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.”

It’s been a summer of death. Shrivl 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 “under treatment” 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 “under treatment” 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.”
seemed to drag 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. It was as if the record was blank 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 inarticulate 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 a 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 overruns control that the immortal queen of the fairies now feasts on a working-class mortal whose appearance is as incongruous as that of a jester. “Blacks! Titania! Bottom! Bless thee! cries a justly startled companion. “Thou art translated.”

*Translated* in Elizabethan English means changed—the loss of the self and its features. 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.

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 encounters, where etiquette 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 *bedside*? Where, and how, do we locate it?

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 tiring. 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 notous appearance: “After all,” as the doctor confesses of his “unusually attractive” young female patient, “the tiring part of doctoring is also inacurate, 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 ethics” on health and illness. Dyadic networks include our immediate 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 infects 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, we doctors tended to disparage 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, catastrophe, and panic. But, important, is the way the contemporary experience of illness provides an incorrigible taste for eros as the species-wide disorder of bodies created by their relation to death: “Lord, what fools these mortals be!” (III.iii).

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. Lovelinessness was even a standard medical diagnosis in the 19th century, as a famous Irish bishop supposedly died from it. In our age, disruptive erotic energies spill across nontradional 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 charged.

Its entanglement with varieties of extreme loss and failure makes eros an uncountably 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 William’s fictive doctor—his self-confessed attraction to his patient, his fury at her resistance, his burning face—illustrates the peril of eros within the charged doctor/patient dyad. He is the medical student’s nega-tive model: a failure to control the erotic, a failure to do the erotic as its definiing mental-emotional state: not just the lyric, the paradox and exhaustion—

*The Tears of Eros* (first published in French in 1961 as *Les Larmes d’Eros*). 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 sometime subversive and often implicit anti-capitalist and anti-business agenda of eros, “to destroy the self-contained character of the participants, they are in the end a blur.”

William’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 self-control, but loss that threatens eros.

No gain, as the widest perspective on eros reveals, without pain. Eros, moreover, in the most distressing implication of Williams’s story, is inseparable. 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 reduce them. But these rules, however, the greater harm in medicine may come from the mindset that ignores, excludes, or repudiates it. (continued on page 13)
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 demystify the object of study 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 that bioethics is 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.
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.

In 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 as a medicine studies revolution. The scholars have nothing to lose but their practicality. They have a discipline to win.


Tod Chambers is Director of the Medical Humanities & Bioethics Programs, Feinberg School of Medicine, Northwestern University, where he is a Associate Professor of MIHEB and of Medicine. A version of this article was presented at the ASBH Spring 2009 meeting. t-chambers@northwestern.edu
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 projects 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/dependency... the list goes on and on. Women’s studies and medical humanities stress the importance of the second term in the binary, and this 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 the binary, the one that has been less valued in the hierarchical relationship between the two sides.

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. I only have the space here to suggest that the practice of medical humanities in the present might benefit from tracing out the genealogies of medical humanities, ones that begin outside and extend beyond medical and visual domains. If an initial impulse in women’s studies was to “add women and stir” 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 Histories

What forces shaped the emergence of these two interdisciplinary fields and how has each field been transformed since its emergent moment? Because Aristotle’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. Carlson offers a fascinating snapshot of the milieu out of which medical humanities emerged.1 The section entitled “Where Do We Come From?” opens with this statement:

In both cases, 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 widely caught up in one of their periodic identity crises. Philosophy was stuck in an analytic mode (which 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 ordinary impulses that propelled the constitution of a new field. First of all, 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.

As 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 are qualities of a morphing esotericism, and an identity crisis. Two sides, two cultures. 2

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. I only have the space here to suggest that the practice of medical humanities in the present might benefit from tracing out the genealogies of medical humanities, ones that begin outside and extend beyond medical and visual domains. If an initial impulse in women’s studies was to “add women and stir” 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 with medicine, and so it encourages the cross-fertilization of medicine with the social sciences, 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, psychology, and narrative competence into medicine? How does medicine change through research 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. 3 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 model of primary care 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

(continued on next page)
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 gentle 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 govenment! 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 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 this government! That ain’t all, nuther.1

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 bedeviled 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 effects 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—and their ability 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.” 2

But alas, as fun as that is to rant about, it is more provocative than I wish to be. For I 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 "wiggly 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),

1 Ronald A. Carson, “Engaged Humanities: Moral Work in the Precincts of Medicine,” Perspectives in Biology and Medicine, vol. 50, no. 3 (Summer 2007).
2 Carson goes on to discuss what I agree is an important strand in the development of the medical humanities. As he notes, “it was mainly focused on medical pedagogy and moral philosophy (and later, from religious studies—still a hybrid field) that medical historians and medical humanists encountered.” Engaged Humanities, 325.
3 Interestingly, Carson’s history of medical humanities sounds like the history, according to Michel Foucault, that medical 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 recast 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 marked beneath their spurious the purity of clinical evidence.” The Birth of the Clinic: an Archaeology of Medical Perceptions, trans. A.M. Sheridan Smith (Milton Keynes: Open University Press, 1975), 54, am.
4 In her new classic essay, “Placing Women in History: Definitions and Challenges,” Genda Leroux describes the development of the field of women’s history from one concerned primarily with “comparative 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. 4 (Autumn 1977), 3-14.
7 The Body Multiple, 162.
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 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. Instead, they should be focused on developing biocultures centers of excellence. I use the term biocultures following Lennard Davis and David Morris. 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 and the crisis in the humanities. 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 financial and administrative problems for humanities are needed to better understand “bodies that matter.” 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 support 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, 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 medicine attempting to make it more human. 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 play this role, it’s no longer an ivory tower from which we 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).

call this a Medical Humanities? (continued from previous page)

Provozion: 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 form of reasoning that support scholarly conclusions lack the power conclusively to settle many of the most significant contemporary disputes. Sensitivity 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 cliniometrics or cognitive literary criticism will transfix 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, go along with it anyway. It’s not like you’re the one who made it, insisting to your deans that what medical humanities does is different from what medical geneticists do only as what physical chemists do is different from what evolutionary biologists do— mere matters of degree, more 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: sweeter reason, 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 literary critics is not a feature that the future may fix—

there’s just honing up and focusing some general human collective wisdom—affectional 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 (continued on next page)
 Persistent controversy is not an infinity 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, be a way of achieving the kind of sense that might help us to achieve the kind of sense that the universe seems to demand of us. It is clear that the work of the contemporary humanist aims at achieving a periphrastic 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 we can be is junior; at worst, we may pretend otherwise. The humanists may allow themselves to suffer from a kind of research envy: we may see the humanists as not doing the research that we see them doing in other fields.

(continued from previous page)

Jim Lindemann Nelson is a Professor in the Department of Philosophy, and Faculty Associate of the Division of the Humanities in the Life Sciences, Michigan State University, and a Fellow of The Hastings Center. He is the author of Eros in the Aftermath of Trauma: The Pathos of Self-Transformation (2004) and Research Leave: The Paradox of Self-Transformation (2013). Nelson is the co-founder of the annual Conference on the Ethics of Research Leave.

(continued on next page)
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 pernicious particularist. I felt like the walking dead. A mechanical man. A zombie. Failure here isn’t an error that might be excused by an accident with a sea 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.”

It constitutes surplus fallibility, a hyper-flawed state of being, not just a momentary loss of control but ineluctable 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 identity, and that cannot be repaired or excused.

A bedside ethic of loss and failure—especially when expanded to the super-adjacent circle of family caregivers—might well consider the commonplace medical experience of waiting. Psychiatry is a mythic prototype in her years of waiting and wandering, but wait and wandering, 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 bestow the self-transformings (albeit uncertain, flawed, and incomplete) that lend to illness-inspired loss and failure, ethical transformations, as a verbal noun—suggests ongoing, unfinished, fragmentary, even repetitive or circular activity, hard to live through but different from the ubiquitous and different, too, from emergence into a new, fulfilled higher state (like a butterfly emerging from a larva).

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 postmodernists 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.

The resident I see almost daily at Ruth’s Alzheimer’s home no longer knew which door in our bed-room was hers—and forgot. I am usually patient, but patience for “accepting the unacceptable.”

It’s tempting, especially for admirers of paradox, to construe all waiting as an action, as a wearily 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. 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 suffering 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 paradoxical or superfluous performance. Instead, they see it as radical inactivity—the utter relinquishment of an active role.

Are they waiting? Or have they entered a sedative-induced torpor? The residents I see almost daily at Ruth’s Alzheimer’s facility seem engaged in an inescapate waiting, with no aim or object, as they slump in a semicircle of overstuffed chairs, often seemingly asleep, as if they entered a sedative 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 inescapate state, without an object, without hope. Like Psyche I am on the go, on end in nonstop para-medical management, so my inescapate state is more deceptive than Ruth’s, but no less a form of exile.

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 postmodernists 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.

...the lover’s desire is rarely satisfied merely with possession of the beloved. The object of love is often always beyond 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 posed 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.” It 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 counterpoint 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, attantive, fullness of being—being as distinct from doing. “Presence,” as Goldman put it simply, “is what counts.”

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.

“Presence,” as Goldman put it simply, “is what counts.”

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.

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.
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 reaction 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,

"In that situation, a number of those girls grow up to be very angry men."
Talking about the incident later, I realized that caregivers are at risk for a condition—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 trance and the caregiver’s role in it. That role could be as active as a surgeon or as passive as an apathetic 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?

Well, this was back before the war. Scalpels weren’t as sharp back then. What am I talking about here? I mean, did I tell you how we had to go on these sort of medical encounters. But what do 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 an anecdotologist to know what 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?

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.

Narrative Disimpaction

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 for him. I had been 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 as part of my scholarship, but others had changed their lives. Practically speaking, I took what they told me and 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 the 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, 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 his 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 an anecdotologist 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 spend last night on the phone with Mark, asking him to tell me about his life with hypoplasdias.”

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 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.

Alice Dreger is Professor of Medical Humanities and Bioethics, Feinberg School of Medicine, Northwestern University. Her Bioethics Forum essay, “Lavish Dwarf Entertainments,” appears in Norton’s Best Creative Non-Fiction collection for 2009. She is now writing a semi-autobiographical book on science and identity politics in the Internet age. a-dreger@northwestern.edu
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 nineteen-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 have been 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 Nichomachean 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, 1995, 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.
As persuasive as these ideas are, few of us think of science in a postmodern 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 postmodernists 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 Bock 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’s symptoms,” one is told, “she’s telling you the diagnosis.” But, “If the patient says he has gal 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, counteracts itself: “When you hear hoof beats, don’t think zebras!” The advice is obvious—and suitably alliterative—substitute for “bench.” But epistemology needs to be added to etiology and epidemiology as a field of study. Until then the new, improved hospital with its systems engineers 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.

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 engineers 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.

Kathryn Montgomery is Professor of Medicine, Humanities & Bioethics and of Medicine at Northwestern University Feinberg School of Medicine. She is the author of Doctor’s Stories: The Narrative Structure of Medical Knowledge (Princeton University Press, 1991) and How Doctors Think: Clinical Judgment and the Practice of Medicine (Oxford University Press, 2006). A version of this article was presented at the ASBH Spring 2009 meeting kmontgomey@northwestern.edu

**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, *Prose 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 (continued on next page)
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)—more on that later.)

But the goal of medical education 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 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 world 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 clinical environment. The “narrative competence” in medicine clearly marks the qualitative domain of the humanities. The “artist” and “humanities expert” in this article confirms the view of “humanities” as synonymous with humanitites teaching is more rigorous than the term “exposure” suggests, and the interchangeable use of “humanities” for the humanities disciplines are not the same thing as the fine or creative arts. This is a profound category error, for the humanities disciplines are not the same thing as the fine or creative arts. This is a profound category error, for the humanities disciplines are not the same thing as the fine or creative arts.

“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.

To begin, we need to make it clear that “humanities” are not synonymous with, and do not necessarily give the same knowledge as, the natural sciences.

The 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. 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 clearly marks the qualitative domain of the humanities disciplines are not the same thing as the fine or creative arts. This is a profound category error, for the humanities disciplines are not the same thing as the fine or creative arts.

[Please note: the text continues on the next page.]
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 plasticine 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 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 consultations represent the “middle option” that can fix their fetuses. It’s my job to inform parents 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 able; we could tell something wasn’t right. Then the doctor came in and told us there was a hole in the baby 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 overwhelmed.

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

“Ventriculomegaly.”
“Myelomeningocele.”
“L3-L4.”
“Open defect.”
“Closed defect.”
“V-P shunt.”
“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 the 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 completely ideal, 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.

Mrs. Smith starts crying, and tears continue to well up throughout our 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 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 overwhelmed.

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

“Ventriculomegaly.”
“Myelomeningocele.”
“L3-L4.”
“Open defect.”
“Closed defect.”
“V-P shunt.”
“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 the 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 completely ideal, 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.
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 or in 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, countering 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 (1935), 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 (2000), “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. Cortard 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 predecessor) 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 circle 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, it comes as no surprise that 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: Giuseppe 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 ignorant.” 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 disadvantageous scholastic exordium, and that Flaubert repeatedly insists on the meager culture of this doctor, not only fatefully 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 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 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 afford a good dinner. Like Bovary, his marital failure is due to 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 flirty 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 article in 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 journal 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 nonsurgical 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 Mine 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 may not be a convincing case for the efficacy of a literary education for doctors.” 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 sensitivity 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. 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. Chantal Marazia has a PhD in History of Science. She is presently research fellow at the Interdisciplinary Research Institute on Ethics and Medical Humanities, Lugano, Switzerland. A version of this article was presented at the ASBH Spring 2009 meeting. chantalmarazia@libero.it

2 George Steiner, Le Stampa, May 11, 2000 (www.wrl.umd.edu/~lts/transparentg/000051.html).


Chantal Marazia has a PhD in History of Science. She is presently research fellow at the Interdisciplinary Research Institute on Ethics and Medical Humanities, Lugano, Switzerland. A version of this article was presented at the ASBH Spring 2009 meeting.

Chantal Marazia has a PhD in History of Science. She is presently research fellow at the Interdisciplinary Research Institute on Ethics and Medical Humanities, Lugano, Switzerland. A version of this article was presented at the ASBH Spring 2009 meeting.
Inequality as Killer App: The Gold Foundation’s Undermining of “Humanism in Medicine”

Shon Dasgupta

“The doctor’s experience of the world is as important to her caregiving as evidence is to her technical decisionmaking.”

—Arthur Kleinman

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, for 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. I fell into the same trap. In the essay I submitted to the Gold Foundation contest about Ya Patricia, an elderly Maya woman I met through my work in Guatemala, I wrote:

She spent the first forty years of her life in a contemporary form of debt slavery on a coffee plantation in rural Guatemala. When she passed, Ya Patricia began experiencing a mysterious constellation of symptoms. Rosa, a community health worker from the same hamlet, began examining her. Ya Patricia’s health began to fail, and her family watched in dread as she slowly proceeded to the graveyard.

Patricia was denied biomedicine’s “comfort measures”—transforming the indigent sick into “no-liners”—that is, invisible. 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 contest winners of the Gold essay competition, I retreated into a gesture of noble futility. Faced with our own real and potential existential limitations, 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 limbo, thereby misrecognizing the insurmountable and existential distances between patient and physician.

Of the three winning contestants, only second-place prize winner Michael Barnett acknowledged that individual dilemmas faced by his patients—and by himself—while healthcare provider—were condensed manifestations of abiding social and physical structures that condition and maintain the patient-provider chasm. As such, he describes the Gold Foundation prize as dehistorized, 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. It as Barnett amply 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 proponent 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 In*toxicated By My Illness (1992) was written makes it evident that this socially decontextualized quotation hails 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. 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 contest prompts to purposely elide a crucial aspect of Broyard’s experience of extreme deblation 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)
Inequality as Killer App (continued from previous page)

“inequality” is patently incommensurable with the natural reality of social relations. Indeed, the word “inequality” 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. “Inequality” marks 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 impressiveness” of their suffering makes on us on this line isn’t surprising. Barnett reflects on the transformation he himself undergoes when he leaves the hospital doors, but constructions of “humanism” like the Gold Foundation 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 stock of “one-liners” when we exit the doors of the hospital, 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 us believe, we are expected to leave behind the outrage and disregarded-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.

Shawn Des yapt a is a staff member of Wayne Keayung, S.A. (nangelkuma -wong.org), a bilateral NGO that provides first-language healthcare services to Maya communities in rural Guatemala. He is also an MA candidate at the Program in Medical Anthropology at Harvard University, and a MPH candidate at Feinberg School of Medicine, Northwestern University. shawndesyapata@gmail.com

2. http://humanism-in-medicine.org/cgi-bin/htmlos.cgi/
d68822d8388702352422956838
9. Georges Bataille, This is Em, trans. Peter Connor (San Francisco: City Lights Books, 1989).

BEDSIDE EROS (continued from page 15)

3. I explored whether this has any contribution to make to medicine or health in a recent essay that views the Greek god Aesculapius as representing an ancient tradition of health care (distinct from superstition or magic) that Enlightenment rationalism—in the name of the classical rationalist-doctor, Hippocrates—deliberately snuffed out. David B. Morris, “On-Forgotten Aesculapius: An Erotics of Illness, New LiteraryHistory, 38 (2007): 419-41. See also—as crucial to the discussion of loss and failure in medical contexts—Lisa Diedrich, Treatments: Language, Politics, and the Culture of Illness (Minneapolis: University of Minnesota Press, 2007), to which I am greatly indebted.
4. William Carlos Williams, “The Use of Force” (1938), rpt. in The Doctor Stories, compiled by Robert Cakes (New York, New Directions, 1984), 58. Subsequent quotations will be documented within the text.
9. Georges Bataille, This is Em, trans. Peter Connor (San Francisco: City Lights Books, 1989).
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 space: 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.

**The Clinic 2.0**

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