have produced, for Harbisson, the unmistakable sonorous tones of Dr. King’s voice. This process of translation is illustrated in a TED talk Harbisson gave in 2012. King’s “I Have A Dream,” speech looks to be the product of the avant-garde school of geometric abstractionism.

Not only is there the possibility that there are tetrachromats walking among us—stubbornly sought prodigies eluding the most determined scientific search—our minds must be open to something still more astonishing: galleries of the future may showcase work by perception-bending cyborgs (Harbisson is their primordium) bringing to life new worlds of infinite color dimensions. Such galleries will hum with melodious vibrations of colors.

**References**


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Lili Elbe (1886–1931).
Photo by ullstein bild/ullstein bild via Getty Images
The “medicalisation of the sexually peculiar:”
Lili Elbe, *The Danish Girl*, and the history of transgender medicine in the 20th century

*By Brit Trogen*

Ms. Trogen is a third-year medical student at the New York University School of Medicine. Her essay tied for First Place in the Alpha Omega Alpha Honor Medical Society 2017 Helen H. Glaser Student Essay Competition.

There is a scene in *The Danish Girl* where the protagonist, transgender pioneer Lili Elbe, walks hurriedly along a deserted street, fleeing a foiled romantic encounter. Flanking her on either side are rows of identical Danish houses, each painted the same shade of honey yellow. It’s one of the many beautiful moments of cinematography that crystallizes Elbe’s isolation: her heels clicking noticeably on the cobblestones while conformity surrounds her on all sides.

The Danish Girl is based on the life of artist Einar Wegener, later known as Lili Elbe, who was one of the first people to undergo sex reassignment surgery in 1931. While the film is fraught with emotion, many of the most disturbing scenes take place in medical settings. In one scene, Elbe is made to strip almost naked while a bald, severe looking doctor watches with disdain. Later, Elbe is forced to climb from a window at a psychiatric hospital, narrowly escaping institutionalization by a team of doctors and orderlies carrying straightjackets. The primary focus of the film is Elbe’s deeply personal transformation and its effect on a previously unshakeable marriage. But the medical storyline, revealed in snapshots, is equally compelling.

The growing social movement for transgender rights has thrown light on the attitudes of health care professionals toward gender dysphoria, the medical diagnosis for those who identify with a gender that differs from their biological sex. Studies suggest that transgender individuals have unique mental and physical health needs that are often compounded by biases and limited access to medical care.

A 2005 survey found that one in four transgender people reported being denied medical care because of their gender identity. In a 2013 study, a similar percentage of transgender respondents said they had experienced discrimination or abusive treatment in medical settings.

*The Danish Girl*, and the historical story around which

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Note: Throughout medical history, various labels and diagnoses were used to describe modern-day gender dysphoria. For the sake of clarity, and in an effort to avoid insensitive language, unless otherwise specified the terms transgender and gender dysphoria will be used in lieu of the historically prevalent terms (e.g. transsexual, transvestite).
it is based, illuminates one of the most significant moments in the history of transgender medicine. Elbe represents the culmination of decades of research on the development of the “medicalized sex change,” which redefined the relationship between physicians and transgender individuals. Doctors in Elbe’s lifetime, as depicted in film and writing, represent conflicting approaches to transgender health that shaped medical thinking and health care policy throughout the 20th century, with relevance to the present day.

A historical perspective

The concept of changing one’s sex has existed throughout human history. One of the earliest accounts of such an attempt comes from Ancient Greece when the philosopher Philo of Alexandria wrote of individuals born with male anatomy who “craving a complete transformation into women, [amputated] their generative members.” For centuries, the desire to alter one’s sex was not considered medically relevant but was seen as a question of morality, the domain of religion. It wasn’t until the late 19th century that transgender people began to gain serious attention in the medical literature as part of what Michel Foucault termed the “medicalisation of the sexually peculiar.” In medical circles at the time, there was, Foucault argues, a “veritable discursive explosion” around, and apropos of sexuality. Medical authority expanded during this period to include conditions related to sexual behavior and gender identity.

Beginning in the mid-1800s, and extending throughout the 20th century, two competing treatment models emerged that relied on very different assumptions about the nature of gender identity. The first “corrective” or “reparative” approach classified the expressed identities of transgender people as inherently pathological. According to this framework, identifying as transgender was a symptom of a disease—either a physical ailment, like the “biochemical imbalance” that is suggested to explain Elbe’s condition in the film, or a psychological one, like schizophrenia or a delusional disorder. Medical treatments based on this mindset were reparative in nature, aimed to convert the patient back to a gender that conformed to their physical sex.

In contrast, the gender-affirming approach saw transgender individuals as part of a natural biological variation. A person’s gender identity—their internal sense of being male or female—could be the same, or different, from their sex at birth. Instead of contradicting a patient’s gender identity, this model accepted and validated it. Medical treatments were aimed not at reversing the patient’s gender identity, but rather at reducing the stress and discomfort that arose from feelings of incongruence with their physical body. In many cases, though not all, this involved medical or surgical intervention to transition to the opposite sex.

Dr. Kurt Warnekros

The majority of doctors in Elbe’s lifetime were adherent to the corrective view. In her memoir, Elbe writes of being called a “hysterical subject,” and “perfectly crazy” by doctors she consulted. Similarly, in The Danish Girl, Elbe’s condition is repeatedly styled in pathological terms.
as “aberrant thinking,” perversion, psychosis, or a “confused state of masculinity.”¹ In one cringe-inducing scene, a doctor attempts to “cure” Elbe with a course of painful abdominal radiation. Another cheerfully suggests a lobotomy.

With incredulity, a doctor asks Elbe’s wife, “Mrs. Wegener, you’re not encouraging this delusion? You do understand that your husband is insane?”¹

A turning point, both in the film, and in Elbe’s life, was the introduction of Kurt Warnekros, a doctor working in Dresden who had a reputation for treating “patients like [Elbe].”¹ During their first meeting in the film, Elbe tells Warnekros that she believes she is a woman inside. Warnekros’ response is starkly different from that of his medical peers: “I believe you’re probably right.”¹

Portrayed in adoring tones in Elbe’s letters and diary, Warnekros was one of the early adherents to the gender-affirming approach in medicine.⁸ The film captures a turning point in the history of transgender medicine: the intellectual narrative surrounding gender dysphoria is beginning to shift.

The role of the physician
Medical theories are often deeply entwined in their social and political context. As the arbiters of what is considered healthy or unhealthy, and normal or abnormal, doctors carry significant social power. Medical consensus can be used either to drive change or to justify the status quo. Frequently, it does both.

Throughout the late 19th and early 20th centuries, medical interest in transgender individuals tended to follow the corrective model. European sexologists classified gender dysphoria as a symptom of an underlying condition of “gender inversion,” a pathological state with numerous manifestations including homosexuality.⁴

Cross-gender identification and same-sex attraction were often conflated in this period. Prior to the 20th century, physicians rarely differentiated between gender identity and sexual orientation. This connection may have originated with Karl Heinrich Ulrichs, the gay rights pioneer, who hypothesized that some men were born with a “female spirit,” which he believed to be the source of his own same-sex attraction. In 1864 he wrote, “Have I a masculine beard and manly limb and body, yes confined by these: but I am and remain a woman.”⁹

The co-classification of gender dysphoria and homosexuality was also directly influenced by Victorian sexual ideology in which men were viewed as sexually active and women as sexually passive, with anyone deviating from this rule (whether abnormally active women or receptive men) ruled to be “sexual inverts.”¹⁰ Vern Bullough has argued that as openly gay and cross-dressing individuals began to migrate to large urban centers in the 19th century, thereby achieving new visibility, police began calling on physicians for guidance on dealing with such “sexual deviants.”¹¹ The result was a rise in medical and psychiatric attempts to control, and put a stop to, what were viewed as unacceptable practices, predominantly via the corrective approach.

Gender-affirming care
An alternative, gender-affirming practice began to rise concurrently with these attitudes. In the first half of the 20th century, sexologist Magnus Hirschfeld became one of the first scientists to recognize homosexuality and cross-gender identification as distinct, developing the separate classification of “eunism” to describe cross-gender
identification and cross-dressing.4

A German physician and researcher, Hirschfeld was key in early studies of cross-gender identification, credited with establishing the terms “transvestite” and “transsexual” in his seminal work, Die Transvestiten, published in 1910.10 Hirschfeld sought to use science in the service of humanistic goals, including the emancipation of gay and transgender individuals. He challenged the widely-held view of the “dualism of the sexes,” the clear separation of sexes into male and female.10 Instead, using research from hundreds of case studies, questionnaires, and patient interviews, he argued that every person has both male and female qualities which they seek, to varying extents, to blend.10

He developed “zwischenstufenlehre,” the “theory of intermediaries,” that posited the existence of “sexual intermediaries” who may have a mix of male and female sexual organs, physical attributes, and emotional characteristics.10 Rather than a distinct gender binary, he advocated for a spectrum of hundreds of possible gender identities, each combining classically masculine and feminine traits to varying degrees.10 With respect to sexual categorization, he wrote, “there are hardly two humans who are exactly alike.”10

Hirschfeld became a leader in advocating for gender-affirming interventions, founding the Institut fur Sexualwissenschaft (Institute of Sexology) in 1919. The Institute would remain at the forefront of sex research until its seizure by the Nazis in 1933, during which time much of Hirschfeld’s research and data were destroyed.10

In the final years of its existence, the Institute served as a launching pad for the development of several groundbreaking surgeries related to sex reassignment. It was here that Lili Elbe was treated by Hirschfeld and Warnekros in 1929.

**Man into Woman**

The 1933 publication of Elbe’s diary entries and correspondence in the book Man into woman: An authentic record of a change of sex caused a sensation.4 The public, then as now, was fascinated by the idea of sex reassignment, and Elbe’s story became one of the first major challenges to the medical paradigm of the permanence of sexual identity.

Because the book was the first account of its kind to be translated into English (it was also published in Danish and German), Elbe’s story was particularly influential in the United States.4 From the 1930s to the 1950s, it contributed to the establishment of a new and asymmetrical power dynamic between doctors and transgender individuals who found themselves, for the first time, in a relationship of necessity with doctors.

Hirschfeld’s school of thought formed a small but passionate contingent within Western science in the 1920s.
and 1930s, influencing the later work of John Money, Harry Benjamin, and Robert Stoller. Even so, much of the medical community resisted arguments advocating for acceptance of transgender identities, remaining critical of sex reassignment as a treatment for gender dysphoria.

Despite the availability of affordable synthetic estrogen and testosterone in the 1930s and 1940s, most European and American physicians refused to prescribe them to gender dysphoric individuals wishing to transition to the opposite sex. Well into the 1950s, psychiatrists, acting as the “moral arm of medicine,” played a key role in promoting the idea that minority sexual orientations and gender identities were expressions of disease. Sigmund Freud dismissed transgender identities as symptomatic of repressed homosexuality and arrested psychosexual development, prescribing psychotherapy. His disciples went further, advocating for “cures” of homosexuality and gender dysphoria in the form of reparative “conversion” therapies. Castrations, hormone treatments, and involuntary commitments were all viewed as medically valid treatments when psychotherapy failed to produce the desired result.

In a 1953 Liverpool case, for example, a 17-year-old gender dysphoric boy presented to a hospital following a suicide attempt. The doctors, noting that the patient had stated that “he [wanted] to become a woman,” prescribed male hormones, sodium pentothal injections, and electroshock therapy. Gender dysphoria, along with other behaviors like cross-dressing and nymphomania, remained classified as a sexual pathology.

A shift in the United States

As Joanne Meyerowitz notes, by the mid-1950s the medical narrative surrounding transgender individuals in the U.S. began to shift. It began with the immense celebrity surrounding actress Christine Jorgensen, who publicly transitioned from male to female in 1952. With the New York Daily News headline, “Ex-GI Becomes Blonde Beauty,” there was renewed public, psychiatric, and medical dialogue around the concept of gender identity. Jorgensen would later report receiving hundreds of “tragic letters…from men and women who also had experienced the deep frustration of lives lived in sexual twilight.” Many individuals who had long suppressed or concealed their cross-gender identification finally understood that their condition had a name and a medical remedy, and began petitioning doctors for gender-affirming treatments.

With frequent reports of sex reassignment surgeries emerging in the media, physicians began to openly discuss and research interventions for transgender individuals. In 1966, the German-born endocrinologist Harry Benjamin—who would go on to treat more transgender individuals in the U.S. than anyone else—wrote, “from what I have seen…a miserable, unhappy male transsexual can, with the help of surgery and endocrinology, attain a happier future as a woman.”

The sexual revolution

With the sexual revolution of the 1960s and 1970s, promoted in part by the research of Alfred Kinsey and the development of the contraceptive pill, medical attitudes toward sex and gender were challenged even further. Breaking with the Victorian ideology, sex and sexuality gradually came to be viewed by the American public as acceptable and beneficial, even outside of the context of marriage and procreation. Doctors, adapting to the times, began to describe sex as a part of healthy human interaction. The emergence of the gay rights movement and “queer theory” (the enormous effects of which are beyond the scope of this essay), led to heightened public awareness of different sexual preferences and gender identities.

In response to broader public awareness and demand for the procedure, in the 1960s, American surgeons began to practice sex reassignment surgeries—decades after their European counterparts. In 1966, Johns Hopkins University opened the first clinic in the U.S. devoted to
the research and treatment of gender dysphoric individuals, with dozens more opening across the country over the next 10 years.

However, the corrective approach still influenced mainstream medical views in the U.S. While many American physicians began to accept sex reassignment surgeries as a valid treatment option, they limited the indications for surgery such that it was largely unobtainable for the majority of interested parties. At the Johns Hopkins clinic, patients were required to meet strict criteria to be considered legitimate candidates for surgery—gender dysphoria that manifested from their earliest memories, sexual attractions exclusively to the same biological sex, and the potential to successfully pass as a member of their desired sex. As a result, out of nearly 2,000 requests for sex reassignment surgery to the clinic in the first two years of its existence, operations were performed on just 24 individuals.

Restrictive as these measures were, others went even further, offering surgical options only to intersex individuals whose biology included some combination of male and female anatomy, but not to men or women seeking to transition from one sex to the other. An intersex person raised as a man, physicians would allege, could have “a legitimate claim to female status, but a male-to-female ‘transvestite,’ even surgically and hormonally altered,” could not. A 1969 survey of 400 physicians in the U.S. found that the majority of respondents were “opposed to the transsexual’s request for sex reassignment even when the patient was judged nonpsychotic by a psychiatrist…had convinced the psychiatrist of the indications for surgery, and would probably commit suicide” if denied the treatment.

As Jodi Kaufmann argues, the intersex narrative described above may in fact have originated with Lili Elbe. In Man into Woman, Elbe describes herself as a female personality born into a “hermaphroditic” body due to the alleged discovery of rudimentary ovaries in her abdomen during her surgeries. Writing in a literal sense, she said, “I was both man and woman in one body.” This claim, believed by many to have been fabricated due to its absence in other records related to Elbe, would color popular accounts of her story. Fabricated or not, the narrative that some individuals possessed a physical condition that justified medical intervention would have wide-reaching implications. Frequently, in the years following Elbe’s popularity, this distinction would be used to undermine, and pathologize, the wishes of non-intersex transgender individuals.

**Advancement and conflict**

Medical acceptance of the gender-affirming model did, nevertheless, continue to advance. A 1986 study found that, compared to 1966, American medical practitioners reported increasingly favorable attitudes toward transgender people, with half of all doctors saying they would support a surgical remedy, compared to 25 percent in the earlier sample. In addition, a majority of physicians stated that transgender people should be “accepted as normal members of society,” breaking with the psychopathologic view that had previously dominated.

One possible contributor to this paradigm shift was a growing body of research demonstrating positive patient outcomes following gender-affirming interventions. Benjamin’s publication of The Transsexual Phenomenon in 1966 included research demonstrating that out of 51 transgender patients he had treated, 86 percent reported good or satisfactory lives following surgery. These findings would be reiterated in the succeeding decades, with the widespread use of hormone replacement therapy in the 1970s. In 1972, based on findings of increased satisfaction and functioning of post-operative transgender people, the American Medical Association sanctioned sex reassignment surgery as the treatment of choice for gender dysphoric individuals.

However, with increasing acceptance of transgender identities also came a vitriolic backlash in some communities. In 1979, the publication of Janice Raymond’s The Transsexual Empire: The Making of the She-Male renewed disease-centric views of gender dysphoria. Raymond argued that transgender women were not women at all, but “castrated,” “deviant” men who had “raped” women’s bodies by appropriating them through surgeries. She falsely alleged that genital surgeries had originated in Nazi Germany, and that gender dysphoria was a recent, politically motivated phenomenon. Raymond’s attacks gained a wide public following that contributed to the closing of several gender identity clinics across the U.S.

In addition, a 1979 study published by Jon Meyer and Donna Reter, from Johns Hopkins, purported that transgender patients who had undergone gender-affirming surgery showed “no objective improvement” in functioning compared to those who had not undergone surgery. Though this study would be criticized for biased, arbitrary
measures of improvement (to have improved by Meyer’s and Reter’s standards meant advancing in socioeconomic status, marrying an opposite-sex partner, and ceasing therapy), and for failing to account for patients’ personal satisfaction with their lives, it had a profound effect, ultimately leading to the closure of the Johns Hopkins clinic.12

Years later, an investigative report found that the research had been “orchestrated by certain figures at Hopkins, who, for personal rather than scientific reasons, staunchly opposed any form of sex reassignment.”12 Corrective approaches persisted, in spite of increasing arguments challenging the ethics of such practices. After decades of widespread use, and as research began to show that gay and transgender individuals experienced significantly higher rates of anxiety, depression, and suicidality than the general population, many began to question whether forcing transgender individuals to conform to the gender associated with their birth sex could cause irreparable harm by increasing feelings of stigma and isolation.17 As research found that gender-affirming treatments could reduce rates of suicide, withholding such treatments came to be viewed as the denial of potentially life-saving therapy.17 Supporters for the corrective view, meanwhile, used findings of increased psychiatric comorbidities to further justify the pathologic view of cross-gender identification itself.

The Trans Rights movement

From the 1980s to the 1990s, advocates of the gender-affirming model would grow into a prominent “Trans Rights” movement, one significant result of which was vocal opposition to the psychiatric categorization of cross-gender identification as a pathology.12 Beginning in 1980, when the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) classified transsexualism as a mental disorder, activists identified the pathologization of cross-gender identification as a major source of stigma against transgender individuals, frequently used by opponents to justify discriminatory policies.12 Activist Riki Wilchins wrote “[transgender people] could portray ourselves in media as patients suffering from a medical disorder, or as an oppressed minority demanding their political and civil rights, but it was very difficult to do both simultaneously.”12 In 1995, a transgender rights group picketed the national meeting of the American Psychiatric Association, protesting the new DSM-4 classification of gender identity disorder for the same reason.12 While homosexuality as a psychiatric diagnosis was removed from the DSM in 1973, it would take decades before cross-gender identification would be similarly depathologized.12

Increased awareness and dialogue

Medical and scientific thought rarely progress in a direct, linear fashion. While a trend toward the gender-affirming approach can be witnessed throughout 20th century medicine, the transition has not been calm and unidirectional but vociferously opposed at every turn, with frequent resurgences of contrasting views. Discrimination and stigma against transgender individuals by health care workers persist to this day, and many within the medical field continue to view gender dysphoria through a corrective lens. Nevertheless, since Elbe’s lifetime, the attitudes of many physicians have shifted. Gender-affirming treatments are becoming the norm rather than the exception. Near the end of The Danish Girl, Elbe describes her recent transition to a friend saying, “A doctor intervened to correct a mistake of nature.”1 Elbe died shortly after her sex reassignment following an ill-fated attempt to transplant a uterus into her body. However, her story left a lasting mark.

In Man into Woman, Elbe wrote:

I feel like a bridge-builder. But it is a strange bridge that I am building. I stand on one of the banks, which is the present day. There I have driven in the first pile. And I must build it clear across to the other bank, which often I cannot see at all and sometimes only vaguely, and now and then in a dream.8
The recent history of transgender medicine reveals a constant clashing of opposing medical views, reflecting both the tenacity of established conceptual frameworks within medicine, as well as the propensity for physicians’ attitudes to both shape and reflect broadly held societal views. Through her writing, Elbe sought to bring her personal struggle into public view, setting into motion a movement that continues to this day. It is my hope that shedding light on these historical trends will assist in “extending the bridge” that Elbe helped to construct.

The new gender symbol that depicts inclusiveness.

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The parking space (Sister)

I always saw your car in the same space. Third floor, two over from the stairs, not right against the wall but close enough to make it a short walk.

Morning after morning you arrived before the rush to find the same space waiting. Some days I’d see you walking slowly in, a little pain apparent in your step.

I’d pause my hurried footsteps for a smile, just time enough to say hello and let you know which child or family would need an extra prayer or hand to hold.

On the rare mornings I had luck to find the whole row empty, I’d leave the spot I knew as your space free and take the next. On my walk in I always thought of you not far behind.

I heard about that night—a nurse left work late and found your car still there. I wonder if you knew something was wrong, but chose to stay to talk with one more patient, pause for breath, then start toward home.

Months have passed. I no longer turn around to look for you each day. Others are there to hold the children’s hands, just as you taught us all to do. But on those early mornings when every space is free, I always choose the one two over from the stairs.

A nod to you in the morning, another when it’s time to return home.

Wynn Morrison, MD

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“...only at forty to be vanquished by a causeless, nameless, untreatable phantom disease. It wasn’t leukemia or lupus or diabetes, it wasn’t multiple sclerosis...it was nothing. Yet to nothing he was losing his confidence, his sanity, and his self-respect.”

This is how Philip Roth's novel *The Anatomy Lesson* begins. Once a prolific and controversial writer, the narrator, Zuckerman (largely assumed to be Roth's alter-ego), is now reduced to lying on the floor with a bottle of vodka and an orthopedic pillow, nursing unbearable back pain. He visits a multitude of doctors who regale him with emollients, pill cocktails, physical therapy regimens, and advice to address his unconscious, spiritual unrest causing physical discomfort. Zuckerman tries to eliminate his pain with some soul-searching, but as a writer whose career has been built on plumbing the depths of his id for artistic material, he cannot find an

Soula Mantalvanos published *Art and Chronic Pain – A Self Portrait*, to face her severe chronic pain.

©Soula Mantalvanos Photography Jason Reekie
unexplored hostility or childhood trauma whose repression may be leading to his chronic pain. “His unconscious wasn’t that unconscious. Wasn’t that conventional.”

Failing to find a physiologic explanation for his pain, and unable to write effectively in an opioid haze, Zuckerman decides that his only recourse is to become a doctor. He does not anticipate finding a cure to his physical pain, but rather achieving relief through a sort of spiritual redemption, the kind that he expects only doctors have access to. “After the popular triumph of his devilish act of aggression,” that is writing, he will attempt the “penitential act of submission,” that is healing.

To Zuckerman, medicine is as straightforward and morally clear as writing is messy and morally ambiguous. “A leads to B and B leads to C. You know when you’re right and you know when you’re wrong.”

Zuckerman’s planned transition from invalid and writer to doctor contrasts with the journeys, as chronicled in their memoirs, of people who turn to literature and writing to gain relief or clarity. In Body Undone: Living On after Great Pain, a memoir of chronic pain and paralysis following a bicycle accident, Christina Crosby, a professor at Wesleyan University, draws from various poets. The eponymous line comes from Emily Dickinson’s “After Great Pain, A formal feeling comes—The Nerves sit ceremonious, like Tombs—
The stiff Heart questions “was it He, that bore,”
And Yesterday, or Centuries before?”

Crosby is not alone in her quest to make sense of pain through literature. Hilary Mantel, the author of Wolf Hall, writes about her chronic pain and infertility from endometriosis with an extended metaphor of ghosts representing the children she never had, the person she could have been. John Milton’s Paradise Lost serves as the structure through which Lyne Greenberg, an English Professor at Hunter College, explains her debilitating headaches in Body Broken: A Memoir. While these authors find a way of shaping their amorphous and elusive experiences of pain through their own writing, there is no concluding sense of salvation or healing.

Writing and literature are ways of facing the pain, sharing the burden, but not transcending it. The pain these authors suffer is more than chronic; it is eternal. Viewing their day-to-day lives as an eternity of suffering makes more sense through the lens of the horror genre than inspirational literature. Crosby concludes her memoir with a parallel between her life and Edgar Allan Poe’s The Fall of the House of Usher, “I’m not writing a horror story, I’m living one.”

Mantel’s ghosts are not exorcised in triumph, but become accepted as her constant companions. Ghost children, she thinks, “don’t age so they don’t know it’s time to leave home.” She continues to be haunted by her alternative life, the one in which she is pain-free. “Mourning is not quick; when there is no body to bury, mourning is not final.”

Greenberg uses Milton’s description of hell to describe her new reality with chronic pain, an eternity of archetypal proportions:

Regions of sorrow, doleful shades, where peace
And rest can never dwell, hope never comes
That comes to all; but torture without end.

Rather than overcoming their pain, these authors are simply trying to make their lives liveable, to give their pain, which has disrupted their sense of reality, a cohesive narrative. One way of doing so is to chronicle the parallel world they now inhabit, where the horrific is mundane.

Accidental perpetrators

For doctors, turning the horrific into the mundane is not a widely acceptable goal. Doctors are often accidental perpetrators of misery as they try to use their well-known procedures to fix a little-understood symptom. More so than many other illnesses, chronic pain remains a mysterious condition that frequently fails to respond to the best treatments.

Greenberg writes, one in five Americans suffer from chronic pain, and even after significant pain management
intervention only 50 percent are functional enough to resume working. Knowledge, technical skill, empathy, and experience are not enough to bring these authors back to their former selves.

Crosby writes poignantly of how the enterprise is doomed from the moment she is asked to rank her pain on a scale from one to 10, an absurd metonym for her “electrified neoprene skin.” She doesn’t blame doctors for failing to communicate; the experience of pain defies communication, adding yet another dimension of suffering and loneliness.

Even writing cannot adequately express the sensations of pain Crosby is experiencing. She tries with various metaphors and adjectives, but concludes, as others have before her, that rhetorical tricks are inadequate. “I’ve learned that the recourse to analogy is not solely mine, since pain is so singular that evades description, so isolating because it’s in your body alone.”

Making it personal

As someone with an enduring faith in the power of the written word, its failure affords a special pang. I turned away from writing towards medicine, as Zuckerman did, because I also longed for a “penitential act of submission,” a way of overcoming an all-consuming uneasiness at facing a life without concrete purpose. A vague sense that, in becoming a doctor, I would transcend the prosaic suffering of what Macbeth famously called “the petty pace from day to day.”

Setting a broken bone, administering antibiotics, removing an appendix, the purposefulness of these actions were beacons of clarity in my swirling, anxious mind. Encountering the phantom of pain in both my personal and professional life has solidified what four years of medical school had already intimated. In medicine, A does not necessarily lead to B, and the nature of B is frequently questionable.

Reading these memoirs reminded me of the way in which writing can help where medicine falters. While words proved inadequate in describing Crosby’s experience, they did give shape and structure to what would otherwise threaten to overwhelm any personal identity. A horror story is still a story, and its characters are still their own entities:

If I am myself, what the hell who the hell is this body...If I can show you, perhaps I’ll be able to see too

Mantel describes a similar effort:

I am writing in order to take charge of the story of my childhood and childlessness; and in order to locate myself, if not within a body then in the narrow space between one letter and the next.

Writing is its own way of healing, if only by giving shape to a life that, while disrupted beyond recognition, is still one’s own. Perhaps that is why Zuckerman’s plan to abandon writing to become a doctor—and arm himself with moral clarity pure enough to render his mortal coil obsolete—fails so spectacularly. The novel ends with him convalescing in a hospital, withdrawing from opioids, and recovering from a drunken accident that has added another layer of physical suffering. Still determined to be a doctor he follows the residents around on their morning rounds, writing questions with his broken jaw wired shut. In the final scene he throws himself into the hospital’s laundry closet and sits there, arms deep in a tangle of soiled hospital linen. He is overwhelmed by the smell and sensation of bodily fluids. “This is life,” he thinks, desperate to return to the reality of a logical universe, where sickness has tangible consequences, where wounds bleed onto fresh linen.

As the final line reminds us, his place in that “real” world is untenable; he belongs to a body following a script of its own. “He still believed he could unchain himself from a future apart and the corpus that was his.”

Hanging over him, and his denial, is the inevitability of a different reality, one yet to be shaped by the character-author but perhaps completed by Roth himself.

References


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I was doing triage that night, a quiet night when he walked in the ED, a muscular man in a paisley shirt and jeans, dog on a leash—a big dog. I didn’t recognize the breed.

“Service dog?”

“Not really.”

“Then no dogs allowed here.”

“You’ll want this one. Say a guy comes in with abdominal pain, give Hunter the command ‘diagnose!’ He’ll bark once for acute appendicitis, twice if its ruptured. A growl for cholecystitis, a howl, it’s diverticulitis.”

“Hard to believe!”

“Not really.” He handed me his card.

Larry Lawrence, MD, Breeder

“I was a surgeon, but that’s another story. You in charge?”

“Tonight I am. How does Hunter do it?”

“It’s in the sweat, each illness a different smell. I took skin swabs from my patients while still in practice. Stored them, correlated smells with CT scans, discharge diagnoses. You’ve seen dogs sniffing for drugs at airports. Hunter takes things one step further.”

“He doesn’t make mistakes?”

“Take a look at this positive predictive value! I’ll leave him with you tonight. No charge, you can’t go wrong. I’ll be back in the morning.”

Richard Bronson, MD

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An American Sickness: How Healthcare Became Big Business And How You Can Take It Back

Elizabeth Rosenthal
Penguin Press, April 11, 2017, 416 pages

Reviewed by Norman H. Edelman, MD (AΩA, New York University, 1961)

The bulk of this book is a passionate, bare-knuckled attack on the health care delivery enterprise in the United States. It focuses on the multitude of devices which have been developed to maximize income without regard for the financial concerns of patients and taxpayers. No sector is spared. There are chapters on hospitals, physicians, allied health providers, the pharmaceutical industry, and the insurance industry.

The author’s style is descriptive, mainly of patients who have been presented with unexpected, exorbitant bills and of income maximizing practices that she considers egregious. The reader is bombarded with example after example. The technique is effective; even this long-hardened reviewer found his anger rising more than once.

This is not a scholarly book. There are virtually no data or trend analyses. There are multiple descriptions of people being driven to the financial brink by health care expenses, but there are no descriptive statistics on trends in health care-related bankruptcies.

It is not even-handed. In only a few scattered sentences does the author admit that there are still some caring and honest providers. In describing the Affordable Care Act she focuses on the ways various providers and payers have sought to subvert its purpose rather than on what, in retrospect, was an almost heroic attempt to mitigate many of the excesses of the health care industry.

Part Two seeks to advise patients on navigating these treacherous waters. It consists mainly of checking bills and comparison shopping, which may be beyond the capacity of most patients. There are also some suggestions for reforming the “system,” which are well-taken but not comprehensive or unique.

The chapter on hospitals is more compelling than others because it is only here that the author tries to understand how an enterprise long characterized by mission-oriented religious and professional leadership quickly morphed into “an industry...[in which] at every point there’s a way to make money.”

The author focuses on the ubiquitous and influential business school-trained consultants whose only goal, she says, has been to optimize the bottom line. Interestingly, this view parallels that of the recently published book *The Golden Passport: Harvard Business School, the Limits of Capitalism, and the Moral Failure of the MBA Elite,* by Duff McDonald, which lays a significant portion of the blame for our purely bottom line-oriented business climate at the foot of the Harvard Business School. McDonald points out that the Harvard Business School was established to train businessmen who “will handle their current business problems in socially constructive ways,” but has morphed into one where the prevailing ethos is that the only obligation of the corporate manager is to shareholders’ profits. Similar to Rosenthal, McDonald opines that this ethic was widely and rapidly disseminated through the enormous influence of key consulting entities, which were typically populated by Harvard Business School graduates.

What is the relevance to readers of *The Pharos?* On the one hand, we can believe that what is going on in health care is merely part of a broad societal shift in business and professional morality, and there is little that can be done. However, we hold ourselves to be the elite of the profession, and many of us are, or have been, in leadership positions. I believe that collectively, and as individuals, we can do more than has been done to advance an ethic that emphasizes service and compassion, not remuneration, as the foundations of health care.

Reference

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The Book of Joy: Lasting Happiness in a Changing World
Dalai Lama, Desmond Tutu, Douglas Carlton Abrams
Avery; September 20, 2016; 384 pages
Reviewed by Dean Gianakos, MD

In The Wall Street Journal, there was the article “Venezuelan Riot Police Tire of Front-Line Duties.”
It tells the story of Ana, a young policewoman who patrols the slums of Caracas at night. During the day, she gears up to confront government protestors who are angry about food shortages and the lack of jobs:

On those front lines, she and her colleagues use tear gas and rubber bullets against increasingly desperate protestors armed with stones, Molotov cocktails and even bags of feces. The showdowns take place in scorching heat, and she says authorities provide her with no food, water or overtime pay.1

Many American physicians also tire of front-line duties. Some are burned out, depressed, or suicidal, and we absolutely need to find ways to help them. However, most of us are grateful to be practicing medicine in our offices rather than fighting protestors on the streets of Caracas. Cultivating gratitude is one way to promote physician well-being.

Today’s physicians spend many hours on their computers completing documentation requirements and administrative tasks. Since the patient-physician relationship is the primary source of joy for most physicians, it’s no wonder many are burning out. They are asking themselves existential questions: How should I live my life? Is it time to cut back on my work hours, downsize my home, and pursue other passions? Should I work to change the office flow in my practice, hoping it will make a difference in my professional satisfaction? Should I advocate for health care change at a local, state, or national level? Should I return to teaching to give back to the next generation? Will devoting more time to these non-clinical activities paradoxically renew my energy, restore joy, and provide an antidote to my malaise? Should I just suck it up and keep grinding?

It is with these questions in mind that I turn to the book, The Book of Joy: Lasting Happiness in a Changing World.

Douglas Abrams spent five days with the Dalai Lama and Archbishop Desmond Tutu in the northern Indian state of Himachal Pradesh, the exiled home of the Dalai Lama. As Abrams notes in the introduction, there are three layers to the book:

1) The Dalai Lama’s and Archbishop Tutu’s teachings on joy;
2) The science on joy, provided by Abrams; and
3) Abrams’ impressions and stories about these joyful men.

These layers are explored in three chapters: “The Nature of True Joy,” “The Obstacles to Joy,” and “The Eight Pillars of Joy” (perspective, humility, humor, acceptance, forgiveness, gratitude, compassion, and generosity).

At the end of the book, there is a section on “joy practices” for readers to incorporate into their daily lives: breathing exercises, meditation, prayer, silence, journaling for gratitude, fasting, humor, physical exercise, and reflection exercises.

Abrams takes notes and make observations as the Dalai Lama and the Archbishop share Buddhist and Christian perspectives on suffering, adversity, and joy. They have remarkably similar views:

Joy, as the Archbishop said during the week, is much bigger than happiness. While happiness is often seen as being dependent on external circumstances, joy is not. This state of mind—and heart—is much closer to both the Dalai Lama’s and the Archbishop’s understanding of what animates our lives and what ultimately leads to a life of satisfaction and meaning.

Abrams adds:

And the more we turn away from our self-regard to wipe the tears from the eyes of another, the more—incredibly—we are able to bear, to heal, and to transcend our own suffering.

Of course, if we spend too much time wiping away tears, we risk burnout. There is only one passage in the book on compassion fatigue. The Dalai Lama said, “We have to take care of ourselves without selfishly taking
care of ourselves. If we don’t take care of ourselves, we cannot survive.”

I suspect he would refer fatigued physicians to the back of the book to experiment with joy practices. Abrams might point to the section on Sonja Lyubomirsky’s scientific work, where she explains the three keys to happiness—expressing gratitude, reframing situations in positive ways, and showing kindness and generosity.

This book will not help physicians to solve the system issues in medicine—office inefficiencies, electronic health record burdens, regulatory and reimbursement demands. These are huge contributors to the physician burnout crisis, and most likely will not be going away any time soon. However, physicians can reflect on the wise words of the Dalai Lama and Archbishop Tutu to help them find joy in their life and work.

No matter how stressful situations may seem, physicians always have a choice regarding how they will respond. After reading this book, perhaps more physicians will choose to change their lives in significant ways, each one “becoming an oasis of peace, a pool of serenity that ripples out to all of those around us.”

References


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The Vaccine Race: Science, Politics, and the Human Costs of Defeating Disease

Meredith Wadman
Viking; February 7, 2017; 448 pages
Reviewed by Thoru Pederson, PhD

In The Vaccine Race, Meredith Wadman writes a book that is readable by all audiences—the medical community, and the general public. She has been a staff reporter at Science magazine, and holds a medical degree from Oxford. The most vivid and successful elements of her book are her descents into the weeds of vaccinology while keeping the reader engaged.

Wadman takes an objective stand. She did thorough research, and conducted interviews with all the key people. It is a very engaging story.

The book presents a cell line, but the tissue donor remains sotte voce. (The donor has never been publicly identified other than as a Swedish woman.) It tells the story of how a particular cell from this fetal tissue was teased into culture and became extremely important in vaccine development. The story is also about this cell line’s disputed ownership.

Beyond the swirling legal issues that Wadman addresses, she reminds us that any vaccine (there are not that many) is a tremendous achievement of laboratory and clinical science. Apart from the controversial cell line issues, Wadman’s book is primarily about a momentous landmark in the history of medicine: the advent of an effective vaccine for rubella.

Although duly covering earlier eras in the ascent of vaccines, Wadman situates the story around the Wistar Institute in Philadelphia. She presents its history in anatomical science in engaging detail, and then moves into the 1960s when the institute became a world leader in virology under the leadership of the Polish-American scientist Hilary Koprowski.

Koprowski viewed scientists at the institute who were skilled at cell cultivation as technical supporters, while regarding staff virologists as the true enablers of the institute’s overall vaccine goals. Koprowski’s quest for a live polio vaccine was underway at the Wistar Institute, but would not be won.

Wadman draws out the story of the then-unheralded cell culturist at Wistar, Leonard Hayflick, a man typified by extraordinary scientific skill, and tremendous persistence. These two qualities became a focal point of the story, and indeed the man’s entire career.

Hayflick had for years been working on the establishment of human cell lines from aborted fetuses obtained from a Philadelphia hospital and one in Stockholm. He focused on assays to determine the absence or presence of endogenous viruses, and scrupulously tracked the cells for the chromosomal aberrations typically seen in tumor-derived cell lines. Wadman’s account of these efforts is meticulous and engaging.

After 25 of these cell lines had been established they
were all lost in a freezer failure. Hayflick had to start all over, and soon established WI-26 (the initials for the Institute). Demand for it by labs around the world was so great that the supply was soon depleted. It was clear to Hayflick that a major expansion of the stocks of any new line would be necessary before distribution.

In June 1962, Hayflick established a lung fibroblast cell line from a female abortus received from a Swedish hospital. He dubbed the line WI-38, a label that would become one of the most famous cell line names in medical history—at least to vaccinology. Even for readers who are not cell biologists, this part of the story is stirring drama.

Hayflick and his colleagues determined that WI-38 cells were demonstrably free of viruses, and that their chromosomal complement was normal and remained so during propagation. Then, they noticed something new: WI-38 cells stopped growing after a certain number of serial cultivations, approximately 50 population doublings. This discovery became the foundation of a new field in cell biology, “cell replication senescence.”

The book returns to its main theme of vaccinology and the quest for an effective rubella vaccine. The author covers the work of Wistar’s Stanley Plotkin, and the parallel race waged (but lost) by Merck. There may not be a better account of the rubella vaccine story, at least in a form as accessible for the general reader. Wadman’s account of the rubella vaccine is masterful.

In 1968, Hayflick accepted a faculty position at Stanford University. Given the widely established importance of WI-38 cells in vaccinology worldwide, and uncertain of how they would be cared for if left behind, Hayflick took most of the stocks with him. There was much controversy about this, as the author details.

I commend this book on the basis of the author’s engaging coverage of the rubella vaccine story. For those who ponder the ethical issues around the proper use of human tissue there is also much to be found here. This is a story about a triumphant chapter in the history of vaccinology.

Dr. Pederson is the Vitold Arnett Professor of Cell Biology in the Department of Biochemistry and Molecular Pharmacology at the University of Massachusetts Medical School in Worcester. His e-mail address is: thoru.pederson@umassmed.edu

More AΩA member books

*Unanticipated Outcomes: A Medical Memoir,* by Jerome P. Kassirer, MD (AΩA, Jacobs School of Medicine and Biomedical Sciences at the University of Buffalo, 1956); Independent (Self-Published), July 5, 2017, 215 pages

*A History of Medicine in 50 Discoveries,* by Marguerite B. Vigliani, MD (AΩA, Drexel University College of Medicine, 1975), Gale Eaton, and Phillip Hoose; Tilbury House Publishers, June 27, 2017, 288 pages

*Wager: Beauty, Suffering, and Being in the World,* by Raymond Barfield, MD (AΩA, Duke University School of Medicine, 2017, Faculty); Cascade Books, March 21, 2017, 148 pages

*Patient-Centered Medicine: A Human Experience,* by David H. Rosen, MD (AΩA, University of Missouri-Columbia School of Medicine, 1970), and Uyen B. Hoang; Oxford University Press, 2017, 148 pages

*Triumph Over Tragedy: The Odyssey of an Academic Physician,* by William H. Frishman, MD (AΩA, Albert Einstein College of Medicine of Yeshiva University, 1978, Faculty); Science International Corporation, 2016, 260 pages

*The Book of Colors: a novel,* by Raymond Barfield, MD (AΩA, Duke University School of Medicine, 2017, Faculty); Unbridled Books, 2015, 211 pages

*The Glasser/Glazer Family History: From Oppression to Opportunity,* by Lewis Glasser, MD (AΩA, Weill Cornell Medical College, 1960); Lewis Glasser, 2015, 160 pages
With more than 5,000 hospitals in the United States, and a public leaning toward single-payer health care, the justice system’s interpretation of what constitutes access to medical care will inevitably become a contentious issue for those in medically-related fields, as well as a crucial concern for all Americans. The documentary Rule of Law confronts this complex issue by focusing on the 2004 Supreme Court case Tennessee v. Lane that developed in a small county where disabled individuals were physically unable to gain access to courtrooms on the upper floors. The courthouse had not been updated, and as a result, did not have proper means of entrance, such as elevators. According to the 1990 Americans with Disability Act (ADA), no person may be denied access to “services, programs, or activities” because of a disability.

Rule of Law provides insight into how the judicial system understands the concept of access to medical services, particularly for people with disabilities.

The case’s key plaintiff, George Lane, labeled an “outlaw” by the filmmaker, lost his leg in an accident because he fell asleep at the wheel after working several double-digit shifts (that accident also killed another person). After recovering from the accident, he went to his court appearance and found no access to the courtroom other than a staircase. Warned by the court that he should appear immediately or be held in contempt, he saw no option but to crawl up the stairs to the courtroom as people, including police officers, jeered at him. Once there, he was ignored, and at the end of the day, he was informed that his case would be recalled at a future time. Left with no choice, he crawled back down the stairs and went home.

On the later date, Lane arrived and demanded reasonable accommodation to the second floor to avoid the humiliation that he had previously suffered. None was provided. In response, he refused to crawl up the stairs, or have police officers—the same ones who earlier mocked him—carry him to the courtroom. As a result, he was held in contempt and placed under arrest—roughly 30 feet from the courtroom that was inaccessible to him.

Sensing an injustice, Lane set up an appointment with
William J. Brown, a local attorney and former prosecutor against him. Lane believed that Brown had always treated him fairly even when they were on opposing sides of the law. During the meeting, Lane asked, “Now, Bill, isn’t there a law that says they can’t do this to me?” Brown responded, “I don’t think they can do it to you, but the question is whether or not they can get away with it, ‘cause they have already done it to you.”

Although he had little experience with disability legalities or the ADA, Brown agreed to represent Lane in a suit seeking that the courthouse provide reasonable access/accommodation to people with disabilities. Brown then wrote to the judge, informed him of the discriminatory treatment by the court, and requested a postponement until an elevator (or other access) was provided for his client. The court responded, saying that it didn’t have the funds to install an elevator or other means of access. Not willing to concede, Brown persisted, and after several failed attempts in other courts for a simple postponement until compliance with the ADA was secured, he wrote the state’s Attorney General petitioning for the same. There was no response.

Curious about how systemic this problem might be, Brown discovered that roughly 25 percent of Tennessee courthouses had inadequate or no accommodations for those with disabilities. Realizing the gravity of the problem, and the state’s unwillingness to address it, he decided to sue the original county, and all the other non-compliant counties.

Throughout the course of the trials, the state filed appeal after appeal. For viewers, it is important to recognize that the state failed to acknowledge the importance of ADA and to comply with it. People with disabilities were on their own.

The case went to the United States Supreme Court where Tennessee argued that because of the 11th Amendment—the sovereign immunity doctrine—they could not be sued. This doctrine asserts that the king or state cannot be sued because it can do no wrong; thus, they cannot be sued for monetary compensation even if they are not compliant with the ADA. If the state lost, Lane and others would have the right to sue for monetary damages because they were unable to access state services, such as a courtroom. If the state won, the ADA would be meaningless, and those individuals with disabilities would have no recourse should a state or employer choose not to comply.

Brown, having never tried a case before the Supreme Court, scrambled to research the court, the justices, and the argument he could make. He met with experts to work through a series of questions set up in a mock trial. The experts indicated that he had little chance of success, so he called the plaintiffs telling them that he had serious misgivings about his ability to plead their case effectively. In response, Lane told Brown that no one else could do the job because no one else knew him, what he had endured, what he felt, and what it meant to him and the millions of others with a disability. Lane’s faith inspired Brown to carry on.

During the hearing, Justice Sandra Day O’Connor asked if there was any relief under Tennessee law to provide access to the courtroom, and if any citizen of the state had the right to sue for damages if a state building was not compliant with the ADA. The answer was no, which
meant that a citizen of the state would have no recourse or ability to gain access or accommodation to a state building if the state decided not to provide it, and then once denied, he/she could not sue for damages. Thus, the only way to gain access would be through the Supreme Court’s action.

The state of Tennessee lost 5-4, with Justice O’Connor casting the deciding vote. After the decision, the state wrote specific requirements for judicial buildings, and several of the non-compliant counties went beyond those basic requirements to make courtrooms more accessible and accommodating. The entire process took nine years.

The film takes viewers on a history of the case with interviews of Brown, support counsel, Lane, a legal scholar, and one of the county’s attorneys. With the exception of the appearance of one opposing attorney, viewers only get the Lane perspective. There is a thorough explanation of how this type of change does not come from the state or national level, but from the local level and the people who deal with struggles like this every day. Their hard work makes its way through the system to create, or to enforce, law.

Although Lane is represented as fighting the good fight for others with disabilities, he describes himself as “uneducated,” and a “redneck” who suffered from addiction. No stranger to the criminal justice system, Lane had appeared more than 20 times on drug and alcohol charges. However, in all those previous appearances before the judge, he was able to climb the stairs on two legs.

Brown and co-counsel describe Lane as a kind and gracious person in contrast to the state of Tennessee’s attack on his character during the legal wrangling.

Lane died in 2014 before the film was completed. Whatever his true character, the focus of the film is appropriately on disability issues and rights, on how the case changed the court’s understanding of disability, and on how it provides a precedent for future cases.

As for the production, all of the in-film text (including closed captioning) can be difficult to read. For those with hearing issues who use closed captioning, there are times in which the text is unreadable. Although it is Subtitles for the Deaf and Hard of Hearing (SDH) captioned, other text sometimes mixes behind the captioning, which makes for a hodgepodge of letters and missed information. From a visual perspective, the text and captions are pixelated and look somewhat outdated (circa 1980) with camera shots of talking heads, and an occasional shot of a nondescript judicial-looking building, which gets repetitive. The music is ominous in nature, probably more appropriate for a horror film than a documentary about disability.

Despite the unsophisticated filming and the technical problems, the information about the case is important. The film provides a historical context for how people with disabilities are often forgotten and neglected. The film reminds viewers of how only through the enforcement of laws and other legal means will people with disabilities achieve the equal status they justly deserve.

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AΩA Board of Directors installs new Executive Committee and three new members

At the conclusion of its 2017 annual meeting, the Alpha Omega Alpha Honor Medical Society Board of Directors installed the 2018 Executive Committee.

President Eve Higginbotham, SM, MD, Vice Dean, Perelman School of Medicine at the University of Pennsylvania.

President Elect Alan G. Robinson, MD, Associate Vice Chancellor and Senior Associate Dean at the David Geffen School of Medicine at the University of California Los Angeles.

Immediate Past President Joseph W. Stubbs, MD, MACP, Albany Internal Medicine, Georgia.

Secretary Treasurer Wiley W. Souba, Jr., MD, DSc, MBA, Professor, Department of Surgery at the Geisel School of Medicine at Dartmouth in New Hampshire.

The Board also welcomed three new members who will be replacing members who have completed their terms of service on the Board.

Samantha Dizon, MSIV, University of Maryland, will serve a three-year term as Student Director.

Atul Grover, MD, PhD, Executive Vice President of the Association of American Medical Colleges, will serve a three-year term as the Medical Organization Director.

J. Mark Kinzie, MD, Clinical Associate Director, Department of Psychiatry at the Oregon Health & Science University, will serve a three-year term as Councilor Director.
Robert J. Glaser 2017 Distinguished Teachers
Presented at annual AAMC meeting

AΩA partners annually with the Association of American Medical Colleges to present four outstanding faculty members—two educators from basic science, and two from clinical disciplines—with the Robert J. Glaser Distinguished Teacher Award. Each award recipient receives $10,000, each recipient’s institution receives $2,500 for teaching activities, and the school’s AΩA Chapter receives $1,000.

The 2017 Robert J. Glaser Distinguished Teachers are:

**Lynn M. Cleary, MD, FACP**
(AΩA, Ohio State University, 1978), is Professor of Medicine, and Vice President for Academic Affairs, State University of New York Upstate Medical University.

Dr. Cleary demonstrated her aptitude as a medical educator before she completed her residency. As a trainee, she worked with fellow residents to develop a didactic curriculum for the medicine clerkship. The didactic curriculum became the first of many contributions to curriculum development that have defined Dr. Cleary’s distinguished career and exemplified her passion for medical education.

Dr. Cleary joined the faculty at SUNY Upstate Medical University in 1985, and became a core faculty member for the medical student and residency programs. Students recognize Dr. Cleary’s teaching excellence in their course evaluations; her courses consistently rank in the top 10 percent of Upstate educators.

“Dr. Cleary’s teaching style is characterized by high expectations and supportive mentoring. She has a particular skill in assessing a learner’s strengths and areas less developed, understands the process of skill acquisition at the stages of development, and helps them move forward along the continuum,” says Mantosh Dewan, MD, a distinguished service professor at Upstate.

Dr. Cleary teaches and mentors medical students as course director for electives in quality, patient safety, and leadership; as a lecturer in pharmacology, and attending physician on the internal medicine inpatient services; and as Councilor of the Alpha Omega Alpha Upstate Gamma Chapter.

**John H. Coverdale, MBChB, MD, Med, FRANZCP**
(AΩA, Baylor College of Medicine, 2010, Faculty), Professor, Psychiatry and Behavioral Sciences, and Medical Ethics Baylor College of Medicine, is one of the most decorated teachers, and a prolific scholar at the Baylor College of Medicine.

As Professor of Psychiatry, Behavioral Sciences, and Medical Ethics, Dr. Coverdale’s primary teaching occurs at the bedside in Houston’s public hospital. Learners witness firsthand how he models patience, humility, and respect for severely ill psychiatric patients. In addition to delivering clinical instruction, he has codirected the evidence-based medicine course for second-year medical students since 2001.

He mentors students, residents, and junior faculty, as well as faculty through the Texas Regional Psychiatry Minority Mentor Network. As an adjunct professor at Rice University, he assists in evaluating the university’s medical professionalism curriculum.

Dr. Coverdale is among Baylor College’s most active scholars, authoring more than 200 peer-reviewed articles, of which more than half address medical and psychiatric education. Other main topics include ethics in obstetrics-gynecology, professionalism, and media depictions of mental illness. Dr. Coverdale coauthors many of these articles with medical students or residents.

**Joseph P. Grande, MD, PhD**
Professor, Laboratory Medicine and Pathology, Mayo Clinic School of Medicine, has been a pioneer in advancing the integration of basic and clinical science in medical education since joining the faculty of the Mayo Clinic School of Medicine in 1991.

From 1991 to 1997, Dr. Grande was core faculty for The Cell, one of the nation’s first integrated clinical and basic science courses. Since that time, he has continued to advance course integration, implementing differential diagnosis assignments to promote students’ clinical reasoning skills.

Dr. Grande also developed and implemented a teaching assistant (TA) program for third-year medical students in the pathology course. In addition to providing students with clinical perspectives and mentorship, he encourages TAs to innovate, and they have with the creation of journal clubs, the development of longitudinal cases, and the implementation of a web-based course platform. Dr.
Grande works with the TAs to share their work in peer-reviewed journals. Students have recognized Dr. Grande many times for his unwavering support and commitment to creating a positive learning environment, naming him teacher of the year more than a dozen times. He is a highly sought-after mentor and has earned acclaim for supporting the research training of more than 70 learners, including high school students, medical and graduate students, medical residents, visiting clinicians, and research fellows.

Richard C. Vari, PhD (AΩA, University of North Dakota School of Medicine and Health Sciences, 1999, Faculty), Professor and Senior Dean for Academic Affairs Virginia Tech Carilion School of Medicine, has developed a reputation as an outstanding teacher, medical educator, and leader of curricular innovation.

Dr. Vari has been instrumental in directing major curriculum developments at two medical schools. At the University of North Dakota School of Medicine and Health Sciences he was a leader in the transformation of the lecture-based medical education curriculum to a case-focused, problem-based, patient-centered learning curriculum. In 1998, the curriculum was redesigned to reinforce the values of professionalism, humanism, and relationship-centered medicine. It earned recognition as an exemplary medical education program in the Carnegie Foundation’s report Educating Physicians: A Call for Reform of Medical School and Residency. Dr. Vari introduced the school’s first interprofessionalism course as part of the redesign.

In 2008, Dr. Vari was recruited by Virginia Tech Carilion School of Medicine (VTCSOM) to lead development of the new school’s curriculum. In keeping with the school’s founding as a partnership between a research-intensive university and a private clinical system, Dr. Vari initiated a novel medical education program that deploys a hybrid problem-based learning approach, and delivers both an intensive research experience and a longitudinal interprofessionalism component.

“Dr. Vari is one of a kind. He teaches his students from his heart, his passion for his work is infectious, he leads his faculty by example, and he is revered by the students,” says Cynda A. Johnson, MD, Dean of VTCSOM.

**AΩA 2018 program deadlines**

- **January 5, 2018**  The Pharos Poetry Award
- **January 31, 2018**  Carolyn L. Kuckein Student Research Fellowship
- **January 31, 2018**  Helen H. Glaser Student Essay Award
- **February 1, 2018**  Medical Student Service Leadership Project Grant
- **April 2, 2018**  Fellow in Leadership
- **April 6, 2018**  Robert J. Glaser Distinguished Teacher Award
- **May 31, 2018**  Postgraduate Fellowship
- **October 1, 2018**  Edward D. Harris Professionalism Award
- **October 1, 2018**  Robert H. Moser Essay Award

For more information, visit alphaomegaalpha.org.
**Letters to the Editor**

**Being a leader**

I read with interest your editorial, “Being a Leader: The effective exercise of leadership” in the Summer 2017 issue of *The Pharos* (pp 2–6), and I was pleased to see that you mentioned the importance of servant leadership. The term servant leadership was introduced by Robert K. Greenleaf in the essay, “The Servant as Leader,” published in 1970.

Greenleaf was Director of Management Research at AT&T for 38 years. His life as a servant leader is documented in the biography "Robert K. Greenleaf: A Short Biography," written by Don M. Frick, in which Greenleaf is described as “the man who invented a new intellectual discipline.”

Although the concept of servant leadership originated in the business and industrial context, it was effectively broadened to include a spiritual dimension by Bennett J. Sims, the former Episcopal Bishop of Atlanta, in his book, *Servanthood, Leadership for the Third Millennium* (1997).

I believe you have done an important service in applying the concept of servant leadership to medical education, administration, and health care.

Watson A. Bowes, Jr., MD
*AΩA, University of Colorado, 1959*
Chapel Hill, NC

**The importance of narrative in medicine**

Catherine Spaulding, MD, in her essay “The importance of narrative in medicine” (*The Pharos*, Summer 2017, pp 7–10) mentioned several physicians who distinguished themselves as writers of medical humanism, including Hippocrates, John Keats, Atul Gawande and Abraham Verghese (*AΩA, James H. Quillen College of Medicine of East Tennessee State University, 1989, Faculty*).

She suggested that the demands placed on physicians today risks their becoming indifferent to their own emotions. As she put it, even death and dying can become routine, resulting in a loss of compassion.

In *The Death of Ivan Ilyich*, Leo Tolstoy described the despair and isolation that can accompany illness as “…the most tormenting thing for Ivan Ilyich was that no one pitied him as he wanted to be pitied: there were moments, after prolonged suffering…when he wanted most of all, however embarrassed he would have been to admit it, to be pitied by someone like a sick child…he wanted to be caressed, kissed, wept over, as children are caressed and comforted.”

If Tolstoy had been a physician and distracted by the many intrusions that doctors experience today would he have had the intuitiveness and understanding to pen those words?

Edward Volpintesta, MD
*Bethel, CT*


**Health care in America**

I thoroughly enjoyed reading Dr. Tooker’s editorial, “Health care in America: A right or a privilege?” (*The Pharos*, Spring 2017, pp 2–8), and Dr. Byyny’s introduction. However, I think you misstated the Medicare program when you said, “After a long-debated political process, Medicare for the aged, and Medicaid for the poor, were established in 1965. Both programs are administered jointly by federal and state governments.” Medicare is funded only by the federal government, while Medicaid is funded by both the individual states and the federal government.

Paul Manganiello, MD, MPH
*AΩA, Geisel School of Medicine at Dartmouth, 1992, Faculty*
Hanover, New Hampshire

**Editor’s Note:** Dr. Manganiello is correct. The editorial staff of *The Pharos* was not clear in delineating that Medicare is a federally administered program, while Medicaid is administered by the federal government in partnership with state governments. As Dr. Manganiello indicates, the federal government funds Medicare and Medicaid is jointly funded by the states and federal government. We are sorry for any confusion this may have caused our readers.
An Open Letter from AΩA Executive Director
Richard L. Byyny, MD, FACP

Dear Members and Friends of the AΩA Community,

Over the past several months, our country has been experiencing the convergence of a number of events ranging from a multitude of catastrophic natural disasters to civic tension significantly affecting the lives of our patients and communities.

Hurricane Harvey left more than two million Texans displaced, many homeless and in need of medical assistance, as well as financial and emotional support. As one of the largest hurricanes to ever hit the United States, Irma devastated Florida and its 20 million inhabitants as well as several surrounding states.

At the same time, more than 26,000 firefighters were battling nearly 80 wildfires that burned more than 1.6 million acres of terrain in 10 western states, the effects of which impacted air quality on the west coast, Midwest, and beyond.

Hurricane Maria struck Puerto Rico as a Category 4 storm with sustained winds of 150 miles per hour. Its impact was truly catastrophic, with many island communities still lacking access to fresh water and electricity.

And, most recently the devastating wildfires in Southern California have destroyed more than 1,000 homes and businesses and still rage out of control.

Superimpose on these events, the uncertainty related to health care and legislation, not only affecting the lives of our patients and communities, but also our colleagues.

These events create public health and social consequences, a surge in the deployment of resources, enduring resiliency among our first responders, and a reaffirmation of our values as servant leaders and medical professionals.

As a Society with 131 Chapters in medical schools across the country, we have innumerable students, residents, faculty, alumni, and members who are directly affected by these disasters. To our medical schools and communities in Texas, Washington, Oregon, California, Florida, Puerto Rico, Colorado, Louisiana, Georgia, South Carolina, and others effected by these calamities, we will continue to keep you in our thoughts and prayers.

As members of Alpha Omega Alpha Honor Medical Society, we need to come together in support of our patients, families, colleagues, and communities, and call on the strengths that come from our Society’s core values—scholarship, leadership, professionalism, teaching, and service.

In our profession, we need to practice what we teach—patience, tolerance, acceptance, and high quality health care for all—and provide ongoing leadership. Now more than ever, with a looming physician shortage and ever-growing public health and health care demands, we need compassionate, adept pedagogy that accepts young people regardless of where they come from, their socioeconomic background, or their country of origin. We need to pass along to the next generation of physicians, other health professionals, and those yet to join our profession that we are an inclusive community of practice. We must continue “to be worthy to serve the suffering.”

As leaders we must overcome the chaos and be present for those who rely on us—patients, students, co-workers, colleagues, neighbors, friends, family members. We must remember that we have a commitment to provide selfless service with passionate dedication to the vision and mission of our profession and the people we serve.

Medical professionalism stands on a covenant of trust; a contract with patients and society, regardless of socioeconomic status, or exigent circumstances. When called upon, we serve all in need with dedication, commitment, respect, civility, reliability, and the high ethical standards of our profession and Society.

Our country is reeling from these disasters and decisions that impact huge numbers of people, but we must not let these adversities, or any other outside influences, deter us from what we have dedicated our lives as healers to do—treat everyone humanely, with benevolence, compassion, empathy, and consideration.
Pharos Art Director Jim M’Guinness created A Pictorial History of Medical Care for The Pharos in 1973, when it was published as a black and white drawing on the Spring 1973 cover. We recently republished the art in color on the Winter 2015 cover of The Pharos, and we are now offering it in three formats for purchase.

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