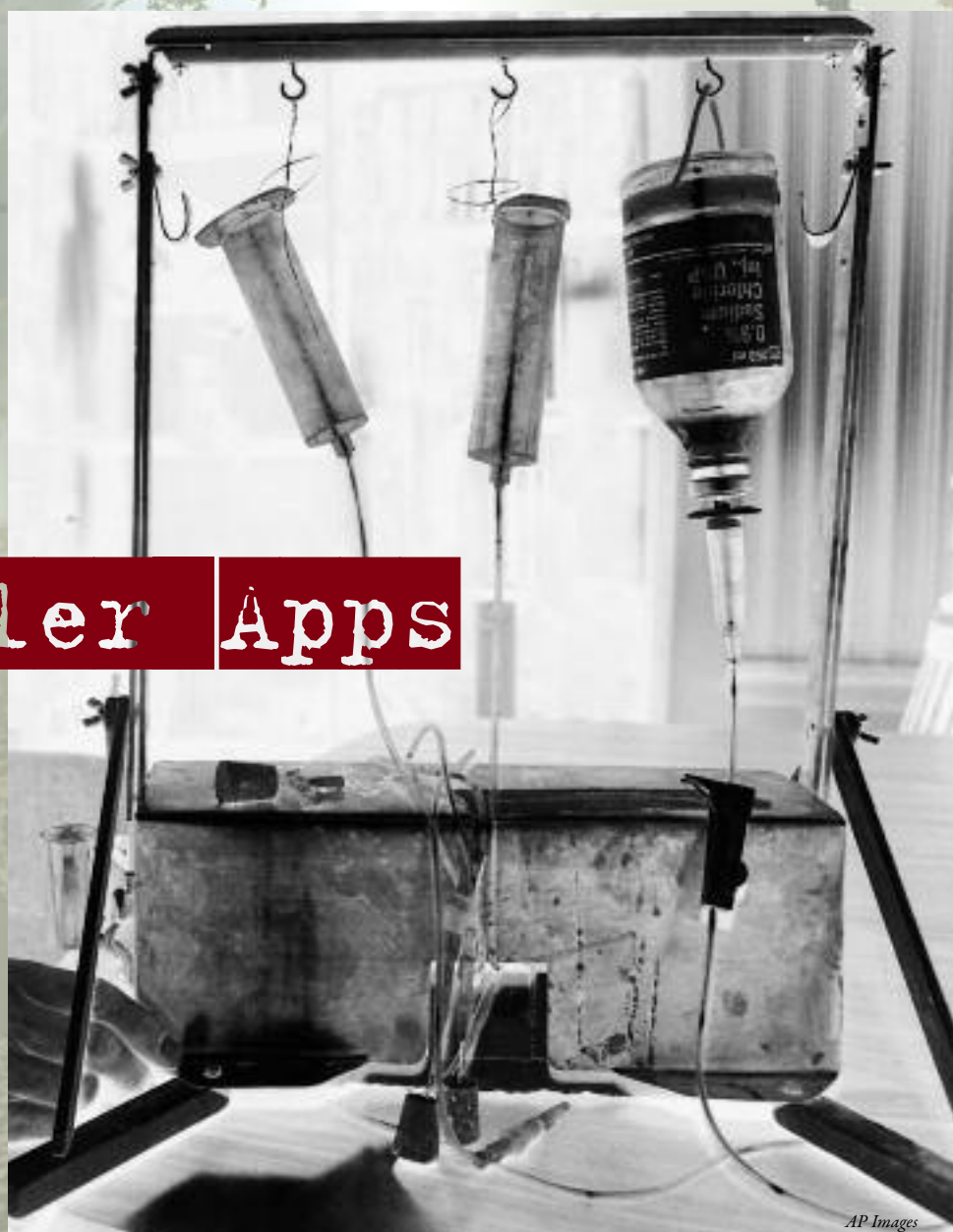


# ATRIUM

2009

The Report of the Northwestern Medical Humanities and Bioethics Program



**Killer Apps**

AP Images



## About the Cover

In the world of computer programmers a “killer application” is any program so necessary or desirable that it proves the core value of some larger technology. In the medical context a “killer app” could be a similarly exciting development, or something more sinister. The 1991 photograph on the cover is a “killer app” in the literal sense—Jack Kevorkian’s “suicide machine.”

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It’s been a summer of death. Shrill arguments flooded the news as a proposed Medicare billing code for end-of-life consultation evolved into “death panels,” critics claimed the VA’s end-of-life planning workbook “Your Life, Your Choices” was the government’s way of encouraging vets to “hurry up and die,” and Ezekiel Emanuel was labeled a “deadly doctor.” Some of these “undertreatment” arguments were political theater, but they wouldn’t be effective if they didn’t tap into genuine fears of a government with a financial incentive to hasten our deaths. Inflammatory rhetoric infected the mainstream too: the September 21 *Newsweek* cover story was titled “The Case For Killing Granny” though it made no such case; it defended terminally ill patients’ right to refuse treatment they don’t want. Ventilators may have been a killer app when they were invented, but the “overtreatment” argument says the same technology’s killing our pocketbooks, and the real threat is doctors with financial incentives to prolong our deaths.

Or maybe the threat is a government that prohibits physicians from hastening our deaths, a different kind of “undertreatment” argument. On September 2 the Montana Supreme Court heard oral arguments in which a lawyer for terminally ill (and now deceased) Robert Baxter asked, “is there a conceivable state interest ... in forcing a dying, suffering patient to remain alive against his will simply so he can suffer a little longer if the end result will be the same?” In *Baxter v. Montana* the lower court held that the state constitution’s explicit protection of “the right of privacy” and “individual dignity” trumps the state’s homicide law as applied to physician-assisted dying, and if the decision is upheld Montana citizens will be the first with a state constitutional right to PAD. In 2008 Washington voters made their state the second to legalize PAD, and in May the first terminally ill Washingtonian hastened her death with a legally obtained prescription.

Taken at face value, all these constructions of the end-of-life threat are fueled by fear of losing control, a bitter anger at the idea of being rushed out of here or of being unnecessarily detained. And whether “do everything” means “use medicine to extend this biologic process as long as possible” or “use medicine to end this biologic process faster,” every individual choice has financial implications in a for-profit system of healthcare and insurance.

Regardless of how these end-of-life conflicts play out, the cover’s killer app will be back in the news soon: Al Pacino is reported to be playing Jack Kevorkian in the upcoming HBO biopic “You Don’t Know Jack.”

Katie Watson



Puck from Arthur Rackham's *Midsummer Night's Dream*

## BEDSIDE EROS



David B. Morris, PhD

*“Doctors tend to have a fierce commitment to the rational.... If there is a credo in practical medicine, it is that the important thing is to be sensible.”*

—ATUL GAWANDE<sup>1</sup>

*“What I fear and desire most in this world is passion. I fear it because it promises to be spontaneous, out of my control, unnamed, beyond my reasonable self. I desire it because passion has color, like the landscape before me. It is not pale. It is not neutral.”*

—TERRY TEMPEST WILLIAMS<sup>2</sup>

My first firm clue that something was wrong came with the blessing of the candles. The secular Jewish family I married into blessed the candles every Passover, and the traditional prayer always fell to my wife Ruth. She stood and stretched her hands—palms down, elbows raised—above the lighted candles and softly, slowly, as she had done ever since childhood, sang the ancient Hebrew words. *Ba-ruh a-tah A-do-nai, E-lo-hey-nu me-leh ha-o-lam....* Ruth’s trancelike state as she re-entered this ritual space softened the armor and edginess that served her well as a mid-level administrator and corporate crisis manager. The blessing, in a reversal of her everyday skepticism,

(continued on next page)



seemed to draw her into a deeper order of time or being. But that night, with family and friends waiting to resume the ancient Passover journey out of Egypt with Ruth's hands floating above the candles, I went stone cold. She had completely forgotten the words.

Illness is like that. It lands on your doorstep like an un-returnable package, and the address is person-specific. The personal dimensions of illness constitute an excess uncontainable within an analysis of medical models and healthcare systems. Ruth's struggle to bless the candles in a voice not just halting but newly unmelodic and oddly flat pointed toward the catastrophic death of brain cells and wrecked neural pathways. It was my starkly non-statistical introduction to the incurable fatal degenerative disease called Alzheimer's.

Serious illness is all about losing control, so it shares one prominent feature with eros. It may sound surprising that my wife's illness threw me back into thinking about eros, but illness and eros both tend to push us into unexpected territory. In *A Midsummer Night's Dream*, the mischievous eros-figure Puck applies a Cupid-tainted juice that impels Titania to fall in love with the first creature she sees upon waking, who turns out to be Bottom the Weaver. Eros so overturns control that the immortal queen of the fairies now fawns on a working-class mortal whose head Puck has transformed into the features of a jackass. "Bless thee, Bottom! bless thee!" cries a justly startled companion. "Thou art translated."<sup>3</sup>

*Translated* in Elizabethan English means changed—the loss of a previous state—and eros, like Puck, is a mighty agent of translations in which change proves inseparable from disruption and loss. Loss of reason too. Eros is the sworn enemy of instrumental reason—rationality (as in medicine) put in the service of a controlling agenda. Its aversion to lost control and to non-compliance helps explain why, very reasonably, medicine tends to flee the erotic. I want to argue a clearly unreasonable, counter-intuitive position: that doctors and patients might reconsider (even embrace) the certain risks and possible benefits of eros. Eros, while it resists the rational bias inherent in medical science and technologies, also affirms the value of experience that cannot be reduced (or translated) into knowledge.

My aim here is to focus on eros specifically as it relates to the loss and failures implicit in illness. The most urgent question that eros forces front and center is not just clinical but ethical: What do we do—what un-thought actions and alien states of being arise—when we accept that we are finally, fully, at a loss?

## THE BEDSIDE

Both illness and eros send us under the covers, so first let's consider the place where the experience of illness so often occurs. In medicine, the bedside is a real-world place of intimate (or at least privileged and protected) exchanges, but it functions also as a metaphor—a theoretical space where patient and doctor meet. In a stripped-down model, the bedside functions as an edge, a boundary dividing the

adjacent terrain of doctor and patient, a borderland where two divided worlds join and sometimes collide. This stripped-down, floating, theoretical edge, however, always acquires thick historical particularities that locate it in specific times and cultures. Eros, then, at *whose* bedside? *When?* And, more or less exactly put, *where?*

The archetypal bedside dyad consists of doctor and patient, then. But suppose, less abstractly, that the doctor is male, the patient female. The doctor middle-aged, the patient young. The doctor well off, the patient poor. The doctor tired, the patient tiresome. These differences are the ingredients of conflict, and they offer almost a blueprint for William Carlos Williams's classic short story "The Use of Force," where eros makes a notorious appearance: "After all," as the doctor confesses of his "unusually attractive" young female patient, "I had already fallen in love with the savage brat..."<sup>4</sup> A routine throat exam goes wildly wrong when the girl resists. "But the worst of it was that I too had got beyond reason. I could have torn the child apart in my own fury and enjoyed it." Eros crashes into an ordinary health care visit like a thunderbolt. Williams's story shows how the consequences of individual human attraction and revulsion reconfigure eros as an ethical—not just natural, biological, or libidinal—state.

Even when translated from abstract to particular, the archetypal bedside dyad of doctor and patient is also inaccurate, or, at minimum, incomplete. On the patient's side of the bed, Kirsten Smith and Nicholas Christakis recently wrote about the impact of what they call "supra-dyadic effects" on health.<sup>5</sup> Dyadic networks include our immediate families. Supra-dyadic networks include not just our families, friends, and neighbors, but *their* families, friends, and neighbors as well. The web of social relations around an individual, it turns out, has direct and indirect impacts on health and illness. It also calls in question traditional notions of patienthood, since the individual patient now appears to possess the power to spread illness—in a new contagion—across the social network. A young mother with Crohn's disease told me, referring not to genetics but to the ways in which serious illness alters people around it, "My whole family has Crohn's disease."

The web of relationships also includes an ambiguous figure: the unpaid caregiver. Professional caregivers may ultimately belong on the doctor's side of the bed. When the caregiver (a healthcare surrogate) is a family member, however, the bedside metaphor begins to wobble out of control as the expanding supra-dyads explode traditional notions of the doctor/patient dyad. As Ruth's disease grew worse, doctors tended to disappear—they had no treatment to offer—and I was the new figure who filled the semi-vacant ambiguous surrogate healthcare position for which, truth be told, I was totally unprepared.

Like me, many primary caregivers are spouses, partners, or family members: overtasked, unprepared, in denial, in love, and otherwise erotically entangled in various familial and unfamiliar relations with their patients. Caregivers who experience strain face a vastly

increased mortality<sup>6</sup>—and strain, I discovered, comes with the territory. Ruth's inability to process a simple request—Could you please close the front door?—met blank stares or led to unimagined blunders. (The cat got out! Now what?) I regularly walked upstairs to discover a faucet running full speed in the empty bathroom. My irritation and frustration, easily brushed aside earlier, now caused Ruth enormous distress, so I schooled myself to an unnatural calm. The house turned into a prison because I couldn't leave her alone. Every day would bring maybe fifty extended tearful half-accusations: "I want a *dog*." It was the last thing I needed. With great difficulty, however, I got her a dog—it's a long story—to which Ruth paid almost no attention. I resigned my professorship. None of this is news to home caregivers. Our standard guidebook is called *The 36-Hour Day*: paradox and exhaustion—a Beckett-like double bind ("I can't go on. I'll go on")—are the surreal norms.<sup>7</sup>

## EROS

Eros, as befits an agent of lost control, resists definition. For the early Greek poet Hesiod Eros was the oldest of all the gods, a primal cosmic creative force. Several centuries later, in *Plato's Symposium*, while its importance is unquestioned, eros has become a subject of debate. Scholars still debate eros and there is no consensus definition, despite a growing recent academic literature.<sup>8</sup> Descriptions are often more useful than definitions, however, and the folly of a diagram at least indicates some of the forces and difficulties involved in eros.

The diagram depicts eros as an energy associated with the human libido that passes into and links quite disparate states: lust, love, empathy, violence. The methodical clock-face schema looks like a comedy of reason seeking to control the irrational, but it also allows for fifty-six additional shades of erotic experience, not all pleasant.

The chief modern theorist of eros is Georges Bataille, and his illustrated and summarizing book is *The Tears of Eros* (first published in French in 1961 as *Les Larmes d'Eros*).<sup>9</sup> It offers a truly disturbing vision of the dark side of eros, where erotic pleasure and sexual passion are, at their limits, inseparable from pain and death. Bataille also celebrates the sometimes creative and often destructive link between eros and violence. From classical lyric to tragedy, Sappho and Sophocles show how eros rips lives apart, tips the state toward collapse, and draws even innocent bystanders into its whirlpool of disorder, irrationality, and catastrophe. Puck, an immortal spirit, explains our incorrigible taste for eros as the species-wide disorder of creatures defined by their relation to death: "Lord, what fools these mortals be" (III.ii).

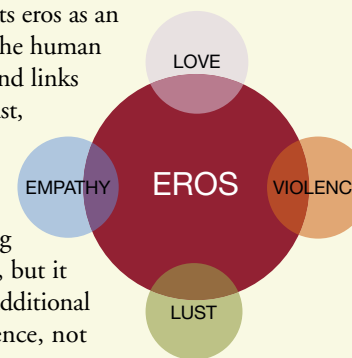


Eros, in short, disrupts consciousness, disorders lives, and fractures communities. Not only is eros not identical with love, it often shatters settled love relations with casual flings and disastrous betrayals. It persists in love's absence or in the death of love. Lovesickness was even a standard medical diagnosis in the Middle Ages: a famous English bishop supposedly died from it. In our age, disruptive erotic energies spill across nontraditional supra-dyads, as in TV ads where sex sells remedies for everything from headache to osteoporosis, or in the dizzying carousel of first-name-only characters hyper-communicating about an absent nameless HIV/AIDS patient in Susan Sontag's 1986 *New Yorker* story "The Way We Live Now." The way we live now, as embodied in her breathless prose, unfolds within media-saturated social networks where illness is always, if only in potential, erotically supra-dyadized.

Its entanglement with varieties of extreme loss and failure makes eros an uncannily familiar figure at the medical bedside. "The Use of Force" is the default cautionary tale against medical eros and its failures of control. For medical students I have known, the shocking behavior of Williams's fictive doctor—his self-confessed attraction to his patient, his fury at her resistance, his burning face—illustrates the perils of eros within the charged doctor/patient dyad. He is the medical student's negative role model: a figure of professional contempt. The story, however, survives reduction to a biomedical parable about the need to keep eros safely cordoned off. In a less didactic reading, the doctor is not so much wrong—that is, unethical, unjustified, or unprofessional—as utterly lost. Free-falling. He appears unaware he is lost, in his blinded attraction to the vitality and passion of his young patient, but isn't that the point? Eros takes vertigo as its defining mental-emotional state: not just the psychic corollary of lost self-control, but loss that threatens even the self who controls. "The whole business of eroticism," Bataille writes approvingly, with a wink at the implicit anti-capitalist and anti-business agenda of eros, "is to destroy the self-contained character of the participants as they are in their normal life."<sup>10</sup>

Williams's doctor (on a "three-dollar" house call) gains an important medical diagnosis, with benefits for the patient and for the community, but he fails to grasp the simultaneous loss entailed by his encounter with eros. No gain, as the widest perspective on eros reveals, without pain. Eros, moreover, in the most distressing implication of Williams's story, is inescapable. Its presence even when we least expect it tends to de-mythologize the *cordon sanitaire* that medicine likes to draw around illness. The official quarantine barriers once erected to stop contagious disease extend now to various unofficial practices, technologies, and applications of state or local biopower that (while not directly designed to do so) isolate patients and rope off eros. Eros, of course, crosses all barriers anyway, but the greater harm in medicine may come from the mindset that ignores, excludes, or repudiates it.

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# Manifesto

## for Medicine Studies



Tod Chambers, PhD

As I write this essay, there is an ongoing crisis within bioethics and the medical humanities. The University of Tennessee's College of Medicine is considering expunging their Department of Human Values and Ethics. Many in bioethics and the medical humanities had thought that their presence within any reputable medical school in North America was at this time simply a given, but this crisis has made me wonder about the status of bioethics and the medical humanities as disciplines. Suppose that there was some odd medical school plague that wiped out all of the bioethics and medical humanities departments, programs, and centers. Would the disciplines continue to exist?

For bioethics I believe the answer is yes. Bioethics has existed within medical arenas due to its ability to provide answers, guidance, and helpful structures to

moral dilemmas, but the discipline also has an existence outside of its practicality. Philosophers and religious studies scholars would, I believe, continue to work on the moral problems in biomedical research even if there were no financial support from the medical or research environment.

I believe, however, that if the medical humanities were eliminated from medical schools, it is highly likely that medical humanities would cease to exist. There might be a few stray literature courses for pre-meds on images of the physician in 20th-century American literature or religious studies courses on death and dying, but the medical humanities is intellectually anchored to (and in being so restricted to) its ability to demonstrate its practicality in improving the moral ethos of contemporary health care.

In a recent essay in *Academic Medicine*, Johanna Shapiro, Jack Coulehan, Delese Wear, and Martha

Montello demonstrate this very feature. They define the medical humanities as an entity possessing three characteristics:

1. They use methods, concepts, and content from one or more of the humanities disciplines to investigate illness, pain, disability, suffering, healing, therapeutic relationships, and other aspects of medicine and health care practice.
2. They employ these methods, concepts, and content in teaching health professions students how to better understand and critically reflect on their professions with the intention of becoming more self-aware and humane practitioners.
3. Their activities are interdisciplinary in theory and practice and necessarily nurture collaboration among scholars, healers, and patients.\*

The authors of this article state explicitly that, "Conditions 1 and 2 imply that medical humanities have a significant moral function."

I'm not against an academic discipline having consequences, I'm against academic disciplines that are defined by their consequences. In order for the medical humanities to become a full academic discipline I believe it must become fully impractical, amoral, and indifferent to its potential social consequences.

Intellectual disciplines must have some conceptual object that they are trying to reach. For example, Ferdinand de Saussure established linguistics as a distinct discipline not by inquiring about the characteristics of French, English, or Chinese, but rather by asking what is language. And the medical humanities has the potential in its core to do something bioethics has largely been uninterested in doing: to understand medicine as a conceptual object. I think that we need a discipline that looks at medicine itself without a concern for any facility to improve it as an enterprise. I tend to refer to this as "medicine studies." I have colleagues who believe such a name brings both the strengths and the weakness of an association with science studies, which at its best forces us to demythologize science and at its worst leads us to the Sokal affair. Others have proposed other names for such an entity—critical medical studies, mediprudence—but I am not concerned about the particular nomenclature. The central issue is an intellectual move from being a field that serves as a handmaiden of medical reform to a legitimate academic field. The academic study of medicine has been fragmented across a number of disciplines: medical sociology, philosophy of medicine, history of medicine, medical anthropology, literature and medicine, rhetoric of medicine. That many of these disciplines tend to overlap in their intellectual work

without being aware of one another's contributions has kept the study of medicine stunted in its intellectual growth. These disciplines need each other in order to avoid presenting merely a series of partial descriptions of the various parts of a medicine elephant.

These are some of the key features of what I believe would entail the creation of this new field, medicine studies.

1. It aims toward understanding the conceptual object medicine.
2. Its purview is limited to the understanding of allopathic medicine.
3. It is critical of medicine's own self-understanding.
4. It focuses on the actual practice of medicine. To make a parallel to a methodological rule of Bruno Latour's, it studies medicine in action.
5. While it is multidisciplinary in its foundations, it strives toward an interdisciplinary understanding of this conceptual object. It admits that such an understanding of medicine requires the disciplinary tools of such academic fields as history, social science, performance studies, rhetoric, literary criticism, visual studies, law, philosophy, and religion.
6. Its primary aim is the description of medicine, not the prescription for any particular practice of medicine. It is separate from bioethics and is agnostic toward bioethics' objectives. It understands bioethics as simply another component of contemporary allopathic medicine. Thus it eschews moralizing but can permit a form of ethical realism when it interfaces with bioethics.

This direction can transform the medical humanities into an academic discipline toward which it has now only made tentative steps.

Manifestos require fist-shaking endings, so in homage to the genre's most infamous representative, here's mine:

Let the medical humanities scholars tremble at a medicine studies revolution. The scholars have nothing to lose but their practicality.

They have a discipline to win.

\* J. Shapiro, J. Coulehan, D. Wear, and M. Montello. Medical humanities and their discontents: definitions, critiques, and implications. *Academic Medicine: Journal of the Association of American Medical Colleges* 2009; 84 (2):192-198.

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# An End to Innocence:

## *Attending to Histories and Methods in Women's Studies and the Medical Humanities*



Suffragette parade,  
(early 20th century)

Photo courtesy of Son of the South

Lisa Diedrich, PhD

As someone whose training, teaching, and research cross two interdisciplinary fields, women's studies and medical humanities, I am frequently struck by the remarkably similar ways in which each of these projects is articulated from within and perceived from without. Defenders of these programs often argue for them in terms of their ability to open up a space for those who historically have been marginalized or silenced in liberal arts and medical education—women and patients. By creating these new spaces in which the voices of the marginalized might speak, we challenge the hegemonic view of men and doctors on how to approach

scholarly and medical diagnoses and treatments. Women's studies and medical humanities bring into view the binaries man/woman and doctor/patient, and investigating these leads us to other related binaries: reason/emotion, mind/body, self/other, public/private, universal/particular, hard/soft, active/passive, autonomy/dependence... the list goes on and on. Women's studies and medical humanities stress the importance of the second term in the binary, the one that has been less valued in the hierarchical relationship between the two sides.

The many detractors to these counter-hegemonic projects reduce them to identity politics masquerading as scholarship at best, and therapy at worst. Many supporters reinforce this perception by emphasizing the importance of the space itself as a refuge for the victims of an unfeeling or even hostile larger academic or medical world. I want to suggest an alternative to the identity politics, therapy, and refuge models for both women's studies and medical humanities by thinking further about the particular histories and methods of these two interdisciplinary fields of study. In doing so, I want to argue for an end to innocence in each field's conception of itself in relation to power. I'm calling for us practitioners of women's studies and medical humanities to resist making sentimental claims to the innocence of our positions in relation to the larger institutional and transnational structures in which we do our work. Giving up the comforting illusion of our own innocence might begin by first attending better to our histories (the multiple and conflicting historical, social, and political factors that resulted in the emergence of these two fields) and our methods (the pedagogical and research practices that are encouraged, rewarded, and passed on—or not).

### Attending to Histories

What forces shaped the emergence of these two interdisciplinary fields and how has each field been transformed since its emergent moment? Because *Atrium's* purview is the medical humanities and bioethics, I will focus my discussion here on the histories and methods of the medical humanities, and not women's studies. Still, in a historical conjunction that I don't think is coincidental, it's important to note that women's studies and medical humanities emerged at roughly the same historical moment, in the late 1960s and early 1970s.

In "Engaged Humanities: Moral Work in the Precincts of Medicine," Ronald A. Carson offers a fascinating snapshot of the milieu out of which medical humanities emerged.<sup>1</sup> The section entitled "Where Do We Come From?" opens with this statement:

In one sense, the medical humanities are a product of the turbulent '60s, when authority and expertise were being questioned and traditional ways of doing things were being challenged. Hermeneutics of suspicion was the intellectual weapon of choice, and "relevance" the preferred criterion for what mattered

most in the mastery of ideas. America's students wanted to know not only what their professors knew but also how that knowledge could be put to use in making the world a better place. The humanities were caught up in one of their periodic identity crises. Philosophy was stuck in an analytic mode (moral philosophy was all but moribund), and literary criticism was about to experience an esoteric theory boom far removed from what was going on in the lived world. Meanwhile, across campus in the medical schools, thoughtful clinicians were expressing concerns about a perceived devaluing of what Walsh McDermott (1978) would later call the "Samaritan function" in the teaching and practice of medicine (322).

I quote at length from Carson's essay because I want to tease out some of the strands of what he sets up as the originary impulses that propelled the constitution of a new field. First of all note that there are two, and only two, sides of the campus—already there is a cleavage between medicine and the humanities—and this binary structure is literally materialized in the architecture of many campuses. On the one side of campus, there is a generally turbulent mood, out of which come diffuse challenges to authority and expertise, and a demand for the relevance of knowledge practices. This side of campus has "identity crises," a phrase that succeeds in personalizing the humanities; that is, the humanities, like many individual humans, have identity crises. This is an interesting conceptual move: the large and diverse group of fields that are organized under the sign "humanities" takes on a kind of personhood. We are not talking about particular scholars with particular intellectual preoccupations and methods; we are talking about the humanities itself, *as if it were a person*.

Next we are presented with two huge generalizations. Philosophy is "stuck" and morally "moribund" and literary criticism is, well . . . it's really a very sad story. In this moment, the late 1960s, literary criticism appears to be simply biding its time, awaiting what will be a decidedly dystopic future, the disciplinary equivalent of invasion of the body snatchers by that deadly monster called "theory." It hasn't happened yet, but it's coming, we can feel it.

Okay, so things are a mess on one side of campus. What does Carson see on the other side of campus? "Meanwhile, across campus in the medical schools, thoughtful clinicians were expressing concerns." Across campus, there are clinicians—individual practitioners—and they are thoughtful—their motives are good. There is also a specific problem that the concerned clinicians seek to address—a devaluation of the ethical imperative (here, specifically, Christian) to extend care to strangers. Good motives, problem solving, and an ethical imperative as opposed to a moribund morality, esotericism, and an identity crisis. Two sides, two cultures.<sup>2</sup>

I don't disagree with Carson that this is one genealogy of medical humanities, but I do want to challenge the exclusions he performs in order to tell his version of history. What gets excluded? Politics and theory.<sup>3</sup> I only have the space here to suggest that the practice of medical humanities in the present might benefit from tracing other genealogies of medical humanities, ones that begin outside and extend beyond medicine's usual domains. If an initial impulse in women's studies was to "add women and stir"<sup>4</sup> in a kind of additive challenge to established disciplinary formations, I see an equivalent impulse in medical humanities: "add compassion and stir." But there's actually more than compassion at stake. Just as one of the key shifts in the practice of women's studies was to challenge the coherence of the category upon which the field was founded, "Women," medical humanities might do well to examine, rather than take for granted, the category "Human" and the practices of humanism.

### Attending to Methods

I don't think the term "medical humanities" gets us far enough. I prefer the term "critical medical studies" to describe how I understand my own work. As I conceive it, critical medical studies encourages the cross-fertilization of theories and methods from the social sciences and humanities into medicine. Medicine is a field that combines science, art, religion, and public policy. Moreover, practicing medicine requires that we take up questions of scale. We have to think about how we move between the micro and the macro, how we scale up and scale down, and how we think big things and small things at once. The experience of illness and its diagnosis and treatment connects the small things—cells, genes, bodies in the world and in relation to others—with big things—national and transnational systems and structures that frame health policy and biomedical research. Critical medical studies takes medicine as a multiple and complex object to be studied with tools that are not usually associated with its practices. What happens when we bring diverse research practices like ethnography, systems analysis, close reading, photography, and narrative competence into medicine? How does medicine change these practices and how do these practices change medicine?

Attending to methods is key, so let me offer what I take to be an exemplary text of critical medical studies: Annemarie Mol's *The Body Multiple: Ontology in Medical Practice*.<sup>5</sup> I mention this book every chance I get, because it's a book that should be more widely known and read than it is. I'm on a bit of a mission. Bear with me.

I think of *The Body Multiple* as almost perfect: not in the sense of being a definitive account of Western medicine or even of a single disease, but as the enactment of a highly original interdisciplinary methodology. We might say that *The Body Multiple* gives us a model for thinking big through its ability to make linkages across medical subfields that don't necessarily share the same language or objectives. At the same time, every sentence has been worked over with attention; her attention is directed not at what medicine says about itself, but at its practices. Mol is concerned less with how medicine knows a particular disease, or how a patient knows

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her illness, than with how that disease is enacted through practices. Mol calls her method “praxiography” because it “foregrounds practicalities, materialities, events” (12-13). Illness, for Mol, “is something being done to you, the patient. And something that, as a patient, you do” (20). In this way, she also gives us a model for thinking small through her assiduous attention to how specific practices, like angiography, surgery, and walking change the object, atherosclerosis.

Mol’s methodological interventions are in terms of how we gather and analyze material, and in terms of the way we structure the presentation of the material we gather, which is why her text gets divided into an upper and a subtext. The upper text presents ethnographic material about how atherosclerosis is done at one hospital in the Netherlands, along with her analysis of that doing. In the subtext she relates to the literature that has led her to this particular example of the practice of empirical philosophy. There is a foundation, literally in terms of the text, to her work.

There are many interventions in *The Body Multiple*, but I’ll just mention one other, which is about writing better. She pays attention to writing itself, because she believes that, we need “to enrich, complexify, and change academic writing practices” by taking our writing methods “as seriously as our methods of gathering and analyzing materials” (162). In her subtext, she celebrates another text with a decidedly un-sexy title, *Health and Efficiency* by Ashmore, Mulkay, and Pinch.<sup>6</sup> What Mol likes about *Health and Efficiency* is that it “brims with conversations, shifts in scenery, alternative presentations of material, self-reflexive remarks, and jokes.”<sup>7</sup> To me, this sentence could also describe *The Body Multiple*. There aren’t many scholarly books that I have read that frequently make me smile,

and sometimes laugh, as I’m reading.

In *The Body Multiple*, Mol teaches us not to take ourselves too seriously, while at the same time she offers us an exquisite example of how to do critical medical studies.

#### Postscript: Why critical?

At the *Books to Bedside* symposium at Northwestern University’s Feinberg School of Medicine in April 2009, I was invigorated by the robust exchanges about the past, present, and future of the medical humanities. It seemed to me that translational work wasn’t just talked about at the symposium; translational work was enacted, sometimes smoothly, sometimes less so. In the final plenary, I presented a version of this attempt to describe critical medical studies, and was thrilled when Tod Chambers ended the conference with a rousing Manifesto for Medicine Studies. Medicine studies, as Chambers articulated it, takes medicine as an object of study, using similar methods that have been developed in science studies by the likes of the French sociologist of science Bruno Latour, who was one of Annemarie Mol’s teachers. Chambers urged that we “cast aside the shackles of practicality and morality” as we seek to understand the conceptual object of medicine. I will be with him at the barricades!

Our slightly different names for the project, medicine studies and critical medical studies, do, however, reveal a slight difference in our conception of the object of medicine. Chambers admitted that he didn’t want what we do to be critical yet. I believe he means that there’s much important work still to be done in simply describing medicine better prior to getting into the messy work of politics. In some respects this is exactly what Annemarie Mol attempts to do in *The Body Multiple*, which is why she takes up a relatively apolitical disease like atherosclerosis of the leg. Still, perhaps it’s my background in women’s and gender studies, but I take the object of medicine to be always already political. I don’t believe we can put the critical to one side. Certainly, there is a danger in bringing either an over- or un-articulated ideology to the study of the object of medicine. But this object that we study must also always include medicine’s relationship to power—and our own. That seems to me to be critical.

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<sup>1</sup> Ronald A. Carson, “Engaged Humanities: Moral Work in the Precincts of Medicine,” *Perspectives in Biology and Medicine*, vol. 50, no. 3 (Summer 2007).

<sup>2</sup> Carson goes on to discuss what I agree is an important strand in the development of the medical humanities. As he notes, “[i]t was mainly from the ranks of moral theology and moral philosophy (and later, from religious studies—itsself a hybrid field) that medicine’s earliest conversational partners came”; “Engaged Humanities,” 323.

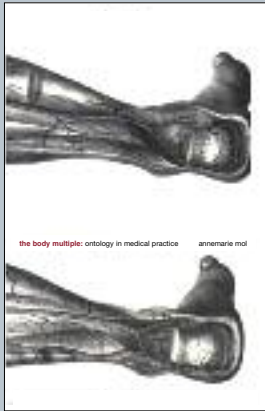
<sup>3</sup> Interestingly, Carson’s history of medical humanities sounds like the history, according to Michel Foucault, that medicine likes to tell of itself, with an unchanging idea of the clinic at its center. “Medicine has tended,” Foucault writes, “since the eighteenth century, to recount its own history as if the patient’s bedside had always been a place of constant, stable experience, in contrast to theories and systems, which had been in perpetual change and masked beneath their speculation the purity of clinical evidence”; *The Birth of the Clinic: An Archeology of Medical Perception*, trans. A.M. Sheridan Smith (New York: Vintage, 1973), 54.

<sup>4</sup> In her now classic essay, “Placing Women in History: Definitions and Challenges,” Gerda Lerner describes the development of the field of women’s history from one concerned primarily with “compensatory history” or “contribution history” to one that develops entirely new frameworks and methods for approaching the category woman in history; *Feminist Studies*, Vol. 3, No. 1/2 (Autumn 1975), 5-14.

<sup>5</sup> Annemarie Mol, *The Body Multiple: Ontology in Medical Practice* (Durham and London: Duke University Press, 2002).

<sup>6</sup> Malcolm Ashmore, M.J. Mulkay, and T.J. Pinch, *Health and Efficiency: A Sociology of Health Economics* (Milton Keynes: Open University Press, 1989).

<sup>7</sup> *The Body Multiple*, 162.



the body multiple: ontology in medical practice annemarie mol

# Provocation: Call this a Medical Humanities?

## From Medical Humanities to Biocultures

Bradley Lewis, MD, PhD

I interpreted my invitation to be a “provocateur” at the ASBH Spring Meeting as an invitation to rant. I found this very liberating. I’ve been known to rant from time to time, but never with permission. It was always the opposite—organizers instructed me to give a sober balanced account of some situation, but before I knew it a thinly veiled rant emerged. This time things are different. This time I’ve been asked to rant!

So I started with some genre research. I turned to the classic rant in American literature, the one let loose by Huck Finn’s alcoholic unschooled racist father.

Call this a govment! why, just look at it and see what it’s like. Here’s the law a-standing ready to take a man’s son away from him—a man’s own son, which he has all the trouble and all the anxiety and all the expense of raising. Yes, just as that man has got that son raised at last, and ready to go to work and begin to do suthin’ for him and give him a rest, the law goes for him. And they call that govment!! That ain’t all, nuther.<sup>1</sup>



by E.W. Kimble, 1884, First Edition, Huckleberry Finn

Now that’s a rant! Huck’s father goes on like this for a couple of pages, and I encourage everyone to go savor it. Along the way, Twain highlights a classic feature of the genre—in a rant it is entirely possible to mix dead certain conviction with absolute idiocy and misguidedness. So, dear reader, if you notice any of that in this essay, you can applaud me for staying true to genre.

The topic I was asked to rant about is this: *Medical humanities are unnecessary to patient care and clinical practice*. The standard way to make this argument is to start with a sharp distinction between human agency and social structure. Medical humanities attempts to improve the clinical encounter by changing the clinician’s human agency, while paying little attention to the social structure of medicine.

But, with the distinction between agency and structure firmly in place, it is easy to argue that the problems with the clinical encounter (that it is too cold, too rude, too arrogant, too patriarchal, too controlling, too in bed with the pharmaceutical and device industries) have little to do with the human agency of the clinician and all to do with the larger political, economic, and cultural structures in which the encounter is embedded.

Using this perspective, one can easily argue that medical humanities is irrelevant to the problems of the clinical encounter. Indeed, from this perspective, medical humanities is not only irrelevant, it is part of the problem rather than part of the solution because it works as a ruse that obscures and effaces the social and political conflicts inherent in institutional medicine. It allows leaders of medical systems to point toward the grand ideals of humanism and empathy while doing very little to change the very standards of care which make it impossible to live up to those ideals. In effect, medical humanities blames the victims—individual students and practitioners—for the system’s inability and unwillingness to deal with structural problems and conflicts. Anthropologist Michael Taussig put all this succinctly years ago:

“Humanistic medicine is a contradiction of terms.”<sup>2</sup>

But alas, as fun as that is to rant about, it is more provocative than I wish to be. I for one am happy that medical humanities scholars make an effort in medical training. Creating too sharp a binary between agency and structure obscures the subtleties. Medical humanities may not be able to do much to help the clinical encounter in the face of larger social forces, but it can do a little. It can help clinicians develop a kind of “wobble room,” an expanded space for navigation within a highly structured standard of care. That’s worth a little. Not a lot, but a little. And sometimes a little is a lot.

However, a little is not enough. To have a more significant impact (and here comes the rant I do want to make),

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[M]edical humanities should be at the forefront of helping breathe life into more holistic and humanistic models of medicine, and connecting those more humanistic models of medicine to a new renaissance in primary care.

Call this a *Medical Humanities?* (continued from previous page)

medical humanities must connect the dots between two crises: the crisis in healthcare and the crisis in the humanities. As someone who has gone back and forth between medicine and the humanities it is clear to me that these crises are not separate. They are deeply interconnected. But what are these twin crises?

The newspapers tell us that the crisis in healthcare is about a crisis in finances (how are we going to pay for it?) and a crisis in administration (how are we going to distribute it?). As humanities scholars we cannot stop there. We must insist that the healthcare crisis is a cultural crisis, and that financial and administrative problems are symptoms of larger human issues. The healthcare crisis is a crisis of meaning; a crisis of how we think about health and healing, about living and dying. It is a crisis of biomedical reductionism run amok and out of balance.

It will not be enough to reform healthcare finances and administration without also reworking the unsustainable faith this culture has put into the biomedical model and biotechnology. As a result, medical humanities should be at the forefront of helping breathe life into more holistic and humanistic models of medicine, and connecting those more humanistic models of medicine to a new renaissance in primary care.

The reason medical humanities should engage in the healthcare crisis is not simply an altruistic desire to save medicine from biomedical reductionism and unsustainable expenditures. The reason is that the crisis in healthcare is the mirror image of the crisis in humanities. The crisis in humanities is also not primarily about financial and administrative issues like low salaries and limited jobs. These too are only symptoms of larger cultural issues; they center on the fact that the humanities have limited cultural value. They have so retreated to the ivory tower that few care about them. The humanities, in short, have become increasingly worthless to the culture at large. For humanities to gain value again, they have to contribute directly to solving problems people care about—like helping the culture move beyond its current crisis in meaning regarding living and dying (previously known as the healthcare crisis).

As a result, new efforts in medical humanities should not be focused on patient care and clinical encounters.

10 Instead, they should be focused on developing biocultures centers of excellence. I use the term biocultures following in the footsteps of the recent “Biocultures Manifesto” written by Lennard Davis and David Morris.<sup>3</sup> In this context, “biocultural” has a double meaning.

First, biocultures refers to alternative ways of life surrounding the struggles over biological practices. Depending on how a culture does biology, in other words, very different biocultural ways of life will emerge. A prime example would be the way of life surrounding the biomedical model (a way that has led to the current healthcare crisis) compared with a way of life organized around more holistic

models of medicine that could occur with a renaissance of primary care. The second meaning of biocultures refers to an emergent genre of academic scholarship. This scholarship recognizes biological claims are a complicated intertwining of biology, culture, and politics. As such, we can't consider facts without also considering the value context in which those facts come into being. The theoretical scaffold for this work comes from contemporary theory in the humanities—including fields like science studies, disability studies, feminist theory, and poststructuralism.

The theory is richly developed and established enough that there is deep agreement in the humanities for the need to better understand “bodies that matter.”<sup>4</sup> But limited work has been done to follow up on these theoretical insights. It is not enough to destabilize the fact/value binary in theory. Much work remains to tackle concrete issues in today's biocultural arrangements and to set up real world institutional sites of biocultural interrogation.

Medical humanities is ideally situated to help build this scholarship and help develop the infrastructure needed to carry it out. And even better, when medical humanities shifts to biocultures, it tackles the twin crises in healthcare and the humanities at the same time. It works to make humanities more relevant as it works to make healthcare more humane. This will happen not simply by adding values to facts or attempting to use facts wisely. It will happen by setting up an intellectual infrastructure that recognizes and works through the value-laden nature of all facts. It will happen by setting up centers of excellence where scholars tease out the values at issue in the many facts that shape our life. And it will happen by creating a world where there is more stakeholder and citizen engagement in the making of facts as a process of making life-worlds and ways of living. When the humanities plays this role, it's no longer an ivory tower luxury—it's part of the real struggle over culture and the world we live in.

In short, my rant is this: *The humanities cannot save itself without also saving medicine. Medicine cannot save itself without also saving humanities. And nothing short of saving both (or at least striving in that direction) should be called “medical humanities.”*

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<sup>1</sup> Mark Twain, *Adventures of Huckleberry Finn*, ed. E. Elliot (Oxford University Press, 1999), 25.

<sup>2</sup> Michael Taussig, *The Nervous System* (Routledge 1992), 109.

<sup>3</sup> Lennard Davis and David Morris, “Biocultures Manifesto.” *New Literary History* (2007) 38: 411-418.

<sup>4</sup> Judith Butler, *Bodies that Matter: On the Discursive Limits of Sex* (Routledge 1993).

Provocation:

## There's No Such Thing as Research in the Medical Humanities (And It's a Good Thing, Too)

James Lindemann Nelson, PhD

We can do this the easy way, or the hard way.

The easy way is to see this thesis as a recommendation about what we should *call* things, like so: what passes as “research” in the medical humanities is better understood as “scholarship.” The proponent of the easy way, a conciliatory sort, will likely admit (or perhaps even insist) that the goals are common: like research—which I'll understand here, very roughly, as exemplified by what is done by bench scientists in their most characteristically professional moments—scholarship aims at uncovering the truth about significant features of the world and those who live inside it.

There are also commonalities of method: like research, scholarship requires of its devotees methodological skills, sensitivity to domain, and creative and critical imaginations. There are commonalities in significance: like research, scholarship is both intrinsically and instrumentally vital to human forms of life.

But here we come to it: *unlike* research, scholarship operates in domains that don't lend themselves to high levels of precision and the attainment of wide and enduring consensus. A conclusion supported by humanities scholarship often stands on a basis of extended inference from data whose meaning is highly complex and contestable. History suggests, alas, that the forms of reasoning that support scholarly conclusions lack the power conclusively to settle many of the most significant contests about method and conclusion among those learned in the field at any

given time. The day may come when medical humanities scholarship will morph into real research. Maybe neuroethics or cliometrics or cognitive literary criticism will transfigure us. But that is not this day.

Why is this the “easy way”? Because there's really no reason for it to ruffle anyone's pinfeathers. It's merely a classificatory recommendation, supported by observations that seem pretty plausible. If you don't like the recommendation, and want to dig in your research heels, insisting to your deans that what medical humanists do is different from what medical geneticists do only as what physical chemists do is different from what evolutionary biologists do—mere matters of degree, mere details—no bones broken. You just push the likenesses, and when someone brings up the differences, change the subject. Whatever the political stakes might be, it's not clear that much else of substance hinges on nomenclature one way or the other.

Thus, it's the easy way of approaching this thesis: sweetly reasonable, rather boring. I think it also suffers the drawback of being false.

Now let's do it the hard way. The hard way is to insist that the humanities and the sciences *don't* aim at the same goal at all—increasing the store of information that is publicly endorsed and consensually accepted knowledge is not what the humanities, and *a fortiori*, the medical humanities aim at. The hard way is telling your dean that the persistence of controversy about key issues of method and substance among the learned is not a feature that the future may fix—

literature and medicine is *not* looking for its Newton nor religious studies for its Darwin. Persistent controversy is not an infirmity to be lamented, but a characterizing feature of this enterprise that helps *account for its value*.

Appeals to method won't help you with a research-oriented dean either—on the hard view, there are no distinctive, essential methods to the humanities as such. Some humanists in their professional moments will draw on the findings of scientists, and some will have their own little tricks (needing to know obscure languages or how to decipher old texts without wrecking them, close reading or phenomenological reduction) but generally speaking

there's just honing up and focusing some general human cognitive and affective abilities: testing arguments for their soundness, attending to likenesses and differences, alertness to context, being creative, empathetic, having good judgment, and so on. It's a disputable point, I realize, whether there is indeed a “scientific method.” But no one has even been tempted to talk about a “humanities method,” have they? For this small blessing, much thanks.

What about intrinsic and instrumental value? Here, the hard way asserts this: if the intrinsic value of research is a function of the way in which it leads reliably to the truth—or to better and better approximations of

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the truth—whatever is important about the humanities, it isn't *that*. If the instrumental value of research is that it leads to technological spin-offs that cure diseases or enable humans to fly or play video games, you can forget that, too.

So what is the point of engaging in the humanities, and in particular, in the medical humanities? The humanities grope toward making sense of things, toward what Wittgenstein called the “notions of a sound understanding”—

Persistent controversy is not an infirmity to be lamented, but a characterizing feature of this enterprise that helps account for its value.

a process that will draw on the best accounts of what is known, and may, incidentally, actually add to them, but aims at achieving a perspicuous grasp of the world considered as a field for living generally, not exclusively for contemplation or for focused techniques. There is in much of what humanists do in their professional hours a kind of normativity that goes beyond simply the value of truth or of efficiency in achieving set ends. It extends to questions of how best to understand oneself and others, and of what patterns of action and feeling make most sense of the lives that are ours to live.

Now, to take the hard way is to swim upstream: in my own academic department, I have to report on my “research” every year, and we refer to the Ph.D. we award as a “research degree.” I don't think there is anything unusual about this—I expect it is repeated through humanities disciplines. So why bother insisting that our work is not research? Is it not easier, to say nothing of more politic, to say that we philosophers and critics and historians do research in our own way on our side of the river, and the high energy physicists and the entymologists and the folks in the sheep center do research in their own way on the other side of the river? Our “research” is small potatoes, since it

generates nothing the university can patent, and even when we get external funding, the indirect costs are usually very low. But the easy framing argues that though we may be junior partners, we're still in the family.

It's that last plea that's the liability of the easy way, as I see it. In allowing the humanities to be configured as a collection of research disciplines the best we can be is junior; at worst, we are on sufferance. (Where I work, we have a president who has many virtues, but who has been quoted as saying “I just don't get the humanities.” The impression wasn't left that she saw this as *her* problem.) Even worse, I think, we humanists may allow our own work to suffer from a kind of research envy: we know those folks who do “real” research have these impressive methodologies that, generally speaking, are endorsed by their whole fields, and that they keep coming up with results that everyone in their disciplines seem to share, and that therefore count as knowledge. If that's the image that is before our eyes, we will be tempted to misunderstand ourselves. Our own aims, our methodological aspirations, and our sense of our own value will be unrealistic, inapt to our needs, and, not to put too fine a point on it, doomed.

Everything I've said here about the hard way of understanding the relationship of the medical humanities to research holds for the humanities in general. Is there anything special about the medical humanities that keeps research from being one of its proper aims? The medical humanities have not infrequently sold themselves (or allowed themselves to be sold) instrumentally: they minister to students stretched on the rough rack of medical education, keeping alive their sense of themselves and their patients as persons by dispensing judicious doses of Emily Dickenson, or William Carlos Williams, or John Stuart Mill. If this is indeed the whole of what's characteristic about the medical humanities, then it provides another ground for distancing this practice from research: the point of the enterprise is decidedly not to generate new knowledge of an

objectively existing world, but, like other nurturing crafts—parenting, for example—to build and refine (or retard the erosion of) character. I confess to some discomfort about this special justification for the medical humanities, and for the attendant argument about research. At most, there may be something like the paradox of hedonism operating here: just as happiness is most reliably obtained when not sought, engagement with the humanities may possibly have a good effect on a person so long as good effect is not what she seeks—no “gaining thoughts” as the Buddhists say.

Yet I think there is something that, at least as a matter of emphasis, distinguishes the practice of medical humanists from their sister scholars in arts and letters. Medical humanists often deeply underscore and vividly concretize intricate dimensions of the struggle to make sense of human lives. Rather than focusing, say, on a common humanities trope such as “mortality” as a general feature of human reality, medical humanists more often attend keenly to the dying of something in particular—even of *someone's* dying of something in particular. It's rather hard, I think, to convince oneself that much of what's important about death on that level of specificity can be exhausted by even the best designed research protocol. If that's right, then one of the particularly valuable things about the medical humanities, despite (or perhaps because of) its having taken up lodging near research's very heart in the modern medical center, is that here more than elsewhere, it's clear that whatever humanists are up to, it isn't research.

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Medicine as a profession, like teaching, has very sound reasons to restrict the free play of eros. Inequalities of power, money, age, and knowledge all require safeguards to protect the weaker, more vulnerable parties. I am not on the empathy bandwagon, preferring professional respect to professional emotion, but the new medical interest in empathy as a clinical tool indicates an openness to eros in its softer, sociable, communicative versions. (My advice: beware of programs to *instrumentalize* eros.) Isn't “com-passion” a quality we want in clinicians? Writer, philosopher, and classicist Anne Carson goes further and wonders at the ways in which eros has transformed her own life: “I would like to grasp,” she writes, “why it is that these two activities, falling in love and coming to know, make me feel genuinely alive. There is something like an electrification in them.”<sup>11</sup> Eros for Carson initiates or accompanies a changed state of being. Passion and desire revitalize the act of learning. Why do we bother with any difficult valued pursuit such as teaching or doctoring? The answer, for Carson, is eros: passion drives us and desire transforms us. Eros may have strictly limited clinical application for many physicians, but I wonder what burnout is if not ultimately a failure of eros.

The patient side of the bed is where eros holds its most significant promise in the face of loss and failures inextricable from serious illness. The personal transformations associated with eros tap into its destructive power in wiping out old patterns and in clearing space for revitalizing or creative change. Eros thus encompasses a possible counter-movement toward reorganization and (especially in the aftermath of trauma) holds open possibilities for the invention of new or revised identity. Spinal cancer and radiation therapy left famed novelist Reynolds Price paraplegic and wheelchair-bound. “The kindest thing anyone could have done once I'd finished five weeks' radiation,” he writes, “would have been to look me square in the eye and say this clearly, *Reynolds Price is dead. Who will you be now?*”<sup>12</sup>

Eros colludes with violence, loss, and the darkest failures of personal identity—*Reynolds Price is dead*—but it can also inspire the passionate tough-love drive for self-transformation that Price sees as crucial to his own recovery. Recovery, in the context of eros, is not a return to health but rather the creation of what Price in his title calls “a whole new life.”

The erotic counter-movement toward self-transformation is important to recognize because Bataille and other theorists of eros usually ignore it, preferring to celebrate eros for its power to destroy bourgeois illusions, including the so-called illusion of a stable self. By contrast, anthropologist Helen Fisher melds neuroscience with field data to analyze three relatively stable biochemical stages of human erotic life: lust, romantic love, and attachment.<sup>13</sup> Attachment is a dull term for a biological function indispensable to various species with long-delayed maturation for offspring. Eros, however, in bonding partners and their offspring, serves purposes larger than sexual pleasure or

a postmodern taste for anti-bourgeois, anti-capitalist outrage. It plays into an ancient human drama of survival.

Eros, in effect, includes not only a drive toward loss and destruction but also a counter-movement toward attachment, reintegration, stability, and new order. “Grieve for a decent limited time over whatever parts of your old self you know you'll miss,” advises Reynolds Price. “Then stanch the grief, by whatever legal means. Next find your way to be somebody else, the next viable you...” (183). Price does not cite eros as the way-finder guide, but fellow patients (to judge by letters he says he receives) clearly respond to an ethic that accepts bafflement, loss, and failure as the ground zero for possible self-transformation.

Self-transformation is also a recurrent theme in myth, and certain enduring myths permit individual private experience to make contact with larger public archetypes. The myth of Cupid and Psyche has personal resonance for me in its archetypal pattern of loss and failure. After thirty years of marriage, including an extended period as official and unofficial family caregiver, I was the sole person left to decide that it was time for Ruth to leave home for a full-time residential Alzheimer's facility. It was the hardest day of my life.

#### LOSS, FAILURE, AND TRANSFORMINGS

Psyche is a young woman so beautiful that the goddess of love, Venus, is consumed with envy. Venus sends her son Cupid to afflict Psyche, but Psyche's beauty overpowers even Cupid. As he bends to kiss her, his own arrow accidentally pierces him, and he falls instantly in love. Eros falls victim to eros in an ironic reminder that no one is immune. The fairy-tale marriage that ensues between a god and a mortal is governed by a single rule: Psyche must never see her winged husband, who visits her only after dark. The rule is impossible, at least for mortals, and Psyche's failure breaks their union. Thereafter she wastes away wandering the earth in search of her lost husband. Finally, as she lies dying, Cupid appears and revives her with a kiss: a kiss that both saves her from death and makes her immortal. It is this specific transformation—the moment when a mortal becomes godlike through the power of eros—that the neoclassical sculptor Antonio Canova represents.

A long neoplatonic tradition interpreted the myth as expressing the soul's desire for union with the divine. I read it differently, as reflecting the power of eros to redeem the loss and failure always implicit in eros and in illness. Eros is both poison and antidote.

Loss and failure are what Alzheimer's is all about. Today 5 million Americans live with this fatal neurodegenerative brain disease, the sixth-leading cause of death in the U.S. Hidden in that statistic are the millions of family members who care for Alzheimer's patients. Such caregivers are wedded to loss and failure. No kiss of mine will ward off death. Some failures and losses—like the early-onset Alzheimer's that struck Ruth in her prime—may be attributed to the human condition and thus may be slightly easier to accept than preventable ones. My failures as caregiver were sometimes preventable. As I put it in an email I sent to close

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friends, explaining details of my personal short-comings: “I know that what I’m describing may offend your principles. All I can say is that it offends my principles too. I just couldn’t survive on principles.”

Sheer survival as a caregiver may require such a violation of your own principles that you cannot but emerge (at least in your own eyes) less. This is not the self-critical lament of a crank perfectionist. I felt like the walking dead. A mechanical man. A zombie. Failure here isn’t an error that might be excused with a *mea culpa* or with a Hamlet-like nod to human frailty. It is implicit in the almost humanly intolerable situation that former caregiver Carol Levine calls “accepting the unacceptable.”<sup>14</sup> It constitutes surplus fallibility, a hyper-flawed state of being, not just a momentary loss of control but indelible losses that come with the territory, that threaten one’s identity, and that cannot be repaired or excused.

Caregiving, writes psychiatrist and anthropologist Arthur Kleinman (a family caregiver too), is a “defining moral practice.” He adds: “It is a practice of empathetic imagination, responsibility, witnessing, and solidarity with those in great need.”<sup>15</sup> Yes. It is also therefore a practice that must accept and take account of its own moral failures. What happens when imagination depicts the chronically trapped caregiver as chained to a corpse—worse, a corpse that “complains all the time,” as John Bayley reports in *Elegy for Iris*?<sup>16</sup> Not all our responsibilities as caregivers are discharged with honor. Respite from non-stop witnessing is so crucial that most medical insurance covers it. Solidarity was pretty sorely tested on the occasions when Ruth put my car keys in her purse—and forgot. I am usually patient, but patience for caregivers is less a moral virtue than a necessity, often in short supply. Ruth no longer knew which door in our bedroom led to the hall and which led to the bathroom. Each toilet trip required supervision, as I wearily rolled back the covers. Non-specific anger and frustration, long held in check by sheer acts of will, sometimes spilled out wildly.

Loss of control, like the vertigo typical of eros, is what family caregivers inescapably experience in taking care of people with progressive dementias such as Alzheimer’s disease, and survival instincts may trump moral imperatives. The serious question raised by caregiving is not how can we avoid failure but, since failure appears inescapable for anyone facing the void that opens when serious illness separates partners linked by eros, what we can make of it.

The myth of Cupid and Psyche hints at a paradigm in which radical loss and failure are linked to possible transformations. My experience suggests that *transformation* is not exactly the right concept, at least not if it denotes the attainment of a settled state. Eros and illness, I found, do not produce completed states but incomplete, tentative, brief transformings. Transformings—as a verbal noun—suggests ongoing, unfinished, fragmentary, even repetitive or circular activity, hard to live through but different from utter catastrophe and different, too, from emergence into a new, fulfilled higher state (like a butterfly emerging from a larva).

Transformings, like healing, can occur in the absence of cure. The myth of Cupid and Psyche, then, might reward a sober revision in which loss and failure are not opposed, effaced, or denied with the promise of a miracle. A revised myth might honor the self-transformings (albeit uncertain, flawed, and incomplete) that lend to illness-inspired loss and failure an ethical dimension involving choice, action, awareness, acceptance, and deliberated, if unwanted, ways of being.

#### AN ETHICS OF WAITING

A bedside ethics of loss and failure—especially when expanded to the supra-dyadic circle of family caregivers—might well consider the commonplace medical experience of waiting. Psyche is a mythic prototype in her years of waiting and wandering, but waiting as a trope for the existential modern condition is the invention of Samuel Beckett: in the absence of God or Godot, we wait. Postmodern waiting, however, is somewhat different. Amid a new discourse relentlessly emphasizing empowerment, agency, and self-actualization, what waiting signifies now is loss of control and failures of will. If you were in control, you wouldn’t be waiting. Your oil would already be changed, the doctor would always be in. In effect, waiting implies an almost shameful powerlessness. It is time wasted, at least until Cupid at last redeems the waste with his kiss. But Canova’s romantic version seems untenable in an age of disenchantment. In the disenchanting version, Psyche’s long-extended wander-years mean that Cupid applies his immortalizing kiss not to a nubile beauty but to an exhausted and dying woman no longer young.

Waiting as a philosophical theme involves complex reflections about time and duration.<sup>17</sup> I propose a simpler

distinction between transitive waiting (waiting for something) and intransitive waiting (waiting without an object or purpose). The residents I see almost daily at Ruth’s Alzheimer’s facility seem engaged in an intransitive waiting, with no aim or object, as they slump in a semicircle of overstuffed chairs. Are they waiting? Or have they entered a sedative-induced state of suspended animation? I don’t know how they experience their condition. Yet I too am waiting. I am not waiting for Ruth to get better (which won’t happen) or to get worse (which will happen). I too occupy an intransitive state, without an object, without hope. Like Psyche I am on the go, engaged in nonstop para-medical management, so my intransitive state is more deceptive than Ruth’s, but no less a form of exile.

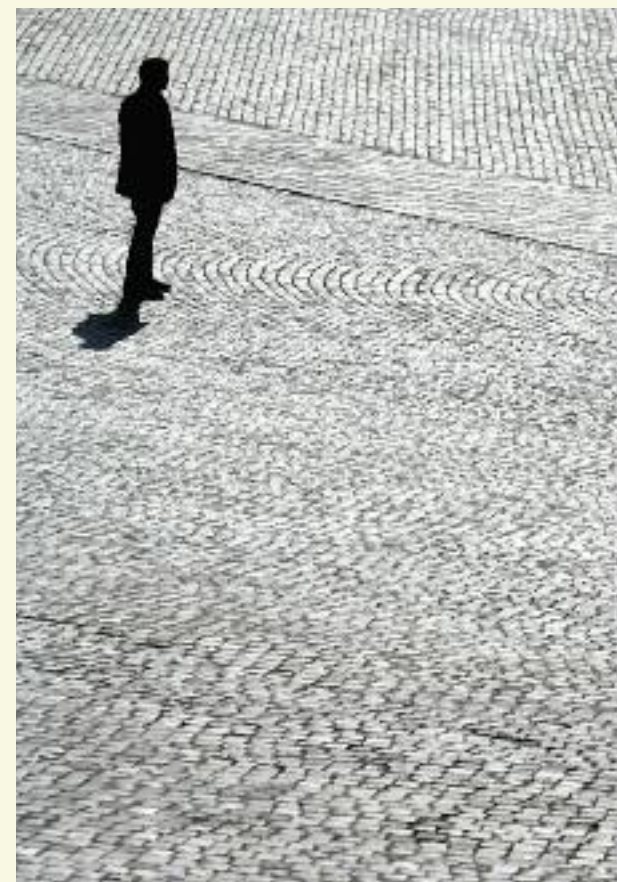
It’s tempting, especially for admirers of paradox, to construe all waiting as an action, as a weirdly static performance, like a television show where, by design, nothing happens. W. H. Vanstone and Henri Nouwen are theologians who offer a very different perspective.<sup>18</sup> They describe waiting as an inescapable passivity: an almost zenlike relinquishment of control. Their paradigm of passive waiting is the passion of Jesus—not just his sufferings on the Cross but the entire period after Gethsemane when his active ministry concludes and, through Judas, he in effect “hands himself over” to the world that will decide his fate. Thereafter he waits. This state of disinterested, objectless waiting (after the completion of an action) is what interests Vanstone and Nouwen. They do not interpret it as a stealth or paradoxical performance. Instead, they see it as radical inactivity—the utter relinquishment of an active role.

Radical inactivity is also connected to eros: modern theorists of eros emphasize an inherent opposition between eros and labor, between erotic acts and economic activities. A term that Bataille consistently associates with eros is *dépense*. It refers to expenditure—but to an irrational expenditure that is deliberately unproductive, an illogical outlay that places eros in direct opposition to capitalist values. Vanstone and Nouwen seek to challenge the bad name we postmoderns almost automatically attribute to inaction. From their theological perspective, inaction and passivity constitute a stage of human life that we desperately, in our pursuit of busyness and self-actualization, exclude from thought and value. Even retirees must be portrayed as golfing until the golden sun sets. Nobody wants to look at the un-tan, un-healthy old folks slumped in their chairs just, as it may be, waiting. Waiting and inaction, from the Vanstone-Nouwen perspective, must now be reinvested with value, and this reinvestment of value is nothing if not ethical.

Waiting isn’t glamorous, and it doesn’t promise miracle transformings. Some losses and failures nothing can mitigate. But an ethics of loss and failure might think hard about waiting as a moral state. It might reflect on how loss and failure hold a built-in link not only to illness but also to eros, since of course lovers are the figures in a traditional story who spend most of their time waiting—often in vain. Some lovers wait transitively for the beloved to appear, but the lover’s desire is rarely satisfied merely with possession of the beloved. The object of love is often always beyond



Antonio Canova, Amor and Psyche Embracing. Cameraphoto Arte, Venice / Art Resource, NY



reach, much like the return to health for an Alzheimer’s patient. Eros, loss, and illness wait hand-in-hand-in-hand.

A gospel song I found after Ruth left home poses a repeated question relevant both to serious illness and to the status of waiting: what do you do when you’ve done all you can? The three-word gospel response: “you just stand.”<sup>19</sup> Just standing doesn’t sound very impressive, but in the world of gospel music it cannot occur without God’s help. Standing and waiting constituted a significant moral state for John Milton. His famous sonnet on his blindness, after imagining God’s servants scouring the globe in divine service, concludes: “They also serve who only stand and wait.” Standing and waiting are for Milton the ethical and theological counter to falling, to the Fall. For octogenarian caregiver E. S. Goldman they are an expression of presence: presence not as the opposite of absence but as being there—in a mindful, attentive, fullness of being—being as distinct from doing. “Presence,” as Goldman puts it simply, “is what counts.”<sup>20</sup>

In a contemporary ethics of loss and failure, which does not flee from its relations to eros, maybe standing and waiting—simply being there—will be barely enough, and at least an honest, if broken or broken-hearted, place to start from.

David B. Morris spent twenty years as a self-employed writer and recently retired as University Professor at the University of Virginia. He is the author of two prize-winning books—*Alexander Pope: The Genius of Sense (1984)* and *The Culture of Pain (1991)*—as well as numerous writings in the fields of pain medicine and of biocultural studies. A version of this article was presented at the ASBH Spring 2009 meeting. dbmkirk@mac.com

(see page 32 for footnotes)



# Narrative Constipation

by Comic Nurse (MK Clearwell, RN, MA)

Over summer break from graduate school, I went to a lecture given by my thesis advisor, Alice Dreger, titled "Medicine and the Future of Normal." Dr. Dreger's work focuses on how medicine has moved away from promoting and creating health toward defining and enforcing "normal." She advocates for those born with anatomies that are, in one way or another, not what medicine - or society - considers the norm. Whether you're born intersex, or a conjoined twin, too small, or too whatever, you don't need to be "fixed" if nothing is really wrong.



After the lecture, questions and comments were invited from the audience. An old man descended to the podium, leaned against it and started telling the story of a child born intersex whom he was asked to "fix." It became apparent that he must be a surgeon. He rambled on for ages. After about five minutes, Dr. Dreger sat down, saying simply, "let me know when you're done." The surgeon eventually summed up his uninvited "talk" by saying,



It was as if he hadn't heard one word Dr. Dreger said. She handled it perfectly, like my favorite aunt used to do when I was being incredibly obnoxious. She ignored him. This approach, in front of an audience, is a far more powerful form of disregard than engagement of bad behavior. And it worked. His equally old colleague later asked about genetic indicators for gender, did the math, and said to the surgeon, "You shouldn't have made the child a girl." Dr. Dreger added,



The old surgeon tried to start up on conjoined twins later, but the moderator stopped him before he could get started again. I had many reasons to feel angry at the old surgeon, and I did. He was boorish, egotistical, and rude. He disrespected someone I respect. His behavior was obnoxious beyond words. Alongside my anger, I sensed that he desperately NEEDED to tell these stories which made me feel sad for him. By raising the issue of babies born with ambiguous genitalia, Dr. Dreger had unknowingly opened a door in his memory that he didn't know how to close.

Maybe I'm projecting here, or giving him more credit than he deserves. But I'm trying to understand why someone would do something so drastic and obnoxious. It was like he wasn't so much telling the story as he was vomiting it. I felt sorry for him because I almost know that feeling - although I would like to think I'd never behave as he did. There have been times, especially in the last year, when a lecture or discussion has brought a troubling patient story so powerfully to mind that I feel like I MUST tell it out loud, or I'll explode. And if I do tell it, after it comes out, I feel like you do when you've just vomited: relieved, because it's out, but also surrounded by a big mess.



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# Narrative Disimpaction

Alice Dreger, PhD

MK and I went out for a drink after that talk, the one where the ancient surgeon started figuratively vomiting during the Q&A. I got the sense MK needed the drink more than I. By then, I was kind of used to that experience, used to it enough that I had stopped fighting these mutinous old twits when they took over my talks. That's why, when this one came to the podium, I just found a

chair, breathed deeply, held a polite smile, and silently repeated my favorite Taoist meditation: "Give evil nothing to oppose, and it will disappear."

But the whole scene had obviously bothered MK a lot. As I listened to her work through her reactions over a bottle of wine, I wondered if I was witnessing the composition of a new cartoon by the master's student known to us also as Comic Nurse. She seemed to be setting up story blocks in the way she talked.

And as I listened to MK, I found myself increasingly surprised. She was obviously angry with the old guy, but wrapped up in that was her growing sympathy for him. Even with the wine sedating me, this pissed me off. Because I like MK, and MK likes me, and well, it felt like a betrayal. I found myself silently defending against her seemingly misplaced sympathy. I mean, I was the one who was cleaning up these surgeons' messes! I was the one covered in the tears they had long since washed off their hands! Or rather,

(continued on page 19)



Talking about the incident later, I realized that caregivers are at risk for a condition - a narrative constipation of sorts. It's the result of NOT telling troubling stories, or dealing with them appropriately, at the time they happen. This narrative constipation is caused by the grief, the guilt, the shame, the doubt, the defeat, the worry, the pain, possibly even the joy turned sadness, that accompanied a patient's drama and the caregiver's role in it. That role could be as active as a surgeon or as passive as simply witness. Or both. With no recognized home for the caregiver experience that accompanied the patient experience, the caregiver stuffed it inside, removing it from the present, but risking that one day it will emerge. I suspect many caregivers, if not most, suffer from narrative constipation to some degree. Like any other chronic illness, everywhere we go, with everything we do, it's with us. We're all nearly bursting with stories. So what should we do? Narrative laxative?



Rita Charon says that caregivers should keep a "parallel chart" of thoughts and feelings about the patients we serve. This will be a very effective prevention, like eating enough fiber. But what about an interventional treatment for an already existing narrative obstruction?

In the hospital, when constipation gets bad enough, we nurses are forced to do the most horrible thing you can imagine. We call it "disimpaction." That's right, we pull it out. Talk about ugly. What's the narrative version of this? I'm not entirely certain, but I'm thinking that taking an oral history might be a better place to start.

WELL, THIS WAS BACK BEFORE THE WAR. SCALPELS WEREN'T AS SHARP BACK THEN. WHO KNEW VEINS COULD BE SO DARNED TOUGH? BLED LIKE A PIG, I'LL TELL YOU. SO ANYWAY, LIKE I WAS SAYING, I THINK IT ALL STARTED THE DAY...



The End (for now...)

I was the one who had met and helped a few of the people wrecked by the surgical interventions meant to save them. The aged surgeon and I had in common an unjustified sense of self-importance in the history of medicine. But maybe not an unjustified sense of self-importance in the lives of individual patients. He had changed their lives by using his scalpel to try to make their bodies look more like people like him. I had come along a few decades later to show that didn't work as well as one might hope. And when I met the people left literally and figuratively scarred, I had sometimes worked on taking their histories. Most of the time I took these people's histories as part of my scholarship or my activism, in order to let doctors know what really happened to those patients who were labeled in the medical literature "lost to follow up." But in the process of doing that, I often ended up helping the individual former patients understand their personal histories, and so reclaim them. Practically speaking, I took what they told me and what I knew of the historical context, put it all into a cohesive narrative, and gave it back to them. The kernel of iatrogenic pain in their lives was now suddenly uncoiled into a cohesive little tale. And they told me having these three or four pages of laser printer ink on ordinary white copier paper changed their lives.

At first I thought they were just being polite. But over the years it has become obvious how incredibly powerful this little service is. So now and then I offer it up, pro-bono and private, to someone I meet. "Would you like me to help you understand your history a little better, to write it up for you?" I ask, slipping them my card. Ostensibly, I do it for them. In fact, it's the most meaningful work of my life. I feel embarrassed that they thank me at all.

So why not institutionalize this, I wonder more and more? Rita Charon has taught us the power and importance of "the parallel chart," the private place where a doctor may tell her story of the medical encounter. But what of the patients? What of all the people left through bad insurance, bad luck, bad social norms supposedly healed, but actually harmed? We don't need my anecdotal experience to know more narrative disimpaction would help. There is plenty of evidence that stories help with trauma. Indeed, there is plenty of evidence that stories are inherent to trauma; they appear to be a natural part of scarring. Story-telling around trauma and loss is so universal that it looks like it must serve an evolutionarily adaptive purpose; such story-making may literally help us survive. So why is it that in medical care we have ointments and bandages and physical therapies designed to optimize physical scarring, but we have no systems to optimize psychological scarring?



My nine-year-old son recently wandered into my home office and read MK's cartoon. After we talked about what it meant, I asked if he had any questions. "Why is the narrative laxative cherry-mint flavored?" I laughed and told him that I guess historians are cherry-mint flavored. He laughed back, and said, "No!" And then he asked, pensively, "Is there really such a drug?" And I started to cry. "No, there are just people who can listen to other people. That's why I spent last night on the phone with Mark, asking him to tell me about his life with hypospadias, writing it up, so I can write it down, for him."

That's when I realized what MK's cartoon said, what I had not understood before: The surgeon needed narrative disimpaction not because he was evil, but because he was good—because he was struggling with his own pain born of trying hard to help. The very same moment of iatrogenic trauma that had left his patient in need of me had left him in need of someone like MK. And you know what? I wasn't really crying for all the people who needed a historian and have none; what a convenient story I had been telling myself. No, I was just crying a little for myself, having been relieved by being witnessed by a fellow historian who knows how to draw. Without warning, without realizing I needed it, MK's cartoon had disimpacted me.

So given that we all seem to need it, given that medicine tries first and foremost to help, why aren't there little armies of cherry-mint historians incorporated into our medical care systems? Why, knowing all we know about humans, does the discharge planner know to call an occupational therapist and a visiting nurse but not an historian? All these people taking all these histories in all these clinics, the medical student, the intern, the resident, the attending, the nurse and none of them giving them back. It wouldn't take much, what I'm envisioning, what MK has so vividly named narrative disimpaction. The people doing this for patients wouldn't need much training in history; it would be more important that they be listeners and writers. I'm not expecting miracles. Just better scarring through history.

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## What's Wrong with Patient Safety?

Kathryn Montgomery, PhD

Much has been done to improve hospital systems: eliminating look-alike bottles and sound-alike medicines, making frequent hand washing convenient, instituting checklists, encouraging no-fault reports of mistakes and close calls. But many of these advances are hard to sustain, and none addresses cognitive error. Both the motivation necessary for sustained improvement and the mistaken idea of certainty that leads to error would be improved by a better understanding of how physicians think.

Medicine is handicapped by the widespread assumption that it is a science. Patients' often desperate need for certainty and physicians' drive for thoroughness in themselves and their students lead us all to assume, to hope, that medicine—at least in our case—is a nineteenth-century positivist science: invariant, replicable, certain, and perfect. The assumption is fed by patients' hopes, by the media's emphasis on the magic bullets of biomedical research, and by the status of science as certain knowledge. Medicine doesn't explicitly claim to be a science (though it sometimes claims to be “the youngest science”); practicing physicians understand the uncertainty of their work. They were introduced to the idea that science isn't simply the old-fashioned Newtonian revelation of the reality of the universe in the physics course they all had as pre-meds.

Nevertheless, this belief that medicine is a science affects the profession in many ways, none of them good. The first two years of medical school, despite reforms, still require students to memorize mounds of soon-forgotten facts and neglect character and professional attitudes. Medical care itself is too often “scientifically” reductionist, treating lungs or gut and not the patient. Risk is misunderstood, and clinical trials are easily mistaken for medical care. Errors are seen as entirely an individual's fault; a malpractice suit seems a reasonable response to failure. Where perfection is expected, mistakes are shameful and covered up.

But medicine is not a science: it's a practice. Physicians are not scientists

—not unless they have laboratories and NIH grants. They are more likely to be social scientists, especially those academic physicians who conduct clinical trials and observational studies. But research is separate from the work that makes them physicians: clinical practice—the care of patients, one by one.

Physicians spend long years learning to reason clinically—and they're not engaged, as we might assume, in hypothetico-deduction. If syllogisms were all clinicians needed, medicine could be learned in the first two years, and patients could enter their symptoms into a computer and get a diagnosis and a prescription. Instead, students and residents must acquire clinical judgment, an intellectual virtue that relies on the scientific information they've crammed into their heads but is quite different from the cause-to-effect deductive reasoning we (and they) associate with science. As third-year students who've just passed a national examination in anatomy, pathophysiology, and pharmacology, they enter the hospital where they must learn to reason the other way around—from particular to general rule—and backward: from effect to cause.

In this they are like naturalists—or detectives, historians, and other interpreters of evidence. They must listen attentively, observe carefully, ask good questions, and fit all they learn into the taxonomy of disease. Except for ruling out maladies in a list of diagnostic possibilities (something that could be done by any of us if we were given the rules) physicians don't think like they think scientists think. Instead, they think practically, analogically, narratively. “Is this case like others I've seen or heard about? Are its differences important?” And, importantly, “Do I know enough to stop here?”

Philosophers have long identified at least two ways of thinking. In the *Nicomachean Ethics* Aristotle distinguished reasoning about action, the practical reasoning or *phronesis* needed in ethics, health, and navigation, from reasoning about objects, the scientific reasoning or *episteme* needed in biology and astronomy. William James wrote that to distinguish two kinds of thinking,

scientific hypothesis and verification on the one hand “and narrative, descriptive, contemplative thinking on the other—is to say only what every reader's experience will corroborate” (*Writings 1878-1899*, 1993, 911).

Yet Western culture has privileged science as *the* way of knowing—even when, as in history or anthropology (or, lately, economics), the scientific method is not suited to human objects. Philosopher Charles Taylor warns that our misunderstanding of practical rationality is so widespread that it corrupts attitudes to all rationality. Because the “model of practical reasoning,” he says, is “based on an illegitimate extrapolation from reasoning in natural science [rather than being described for itself], little can meet its criteria and skepticism about reason itself is the consequence” (*Sources of the Self*, 1989, 74-5).

Recently social and cognitive psychology have backed up the philosophers. Drawing on neuroscience, dual-process theory postulates two knowledge systems. System one is formed associatively and slowly, and gives us quick, almost effortless access to regular, patterned generalities. System two is acquired consciously and more quickly, and it is a slower, more intentional process of rule-based inference that requires a measure of learning—either from systematized observations from system one, or from memorization done for the purpose. Medicine uses both of these knowledge systems, and as a practice draws strongly on system one's associative process.

What's missing from the patient safety conversation is this dual-process view of medical thinking. Dual-process theory leaves room for uncertainty, contingency, incompleteness, and variability: in short, error and the correction of error. It fits the understanding of philosophers and sociologists of science, who from Mary Hesse to Steven Shapin have argued that science, unlike its objects, is created by human beings in social groups and cultural situations. In this view, scientists are likely to think practically, analogically, and interpretively about what Aristotle called the “fixed objects” of the universe even though, since those objects are at some level invariant, they can think about them deductively as well.

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As persuasive as these ideas are, few of us think of science in a post-modern way. In medicine and out, we go on thinking of it as a purely syllogistic enterprise, the top-down investigation of reality that produces truths about the universe. Contingency and social construction are *not* characteristics of the science that medicine aspires to be. Oddly enough, however, clinical education operates as if the postmodern understanding of science were well accepted. Even as the claim that medicine is itself a positivist science goes unchallenged, the long clinical apprenticeship—five years at least—has as its goal the cultivation of *phronesis*, clinical judgment. Facts are important, of course, but the length of clinical training cultivates habits of mind essential to the “system one” associative learning that will be effortlessly recalled. Clinical pedagogy is nothing like what we’d expect of a science. Because learning to take care of patients is experiential, case narrative (which provides both vicarious experience and a record of events) is the medium of teaching, informal assessment, and memory storage and retrieval. Apprentices proceed by slow steps through a hierarchy that, as Charles Bosk demonstrated three decades ago in *Forgive and Remember* (1979), is as concerned with character as with intelligence and skill.

Least scientific of all are medical elders’ appeals to maxims and proverbs that, far from providing invariant laws of practice, can be countered with other maxims and proverbs that will be equally valid in other circumstances. “Listen to the patient,” learners are told, “she’s telling you the diagnosis.” But, “If the patient says he has gall bladder disease,” they are cautioned, “ignore him.” They are warned to “Avoid the anecdotal!” although soon after someone is sure to caution, “Pay attention to the stories.” The zebra maxim, a clinician’s fundamental epidemiological rule, counters itself: “When you hear hoof beats, don’t think zebras!” The advice is obvious—ordinary signs ordinarily have ordinary causes. But the clinical reasoner is reminded that, however unlikely, the unusual exists, and zebras, once mentioned, have now been remembered and can’t be un-thought.

No one is confused. What is being taught is situational reasoning or *phronesis*.

Conditions change, patients vary, and generalization is possible only at a low, very particularized level. Occasionally a medical student will lament, “Just tell me what to do and I’ll do it!” But the biological facts and therapeutic responses students learn are only part of clinical education, the part that is very likely to change over time. Learning how to think interpretively in uncertain circumstances is far more important; it is the linchpin of decisions that work for the patient, the ones that are *not* mistakes.

Clinical thinking is well taught in medicine—so why aren’t physicians also taught *about* the way they think? It’s as if medical practice were one of Bruno Latour’s hybrids, asserting “science” as a cover story so as to achieve its purpose more efficiently (*We Have Never Been Modern*, 1993, 6). Or perhaps medicine’s willful ignorance of its epistemology might be necessary because thinking about thinking could make it impossible to act. For a long time I wondered if physicians might be like the centipede that’s asked how it manages to walk with so many legs and, trying to think, it keels right over.

This obliviousness seems to be characteristic of all practice. As the philosopher Hans-Georg Gadamer observed, “Practice requires knowledge which means that it is obliged to treat the knowledge available at the time as complete and certain” (*The Enigma of Health*, 1996, 4). And Pierre Bourdieu, master theoretician of practice, wrote that every practice “exclude[s] from the experience any inquiry as to its own conditions of possibility” (*The Logic of Practice*, 1990, 91). Some physicians know—and write!—very well about the uncertainty of their knowledge. Yet even they become quite certain when they put on their white coats.

The obliviousness of practitioners to the grounds of their knowledge, even if it’s unavoidable, is not a good reason to omit the *phronesiology* of clinical medicine from medical education. Physicians are not always engaged with patients, and patient safety depends on the “system two” thinking they do when they take off their white coats. They plot therapeutic regimens, rethink diagnostic categories, design learning exercises, plan research, shape curricula. Before physicians can think outside the box, they must understand the box and how it’s conventionally seen.

If students were explicitly introduced to the realities of clinical thinking, the effects on patient safety could be profound. Uncertainty might be recognized as an irreducible component of decision-making that needs to be accommodated rather than the bogeyman of failure. Safety procedures would make more sense as accommodations for uncertainty—for oneself as well as those others. Teams and the contributions of their members would be better recognized; challenges up the hierarchy would be heard and rewarded. With uncertainty recognized as an inescapable part of medical care, risk could be explained and rationally limited care might stand a chance in our do-everything culture. Above all, the shame of cognitive error would be lessened. Mistakes would be more widely studied; clinicians would read “Clinical Problem Solving,” the first-of-the-month section in the *New England Journal of Medicine*, with as much suspense-filled interest as the clinical-pathological conference it has replaced.

If physicians were taught to understand their own knowledge systems and thought processes, the ideal of “being scientific” that’s now used to reinforce thoroughness would be replaced by the ethical imperative to be thorough for the good of the patient. “Thoroughness” itself could be investigated: what is it and when is enough enough?

The culture of clinical medicine encourages skepticism, curiosity, and investigation. But epistemology needs to be added to etiology and epidemiology as a field of study. Until then the new, improved hospital with its systems engineered for patient safety is like an excellent piece of hardware that won’t catch on until it finds its killer app. What’s missing is not a new label or a new procedure but a better understanding of how physicians think.

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*Provocation:*

## The Medical Humanities as Reading: Good Intentions and Semantic Rigor

Catherine Belling, PhD

*Since we can never perceive perfectly the absolute whole of anything instantaneously, all perception is impure, a reading of signs rather than an apprehension of things. The condition of reading is the human condition.*

—ROBERT SCHOLES, *Protocols of Reading*

The title of the ASBH spring conference “Books to Bedside: Translational Work in the Medical Humanities” raises the question of application: does work in the medical humanities translate to patient care in ways that are analogous to translations of bench science’s descriptions of its objects into useful treatments?

The medical humanities have been defined by usefulness; the field exists because it’s expected to have broadly salutary effects on medical students, and hence on physicians, and thereby on patient care. This effect is usually described as “humanism,” or “professionalism.” But what is used to cause this effect, and should application ever precede investigation? What is the “bench science” of medical humanities? “Books” is an obvious (and suitably alliterative) substitute for “bench” in the standard translational formula, “bench to bedside,” but the term raises some tricky questions. Which books? It’s not the primary texts we read, and have our students read—focusing on primary texts is analogous to science translating from bacteria to bedside; from unexamined object to application. That’s not what science does, and that’s not what humanities work does either.

Those primary texts, be they books, poems, films, or instances of human behavior, are the objects of our study. A text is an interpretable entity that need not manifest in the form of a book or even in words. When you read or interpret something it becomes your text. As a humanities scholar, your work

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is also to produce a new text that articulates your readings, just as bench scientists must articulate and publish their findings. Our initial product is what we publish. So a more fitting analogy to the scientist's bench is the books and articles we write. (The overlap in form between our object of study (often writing) and result of study (our written scholarship) is the source of some confusion—but more on that later.) But translational medicine is not “*Nature* article to bedside” either.

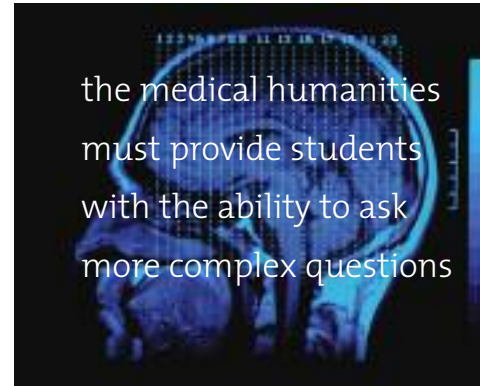
In the humanities, our practice, equivalent to the empirical activity that constitutes laboratory science, is analytical, interpretive, and critical: *reading*. Our object is not the natural world but the cultural world that humans always make of it. (And for this reason, science and medicine themselves are among our object-texts.) Our metaphorical (or metonymic) “book” (or “bench”), then, is not the text we interpret, or the one we produce, but the practice the word stands for, the descriptive-interpretive-explanatory method of doing our research (or scholarship, if you will), before application is an issue. It is our exploration of meaning as an end in itself. We put medicine under our metonymic microscopes and read it in order to find out what, and how, it means.

For some time, narrative has been our key into the curriculum and the clinic. The term “narrative competence” in medicine clearly marks the skill-based contribution humanities approaches offer to thinking about clinical interactions, patient experiences, and the story-based functioning of medicine in all its cultural manifestations. It also meshes neatly with the current move in medical education to a model based on competence attained rather than courses passed. “Narrative” is a term, however, that is defined poorly and used loosely within the medical humanities. It is both too broad (often used to encompass everything non-quantitative) and too narrow (the humanities do not read only narrative texts). Instead, our work would be better framed in relation to practices of reading—which includes reading the written and oral narratives that constitute so much of medical practice and thinking and experience.

The humanities scholar—a professionally-trained reader and teacher of reading—can show how texts usually come with basic instructions for reading them (generic protocols, in effect) and that a good reader must find ways to recognize and then transcend these, reading critically. This does not mean destructively or cynically. It means, for instance, reading a text we think of as subjective (a poem, a patient's complaint) with rigorous attention to evidence, and a seemingly objective one (an abstract in JAMA, a CT film) with informed skepticism. It means not being subject to one's own assumptions about an author's intended meaning, or to a text's hidden agenda, and it means having the semantic repertoire to know which readings of a text are more, or less, legitimate than others. It means knowing that no text is ever either a transparent window onto accessible reality or an opaque mirror simply reflecting back the reader's own feelings and experiences.

The translation of “books” to “bedside,” then, should mean the application of our practice (reading) and our results (precise and nuanced accounts of medicine's representations) to the training of students and the treatment of patients. We must first establish clearer disciplinary guidelines for our practices of reading. To begin, we need to make it clear that “humanities” are not synonymous with, and do not necessarily entail, “humanism.” Close reading of articles that describe the value of the humanities in promoting humanism in medicine reveals a methodological vacuum. For example, a curriculum is said to include “several types of interventions to create learning environments that teach and enhance humanism.”<sup>2</sup> The language reveals how hard it is for the authors to say exactly what they mean. The sentence doesn't describe teachers doing the teaching. The environments are expected to do it, but we can't tell how. The object of study is unclear, and so is its connection with the quality called humanism. More detailed descriptions that follow still struggle to articulate method: in “workshops ... co-taught by supportive physicians paired with an artist or a humanities expert, [students] are exposed to the dual perspectives of the scientist and the artist. They ... help students bring humanity into their day-to-day activities.” In practice, most medical humanities teaching is more rigorous than the term “exposure” suggests, and the interchangeable use of “artists” and “humanities experts” in this article confirms the view of “humanities” as synonymous with “art” (both of which are defined by their difference from the natural sciences). This is a profound category error, for the humanities disciplines are not the same thing as the fine or creative arts.

This dualistic view is also reflected in an American Board of Internal Medicine report that classifies “humanism in medicine” as “noncognitive” and calls this orientation the domain of the humanities disciplines and their scholars.<sup>3</sup> The distinction relies on a pseudo-Romantic idea that the subjective is the domain of the heart (or the gut), and that the mind's brain-based cognitions are capable of cold reason



untrammelled by feeling or language. It's a surprisingly unmedical view of human thinking. The humanities disciplines are profoundly cognitive and rational, and they can be taught, measured, and evaluated, but they tend not to be taught in medical schools. Instead their contribution has been limited to what we trust will be conveyed by the good intentions of teachers. This puts an unnecessary burden on those teachers and renders the value of the medical humanities ephemeral, undefinable, and resistant to assessment. While the argument that the humanities promote humanism has worked to establish a sphere of contribution, it has also limited that contribution by merging the humanities disciplines with the fine or creative arts. Our field must move beyond this argument before it can make its full contribution to the field of medicine.

The more productive position is to cut through the books/benches distinction on a different plane: Andrew Edgar and Stephen Pattison argue that the role of the humanities—in medicine and anywhere else—should be equivalent to their role in relation to their more traditional texts (novels, paintings, and so on) as a “second order critical activity.”<sup>4</sup> In other words, the humanities scholar is to cultural texts (including, but not only, literature and art) as the lab scientist is to natural phenomena. This means that to earn the name, the medical humanities should focus less on what is read than on how it is read. It also means that the medical humanities should become evidence-based, capable of giving an account of how and why something is known about a text, even if that knowledge is speculative. Intention is not enough. Semantic, linguistic, textual evidence must be expected, from scholars and from medical students. Edgar and Pattison make the difference between arts and humanities clear:

The humanities ... perform the role of checking the propagandistic, conversionist potential of the arts [or any other cultural artifacts, include those produced and used by bioscience and in medicine.] The *humanities* can say that [a] particular vision, however pleasing or exciting it may be, is epistemologically, morally, or politically wrong, and provide arguments and evidence for that claim. (97)

Rather than using the arts for their “conversionist potential” (assuming that watching *Wit* will inoculate students against the bad behavior of the play's doctors), the medical humanities must provide students with the ability to ask more complex questions (Are the doctors in *Wit* stereotypes? If they're “unrealistic” shouldn't we just dismiss them? How do they work as representations? How do literary representations connect to professional roles? How are similar representations conveyed in the subtexts of the medical school curriculum? What assumptions underlie these? What intellectual tools and strategies do students need to identify and resist them?).

Such questions are often asked in medical humanities scholarship, and sometimes asked in medical humanities classes, but they are not often highlighted in accounts of the value of the medical humanities. We should be less modest about a discipline that allows such questions to be identified and asked in ways that, if conceptualized and taught with the technical and intellectual rigor—the *discipline*—that the humanities offer, could enable students and physicians to read their work in medicine with sustained and skilled attention to meaning.

Medical educators who limit the contributions of the humanities to the Romantic idea of literature as an inarticulate art with ineffable effects are depriving medical students of a useful set of tools: a technical vocabulary enabling physicians to understand and articulate how representations work, how they're made, and how they're understood in all human spheres—from lab notes to drug ads to a mom's explanation of why she doesn't want her child vaccinated. Learning to read (and yes, practicing those reading skills on John Donne or John Stone or Atul Gawande or Tess Gerritsen or a CT scan) should enable physicians to navigate the old science-art divide, to enact the phronetic thinking required of them, and to convey their knowledge clearly—to themselves, to their patients, and to their students. In this way we might come up with something robust enough it won't get lost in translation.

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<sup>1</sup> Robert Scholes. *Protocols of Reading*. New Haven: Yale UP, 1989: 69.

<sup>2</sup> David T. Stern, Jordan J. Cohen, Ann Bruder, Barbara Packer, and Allison Sole. “Teaching humanism.” *Perspectives in Biology and Medicine* 51.4 (Autumn 2008): 495-507.

<sup>3</sup> ABIM. Subcommittee on Evaluation of Humanistic Qualities in the Internist. *Annals of Internal Medicine* 1983; 99:720-724.

<sup>4</sup> Andrew Edgar and Stephen Pattison. “Need humanities be so useless? Justifying the place and role of humanities as a critical resource for performance and practice.” *Medical Humanities* Dec 2006; 32: 92-98.



# NEVER AN ORDINARY DAY: STRUGGLES OF A PERINATOLOGIST

Serena Wu, MD

I prep the room before I call the family: I enlarge images of their fetus onto a 24" screen, I put tissues on the round table, and I put a plasticene model of a brain discreetly to the side so I can describe the pathophysiology of the defect when the time comes. The Smiths sit in the waiting room staring blankly at the TV. Today they've had an ultrasound, fetal MRI, and fetal echocardiogram. I'm one of many strangers this couple has to meet, but our meeting is the day's climax, the time when the pediatric surgeon and perinatologist (a high-risk obstetrician) will synthesize and distill all those test results. They look exhausted and apprehensive, but they smile tentatively as I usher them into the counseling room.

Being a perinatologist is heartbreaking. I love giving my patients information and answers. It may be difficult to hear but it gives families the knowledge, and sometimes even the strength, to take the next step. I hate that too often I'm giving the diagnosis and offering no options. I'm usually the bearer of bad news, and only sometimes the bearer of a tiny life preserver in an otherwise sinking ship. But now these consults represent the hope for a middle option that lies between "doing nothing" and termination, the new option of fetal surgery. Parents hope invasive fetal therapies will be the "killer app" that can fix their fetuses. It's my job to inform them these technologies and procedures aren't always the solution.

Mrs. Smith starts crying, and tears continue to well up through out the entire session. She's about 20 weeks and the pregnancy isn't a threat to her health, so if she wants to terminate she needs to decide fast. I ask the Smiths their understanding of the pregnancy and they speak as a team, trading sentences.

*Everything was fine until a week ago when we had the ultrasound. We didn't want to have any prenatal testing because we don't believe in termination. The technician got quiet during the ultrasound and seemed uncomfortable; we could tell something wasn't right. Then the doctor came in and told us there was a hole in the baby's spine called spina bifida. It seemed like forever before we could see our OB, and she confirmed it—our baby will have to wear diapers forever, she'll have problems walking, and she might have developmental, behavioral, and mental issues. There's pulling on her spinal cord, so her brain's affected. We felt so overwhelmed.*

I review the day's radiologic findings with the family:

"Ventriculomegaly."  
"Myelomeningocele."  
"L3-L4."  
"Open defect."  
"Closed defect."  
"V-P shunts."  
"Wheelchair."  
"Leg braces."  
"Incontinence."  
"Intermittent catheterization."  
"Bowel regimen."  
"IQ points."  
"Bell-shaped curves."

Drawings and a model seem to help, but I'm still not sure what they hear. For this family, I sense a lot of indecision and inner turmoil.

*Our doctor asked if we'd be interested in a repair. Open the uterus, cover the hole, close the uterus, and continue the pregnancy? Our hearts lifted a little.*

The pediatric surgeon steps in. First he focuses on the technical aspects of prenatal surgery, then practical aspects like length of surgery, recovery time, complications for mother and fetus, and the absolute need for cesarean section for delivery. He discusses the research and outcomes for children with and without in utero surgery. He states that this surgery is not a cure. It doesn't reverse what already has happened, the fact that the neural tube didn't close and the spinal cord has been exposed to amniotic fluid.



Courtesy of The Center for Fetal Diagnosis and Treatment at The Children's Hospital of Philadelphia

This couple is clearly looking for a miracle, but at what cost? I want to be sure Mrs. Smith doesn't compromise her health unnecessarily, and that she understands the risks of what she might be undertaking. I want to be realistic but hopeful. I emphasize that the bottom line is that fetal surgery is still considered experimental.

I'm uneasy. It's hard to fathom the difficulty and enormity of their decision making. Mrs. Smith's first pregnancy had been uncomplicated, this was going to be a little sister and their second daughter. After almost five months of carrying a pregnancy with many expectations and hopes, Mrs. Smith now faces an uncertain future. I present the options and attempt to be non-directive, but I don't think a physician can be truly objective and non-directive in counseling. We come to the table with our own morals and biases, our own life experiences, and our intimate knowledge of the physiology and how it impacts normal bodily functions. We also know about the worst of the worst scenarios. There are no guarantees until birth, only a range of possibilities, and we can't predict the impact each one will have on any particular family. No matter how many families I counsel, there is no way of conveying this intangible aspect. I can't predict the future, and I can't speak to the social, emotional or financial impact of their decisions.

So far we've been discussing quality of life in terms of the medical model, fixing physical problems to fit into society's understanding of "normal." I introduce a discussion that this fetus and pregnancy could be another version of functioning and try to juxtapose the concept of disability with the focus on correction and cure. It isn't an easy discussion. The Smiths are quiet as they look at me; I'm not sure if they hear me. Their questions about ambulation, incontinence, mental capacity and school leads me to believe they are trying to fit this possible reality into their current life, and that makes sense—the families I see are generally focused on cure, not handicap. I'm not so different: years of medical training have taught me to think of the human body in terms of function and repair of function to normal too.

The mothers I meet will usually sacrifice their health and body to achieve a chance of a cure. Acceptance of the disability usually isn't made until after all curative options are exhausted and if termination is not an option. Nevertheless, I feel a need to raise the "social model of disability" in this meeting. It may seem odd to the Smiths, they came to us to hear about repair. I feel off-kilter myself since they haven't made a decision yet. But if I don't raise it

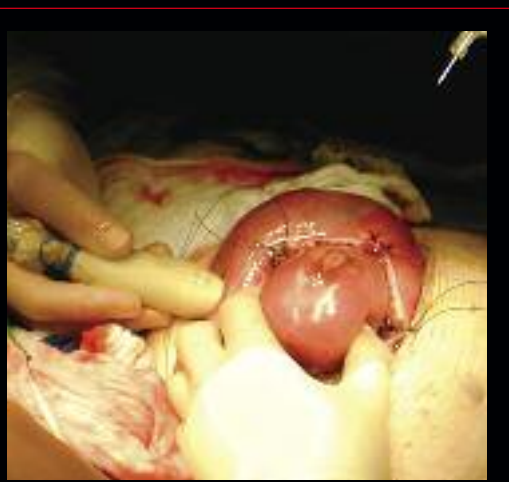
now, who will? Most medical offices aren't equipped to answer these questions or provide cogent answers. At the very least, we can provide resources and support if the families need information.

It's exhausting. These counseling sessions weigh heavily upon me. My recommendation and description will influence a family decision that will alter their lives. I've never met these people before and this is probably the last time I'll see them. I usually get one snapshot of their lives and family dynamic, and one chance at a coherent explanation of what's going on. These strangers give me their trust, and in return I must use the power I hold responsibly and balance the mother and family's best interests. But what does that look like, exactly? I feel conflicted because the entire day's focus is on the problem, its diagnosis and solution. I am not sure how to shift the focus beyond the "problem" and focus on the child.

Before the Smiths were able to decide on fetal surgery, that "middle option" was taken away from them—they didn't qualify for the trial based upon the prenatal diagnostic images. Maybe that was devastating, maybe having one less decision to make made it easier—I wish I knew.

Parents come to me in varying degrees of understanding and denial. They come for hope (maybe the initial diagnosis was incorrect), for confirmation, and for the possibility that "something" can be done. I've counseled over a hundred families, and I still can't imagine how my husband and I would react in the same situation. All I can do is continue to grapple with this quandary, and work to help families come to an understanding that encompasses all views, so they can make a truly informed choice.

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Courtesy of The Center for Fetal Diagnosis and Treatment at The Children's Hospital of Philadelphia



## FROM BEDSIDE TO BED:

### Doctors' Unfortunate Love Affairs in Modern Literature

Chantal Marazia, PhD

Wrecked marriages aren't restricted to the medical profession, in real life or in novels. However, fictional physicians seem to be particularly exposed to marital unhappiness. In fiction a disloyal wife seems to be almost a side effect of the Hippocratic oath. Whether it's a consummated betrayal, as in most of the cases, or simply an unfulfilled desire, as in Schnitzler's *Rhapsody: A Dream Novel* (1927), the betrayed doctor is so recurrent a character as to approach the status of literary topos. The theme of betrayal, which transcends historical and geographical boundaries, often comes to constitute the very dramatic core of the story.

The infidelity of the physician's wife in modern literature is not always due to boredom or caprice. Often the physician's wife really falls in love, and often it's with a man representing the very opposite of her husband's professional and character attributes. It's common to find that the rival is an artist or an intellectual, or at least a histrionic personality, counterbalancing the scientific and human pedantry of the doctor. The instances of a doctor and a writer competing for the same woman are rather suggestive, and they provide an example of the literary representation of the rivalry between the "two cultures" of science and the humanities.

Don't be misled—erudition doesn't automatically grant the fictional doctor immunity to adultery, or guarantee marital happiness. Suffice it to think of Dick Diver in Scott Fitzgerald's *Tender is the Night* (1934), or of Dr. Juvenal Urbino in Garcia Marquez's *Love in the Time of Cholera* (1988). Moreover, the fictional character of the doctor wasn't always sketched as a rough alternative to the man of letters. As Solomon Posen emphasized in *The Doctor in Literature: Private Life* (2006), "authors of fiction portray both versatile and unidimensional doctors, contrasting the surprising erudition of some members of the profession with a total ignorance of non-medical topics among others" (140). However, although numerous and meaningful counterexamples can be counted, generally speaking, as Posen puts it, "the scholarly physician predominates in the nineteenth century, the ignoramus in the twentieth".

In the twentieth century the character of the cultured family doctor is often replaced by the illiterate but competent technician, endowed with diagnostic acumen and refined ability.

Such a combination can be found in the famous Dr. Cottard of Proust's *In Search of Lost Time* (1913-27), who can be considered the archetype of the professional success of ignorance. At first sight, this new typology of doctor can afford (quite unlike his nineteenth-century predecessors) even a complete ignorance of the humanities without this lacuna seriously diminishing his diagnostic and therapeutic abilities, almost to the point of suggesting an equation between clinical skills and lack of wider cultural interests.

In medical humanities circles the instrumental role of a literary education for medical students and doctors is often justified by the argument that it enhances the capacity for identification and empathy, thus positively contributing to the doctor-patient relationship. If, as I suggest, we consider love affairs as a most symbolic kind of empathic relation, involving care and moral identification, then a closer analysis of the marital destiny of some fictional doctors might provide material for discussion about the usefulness of humanistic values to medicine. To this end, I'll focus on three books, belonging to three different geographical areas and centuries: Gustave Flaubert's *Madame Bovary* (1857), Sinclair Lewis's *Martin Arrowsmith* (1925), and Ian McEwan's *Saturday* (2005).

The common denominator among the three doctor-protagonists of these novels is that they are all professionals who illustrate Posen's figure of "the ignoramus." They all have a deep ignorance of non-medical subjects, if not a patent aversion for culture in general and literature in particular. It is no minor detail that *Madame Bovary* begins with Charles Bovary's disastrous scholastic exordium, and that Flaubert repeatedly insists on the meager culture of this doctor, not only fatally incompetent but also deeply ignorant, whose "volumes of the *Dictionary of Medical Science*, uncut ... occupied almost alone the six shelves of a deal bookcase" (25). On the contrary, his rival, the young and brilliant Leon, shares with Emma Bovary the passion for novels and music. It's no surprise that the formal changeover between Charles Bovary and his wife's lover takes place at the opera, where the doctor shows all his embarrassing cultural inadequacy. In Charles Bovary this inadequacy immediately translates



Photo still from "Madame Bovary," 1991, directed by Claude Chabrol

into psychological insensibility, and his inability to intellectually stimulate his wife translates into the inability to understand, cure, and finally save her from suicide.

Quite unlike Charles Bovary, Martin Arrowsmith, the main character of Sinclair Lewis' homonymous novel, is a brilliant scientist even though he cannot be defined a good doctor. Like Bovary, he shares responsibility for the death of his wife. Dr. Arrowsmith's marital relation can be considered idyllic, but the superficiality that characterizes Arrowsmith brings him to the fatal error that will cost his wife her life. In Lewis's book, the relation suggested by the author is not that between culture and psychological subtleness. The relation is that between a more versatile education and the insufficient moral imagination of the protagonist. In *Arrowsmith* the adulterer is not the wife but the doctor, who, for the sake of flirting with the woman who later becomes his second wife, abandons the first to the atrocious sufferings of plague and, finally, to death. Few would disagree with

Frank Palmer's statement in his *Literature and Moral Understanding: a Philosophical Essay on Ethics, Aesthetics, Education, and Culture* (1992) that "a man of fine artistic sensibilities may, in other respects, remain a swine" (240), but Lewis himself seems to suggest otherwise by repeatedly insisting on the ignorance of Dr. Arrowsmith's character. Lewis describes Arrowsmith as "half educated. He was supposed to be a college graduate but he knew nothing of economics, nothing of history, nothing of music or painting. Except for hasty bolting for examinations he had read no poetry ... and the only prose besides medical journalism at which he looked nowadays was the baseball and murder news in the Minneapolis papers" (185).

The humanistic education of the neurosurgeon Henry Perowne, the main character of Ian McEwan's *Saturday*, is also remarkably defective. However, whereas Arrowsmith takes some timid steps towards improving his general culture in the course of the novel, Perowne is an unrepentant illiterate. He thinks openly, and not without some pride, that "he has seen enough death, fear, suffering and courage to supply half a dozen literatures" (6). In this case, as in Arrowsmith's, it is the atrophied imaginative capacity of the doctor that puts his wife's life at risk, as well as that of his whole family. It is Perowne's lack of identification that leads him to publicly humiliate a dangerous neighborhood bully, who takes Perowne's entire family hostage for revenge. His vast neurosurgical skills will not provide any remedy against that. It will be poetry, instead, that moves and disarms the aggressor. Moreover, it will be a poem enounced by Daisy, Perowne's intellectual daughter, upon suggestion of her grandfather, a famous poet named "John Grammaticus." It might be a simple coincidence, but the fact Daisy insists her father read *Madame Bovary* seems to me an intriguing coincidence: "Look at your Mme Bovary again," she says. "[Flaubert] was warning the world against people just like you" (68).

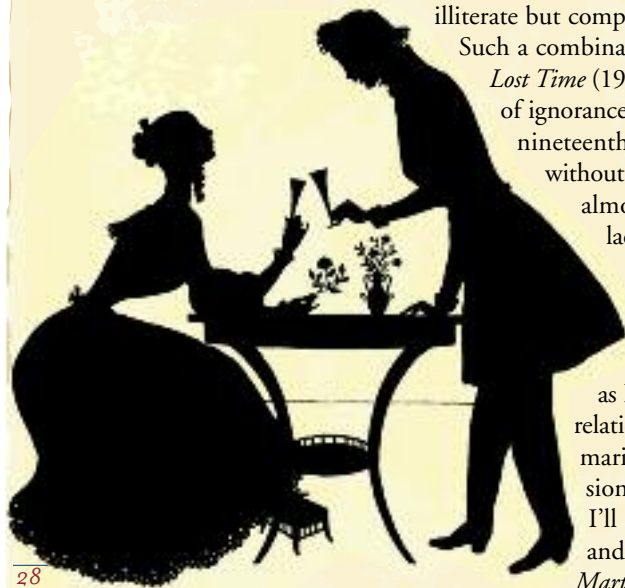
In Jane Macnaughton's essay on McEwan's book, she argues "*Saturday* does not make a convincing case for the efficacy of a literary education for doctors".<sup>1</sup> I do not fully agree. Wider understanding of culture may not have affected the clinical competence of the physician protagonists; it is difficult to maintain that reading Shakespeare would have improved their professional results. However, in all three cases a better cultural sensibility would have endowed the doctors with better analytic and interpretative skills. A more refined capacity for interpretation and identification probably wouldn't have helped save more patients, but might have saved their marriages and, what is most important, their wives' lives.

"Books are the 'password' for getting better than we are," George Steiner wrote.<sup>2</sup> Precisely—they are just the password. The correct pronunciation of the shibboleth is not a guarantee for the pronouncer's identity, and erudition is not a guarantee for a better caring. Literature constitutes only a supply of precedents we can draw from in case of moral dilemmas. Knowledge is only the prerequisite for recognition (from the Latin *recognoscere*, literally "to know again"). And even if we recognize, we can continue to ignore. To ignore, in fact, does not only mean actually not to know. To ignore is also to feign ignorance. To ignore is also to overlook, to pass over, to disregard. To neglect.

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<sup>1</sup> Jane Macnaughton, "Literature and the good doctor." *J Med Ethics: Medical Humanities*, 2007, 33.

<sup>2</sup> George Steiner, *La Stampa*, May 11, 2000 (www.swif.uniba.it/lei/rassegna/0000511.htm).





# Inequality as Killer App:

## The Gold Foundation's Undermining of "Humanism in Medicine"

Shom Dasgupta

*"The doctor's experience of the world is as important to her caregiving as evidence is to her technical decisionmaking."*

—ARTHUR KLEINMAN<sup>1</sup>

Without any contextualization of Anatole Broyard's life and work, the prompt for the 2009 Arnold P. Gold Foundation "Humanism in Medicine Essay Contest" asked medical students to "reflect on the following":

To most physicians, my illness is a routine incident in their rounds, while for me it's the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity.

It's tempting to consider solidarity accomplished with a simple gesture of affirmation and acknowledgment. That's the trap laid by the Gold Foundation essay prompt, and the authors of the three winning essays (out of nearly 300 submissions) fell into it. All three authors developed poignant, sensitive accounts of engagements with suffering, and all seem to agree that the appropriate response to this incongruity of experience is for physicians to adjust their cognitive posturing vis-a-vis the suffering of the Other(s). A literal interpretation of Broyard's lament permits a facile escape in the trope of epiphany and cognitive reintegration.



ANATOLE BROYARD

I fell into the same trap. In the essay I submitted to the Gold contest I wrote about Ya Patricia, an elderly Maya woman I met through my work in Guatemala. She spent the first forty years of her life in a contemporary form of debt slavery on a coffee plantation in rural Guatemala. Several months before she passed, Ya Patricia began experiencing a mysterious constellation of symptoms. Rosa, a community healthworker from the same hamlet, was able to contact a physician by phone; he declined to make the trek to attend to Ya Patricia, explaining that she was a "chronic case" and that there was little he could offer her. Despite the efforts of her family, she received no care from a professional healthcare provider during the last days of her life. Depressed, cachectic, and in pain, Ya Patricia was denied biomedicine's "comfort measures"—pharmacologic or moral—in her final agonizing moments. Instead, her family watched in dismay as she slowly progressed through what sounded like a catastrophic stroke. I don't know if that physician's refusal—that is, his inability to *at least perceive this incongruity* separating the patient from her absent healers—was ever communicated to Ya Patricia. If it was, her reply (uttered from her deathbed

in a remote hamlet instead of a hospital cot in the larger town where the physician lived and worked) went unheard by any physician—and it was spoken in Kaqchikel Maya (instead of Spanish, the colonial language of Guatemalan biomedicine) so this physician wouldn't have understood it anyway.

Far away in Boston, as I read about ethnographic appropriations of "suffering" as a graduate student in medical anthropology, my social and geographic context prevented me from hearing Ya Patricia's last words as well. The evening after her death I received a long-distance phone call from Rosa. I listened in disbelief, overwhelmed by my impotence as Rosa told me what had happened. Unable to get through to Ya Patricia's family, and not knowing what else to do, I began to write. Like the other Gold essayists, in the face of the vast displacements that divided me from my patient the only response I could muster was lamentation:

I am ashamed that I did not do more. I am ashamed that I do not have a picture of her, and I am ashamed at my selfish sadness that I will not have another opportunity to sit at the edge of Ya Patricia's bed, listening as she tells me how she is feeling.

It's no coincidence that, like the winning contestants of the Gold essay competition, I retreated into a gesture of noble futility. Faced with our own reified positions and the powerfully reifying processes of biomedicine-as-usual, medical students feel relegated—and encouraged, even pressured, by the hallowed pronouncements of entities like the Gold Foundation—to fall into socially sanctioned emotional and moral responses, thereby mis-recognizing as insurmountable the experiential and existential distances between patient and physician.

Of the three winning contestants, only second-place prize winner Michael Barnett acknowledged that the individuated dilemmas faced by his patients—and by himself as their healthcare provider—were condensed manifestations of abiding social and physical structures that condition and maintain the patient-provider chasm. As such, he describes this chasm in architectural (and thus appropriately spatial) terms: Barnett shows us a hospital divided by doors—divided from the rest of the world, and within itself—where patients and their caretakers become alienated from one another and from themselves. Despite this incisive analysis, Barnett resigns himself to these structural etiologies, leaving them intact in a gesture of noble futility. He says he will continue "unlearning and relearning" the hidden curriculum of medicine, but even if the effects of these alienating structures can be linguistically described and cognitively resisted, in the end individual providers are doomed to reproduce them in their everyday practices. If I understand Barnett's



Home of a family in Pa Poqolaj, Chirichoy Municipality, Guatemala (April 2008) by Elena Tsirikas

closing sentiments correctly, his only escape from this ineluctable sense of failure comes when he walks past the threshold of the hospital and back into his life, where the suffering of hospitalized Others makes a "deep impression" and shapes his "sense of self, ethics, and spirituality." Thus, while he persists in his ambivalence longer than the other winning contestants (and me), Barnett ultimately flips into the self-exculpatory brand of humanism of the Gold Foundation, which teaches us to decry the existence of doors while failing to ask when and how they were erected.

To move beyond this error, we must reject the Gold Foundation prompt's dehistoricized, desocialized presentation of an individual in suffering. Read in a vacuum, Broyard's dilemma seems like it could be resolved if just one physician offered a gesture of recognition of the psychological, social, and symbolic space dividing patient from healthcare professional. But such a humanism seems weak and irrelevant, serving only to assuage our own guilt. Basic human solidarity with communities like Ya Patricia's requires us to reject the reductionist interpretation of the "incongruity" Broyard identified that limits it to catastrophic illness. Broyard's painful words would make my heart skip a beat if voiced to me by a patient. But the horrendous frequency with which "non-patients" like Ya Patricia suffer undiagnosed and untreated illnesses should make our hearts stop altogether. To be very sick is one thing, but to be very sick and extremely poor—or similarly deprived, as in the most virulent forms of racism—is quite another. If, as Barnett astutely observes, the doors of a hospital transform sick people who enter them into "one-liners," those same doors are closed to the overwhelming majority

of humanity, transforming the indigent sick into "no-liners"—that is, invisible.

This lesson—that social-structural etiologies and manifestations of suffering are intimately bound up with the "biological" form of suffering that falls under the conventional purview of biomedicine—is applicable in Broyard's case as well. Anatole Broyard was a passionate exponent of liberal humanism, and his philosophical roots share many points of intersection with those of the Gold Foundation. However, closer attention to the life-world and positionality from which *Intoxicated By My Illness* (1992) was written makes it evident that this socially decontextualized quotation hides a great deal of complexity. Broyard spent his entire adult life hiding his black creole ancestry from friends, co-workers, and even his own children.<sup>3</sup> Whether Broyard's decision to "pass" as white grew out of schoolyard traumas in Bedford-Stuyvesant or was simply an expedient career move, his ambivalence about his natal family's ethnic identity plagued him until the end of his life: as he lay dying of metastatic prostate cancer, he repeatedly rejected his wife's entreaties that he reveal this "secret" to their son and daughter before he was too incapacitated to tell them himself.

The Gold Foundation essay prompt seems to purposely elide a crucial aspect of Broyard's experience of extreme debilitation and suffering. In doing so, it hides the role of social-structural contexts as a powerful source of physical suffering. The ambivalence in Broyard's sense of self, and the threat of a racist society's denial of that self, reveal literal interpretations of his words as profoundly violent. In both Broyard's and Ya Patricia's case, the word

(continued on next page)



“incongruity” is patently incommensurate with the real nature of social relations. Indeed, the word “incongruity” mis-recognizes the distances separating people in hierarchical social contexts, substituting a metaphor of difference in shape for what’s really a difference in social status. “Incongruity” masks stark and troubling “inequality.” That’s the prompt’s perverse irony: by invoking Broyard’s suffering without attending to the social context of his experience, the prompt further magnifies the distance between Broyard as patient and us as physicians-in-training.

Given the Gold Foundation’s anti-social, depersonalized vision of what it means to infuse the practice of biomedicine with “humanist values,” Barnett’s statement that “it never occurs to [him]” to tell his patients about the “deep impression” their suffering makes on his life isn’t surprising. Barnett reflects on the transformation he himself undergoes when he exits the hospital doors, but constructions of “humanism” like the Gold Foundation’s make it easy for us students to ignore the possibility that doors can also serve as a barrier, shutting closed and keeping humanity out. If medical students like Barnett and me are expected to leave behind our stack of “one-liners” when we exit the doors of the hospital, what are we obliged to leave behind when we enter? Perhaps that is the way in which the perplexing insistence

of the Gold Foundation banner “humanism in medicine” begins to make sense. If, as protectors of biomedicine-as-usual would have it, we are expected to leave behind the outrage and disgusted disbelief that are perfectly humane responses to the social-structural etiologies of extreme suffering, we must ask whose interests are served by an understanding of “humanism” that leaves such profoundly dehumanizing structures in place. Otherwise, we’ll fail to hear the full extent of our indictment by profound forms of suffering at the margins of society, and we’ll fail to destroy the doors that shut out the humanity of our non-patients, all the while safeguarding our sense of our own humanism.

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*Photo of Municipal Cemetery, Chirichoy, Guatemala (January 2009) by Shom Dasgupta*



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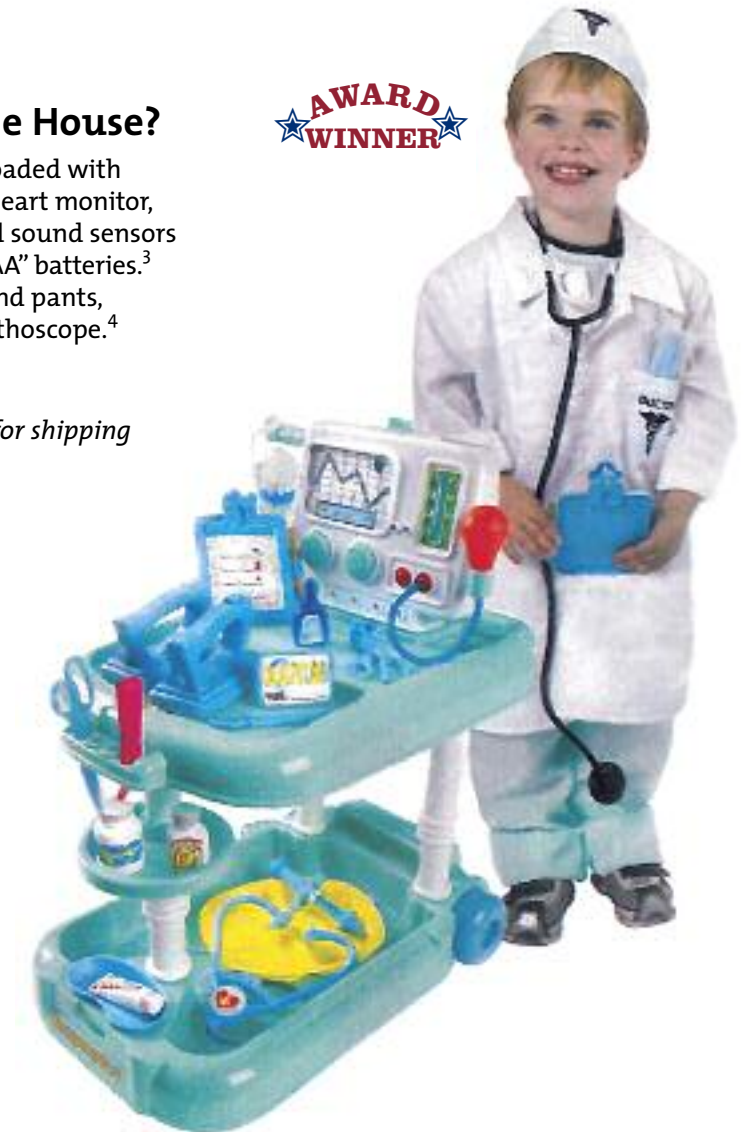
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## The Clinic 2.0

*Jon Hallberg, MD*

Last May, *Fast Company* magazine published an article titled, “The Doctor of the Future.” To show us what we’re in for, Chuck Salter profiled Brooklyn’s Dr. Jay Parkinson, 33. He’s bearded and muscular, wearing black jeans and a black t-shirt, black leather bag in hand, black stethoscope draped over his shoulders—the epitome of cool. Dr. Parkinson doesn’t have an office; he sees his patients through e-visits and house calls. He doesn’t take insurance; he works with PayPal. He has a website and a blog. This “digital doc” understands and embraces technology and he’s changing the face of medicine. But is his “micro-practice” version of healthcare really where we’re headed? I think he’s really onto something, but I’m not ready to give up on actual clinics...yet.

As a family physician I’m convinced there’s a need for “medical homes,” clinics that provide compassionate, coordinated care. At the same time, I love the idea of using technology to improve access, reduce paperwork, and save money. But the thought of practicing alone, without support staff and without a physical clinic, is hard for me to grasp. Something’s missing in this version of primary care’s future. If your provider doesn’t have an office, where’s your medical home? Though this technology seems cool and cutting-edge, it also seems lonely—a little sad, even. Instead, I think it’s time to re-invent the clinic.

In Clinic 2.0, new technology meets humanistic practice. Evidence-based medicine melds with compassionate care. Great physical design complements design thinking—a focus on how to design everything better, from greeting patients to

refilling prescriptions. Healing space blends with lean ideas—a quest to reduce repetition, overhead, and ultimately cost. Music soothes the soul, art pleases the eye, dramatic readings stir the heart. Frequent evening receptions and gallery openings encourage conversation among patients, neighbors, and clinic providers. Here, a trip to the doctor is something you might actually look forward to. You like this place; you *want* to come here. As a result, your health might actually improve—an idea worth studying.

In November 2008 I helped open a clinic like this in Minneapolis, a new *kind* of clinic and a true medical home. The Mill City Clinic was designed to be an incubator of innovation for our system—and for primary care. Tucked into the ground floor of a new condominium building located near the Mississippi River and across the street from the spectacular Guthrie Theater complex, it’s a place where art, science, the humanities, and medicine are given equal measure. Our Clinic 2.0 is more than a clinic, it’s a gathering spot: a place for reflection, new ideas, and great care. It’s not virtual; it’s not a concept. It’s a real physical space that completely changes your notion of what a clinic can—and should—be. Marcus Welby would feel at home here. And so would Dr. Parkinson.

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*Photo courtesy of Mill City Clinic and Perkins + Will*

Snapshot