

UC San Diego

Independent Study Projects

Title

An exploration of narrative medical writing

Permalink

<https://escholarship.org/uc/item/8n40m6sz>

Author

Wackerbarth, Jesse

Publication Date

2018

An Exploration of Narrative Medical Writing
ISP Project
Jesse Wackerbarth, MS4, UCSD School of Medicine
3/19/2018

The Performance Art of Student Doctoring

He sat upright on the emergency room bed, face gaunt and sallow beneath salted black hair, both arms cradling his protuberant belly with the wariness of a man who knew something was terribly wrong but feared that acknowledgement would make it real. Chronically infected with HIV and Hepatitis B, he had been plodding along at a regular tempo when two weeks before our meeting he noticed his weight was up on the bathroom scale. At first thinking he had been overeating, he resolved to cut out dessert. But the gradual gains continued and as his belly began swelling so did his worries.

By the time he made it to the hospital his abdomen was so taut and distended that it appeared five months pregnant. A CT scan revealed an extensive blood clot obstructing the portal vein and a sinister, golf-ball sized mass lurking at the base of his liver with numerous thickenings of the peritoneal membranes in orbit around it. Even before meeting him, we suspected metastatic liver or bile duct cancer, either of which would be devastating and almost certainly terminal.

As a third-year medical student rotating on the inpatient internal medicine team it was my job to perform the history and physical. The verb “perform,” here is particularly apt, for in the early stages of training, such interactions often felt stilted, artificial, and easily mangled with all the grace of an understudy tossed in front of an audience for the first time. And as a beginning student I was always aware of my audience: the patients, whom I feared would see through my feigned competence, and the attendings and residents whose approval could be converted into favorable evaluations and grades—the universal currency of medical education that would pay my way to an ideal residency and prove my worth as a doctor-to-be.

He looked small and frightened as I hovered over him with my notepad. My resident stood beside me, recording our conversation with staccato keystrokes on a mobile computer workstation. The attending doctor leaned up against the back wall, interjecting every few minutes with a question or clarification before surreptitiously glancing down at her watch. As I stammered my way through the who, what, when, and where’s of his current illness and medical history, I also wracked my brain for any unchecked box or unasked question, simultaneously worried that I might either overlook some key part of the history or be so impractically thorough that I wasted my team’s time—a classic pitfall for beginning medical students. I stole furtive glances at my superiors throughout, hoping to find validation in an approving smile or engaged inflection of the eyebrows. I grew clammy as my interview neared its end, unsure what to say about his likely diagnosis, unsure how to say it—not blind to his fear but worried that a botched attempt to connect would reveal ineptitude or elicit questions I was incapable of answering. Better to leave it to my supervisors, I reasoned.

Exiting the room, I breathed a deep sigh of relief. I hadn't needed to be fed any key questions, had only stumbled over my words a handful of times and even correctly rattled off the physical stigmata of cirrhosis at the behest of my attending. Preoccupied with my performance as a student, it was easy to deemphasize the plight of the patient in front of me—and temporarily ignore that, for him, our conversation had significance far beyond a passing or an honors grade, but was the beginning of a final chapter which would end in his death.

I continued to see him for the next five days as we attempted to solidify a diagnosis and get him home. Budgeting time with my other patients and mountains of still foreign electronic data, I

always felt rushed. Our conversations were short and businesslike, rarely derailing from pleasantries and the quotidian medical questions I was expected to ask: How's your breathing today? Are you having pain? Are you having bowel movements? I often returned to his room in the afternoons, to check in and speak less formally, but carefully tip-toed around his likely prognosis, afraid that I might start a conversation I was ill-prepared to finish. As data from his workup trickled in, I sought nuanced medical interpretations and fretted over how to intelligently incorporate each development into my daily plans and presentations. When these efforts were well-received I glowed with validation, when they flopped it was enough to ruin my day—despite knowing that, with my team's careful revisions, such exercises had little impact on patient care. Sadly, that each piece of evidence, each talking point, was building the case for a real man's death sentence seemed strangely peripheral.

When we finally discharged him to follow up with an outpatient oncologist, he thanked me for my attention and told me I would make a good doctor someday. Flushed with pleasure at his and my team's approval, I bid him a warm farewell. Four months later, struck suddenly with curiosity on a slow call day, I opened his chart to check on his progress. The pale grey alert—patient deceased—landed like a gut punch. He was *dead*. Why was I so stunned? Of course, I had understood his prognosis, having consulted several papers and commented on them frequently for my presentations, yet I had spent little time emotionally processing the ramifications. Scrambling to stay afloat during those first few clinical months, with as much experience interviewing actors as real patients and often feeling like an imposter myself, I had not yet seen first-hand that medicine plays for keeps. I suddenly understood that I was like some myopic thespian acting out a wartime-drama on a real battlefield—posturing to impress with elegant soliloquies, impeccable costume, and false bravado while real patients suffered. My patient's death made it real. I felt suddenly ashamed that I had let my trivial student concerns so dominate our interactions—how insignificant they now seemed in comparison.

My experiences with this patient were emblematic of a tension I felt throughout my early clinical training in medical school. There are real pressures to succeed as a trainee, to ask the right questions, to present eloquently and intelligently so that one is judged a “good” medical student and evaluated accordingly. Having worked alongside my classmates, I know these preoccupations are not mine alone—in fact, on the spectrum of the neurotic perfectionism endemic to medical students everywhere I think I am decidedly middle-of-the-road. For most of us, behind the mask of unshakable enthusiasm and solicitude the awareness that we are being evaluated is rarely far from mind. This motivated me to work hard and learn rapidly, to arrive early and stay late, always hunting for ways to be useful, ever hungry for positive perceptions. But living under a microscope is exhausting and too often in those early months my private educational drama distracted me from what should always be central: genuinely empathizing with patients. Certainly, I made attempts to comfort and connect. I wanted deeply for my patients to like me. Like many medical students my evaluations frequently read “that I went the extra mile for my patients” and applauded my “genuine care and empathy.” But even these moments sometimes occurred at an intersection of altruism and self-concern that makes me uneasy—was I doing the right thing because it was the thing worth doing or because I wanted to be seen doing it? Both, undoubtedly.

In the end, evaluating medical students rigorously in clinical settings is probably unavoidable. Consistent scrutiny and critique motivates rapid development and improvement and anyone who has trained in medicine knows that there is no adequate substitute for real patient experiences. Yet it is worth acknowledging that by utilizing real human cases as evaluative substrate we generate a strange juxtaposition of the tragic and the mundane. In other words, when patients are used as the problem set, it is easy for the pursuit of the right answer to overshadow the heartbreaking nature of the question.

Training to be a doctor is challenging and even with the inevitable refinement of curricula and evaluative schemata that the future promises, I suspect it will always disorient students by intermingling personal struggle and patient suffering. Thankfully, this patient's passing marked a turning point in my clinical years. Of course, I still did my damndest to shine as a student. But by consciously carving out moments to more honestly reflect on the tragic dramas unfolding in my patients' lives, I tempered my own agenda. Rather than adding extra burdens this new perspective helped to minimize and contextualize my own—reminding that even as a bumbling junior medical student wilting under the evaluative glare of one's superiors, to stand at the bedside is a privileged posture that should never overshadow the plight of the person in the bed.

Death Disconnected: A medical student faces mortality in the ICU

I slept fitfully before my first day on “the unit.”

In most hospitals the intensive care unit houses the sickest of the sick—a medical purgatory where patients await judgement from strained physiology with tubes snaking out of every conceivable orifice, bathed in the tireless whir-beep-click-hiss of monitors and advanced life-support systems. At its best, it is a place where patients weather the worst storm of their lives to emerge battered, broken, but limping toward safe harbor. At its worst, it is the theater for total war against hopelessly terminal disease where dignity and comfort are first to be sacrificed, all the more tragic for its foreseeable inevitability. In either case, it is often where hospital patients go to die—which is precisely what unnerved me.

Prior to entering medical school, I had some peripheral encounters with human mortality: foggy memories of two grandparents lost during early childhood; the sickening crackle-pop of cartilage beneath my hands as I performed chest compressions on an unresponsive man in the park before he was whisked away by paramedics; the sight of stiff, colorfully wrapped corpses tossed like sacred wood onto the ever-burning funeral pyres that flank the holy Ganges river. But I had not known death intimately. I had never delivered a terminal prognosis, never felt the skin cool and the breath quiet, never experienced the sickening dread that perhaps my medical decisions had hastened that outcome. Like many incipient doctors, I perseverated over these aspects of my future career, awed by the responsibilities that would be given to me and anxious to prove to myself that I would be up to the task.

As I moved through my third and fourth years of medical school, when students are flushed out of the lecture halls and into hospital wards and clinics to complete a succession of demanding clinical rotations in the major medical fields from psychiatry to surgery, no setting in medicine seemed as likely to push my limits as my institution’s ICUs. In addition, I had grown interested in critical care as a possible specialization, thanks to several brilliant mentors in that field and my belief that such work would be both intellectually and technically gratifying. And so I lay restlessly awake in bed before that first day, animated by equal parts excitement and apprehension bordering on dread, mulling over expectations that would be upended over the weeks to come.

As is typical of our digital era, I met my first patient through a computer screen. Earlier that day her neighbor, alerted by uncharacteristic silence through the thin, shared wall of their senior apartment complex and a subtle feeling of wrongness, had entered to find the elderly woman sprawled on the kitchen floor, eyes wide but unable to move or speak with pajama pants soaked in urine. Soon after arriving at the hospital, she stopped breathing. As there was no documentation of her wishes regarding life support, emergency doctors threaded a breathing tube into her trachea and switched her onto a ventilator to take over for the respiratory center of her ailing brain. Our critical care team was consulted with this grave development and gathered around a workstation to review her imaging. As we scrolled through the grey-scale CT pictures, a plume of white density blossomed into view, obliterating an extensive swath of her left brain hemisphere. One resident recoiled visibly and another let out a low whistle. The stroke was massive, the imaging unequivocal—even I could predict there would be little hope for a meaningful recovery.

She lay sprawled across her bed as she was wheeled onto our floor—her head lolled to the side and mouth jaggedly agape with a breathing tube arching out like the plastic manifestation of a scream. Following into her room, I rubbed abrasively on her chest and hollered “Can you open your eyes?” Nothing, as expected.

I continued through the rituals of my exam: prodding, palpating, and listening to a body that was warm and supple but indifferent to my touch. What history we gathered came from other doctors and the paramedics, none of it in her own voice or colored by the context of her life. At most, with her sedatives turned off, we could elicit a flutter of movement in her left hand and right eye. Her face remained fixed and expressionless—as inscrutable as some ancient death mask.

As I witnessed her deterioration over the next few days, the looming conclusion was unmistakable, but with no sense of the person to whom it was happening, it was difficult to really feel a sense of grief. When I arrived one morning to find that she had died overnight, I felt sobered, some relief that her ordeal had concluded, but little grief or sadness. Like-mindedly, the team took an exceptionally brief moment to acknowledge the loss, then trudged ahead with little fanfare.

Later that week I responded to my first code blue—the highest level of healthcare emergency—blared out through the hospital PA system. Bursting onto a scene thick with frenzied nursing staff and shrieking monitors, we found a frail, lifeless man in his 90’s, porcelain white but for the spreading blueness of deoxygenated blood pooling about his lips, fingers, and toes. Still not knowing his name, we started CPR.

His ribs cracked audibly under the shocking violence of chest compressions done properly—far more brutal than typically depicted on television. A breathing tube was inserted with practiced efficiency. Soon blood, fluids, and a powerful cocktail of medicines to stabilize heart rhythm and increase blood pressure were flowing into his veins and then, when these failed, into the spongy center of his arm bone through a line placed with a special drill. Several times we stepped back to analyze his heart rhythm, then convulsed his body with shocks that failed to bring his heart back online. After twenty minutes of brutal resuscitation attempts the code leader pronounced his death.

Exiting the room, it took several minutes to calm my pounding heart and quaking hands, every nerve seemingly inflamed by adrenalin. But an hour or two later, with the situation’s visceral intensity receding fast into memory, what remained was surreal, dreamlike, and strangely devoid of emotional content. I had just witnessed, indeed participated in, the most dramatic episode of a stranger’s life—the final punctuation mark on a nine-decade-long story—and then I went home, jogged to the park, ate dinner, and went on with my life mostly unperturbed.

For all my foreboding, facing death in the ICU those first few weeks felt like emotional shadow boxing—gritting and bracing for punches that never quite seemed to land. This admission may seem cold and callous to the layperson—indeed, it seemed that way to me at the time—but I think it reflects a peculiar reality shared by many who work with the extremely ill.

Even for those well acquainted with it, there is almost nothing natural or familiar about severe illness in the ICU. By the time critical care doctors meet their sickest patients most are husks of themselves, tragically alike behind nondescript gowns and disheveled visages. Sadly, prolonged unconsciousness from either extreme illness, sedating medicines to treat pain and make breathing tubes more tolerable, or often a combination of both, is the norm in the ICU.

Caring for an unconscious patient *feels* distinctly different. This seems most dramatic in the operating room when the anesthesia kicks in. The patient's suddenly slack body is moved, strapped, and cleaned carefully but without the tentative gentleness usually reserved for breaching a stranger's personal space. Confident consciousness has fled, surgeons can do dramatic violence to a body—slice open the belly or drill into the skull—while casually chattering about a favorite restaurant or the most recent frustration with their teenage son. With the sterile blue surgical drapes covering all but the area being operated on, itself flayed open to expose slick, pink viscera, undulating in alien rhythms—it is easy to put aside the fact that there is a human being underneath. Fortunately for surgeons, such objectification is usually short-lived and tempered by prior interactions with the patient during clinic visits and just before the operation. In contrast, ICU patients very rarely have prior experiences with their doctors and can persist for many days in a unconscious or semi-conscious state that invites much more robust objectification.

Without any prior interactions to anchor a patient's humanity, without ever having seen them anywhere near normal, caring for such people can feel more like grappling with an out-of-control machine constituted of pressures, volumes, cell counts, and blood chemistries but not experiences, aspirations, or fears. If the machine rattles apart, there is a sense of failure and some loss. But knowing intellectually that someone is or was a person cannot replace the emotional depth of experiencing it yourself, much like how, for most of us, reading about a far away human tragedy might elicit a sigh or shake of the head but lacks the cutting poignancy of being there.

This differs dramatically from death in other areas of the hospital, such as cancer wards, where doctors can recall long relationships from prior office visits or continue to commune with patients who remain lucid in the days and even hours leading up to their passing. I still occasionally reminisce about one fatherly patient, who, when not doubled over by the bouts of agony that regularly afflicted his belly, continued to grin his way through wisecracks and irreverent anecdotes of his youth as he gradually succumbed to pancreatic cancer in my care. The more I got to know a patient personally, the more challenging it was to emotionally process their passing. Unexpectedly, it often felt hard to know my critically ill patients at *all*.

Struggling to find my place in the ICU, these realizations left me ambivalent. It was hard not to feel guilty that confronting death could be so tolerable. Yet, the grim utility of such emotional dissociation seemed undeniable. After all, doctors working on these units must shoulder far more than their fair share of death. Depending on the population they serve, an ICU physician can expect that 10-30 percent of their patients will exit the hospital through the morgue. This is a heavy burden and undoubtedly contributes to burnout rates for critical care physicians hovering at around 50 percent—the highest of any medical specialty. Perhaps, embracing some emotional distance might provide a welcome buffer against such a calamitous work environment and promote peak performance throughout a long and demanding career.

But what would this mean for patients? If I am unfortunate enough to end up in an ICU myself—intubated, sedated, unconsciously staring into the void—do I care if my doctor feels emotionally connected to my plight? In most other medical settings, my reflexive answer is an emphatic yes, for effective patient care requires effective communication, which is itself predicated on a genuine empathic connection. In the ICU the answer is less clear. Taking for granted full professional attentiveness and dedication to the case, if my illness prevents me from ever interacting with my doctor, it seems to make no difference that they grieve when I pass away. And if by not weeping for the previous patient my doctors are able to approach my case with a clear head, all the better. In such high-stakes, high-pressure situations, one could even argue that steady hands and a dispassionate gaze might offer better outcomes, with a similar justification as the surgeon who refers friends and family to a trusted colleague rather than risking operating on them herself. Eager to thrive in an unfamiliar world, I donned this thinking like a suit of armor—unaware that other experiences would soon challenge this paradigm and reveal flaws in my protective shell.

After spending several days caring for an unfortunate man with a life threatening infection related to metastatic cancer, I was startled to find his room suddenly crowded with family flown in from across the country. Until then our relationship had been characteristically limited by breathing tube and sedation and had consisted mostly of quick visits to jot down the readouts from his respirator, listen to his congested lungs, then shake my head grimly and exit with my emotions comfortably sheltered by his anonymity. With the quiet sniffles and muted conversations of his three adult children and numerous grandchildren filling the room, my entrances began to feel like intrusions into the intimate space of someone else's life. Such visits became occasions for questions and concerns but also for stories of who my unconscious patient had been. Learning the little details of his life, that he had emigrated from Europe as a dirt poor young man, had started a successful furniture repair business, and habitually spoiled his prized grandchildren with kisses and surreptitious sweets, fleshed out an anonymous body into a man to whom I now had a connection. Sadly, there was no miraculous recovery. He never drew breath on his own, opened his eyes or asked me my name. Still, as he slid slowly toward death surrounded by human context, I felt my emotional distance give way to an aching melancholy that clung to me when I left the hospital. When he died, I was surprised to find myself choked up alongside his family as the attending physician pronounced his death.

Such experiences revealed that my earlier reasoning had erred by conceptualizing patients in isolation, and many are not islands but archipelagos rich with connections to family and friends. At the end of life, critical care physicians often interact much more with these communities than with their individual patients. Orchestrating family meetings, breaking bad news, and guiding distraught loved ones through emotionally challenging decisions, such as when to withdraw life-sustaining care, are all delicate and surprisingly technical tasks that require empathy and an emotional connection to be done well. If too much protective emotional distance is cultivated we threaten the ability of doctors to compassionately communicate with the families of critically ill patients, which may sow distrust into end of life care and perpetuate the suffering of both dying patients and their families.

Fortunately, the natural tendency to objectify critically ill patients is not irresistible. Close involvement of loved ones serves as powerful humanizing force to reorient doctors toward a

more normal, empathy driven relationship by reconstructing a small part of the patient's world in the hospital. When family is unable to be physically present, electronic conference technologies or even simply photographs of the healthy patient at the bedside can be a useful substitute to anchor an empathic connection. Even in cases without involved family, more subtle and surprising cues can collapse emotional distance and reveal a patient's humanity.

This is doubly fortuitous as doctors may themselves be threatened by too much emotional distance. Most doctors were motivated to pursue careers in healthcare, at least in part, by a craving for impactful human interactions. While letting one's guard down in intense settings invites more painful emotions for doctors, such opportunities for connection can also imbue critical care work with meaning that may guard against burnout and justify long, demanding days in the hospital as much as an ample salary. Indeed, while grieving with my patient's relatives clouded my days with more gloom than the anonymous deaths, it also offered a compensatory emotional catharsis and fulfillment from having made a difference to a thankful family that more than made up for the negative emotions.

So how then should death be approached in the ICU: armored or emotionally open? Now poised to graduate medical school and pursue a career in critical care, I have encountered no magic formula, no-one-size fits all approach to answer this question—and I suspect that I will never find one. Some deaths bite deeply, while others slide off the psyche like droplets shaken from a jacket on a rainy day. This is as true in the ICU as it is in life—though the former sees far more precipitation. In my own career, I hope to address each patient individually to budget my emotional resources—to connect and empathize when there is potential for benefit but to remain armored against repetitive anonymous tragedy when there is not. Admittedly, this strategy is fallible and will demand constant revision and compromise—for at the edge of death nothing ever quite goes according to plan and, even in the ICU, emotional reactions retain the capacity to be altogether more nuanced and surprising. I will end with one such story.

The beginning sounded all too familiar: another aged woman brought in after falling in her apartment. But from the moment she entered the ICU it was clear that she had been down for many days. The smell was beyond belief—a mixture of festering flesh, fetid urine, and excrement that stung my nose, watered my eyes and ignited a roiling knot in my stomach that would persist until I had the opportunity to be sick after the ordeal was over. Her skin had broken down and sloughed off where she had rested against the floor and blistered with infection around her soiled pelvis. With hollow cheeks and ragged features she could have easily been mistaken for a corpse but for a feeble pulse and dwindling blood pressure on the monitors. Mercifully, she was unconscious.

As we scrambled to assess and stabilize her injuries, the paramedics handed the chief resident a hand-written note from her fridge. She scanned over it hastily, then froze. Suddenly, she was weeping. She told the intubation team to stop and then slowly read aloud the personalized do-not-resuscitate order inked in purple, flowery cursive.

The words filled the room with the patient's voice and personality, meandering from her wish to avoid invasive life support to her love of her children and grandchildren and thankfulness for being granted such a long, fulfilled existence. Finally it addressed the audience: "I wish you the best and hope you find a life filled with peace and love."

For a moment nobody spoke. The words seemed to float above her tattered and wretched body like an emancipated spirit: defiant, transcendent, refusing to be reduced to the nightmarish scene. Deep within my chest I felt the armor crack and then crumble. My vision blurred with tears. She was suddenly someone; someone who lived and loved, someone's mother and someone's grandma. With this awareness came piercing grief for the indignity of her suffering. I stood by her bed watching in a somber vigil as her breathing grew ragged and heart slowed. I was still beside her when, with a final shudder, she stopped.