The Case I Can't Forget

Two Patients: Professional Formation before "Narrative Medicine"

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Abstract: In this essay, the author reflects on his development as a physician by recounting two patient narratives of patients he cared for as a third year medical student. In the process of telling these stories of sickness, the author also provides a window on medical practice in the 1980's in an academic medicine center and how practices have changed. Decades before what has been dubbed "narrative medicine," the author learned the power of words to shape relationships and promote professional formation.

The World was Our Stage

When asked to recall memorable patients, two cases immediately came to mind. Each were patients I cared for as a medical student decades ago. The first was a patient on my psychiatry rotation. The second was a cancer patient I cared for while on neurology. Though the years have passed since they were under my care, each was on my service within weeks of each other.

I find it curious that the patients I would remember came from the same period. Was it because my hippocampus was especially formative in those days or weeks? Was it the process of professional formation that happens uniquely during the third-year clerkship that led to the vivid imprint these patients made on me? Or was it simply that these two cases were exceptional and noteworthy? Although the mind of a twenty something is more apt to embed enduring memories, I think the reason why these patients came to mind now was their arrival at a pivotal time in my development as a doctor. As the adage goes, a doctor's greatest teachers are his patients. And these two taught lessons that I draw upon to this day in my work as a clinician and as a teacher of my own medical students.

When we write of patients, we often refer to them as narratives, stories to be told. But as I sit at my desk, I feel uncomfortable with that designation as I was also an actor in the dramas that I will recount. What unfolded was more a play than a simple story. Through the hazy gauze of memory, what I recall are scenes more than words, movement, and actions. Practical things like where the medications were stored on the neurology ward or the pale tan walls of the psych hospital.

And I think of a different era in medicine. It was the mid-1980s before informatics and hospitalists. Managed care was just creeping over the horizon. I was educated in an academic medical center where department chairmen reigned supreme. There was very little central authority and chairs acted like princelings with their own fiefdoms. My chairs came from a different era, as well, only two generations removed from legendary figures like Osler or Cushing.[1] Most all were members of the Institute of Medicine of the National Academies of Sciences and superb clinicians. Their brand of medicine was translational, inductively focused on keen bedside observation from which came hypothesis generation and the cultivation of

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new knowledge. Many edited the leading medical texts of the day. Their power came from what they knew, their academic contacts around the country, and the research they did. They determined what happened in their departments and were impervious to the will of deans and hospital administrators. They were patricians, almost godlike role models for all of us aspiring academic physicians.

Beyond the leadership, the entire power structure was radically different from today. Attending physicians were not hospital employees. They ran their own practices and were autonomous, controlling the flow of admissions to one hospital or another. This conferred immense power on these practitioners as hospital administrators depended upon the goodwill of their attending medical staff to balance the books. The central authority which would be necessary to reign in costs and stave off fiscal disaster and address worrisome variance in practice patterns was still a decade away.

As medical students, we had no sense of how close we were to the edge of fiscal unsustainability. With a historian's lens, I think the training environment I experienced was more akin to the Hopkins model set up by William Welch, William Halsted, William Osler, and Howard Kelly—the four founding professors at Johns Hopkins made famous in John Singer Sargent's portrait.[2] Although we did not learn a whit about health care economics, or medical ethics for that matter, it was a marvelous time to train as a medical student. The hospital was there to take care of patients and the patients were there so we could learn how to become doctors. It was that simple when seen through a medical student's eyes.

Indeed, in that era, patients were referred to as "raw material" for medical education. The prevailing view was that medical schools in small and mid-sized cities could never be great because they did not have a sufficient patient base to educate students and trainees. The great hospitals would be sure to supply the rare cases that would hone our skills as novice diagnosticians. Although we might never again see a rare tumor like a pheochromocytoma which effects the adrenal glands, a training program would be subpar if such cases did not make their periodic appearance. The goal was to be able to hunt down an obscure diagnosis, not necessarily to prepare us for the routine challenges of everyday practice.

Training for more mundane diseases were neither the priority nor of much interest. On professor's rounds, we did not present the routine cases that would occupy most of our professional lives in practice. They were considered too pedestrian. We were smart kids and we could be trusted to learn how to treat pneumonia and hypertension on our own. Indeed, the focus was more on differential diagnosis than on treatment. The best practices movement was still in the future.

In a weird way, we were be trained to think diagnostically and the structure of care was set up to satisfy this need. Patients were kept in the hospital until we could figure out what was going on, pursuing the rarest of diseases, even if that meant a delay in discharge. The point of training was to be complete and comprehensive. And at the risk of a bit of hyperbole, no diagnostic possibility went unpursued. Sometimes, we would hold off on a discharge until a test came back from a special lab across the country. It was the opposite of what Edmund Pellegrino would later call parsimonious care[3] or the "choose wisely" mantra advanced by the American Board of Internal Medicine.[4] With our residents' encouragement, we ordered tests without any idea of what they might cost or their true utility. As long as it did not

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put a patient at risk, our academic curiosity was enough of a justification to order a test or keep a patient in house. Care was indulgent and bloated.

Although the deficiencies of that era should not be discounted, one virtue was clear. We had time to get to know our patients. They were with us for weeks on end, a rarity in today's environment. Indeed, the two patients who are the object of my reminiscences were under my care for the entirety of my rotations on psychiatry and neurology. And when I left to go on to my next rotations they were still there. Perhaps it was this prolonged contact that made them so memorable.

Yet for all its liabilities, now so evident in retrospect, that world was our stage and I loved every moment.

In Living Color

It is rather strange to consider that the person I came to know best, outside of close friends and family, I barely remember now. The memories of her are faint and as ethereal as her thinking. What I vividly recall was the kaleidoscope of language with which she greeted me each morning as I conducted our daily therapy session. She spoke in living color, a visual language that I had to learn in order to communicate with her. I became fluent in the weeks we worked together. But it is a language I have not spoken since.

She was an African-American woman in her early 30s, disheveled and recently off the streets, a victim of the crack-cocaine epidemic. She paid for her habit by working as a prostitute, or so it was thought. Her life had spiraled out of control and she was admitted for an acute psychosis.

I would greet her at her room and walk her to an office down the floor. My attending had told me it was the polite thing to do and as important as seeing a patient's room could provide insight into what was going on inside her head, which was no easy thing to do.

No one had figured her out and it seemed that nothing could be done. No one understood what she was saying. Since she could not be reached, they assigned her to me, a fledgling third-year medical student. Why waste one of the residents on a hopeless case? They were already stretched thin and could do more good elsewhere. So, her case was left to me.

Yes, I had studied Freud in college and written my college thesis on the French psychoanalyst, Jacques Lacan.[5] Neither qualified me for the task at hand, making some sort of connection with a patient who did not even have a diagnosis. No, she had a whole collection of them, which indicated that basically none of the psychiatric sages knew what she had.

She was alternately described as being a schizophrenic, having bipolar affective disorder, schizoaffective and borderline personality disorders, anxiety, and substance abuse. Choose one or more. It was as random as that. The collection of diagnoses she had accumulated said as much about the gravity of her condition as the poverty of psychiatric diagnosis. It was all descriptive and slightly subjective depending on who was the attending psychiatrist and their diagnostic orientation. This variance persisted despite the recent emergence of the new Diagnostic and Statistical Manual (DSM-III) which sought to bring some epidemiologic order to diagnostic chaos.[6]

The problem was that the DSM-III was descriptive and ill-informed by any sense of the underlying circuitry that may be causing psychiatric disease. Functional

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imaging for psychiatric conditions was still on the horizon—one of my medical school classmates would be among the first to image schizophrenics[7]—and there was still a heavy overlay of psychoanalysis in the air, not necessarily a bad thing. But it was not particularly useful when working with patients with major thought disorders, which she certainly had.

That became immediately apparent when we began our conversation. I would speak to her logically, using the approach we had been taught in our psychiatric interview classes. I had an interest in going into psychiatry and had read the venerable *The Psychiatric Interview* by McKinnon and Michels,[8] a really fine book that sadly did not provide much guidance when it came to my patient.

It turned out she spoke a different language than the rest of us. Colors had taken on meanings and personalities. Some folks have a colorful personality; she had a colorful vocabulary. She used regular words of course, but the content, the affective tonality of what she was saying were drawn in the visible spectrum. If you wanted to understand what she was saying you had to understand her palette of orange, green, and blue. Each represented an emotion or a person. It took a while to figure out what seemed like a paint by numbers scheme. Nonetheless, after a couple of weeks, I began to understand. I cannot remember the particulars now, but I do recall confirming whether I had understood her by asking, *ok so its kind of like orange?*

Once I got the hang of it, she grew relieved. It was not that she did not have things to say that she desperately needed to express. Rather it was that no one had tried to understand her, or had the time to try. During my psychiatry rotation, I had an hour-long session 5 days a week for 6 weeks. Overall, it was nearly 30 hours together, just enough time to become passably fluent.

I learned that she had turned to drugs because she needed relief from her symptoms. She did not have access to much medical care, much less psychiatric care so she took it upon herself and self-medicated with cocaine. It did not go well. She had more hallucinations and anxiety and became paranoid. Eventually, she became so ill that she needed psychiatric admission. And there she lingered until I learned her language.

And then it ended. My rotation on psychiatry was up and I had to move on to neurology, which was next in the queue. I moved on with my education and my patient was returned to her not so splendid isolation. At the time, I neither realized that this was her fate nor felt a sense of obligation to stay on or at least teach someone how to speak her language. I just assumed that someone would read my long notes and work it out as I had done. With hindsight, I am not so certain that the system would rise to the occasion and attend to her needs. More likely than not, no one would ever really talk with her again.

It is strange that three decades later, I do not have memories of the content of what we said to each other. Instead I only see colors.

To Be or Not to Be

Weeks after my psychiatry rotation, I was on neurology and I met another memorable patient…

The image lingers: a man in his 60s, his head buried under a fenestrated drape bellowing the soliloquy from *Hamlet*.[9] "To be or not to be …" Yes, that was the operative question as he lay dying of lung cancer, an adenocarcinoma to be precise, that had spread to his brain. His cerebrospinal fluid was swimming with cancer cells

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and his case was futile. His future was measured in weeks, maybe months. In retrospect, I guess that was why a third-year medical student was tasked with giving him his thrice-weekly infusion of methotrexate chemotherapy.

His assignment to me was reminiscent of Martha Weinman Lear's memoir, *Heart Sounds*, in which she describes the progressive abandonment of her urologist husband by senior physicians as his heart failure progressed.[10] Long before the palliative care movement, when cure eluded the patient, doctors abandoned their patients. They moved on to salubrious ventures, progressively leaving the clinical detritus to increasingly junior colleagues. Getting a medical student as your primary care provider was a sociological biomarker that the end was near.

But of course, in a world of winners and losers, for a third-year medical student getting the chance to do a procedure like administering chemotherapy was a plum assignment. Through younger eyes, it was like surgery, a daunting, complicated procedure for the novitiate. First, I would go to the prep room and mix the methotrexate power with sterile saline, carefully infusing the liquid into the power. After I removed the syringe, I would shake up the mixture until the liquid turned white—at least that is how I remember what it looked like. Had anyone actually trained me to do this? Well, sort of. My intern or resident gave me a quick run through and then I was left to my own devices following the old adage, "see one, do one, teach one."

It was a different time. Today, the chemotherapy would come mixed from the pharmacy, where folks who knew what they were doing, and experienced at doing it, would send the medication up to the floor. In the pharmacy, it would be likely that the mixture would have been concocted under a sterile hood to prevent infection and also to prevent aerosolization of the medication. After all, what self-respecting chemotherapeutic agent is not itself carcinogenic?

Well, none of that happened and I would do my earnest best back in the prep room. I worked on a sterile paper towel next to the industrial sink. The nurses came and went, barely noticing my little chemistry project. Why the indifference? Did not they appreciate the complexity of my task? Nope, they ignored me because there was nothing unusual about what was happening. They knew it was rather trivial. Besides, this was what medical students did. These tasks were part of our training.

We assumed this sort of responsibility far earlier than today for two reasons. The laudable one: we had to learn to do these things. Second, we were cheap labor. The infusion specialists, phlebotomists, IV techs, and EKG technicians were in the future after house staff hours were regulated and cut back from 120 to 80 hours a week. Only then was the scut work we routinely did farmed out to ancillary staff.

For me, that all came too late. I was an intern under the old system and a senior resident when the Bell Commission Reforms took place in New York curtailing work hours. Indeed, I wrote my first articles in medical ethics about how this change would affect professional formation.[11] I made the contrarian argument against the change in hours until concomitant attention was paid to professional responsibility. I worried that when an ethic of patient need was replaced by one governed by the clock professionalism would suffer. I think history has vindicated my worries.[12] But I digress…

After I mixed the chemotherapy, I would go back to the patient's room and set up the infusion. This prep time afforded me the chance to really get to know him. He was a wonderful man, a highly skilled lawyer who had become an alcoholic. As I recall he lost a partnership in his firm and nearly hit rock bottom before he pulled

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himself out his personal nose dive. He regained sobriety and worked his way back as corporate counsel at a financial institution. It was not as prestigious as his early work but it was a wonderful comeback. His recovery was accompanied with a first marriage late in mid-life.

But he was a smoker and the cancer struck. As I recall, he had the tumor resected from his lung but it spread, as it invariably does, to his brain. Later he had brain surgery and this left him a homonymous hemianopsia. He only saw one side of his visual field even though his eyes were fine. Without the resected part of his visual cortex he lost sight from the opposite visual field.

This rather rare neurological finding made my patient a special prize. The lucky medical student assigned to his care would get to present his case to the professor of neurology. This was the kind of patient medical students covet. He had a fascinating diagnosis that revealed complex neuroanatomy which allowed ever-competitive third year students the chance to shine while also providing a chance to do a procedure.

So, several times a week, I would clean the skin over the Omaya shunt with Betadine, an iodine-based soap, and place the fenestrated drape carefully over the site. I loved the prep and the word, *fenestrated*, from the Latin for window. Sleep deprived, I was easily amused, but I loved the use of language which described the clinical world I was entering. Fenestra was a window on a new way of knowing of communicating and I relished this new language I was learning. We were once told that we would double our vocabulary in med school. I do not know if it was true but getting to the third year was like moving from the grammar lessons of the preclinical years to the literature of patient care.

You can learn a lot about a person when you spend hours with them each week as you slowly infuse medicine into their brain. That same brain which is battling a cancer that will eventually rob it of sentience was still very much intact and my patient and I would talk, his breadth moving the drape up and down as he spoke. What started off as an exercise in diagnosis and treatment soon became something else, something far more important.

You see he really loved his wife. She knew he was sick of course, but she did not know how bad it was. And he did not want her to know. She must not know. He was deeply worried about her and had made all sorts of arrangements. Using all his lawyerly skills he had made financial provisions for her. She would be fine when he was gone but he did not want her to be upset. He could not bear her sadness. She must not know. But of course, she did. She wanted to protect him from sadness and encourage him. Although she did not believe him, she told him that he was getting the best of care, things would be fine. They would travel together again. This was going to work out.

Each shared themselves with me, but when they were together the conversation was light and superficial. It was so sad that they were wasting the precious little time they had left together. Their motives were good, but almost too good. Each with good intentions, they were depriving each other, and themselves, of the true communion of communication.

It reminded me of O. Henry's *The Gift of the Magi* when a husband buys his wife fancy combs for her lovely hair. Not knowing of his generosity, she cuts her hair so she could buy him a gold chain for his pocket watch. He sells his watch to buy her a gift. At the end of the story their love is revealed as the gift which motivated their selfless generosity.[13]

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For my patient and his wife, the stakes were far higher and more tragic. Instead of fancy combs and a gold chain, their gift to each other was a veil of denial they used to protect each other but also deprived them of each other's love and affection.

Over time, I became their mutual confessor and they spoke of their sadness and loneliness. I could sense they yearned to talk with each other about their life and love but when they were together the conversation became stilted and superficial.

Would not it better if they could have a good cry together and then an honest talk? She could tell him how she felt instead of hollow bromides. And would not he sleep better knowing that his wife understood the financial arrangements that he had so dutifully arranged?

As a young novice, I did not know what to do. I do not think the neurology attendings on the service really cared. Their focus was on the workings of the brain not affairs of the heart. But then there was this nurse, who I will call Mary…

Mary was an older Irish nurse, and to me practically a saint. She had worked on neurology for decades and was a natural healer. Even her uniform looked different, almost like a habit. I imagined she had come from some ancient Hibernian hospice.

Mary was competent and compassionate. There were generations of inexperienced young doctors who were plucked from disaster by her helpful admonitions, which were always shared with the sweetness of her brogue. Helped, that is, if they cared to listen and acknowledge that she knew more about neurology than they did. Woe to the arrogant house officer who ignored a heads-up from Mary. When she told you that a patient did not look right, or a family needed a chat, it was always a good idea to listen.

Well, Mary took pity on me, a third-year medical student who had inherited a dying patient and a broken family. She knew I was way out of my depth and helped me find a safe harbor. I do not remember exactly what she advised but the plan was to suggest to the patient and his wife the improbability that the other did not know what was happening. Although I knew the truth, they had deceived themselves into what Joan Didion would call magical thinking.[14] Such was the power of denial and their selfless love.

So, when I spoke with my patient, I talked to him about those financial arrangements. Maybe he could cue her in on that? It was not an admonishment to talk about his prognosis but a roundabout way to acknowledge that he had made plans for an eventuality that would remain unsaid. When I spoke to his wife, I asked if she really believed her husband did not have a grasp of his situation. After all he had been in the hospital for months, recently had a brain operation and was getting thrice weekly chemotherapy. Things were going in the wrong direction, he was a smart guy, how could he possibly not know?

I was not sure if either of them had picked up on what I had suggested. I had planted some seeds and hoped that they might take, not knowing when and if they would. Then one day, I came into my patient's room and they were sitting together holding hands. There was love in the air and an ease that I had never seen before. They had talked honestly and then reaffirmed their love. Even amidst sadness, there was joy. It was perhaps the most meaningful moment I had in medical school. I still do not know how it happened, who said what or what role Mary might have played in their rapprochement.

Six weeks later he passed. Their time together was too brief but during those precious days, they shared a lifetime together. I took some solace in that and in maintaining contact with the patient's wife. For years, she would send me cards

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from her travels. One was a Mass card from the Vatican. Then the cards stopped. *Tempus fugit.*

Mary remained at the hospital for years. As I became an intern, resident and eventually an attending physician, she continued to work as a nurse. For decades, whenever we saw each other in the hospital there would be a twinkle in her eye and a mutual nod. Neither of us had to say anything. We both knew our thoughts took us back to our patient and the magic that we wrought. No, we did not cure his cancer. That was beyond our means. But we restored a marriage and a relationship.

And Mary helped me become a doctor...

Narrative and the Practice of Medicine

Decades before the creation of what has been dubbed "narrative medicine,"[15] I learned the power of words to shape relationships and promote professional formation. Even as a third-year medical student, it was obvious that patient stories held the key to diagnostic assessment and therapeutic engagement. Howard Brody understood this in his seminal *Stories of Sickness* published in 1988.[16] Narrative medicine had not yet been invented but listening to patients had always been central to the doctor–patient relationship. Narrative medicine is not a graduate course but rather medicine itself. How else could one care for patients? The humanities add immeasurably to the clinical sciences.[17]

Without attention to narrative, these two cases could have been dismissively categorized. The first as a hopeless psychiatric case compounded by tragic social determinants. The second, terminal cancer in a smoker who had a history of alcoholism. But of course, they were much more than that. Both patients were trapped by circumstances that could only be breached through the power of language. The first patient needed someone to understand how she was able, or chose, to communicate. The second was as much a victim of loneliness and isolation as of cancer. He had an adoring wife whom he loved, but it was a love challenged by unspoken truths that dare not be said. In both cases, the need for care and its delivery was understood through narrative.

But attention to narrative did more than help these patients. They also helped me grow into a doctor. Physicians have to learn how to elicit stories of sickness and work with patients as part of their professional formation. This is essentially an editorial skill.

Consider when a medical student writes up a case report or presents a patient on morning rounds. In the recounting of the history, she is engaged in an editorial process deciding what to include and what to emphasize. There is the question of voice and that of evidence and its quality. Who is telling the story and how credible are the cast of characters sharing historical or clinical data? Then there is plot and chronology, changes of scene and the broader contextual issues of geography and social determinants. A good case presentation requires the skill of a discerning editor: if the tale is too short, conclusions cannot be drawn; if the story wanders key elements get lost. The stakes are high and consequences transcend the aesthetics of fiction writing. In clinical medicine, the identification of a diagnosis can hinge on the quality of a case report and the way a story is told.

Some case reports are like short stories and abbreviated episodes. Others, like long struggles with cancer recurrences, can read like novels. But whatever the genre, there is always the drama of a patient's fear and uncertainty. And here the physician

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as editor becomes a true collaborator[18]—or co-laborer—helping the patient give voice to his story, all in the service of healing.

Now a teacher of medical students, I have seen how attention to narrative, this editorial work, is essential to professional formation. Through stories that students craft with patients they accumulate a reservoir of paradigmatic cases. These coalesce into the corpus of knowledge that they carry forward in their medical careers. Informed by what they have read in texts and been taught, these narratives become the locus where theory and practice intersect. And at that juncture knowledge matures into wisdom.

To make the pragmatic transition from theory to practice, students need patients and their stories. In an essay aptly entitled, "Books and Men," William Osler, observed that "To study the phenomena of disease without books is to sail an uncharted sea, whereas to study without patients is not to go to sea at all."[19] Himself a great humanist,[20] Osler understood that our lives and the practice of medicine are told in stories. This essential truth endures and continues to inform the art and science of medicine.

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