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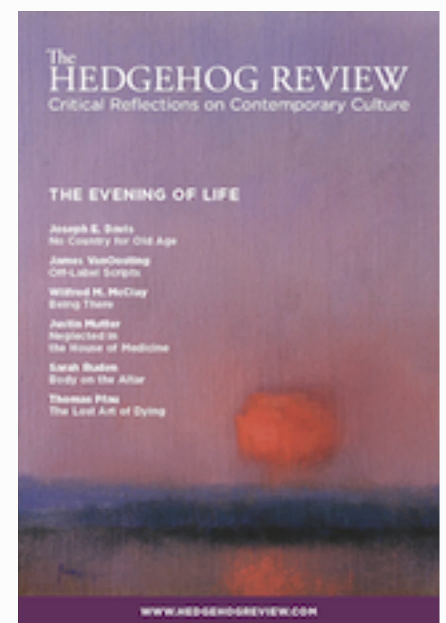
Off-Label Scripts: Physicians-as-Writers, Patients-as-Readers

James VanOosting

My favorite opening line of any novel comes from *War in Heaven* (1930), by the English writer Charles Williams: “The telephone bell was ringing wildly, but without result, since there was no-one in the room but the corpse.” Lionel Rackstraw, a book editor, rushes into his office to answer the phone and, while chatting, notices two boots and a pair of trousered legs protruding from the kneehole under his desk. He bends down to see who’s there, thinking it must be a repairman. “Shall you be long?” he asks. Taking off hat and gloves, he repeats the question, and grows impatient when he receives no reply. “Hallo! Hallo! What’s the idea?” Then it occurs to him: “Damn it all, is he dead?”



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So begins most every murder mystery: the discovery of a body, followed by an investigation of how it came to be there and, more importantly, how it came to be dead. Diagnosis of a fatal disease proceeds along the same basic lines: the discovery of a body, though not yet dead, followed by an investigation backward through time to assemble a patient’s history. The telling distinction between diagnosing a disease and solving a murder lies in how one may interrogate the body. The first allows for Q&A; the second relies on autopsy. Benefits accrue to both approaches.

No writer applied a doctor’s training to a detective’s cunning more effectively than Sir Arthur Conan Doyle (1859–1930). He was not alone, however, in crisscrossing the terrain between medicine and literature. The two disciplines have intertwined since classical antiquity, like that serpent wrapped around the staff of Aesculapius, emblem of the American Medical Association. The god Apollo was patron of both poetry and medicine. Aristotle used a medical term, *catharsis*, to explain the benefits of tragedy. A list of physician-writers would have to include, at minimum, Maimonides (1135–1204), François Rabelais (c. 1494–1553), Henry Vaughan (1621–95), Tobias Smollett (1721–71), John Keats (1795–1821), Anton Chekhov (1860–1904), W. Somerset Maugham (1874–1965), A.J. Cronin (1896–1981), Walker Percy (1916–90), and Anne MacLeod (b. 1951). These clinicians, as well as others, have bequeathed to the contemporary writer a critical vocabulary that links the detective’s *who*dunit to the physician’s *what*dunit, producing thrillers of equal magnitude when inspected under comparable microscopes.

The investigator who arrived first on my crime scene was an infectious disease specialist who set about, straightaway, trying to identify any suspect with means, motive, or opportunity to kill my kidneys. She began by asking me to list everywhere I’d ever traveled outside the United States.

I asked her if this included Canada.

She asked me if Canada was inside the United States.

This doctor had an odd way of squinting over the top of her clipboard.

“Well,” I said, “I’ve traveled to Canada, as you’ve probably deduced. And to Mexico. Both San Miguel and Rosarito.” I tried jollying her up. “Did you realize that the movie *Titanic* was filmed in Rosarito?”

(How was I supposed to know she wasn’t a film buff?)

“I’ve been to Japan, three times. To China, only once, but we covered a lot of territory. And then there’s London, of course. Who isn’t crazy about London, huh?”

She had to have rehearsed that squinting bit in front of a mirror. Otherwise, no way she could pull it off exactly the same every single time.

“We went to Lisbon one Christmas. And to Rome. Paris doesn’t count because we were there for only 24 hours. Both my wife and I are dying to go back.”

She could roll those eyes of hers, startlingly, at the same time she was squinting them.

"And that's all?" the interrogator asked me. "That's the full extent of your foreign travel?"

"Pretty sure it is."

She executed a perfect squint-and-roll combination.

"Oops, I almost forgot. I spent three weeks in Pakistan."

"In *Pakistan*?"

"Conducting research in an Afghan refugee camp north of Peshawar."

"And this is what you *forgot* to tell me?"

Her voice sounded accusatory. I tried smiling, boyishly, impishly, hoping to insert a bit of levity into the situation. Now, after reflection, I've come to wonder whether all infectious disease specialists are impervious to jollification, or if it was just mine.

When the doctor completed a myriad of exotic tests for a myriad of exotic diseases, it turned out I didn't have any. Reporting these results to me, she looked disappointed, nearly despondent. By then, however, I'd determined *not* to play the role of corpse in our little drama merely to please her. There should be a limit, I believe, to any patient's compliance.

William Carlos Williams, acclaimed poet and general practitioner in Paterson, New Jersey, understood the intimate connection between medical diagnosis and literary invention. From the 1930s through the 1950s, he made daily house calls throughout that depressed city. In a 1953 interview with Robert Coles for his book *House Calls with William Carlos Williams, M.D.*, Williams described a typical appointment with a sick child:

> A kid is telling me what happened, and where it hurts and what he does to make the pain better, or what he's tried to do. Some of those kids, they're playwrights, they're storytellers! They'll set the scene for you. They'll introduce other people, not just themselves; I mean, they'll mime people, or try to use their kind of words. They'll say, "And then he said…and then she said…and then I said…." They'll work all that into their own list of complaints.

From such conversations, Williams concluded,

> I'll pick up a good story or novel and the same thing happens: I'm in someone else's world, thank God. I'm listening to their words. My own words become responses to what they say—the novelist or one of my patients.

For William Carlos Williams, writing prescriptions and shaping prosody were separate labors with inseparable logics.

The best sleuth in my own case—*on* my own case—was a nephrologist. The second day of my first stay in the hospital, she walked confidently into the room and introduced herself. Prior to admittance, I had gained 27 percent of my total body weight in less than two weeks. Visual evidence was corroborated by forensic findings, namely, protein in my urine and creatinine in my bloodstream.

Four months, two biopsies, and one trip to Johns Hopkins later, I received a definitive diagnosis: focal segmental glomerulosclerosis (FSGS). (*Glomerulosclerosis*, if you'd like to take it for a spin, is spoken in iambic trimeter, with the greatest stress placed on the second syllable, which is homonymous with *mare*.)

Most medical narratives follow a common story line that begins with pain and proceeds through diagnosis, the naming of a disease, and then the prescription of some treatment. Thereafter, plot lines diverge according to theme: recovery (i.e., getting better), maintenance (i.e., chronicity), progression (i.e., getting worse), or death.

Pain, a story's inciting action, is the sole property of a patient, and the patient, paradoxically, is also the sole property of pain. Emily Dickinson put their inextricability this way:

> [Pain] cannot recollect
> When it began, or if there were
> A day when it was not.

Stories of pain make up a medical genre, their proper audience being clinical professionals. Stories of suffering, on the other hand, represent the emotional pain of pain, and their best audience is a sympathetic friend or family member. Physicians work to reduce pain; friends wish to reduce suffering.

In storytelling terms, pain constitutes *character*; disease designates *place*. No patient wishes to become a long-term resident of disease, or for disease to become a long-term resident of the patient.

Treatment, a third narrative element, represents *time*. For FSGS, the frontline protocol is a large daily dose of corticosteroids. These are not the kind that add distance to a batter's home runs, more's the pity. Those are called "anabolic." The longer one takes corticosteroids, the more side effects they can produce, including Cushing's syndrome. This manifests as truncal obesity, moon face, or buffalo hump.

Another side effect of taking corticosteroids over a long stretch of time is racing brain. One morning, I sat down at the piano to play “Jesu, Joy of Man’s Desiring,” a piece I usually take at sixty-two beats per minute, which is a slowish tempo but not a dirge. On this particular morning, I blasted through Bach as if he were Rimsky-Korsakov. The poor Baby Jesus zipped around the living room *molto vivace*, on enough uppers to outpace “The Flight of the Bumblebee.”

The second treatment for FSGS, if corticosteroids don’t do the job, is immunosuppressive drug therapy. The trouble here is that when the immune system is incapacitated in order to impede kidney failure, it becomes incapacitated for all other purposes, too. The tiniest cut can result in an infection that may run amok and require emergency, middle-of-the-night surgery, such as I’ve experienced.

The happiest kind of medical story is a tale of recovery. This is about getting better. The story of Rip Van Winkle waking up from a twenty-year coma is a tale of recovery. So is that of Sleeping Beauty when she receives the restorative kiss that breaks a 100-year spell.

A tale of maintenance is about hanging in there, surviving one day at a time. Scheherazade provides the archetype. She manages to hold off death, day after day after day, by spinning a yarn so suspenseful that her executioner keeps staying the sentence in order to find out what happens next. After the fabled 1,001 nights, her story saves the day, or, more accurately, her storytelling saves the narrator. Maintenance is a highly desirable plot line for patients with multiple myeloma, lupus, or Crohn’s disease.

A story of progression tells about getting worse. Folks with FSGS get worse because our disease is progressive, irreversible, and incurable. For that reason, I am more cheered by the tale of Jack and the beanstalk than I am by the myth of St. George. Jack *passes* by his giant; George *slays* his dragon. Persons with FSGS try to pass by our beast, daily, because there ain’t going to be no slaying it.

A story about life’s ending may be told either by the patient (*As I Lay Dying*) or by a survivor (*Death Comes for the Archbishop*). In both cases, poignancy derives from famous last words.

Doctors are akin to writers, it seems to me, who, when framing a narrative, ask the structural questions: who? what? where? when? Patients are more akin to readers who must confront the existential questions: why me? why this? why here? why now? They—the doctor/writers and the patient/readers—need to work together in order to create shared meaning.

Before the denouement of any medical narrative, authorial control will have passed back and forth several times between patient and doctor. The story begins with a patient’s report of symptoms. Then, control shifts to the physician, to make a diagnosis. At this stage, some patients push back against their doctor’s diagnosis. However, argument is futile. A medical degree trumps a Google search every time. Thereafter, only a physician may incant the magical name of a mysterious disease.

Narrative authority, in this matter of illness, matters. For the patient, personal authenticity is on the line. For the physician, professional reputation is at stake. For both, integrity weighs in the balance.

A diagnosis of FSGS comes with an expiration date attached to it. I happen to have exceeded mine, and, candidly, this troubles me. I’m wondering if, by remaining vertical, I haven’t ceded some right to continue telling the story. After all, I’ve gone public with a prognosis that includes a number. I take solace in knowing that physicians, too, are fallible when it comes to foretelling the end date of any specific case.

The surgeon and author Atul Gawande summarized the research of Nicholas Christákis (then at Harvard, now at Yale), who asked the physicians of nearly 500 terminally ill patients to estimate how long each one would survive. Comparing their predictions to the actual results, Christákis found that 63 percent of doctors overestimated survival time, whereas only 17 percent *under*estimated it. The average overestimate was 530 percent (not a misprint). The better a doctor knew a patient, the greater the likelihood of error.

Narrative produces data different from numbers, protocols, or nomenclatures. By alternating between the roles of writer and reader, a physician may gain access to the patient’s world, and the patient may be guided through a physician’s maze. Too many medical stories degenerate into melodramas—overgeneralized, interchangeable, and, hence, forgettable. Nuanced narrative, on the other hand, can animate experience, rendering it individual, distinct, and memorable.

Montaigne, the sixteenth-century essayist, imagined the end of his own life thus: “I want death to find me planting my cabbages, but careless of death, and still less of my unfinished garden.” That sounds good to me, except, in my case, death will have to come looking in the gladiola patch.

James VanOosting is a novelist and essayist who lives in South Orange, New Jersey. He has published ten books and many articles, most recently in The American Scholar, Commonweal*, and* Eclectica*. He taught at Fordham University and was dean of the College of Arts and Sciences, Seton Hall University.*

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