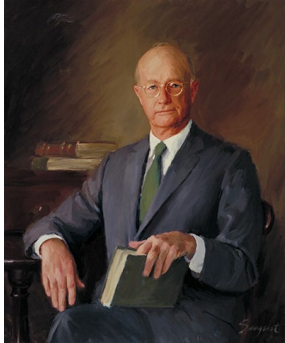


Lives In Medicine: Teaching Hopkins Undergraduate Pre-Medical Students

Presented at the Brady Research Symposium June 7, 2024
In honor of Dr Patrick Walsh's 50 years at Johns Hopkins



When in the fall of 1982 I was in the final year of my urology residency in Baltimore, it fell to me to drive Dr. Hugh Judge Jewett to the Mid-Atlantic sectional meeting of the American Urological Association. Dr. Jewett had been one of the earliest residents in urology at Hopkins, entering the medical school there in 1926, completing his urology residency in 1936. He was classically educated and came from a privileged background, rarely hesitating to correct speakers in conference for using incorrect pronoun cases. He dressed immaculately in shirts imported from London and always wore a suit. He did not, as they say, suffer fools gladly.

During his many years at Hopkins, he had become a highly sought surgeon who was an expert in perineal prostatectomy for both benign and malignant diseases. By virtue of treating many patients who had developed bladder cancer while working at the the DuPont chemical plant in nearby Delaware, he created a system of classification based on tumor penetration depth into bladder muscle for prognosis. He was an editor for the *Journal of Urology* and *Investigative Urology* and had been president of the American Urological Association.

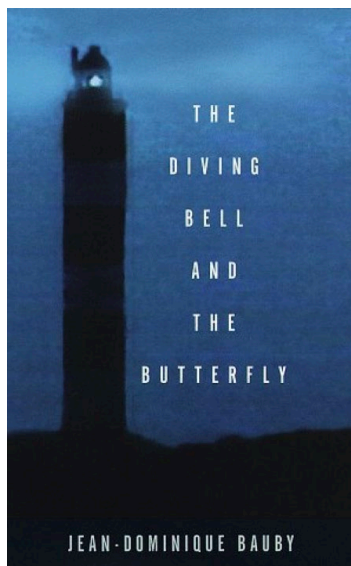
Now he was approaching 80 and knew that he had prostate cancer. At his request, I drove him in his car to the meeting. We arrived a day early and had dinner together in the Old World dining room of the Greenbrier, a West Virginia resort near underground sources of hot springs, characterized by Southern charm and hospitality, as sentimental residents would like to refer to it, tables set with linen, crystal, heavy silverware, flowers, all with an older, refined set of privileges of an elite professional group that I thought I was becoming part of. It was a quiet dinner, mostly filled with Dr. Jewett's reminiscences, at the end of which he said, "It's been a good life, after all." Over the next few days of the meeting, he began to develop bone pain from metastases from the prostate cancer. I searched around the local pharmacies to find a synthetic opiate to ease his pain, and also obtained a supply of the recently released ketoconazole, an androgen deprivation medication that would immediately reduce his testosterone levels to provide rapid relief of the pain caused by the expanding tumor in his spine. The following day, we drove back to Baltimore in relative silence. As we neared his apartment, he said to me, "All my life I've treated this disease, but I never understood it until now."

In 1930., Virginia Woolf, who had herself suffered from migraine and depression noted in her Memoir entitled *On Being Ill*: "Considering how common illness is [...] it becomes

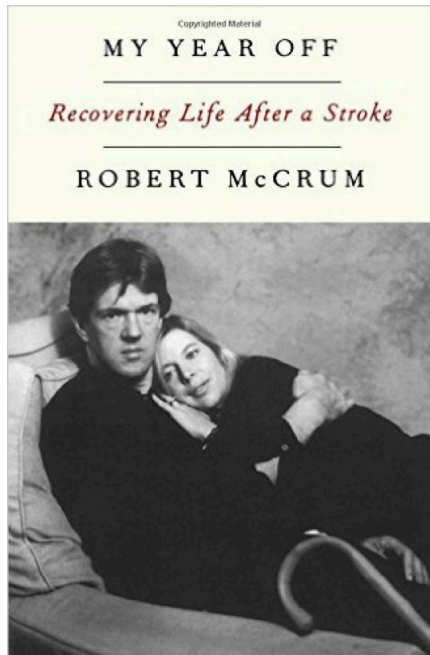
strange indeed that [it] has not taken its place with love and battle and jealousy among the prime themes of literature.”

In 2022, I had been studying the memoirs and biographies of patients and practitioners for several years, and was offered a chance to teach a course as part of the Medicine, Science and Humanities program of the Krieger School of Arts and Sciences (KSAS) at the undergraduate campus. It was structured as a seminar course open to 12 students. We read and discussed books written by patients and by doctors, some six books altogether, allowing for 1-2 weeks per book of careful reading and discussions. We also read a few shorter selections, but books offer a fuller experience of immersion. Students were asked to write in class to capture their immediate responses to prompts related to the material and to make it easier for them to complete the assignments. We viewed two films and read the texts from which they had been adapted: one was the Pulitzer Prize winning play WIT by Margaret Edson, adapted to screen by Mike Nichols, and the other was the Elephant Man, based on the original account of Sir Frederick Treves, adapted to screen by David Lynch. In one class we were joined by a private internist in Washington, D.C. who was able to share his experiences with the class about medical school, training, working for a larger practice, and finally transitioning to being a solo practitioner. It was a great luxury to conduct such a longitudinal course in which everyone got to know each other and conversations could be free and open. This past year, the course was offered to first year students. After the initial limit of 12 was reached, an additional 22 signed up for the waiting list. Plans are now underway to expand opportunities for these students.

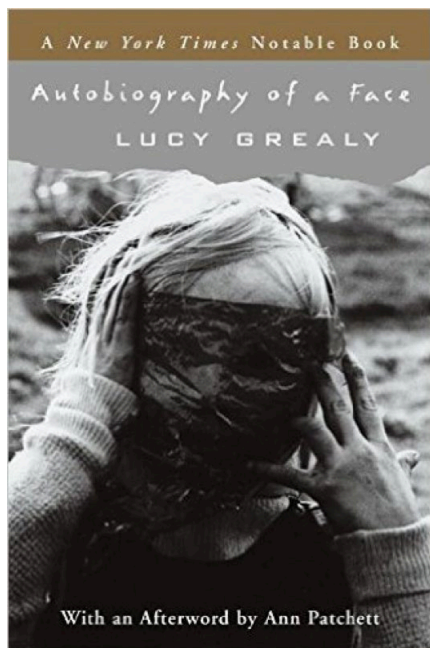
Among the books we read were the following:



The Diving Bell and The Butterfly by Jean-Dominique Bauby. Bauby was the 40 year old editor of Elle magazine in Paris. He sustained a thalamic stroke, a sudden vascular injury to a central part of the brain that left him completely paralyzed, unable to move or speak, able only to flicker one eyelid. Using a code that he developed with his secretary, he was able to prepare and then to dictate the text that appeared in this book during her regular visits, describing his spirit or soul as the butterfly that was trapped within a heavy diving bell that had sunk deep into an ocean to a place from which he could not get out, yet yearning to do so. There is a surprisingly light and transcendent quality to his writing, both lyrical and uplifting. It is a short, powerful book made up of episodes and vignettes, giving voice to a person that is otherwise immobilized in a body that cannot gesture or move, a body often overlooked and disregarded in hospital corridors or rehabilitation centers.

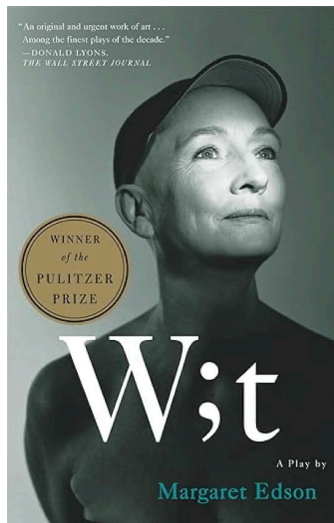


Robert McCrum was also about 40 years old when he suffered a stroke that left him partially paralyzed on one side of his body. He had been the brilliant editor-in-chief of Faber and Faber publishers in London. Recently married, he was forced to convalesce for a year while he re-adjusted his life, left Faber and then returned as literary editor of the Observer. He wrote a book about his “Year Off” as he called it, combining his remembered experiences with extracts from his wife’s journal that reflected the intensity and immediacy of the day to day events and struggles of survival and re-adjustment. A man of learning and literary erudition, McCrum addresses questions of identity, mortality and the meaning of life, or at least his life, drawing from neurosciences, deep reflection on the smallest events and observations, and epigraphs from John Donne’s *Devotions on Emergent Occasions*, written 400 years before our time, but in McCrum’s hands, made as relevant today as it was then.



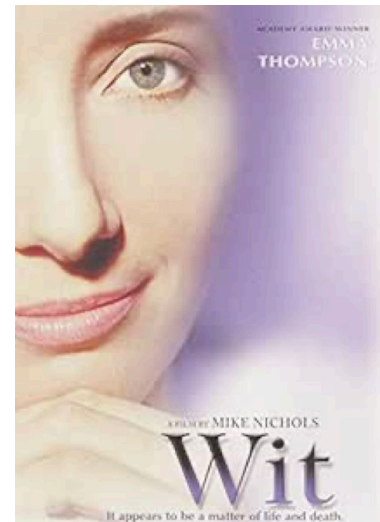
Lucy Grealey had just come to New Jersey with her Irish family so that her father could pursue his career in television production. At age 9, she was found to have an osteosarcoma of the lower jaw that led to resection followed by radiation and chemotherapy. She would eventually go on to have some 30 operations. In her *Autobiography of a Face*, she describes in excruciating detail the world of illness and treatment as seen through the eyes of a child who gradually grows to become a young woman seeking to find her own identity, which has been so inextricably linked to the appearance of a face from which she could not hide, and how it affected her desire to be loved. Having for a long time believed she could never be loved because she was ugly, she eventually found peace in her later years, achieved success as a poet, but then died of an overdose from opiates upon which she had become dependent because of the many operations

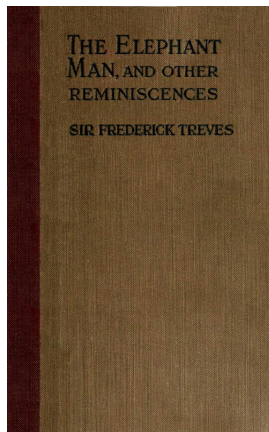
that followed the original one. Her lyrical and poignant writing is compelling and deeply personal, shining a light on the long path that surgical patients may follow as they travel from one doctor to another, from one treatment to another, all the while trying to remain human.



Margaret Edson was a recent college graduate working as a ward clerk at an oncology center in New York City. She created the character of Vivian Bearing, a professor of English literature, specializing in the holy sonnets of John Donne, most famous of which is "Death Be Not Proud." Vivian is found to have advanced ovarian cancer and enters the medical system where she encounters, one by one, a number of figures: a senior attending, an oncology fellow, a nurse, and her former teacher. We see how the different characters in the play, presented in somewhat stereotypical but plausible forms, treat her. At first, proud and resilient, she gradually succumbs to the weakening by her illness and the effect of treatment to accept her own frailty and need for simple kindness and tenderness. We see how the different characters in the play treat her.

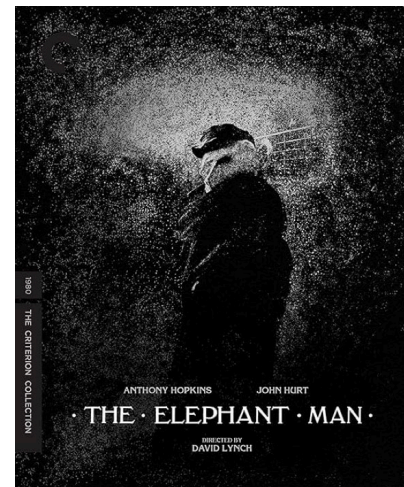
The kindness she seeks is only somewhat expressed by her nurse, and mostly by her former teacher, who had been so strict with her as a younger student, but then consoles and comforts her as might a mother. Vivian Bearing is a fictional character, a composite, made of a series of individuals whom Edson met and later interviewed. But from my perspective as a clinician, all the characters are believable, and in a fiction that seeks to convey a moral truth, that is sufficient. I've seen all these behaviors displayed throughout my career. The movie adaptation by Mike Nichols with Emma Thompson in the leading role is a powerful and sober presentation, which I have previously shown to medical students, who many times found it more compelling than listening to the stories of live patients. As a transitional piece, it offers a way to introduce healthcare professionals to illness as seen from the patient's perspective.





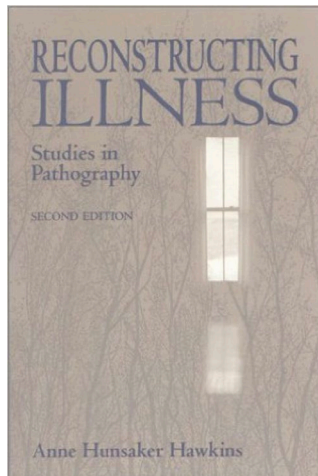
Sir Frederick Treves was one of the most distinguished surgeons of his generation in late Victorian England. He saved the life of King Edward VII in 1902 shortly before his coronation by performing an appendectomy, which at that time was still an early and dangerous operation. Treves discovered Joseph Merrick, a young man with a horribly disfiguring condition, which today is known as Protean Syndrome, but then was thought to be neurofibromatosis. Merrick was exhibited as a freak in a Victorian sideshow. Treves initially brought him into the medical academy to display him as an anatomical specimen to his colleagues, but gradually, as he got to know him, he saw his sensitive nature, intelligence and human qualities, and made him a permanent resident of his hospital, opening

the doors for Merrick to engage society. His memoir, *The Elephant Man*, describes, in what might at first appear to be cool terms, the discovery, presentation, and remaining few years of Merrick. If one were to read on in Treves' other stories, which are presented in this collection of anecdotes, one finds that Treves was actually a very sensitive and thoughtful individual. The film adaptation by David Lynch is a powerful adaptation of this true story. In dramatic black and white, it presents many unforgettable scenes, including one in which Merrick is cornered in a London railway station lavatory by a mob until he turns around to yell, "I am not an animal, I am a human being." In contrast to *WIT*, which is a fictional composite of individuals, the story of Treves and Merrick is real and shows the complexities of interacting with people with strange and disfiguring ailments, raising questions about identity, stigma, and the role of physicians as protectors, investigators and human beings.



Merrick would have agreed with Joseph Conrad, who had himself suffered a stroke in advanced age, writing in his 1920 Preface to *Twixt Land and Sea*. "The memory of an illness is very much like the memory of a nightmare.."

Anne Hunsaker Hawkins, an anthropologist who was studying religious conversion narratives found that her academic course was changed when her father had a stroke and she saw the similarities between his experience and ones she was studying in religious conversion. She directed her attention to patient narratives and created a new term, "pathography". In her 1993 book, *Reconstructing Illness*, she describes an anecdote presented by one of her patients and introduces her newly created term.



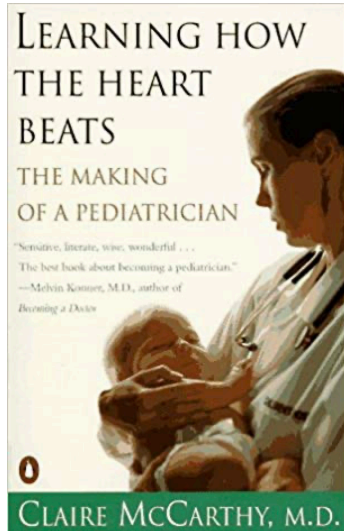
Robinson Crusoe - that is what I think of. Surviving a terrible storm at sea; then being shipwrecked; waking from catastrophe and finding oneself alone in a new, alien and dangerous world." / This was written not by the survivor of a shipwreck but by a woman who suffered a brain tumor and the operation that removed it. / Her book, entitled Surviving, is an example of what I call pathography, a form of autobiography or biography that describes personal experience of illness, treatment, and sometimes death..../ By writing pathographies patients not only restore the experiential dimensions to illness and treatment but also place the patient at the very center of that experience.

Hawkins reviewed some 280 books which she collected on her own before the modern era of internet searching. She classified these books according to the illnesses described, but also according to the various myths and assumptions that provided structure for the narrative. These included athletic contests, spiritual transformation, journeys, war and battle. This was a landmark contribution that was not re-examined again until the year 2000 when Jeffrey Aronson, a clinical pharmacologist and physician teaching at Oxford University, collected another 250 books and reviewed them very briefly in a paper presented in the British Medical Journal.

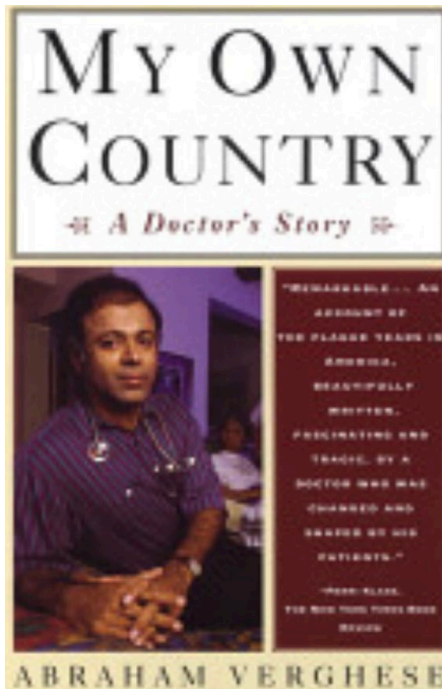
At the end of her monograph on pathography, which had concentrated entirely on patient narrative, Hawkins made an unusual plea:

Another voice we need to hear is that of the physician. This may seem a paradoxical statement at the end of a book that so insists on returning the patient to the medical enterprise and so often contrasts the patient's voice to that of medicine. But the "physician's voice" I am referring to [... is] the voice of the individual who is inevitably lost in that impersonal professional voice. We need to hear from them. [...] / We need more writing that conveys the inner reality of what it is to be a physician in today's technological medical system. / Only when we hear both the doctor's and the patient's voice will we have a medicine that is truly human.

In our undergraduate course on Lives in Medicine, then, we included several of these:

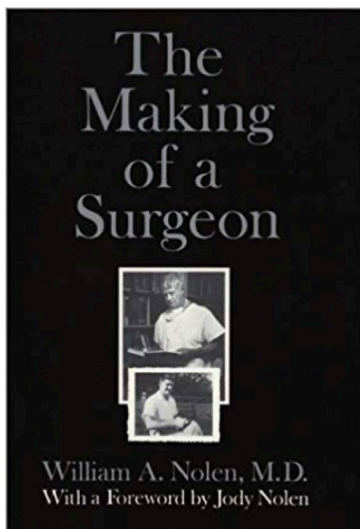


In *Learning How The Heart Beats*, Claire McCarthy presents a chronological sequence of vignettes and anecdotes, beginning with her earliest days as a medical student and continuing to the end of residency in pediatrics when she gives birth to her first child and selects primary care pediatrics in an inner city. McCarthy was the recipient of a privileged education in Ivy League schools with medical school and residency both completed at Harvard. Her voice could be the voice of any medical student at Hopkins, describing her awareness and carefully observed responses to the slow socialization that takes place as one's personal values meet the social demands of the profession and at the same time encounter the very complex human demands of the sick who have their own effects on developing physicians in training. She distinguished between the scientific and technical aspects of medicine which are refined and well developed, and the emotional aspects, which are relatively neglected. Like McCrum in his questions about how his stroke had affected his identity, or Grealey's questions about whether she was only the disfigured face that could be seen or something more, McCarthy asked questions about her own identity and who she wanted to be: someone that she had always been and wanted to remain true to or someone whom she felt she was being turned into by other forces. All of them are asking in some ways the same question: "Who am I?" McCarthy's book is easily read, but is rich in lessons and questions for students who find they relate to it very well.



Abraham Verghese was an FMG, a “foreign medical graduate”. He grew up in the greater Indian diaspora scattered around the world. In his case, it was in Eastern Africa where his parents were part of the administration of Indian built railroad systems. After medical school there, he came to the United States for residency in internal medicine at the Johnson City Veterans Administration Hospital. Following this, he went to Boston University's City Hospital for a specialization in infectious disease. He returned to a position at the VA in Johnson City, where he found himself doctor to young men who had acquired AIDS from needles or sexual activity, and in some cases from transfusion. Very few people wanted to take care of these stigmatized patients. They inspired fear, revulsion and were treated like ancient lepers. Most would die. Verghese immersed himself in their care and became their champion. In so

doing, he found his identity as a physician and a member of American society, finding “his own country”, defining his identity. Starting at the margins of the medical hierarchy of America, Verghese would go on to become a distinguished writer in the United States and also a professor of medicine at Stanford University, focusing on the human elements of contact with patients in their program of “high tech, high touch”.



William Nolan was the everyday guy you knew in high school, who played on the basketball team, was affable, and expressed some interest in being a doctor. Eventually he found his way to the New York University surgical program at Bellevue Hospital, from which he wrote about his everyday experiences during residency training. His writing is friendly and accessible. It is impossible not to like him. He presents surgery as a natural and engaging activity that provides enormous satisfaction by helping people concretely. I read this book when I was a first-year medical student and loved it. Over time I realized that many of the things he described were only partially true, but some were remarkably true, such as the description of his first appendectomy, during which tissues

slip and slide and sutures pull out. A nightmare for him at the time, it was all too real to anyone who has had to learn the craft. It is only one of many such “training tales”, but it is unique and an excellent read for students. As a companion to this, we also read some early accounts of Mikhail Bulgakov's first years out of medical school in rural Russia outside of

Moscow where he was the only doctor, during years just before the Russian revolution. Forced to perform operations he had only seen in books and attended lectures about, he learns from his assistants and operating room nurses to perform complex versions, amputations, and to set fractures, slowly coming to realize that experience alone is the only real teacher. Given his brilliance as a writer, he creates scenes that are vivid and sometimes hilarious, while at the same time being perfectly realistic and true to my own experiences in medicine. The advantage of being a physician when teaching such a course is that one can vouch for the authenticity of such accounts when supported by personal experience.

And so I return to Dr. Jewett's comment with which we started. I remember it so vividly. When his prostate cancer progressed, he told me: "All my life I've treated this disease, but I never understood it until now." At the time, it would have been unimaginable to question his intention, his sincerity or the depth of his statement. It seemed so final and definitive. And yet today I might ask: did it matter that he did not understand the disease in the way he eventually did? Was he any less of an effective or caring clinician for all the many years during which he took care of those patients with prostate cancer? Did it make a difference now that he understood? And what difference might it make for young physicians and medical students to understand? Students in my classes provided feedback on what they had learned, what their experience in the class had been like. Three such responses follow, which I present to partially address the questions that I've just posed.

In all honesty, I expected that the class would grow dull after reading a book from a physician and a book from a patient. I thought that there were only so many perspectives we could possibly read, and that all of the books would tell the same story about how physicians need to treat their patients as human beings. I could not have been more wrong. The stories we read in this class helped me craft an identity that I want to work towards as a future physician. I have learned that medicine is so much more than what gets written into the patient chart or sent to billing.

I have learned so much throughout this seminar about the lives of physicians and patients in the world of medicine. I never expected to become so interested in these ethical and moral questions of medicine...This course introduced me to topics I had never considered before reading these accounts...and through our ... discussions, helped me reach a more sophisticated level of thinking about these concerns.

It is not what I expected; I thought the focus of the course would be much more concentrated on the physician's perspective. As a pre-med student, I thought this perspective would be the most relevant to my future. However, after reading the patient's memoirs, I believe those are almost more valuable because their experiences shape how I want my future patients to feel.

My idea of medicine hasn't necessarily changed because of the course, but it has evolved into a more accurate picture of what practicing medicine and receiving care looks like. Before

this course, I think I had a picturesque view of what being a doctor would be, as I understood the difficulties of managing work and personal life as well as getting too attached to patients, but those views have adapted to become more realistic.

Additionally, I had not considered the patient perspective in the interaction between doctor and patient ... that was incredibly helpful in guiding how I want to provide care as a physician.

I have learned so much - so many new perspectives and ideas on what it means to be a doctor, what the role of a doctor and medicine is, what interactions between patients and doctors are like, the experience of the patient and what the patient views as important from a doctor, and how many doctors approach their practice.

This class isn't what I expected - I'm not really sure what I was expecting, however I think it just surpassed all of my expectations in general. I've never been able to have such authentic discussions, especially over a long period of time with so many different sources and all tying back to the same common theme. Because of this, I don't think I was ever able to imagine the effect that such would have on me, and how much I've been able to learn and take away from it. Traditionally, in school, discussions were graded on strict rubrics and felt scripted, but these were an entirely different experience that I thoroughly enjoyed.

Coming into this course, my knowledge of and on medicine was limited - it was from my own (very limited) experiences of interactions with doctors, media such as tv shows and videos on the field of medicine, stereotypes, and information that I had heard through other people. So, to say that I learned a lot feels like an understatement. I feel like I got so much insight into the field of medicine from both physician and patient perspectives that was real, redefining the stereotypic and idealistic view that I had before.

These represent only three responses, but in the spirit of Dr Patrick Walsh, in whose honor we gather today, and who asked the now famous question, "If one, why not all?" I ask the same question about our students: If one student can see it this way, why not all, or at least, shouldn't all have access to such materials so they can decide for themselves? This is the area of research and discovery towards which this work is heading.

My interest in the biographies and memoirs of patients and practitioners continues to grow. Using more modern library and internet search methods and keywords that both Aronson and Hawkins used in the past, we've been able to identify at least 16,000 titles from about 1990 to the present, about half of which are from patients and the other half from practitioners. The list is growing and we are going to continue to search back to 1950. Any one book is so compelling, it is itself a life in medicine. I don't know what it would take to reach a saturation point, reading a sufficient number to give a comprehensive idea of what people's lives have been like. And of course, there is no substitute for the living experience of medicine to provide this kind of opportunity. But these books do expand

those opportunities and they offer educational resources, not only for our students, but also for the public at large.

As time goes on, however, I find myself increasingly sympathetic to the outlook attributed to Albert Schweitzer.



I have given up the ambition to be great



scholar. I want to be more simply a human...

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