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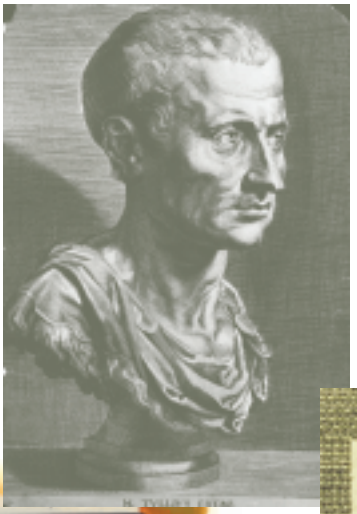
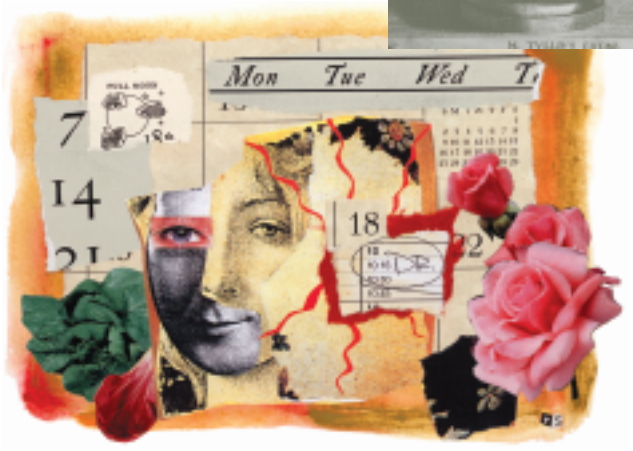
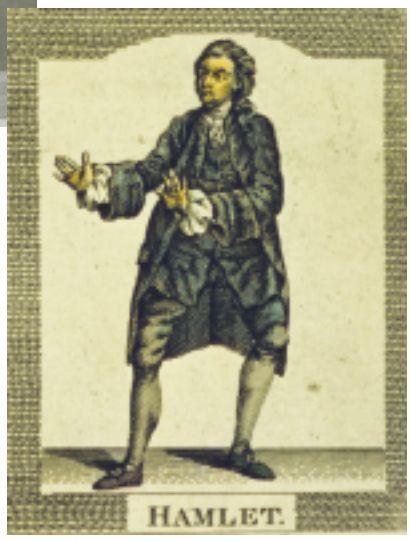
INAUGURAL ISSUE: PROCEEDINGS FROM THE DREW UNIVERSITY MEDICAL HUMANITIES SYMPOSIUM

Why Study Humanities?

Howard Brody, MD, PhD







Bioethics and Human Experience

Tod Chambers, PhD

Narrative and Healing, or Probing the Well-Dressed Wound

Catherine Belling, PhD

Public Health, Technology, and Culture

Jonathan Cohn

DREW UNIVERSITY

This inaugural issue of the
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Jo Ann Middleton, PhD

James H. Pain, D Phil

John R. Middleton, MD

Vision for the program in medical humanities . . .
teachers, colleagues, and friends.

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VOLUME 1, NUMBER 1 PREMIER ISSUE NOVEMBER 2008

An Inaugural Symposium: Bridging Health Care and Human Experience

From left to right: Richard Marfuggi, MD, DMH; Phyllis De Jesse, DMH, RN; Jo Ann Middleton, PhD; Nancy Gross, MA, Edye Lawler, PhD; Interim Dean, Rosemary McGee, MMH; Thomas Magnell, D Phil, Oxon; Leda Reeves, DMH; Philip Scibilia, PhD, DMH

The practice of medicine requires engagement with individuals and society. In this engagement, the science of medicine is applied as the art is revealed. This study of this art forms the discipline of medical humanities.

To explore the role of medical humanities on both the medical and human communities, Drew University hosted an inaugural symposium, *Bridging Health Care and Human Experience*, in November 2007. Lead by Dean James Pain and guided by faculty from Drew's Caspersen School of Graduate Studies, more than 100 scholars, professionals and students came together in a day-long dialogue that provided four unique perspectives: history, philosophy, narrative, and public policy.

Keynote speaker Howard Brody, MD, provided an overview of the study of humanities from Cicero to William Osler. Since the establishment of the first faculty of medical humanities at Penn State College of Medicine in 1967, Dr Brody said, the field has steadily grown in the United States and abroad, and described a variety of approaches used to define and examine it. "I believe that medical humanities today can make considerable contributions to medical student education. I also believe that we need well-educated humanist scholars to assume those faculty roles and to assist in a variety of different levels with this educational effort," Dr Brody said. "Ultimately, we must address the challenge of helping students to become wiser and more virtuous, socially just and socially aware."

A discourse on narrative, bioethics, and human experience was provided by philosopher Tod Chambers, PhD. Rather than the existence of a basic story of illness that is independent of the teller, Chambers proposed that narratives of illness are individual and evolving stories in which the teller is both actor and author. Illness is a call for stories, he said, a means of recreating a self-story as the teller attempts to weave illness into the narrative whole of his life.

Catherine Belling, PhD, further illustrated the importance of narrative with selections from Susan Mates' story, *Laundry*, and Shakespeare's *Hamlet*. "What does it mean to heal wounds?" Belling asked, as she used story to examine the educational process of creating a professional that renders doctors separate from other human beings, until the healer becomes dehumanized. In describing Hamlet as a tragic hero who is compelled to apply his critical capacities with therapeutic violence, Belling states, "Something is rotten in the state of Denmark and Hamlet has been called on to treat the infection. The time is out of joint, and Hamlet is chosen—was born, in fact—to set it right, to rearticulate the dislocated bones of his family and his government." The hero ruthlessly investigates then takes bold action, and in the aftermath, "it is Hamlet's apprehension of the complexity and contingency of all action…that makes possible the play's final and very conditional optimism about a future less corrupt and a healthier world. And perhaps in that stubborn struggle to find and make meaning lies the value of medical humanities," Belling concludes.

Author Jonathan Cohn concluded the program with the presentation of a more pragmatic approach. As a journalist, Cohn explained, he believes it is not possible to understand the world without talking to people. Statistics tell how many people are uninsured, how many die from medical errors, but statistics alone do not tell the whole story. Cohn's narratives about real people tell the larger story about the state of health care in America. In Cohn's view, setting public health care policy is less about dollars and cents than about making the ethical decisions that will affect the fabric of human lives.

–Kristen Georgi, MA/MAT

Drew University
Medical Humanities Program

When the Liberal Arts were identified in Classical Antiquity, Medicine played a vital role among them. Subsequently, the Medical Arts (along with Architecture and Theology) were banished from their midst. And, even today, when pre-medical and other health care curricula are normally included in the Liberal Arts colleges, the effects of that historic schism persist. The academic discipline of Medical Humanities is grounded in comprehensive scholarship that recognizes health care as an inseparable part of the broad spectrum of creative human discourse. This recovery of an antique perspective is definitely not antiquarian in character. It is in keeping with the most contemporary insights of both the arts and sciences.

However, developing comprehensive perspectives means that we must learn to know each other's words. We must come to understand a common language. We must explore our values and ethics. We must practice new interactions in the healing arts. We must study to keep both our objectivity and compassion alive. We must keep in view the urgency of our vocations.

This is an exciting and demanding field of education. Drew and Raritan Bay are proud to provide distinctive settings in which you may take an active part in that education. Our community of dedicated faculty welcomes qualified graduate colleagues on a dynamic quest for health care among the Humanities.

J. H. Pain, D Phil
Dean, 1992–2006

Medical Humanities Writer's Group

While pursuing their own graduate studies, three Drew University Medical Humanities students saw the need to create meaningful opportunities to come together for scholarly exploration and inquiry outside of the classroom. The trio proposed that such opportunities would provide themselves and other students with time and space to explore and present their particular academic interests, learn from each other, and strengthen their bonds as fellow practitioners of the Medical Humanities. The creation of a writer's group grew from this vision.

The Medical Humanities Writer's Group was established in the fall of 2005 as a place for graduate students to submit their evolving theses and dissertation manuscripts for peer review and mutual support. The group, which has met regularly during the past three academic years, has become a working committee, providing feedback and camaraderie during the usually isolating period of scholarly research and writing. All Medical Humanities students are welcome, including those involved in writing course research papers and literary endeavors in the field of Medical Humanities beyond the requirements of their studies at Drew. The Writer's Group takes pride in the many members who have successfully completed their papers and gone on to graduation.

The Group has also hosted numerous events to which faculty members were invited to make presentations concerning all aspects of the dissertation process from research methodology, to defense of the dissertation, to offering writing tips and personal reflections.

The Writer's Group further expanded its role by conceiving of, and implementing, the Drew Medical Humanities Symposium, Bridging Health and Human Experience. The Symposium brought recognized academicians and authors to the Drew campus for an exchange of ideas that explored the current and potential future effects of Medical Humanities on the community, health, and health care.

– Rosemary McGee, MMH

Why Study Humanities (Medical or Otherwise)?

Howard Brody, MD, PhD, Keynote Speaker
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Editorial assistance by Kristen Georgi, MA, MAT

Can we define the medical humanities without first defining humanities? How hard or how easy is that to do? Here is the definition on the Drew Web site: "Medical humanities, in its most basic connotation, deals with the intersection of human experience, medical practice, and scientific technology. The field transcends the disciplinary boundaries of academe and engages all aspects of human culture—science, history, ethics, philosophy, literature, religion, art—in a discursive dialogue centered on what medicine means in relation to the individual in society."

This is what I'll call the "list" definition of medical humanities, and until very recently I would have said, "Of course, that's the right definition." It stresses the interdisciplinary inquiry and methods. Basically, the humanities are defined by giving a list of disciplines that match the departments in a liberal arts college, and it's assumed that these illuminate certain important medical issues in a valuable way.

Are there any problems with that definition? Robert Proctor made the following observation in his important book on the humanities and modern academia, *Defining the Humanities.*[1] Around 1996, the presidents of many of the country's most selective liberal arts colleges hired a public relations firm to define liberal arts education—because they couldn't define it themselves. Needless to say, neither could the firm. Proctor's point is that the list approach cannot tell us what is either unique or important about that definition.

When I turned to the Web site of our program at the University of Texas Medical Branch, Galveston, I found a quite different approach. I'll call it the "historical transformative" definition. As the Web site goes on: "Becoming a medical humanist is not simply a matter of taking an array of interdisciplinary courses in the medical humanities . . . formal humanities knowledge and clinical competence must be personally integrated so that they become *humanistic* . . ."

"By humanistic we refer to knowledge (not necessarily in the humanities), clinical competence, or practice that is informed by the ancient ideal of *humanitatis.* The original meaning of the Latin word humanities was human feeling; the word gradually became associated with an educational ideal that blended knowledge, humane feeling, and compassionate action. It is this wonderful and elusive mixture of knowledge, feeling, and action . . . that we are trying to recapture and refigure in a contemporary health-care setting.

"The personal integration essential to humanistic knowledge is a fluid, holistic ideal that can occasionally be achieved and exemplified but cannot be taught directly or didactically. It is an ongoing personal and interpersonal process . . . the development of a medical humanities graduate student is a kind of moral career in itself—one that involves collaborative cultivation of a responsible engaged self who seeks his or her own unique blend of knowledge, feeling, and action . . . .

". . . Becoming a medical humanist—and striving for humanistic knowledge and competence—requires strong historical and conceptual grounding in the humanist educational ideal in the West. This effort to connect graduate education in the medical humanities with the humanist tradition is what makes our program unique."

This definition is different from just a list, and certainly meets Robert Proctor's criticism of the list because it tries to explain why these disciplines are unique and important, and is tied to the historical tradition. But it

also has problems. The definition talks about the moral career of the graduate student. What about the moral career of the physician or the nurse in the health profession?

To understand the historical tradition of the humanities, we have to go back to the 14th century, says Proctor, and look at the Renaissance humanities, or *studia humanitatis,* as particularly exemplified in the philosophy and teaching of Petrarch, the Italian poet. Petrarch got the idea from the 1st century Roman orator and philosopher Cicero, and particularly from the description in *Pro Archia.*[2]

With much help from the dictionary and existing translations, I will render this description of *studia humanitatis* as, "These studies nourish youth, delight old age, adorn prosperity, and offer refuge and solace in adversity. They delight at home and they do not embarrass one abroad. They accompany us overnight, as we travel, and into the countryside."

We seem now to have another definition. We have the "list" definition, the "historical transformative" definition to which the notion of "moral career" is related, and now it seems we have at least one other model or metaphor. What Cicero seems to be describing is the humanities as your best friend, the lifelong "boon companion" whom you can count on no matter what; in good times and bad, at home and away, wherever you are, whatever you're doing, whatever the fates throw at you, the humanities will be at your side and give you support, nourishment, and comfort.

Studia humanitatis: These studies nourish youth, delight old age, adorn prosperity, and offer refuge and solace in adversity.

What Cicero meant by the *studia humanitatis* was the study of all subjects that would shape the growth of the young toward humanity and virtue, as he said in *De Oratore.*[3] That included all subjects taught at that time: math and the sciences, as well as literature, the arts, rhetoric, and dialectic. But how did this teach one wisdom and virtue?

Here we might have to part company with Cicero, because Cicero was a stoic philosopher in the ancient Greek tradition who had a view of knowledge that most of us today would not share. He believed that real knowledge was knowledge of something eternal—the Platonic Forms—that inhabited the celestial world, the same sphere as the stars and planets. Our base world that we live in every day is inhabited by the emotions and passions with everything changing, so you can't have knowledge of them. You can only have knowledge of what is in the higher celestial world.

Cicero believed in a two-part person, where one part, what we might today call the soul, could inhabit the celestial world and have direct apperception of knowledge in that world. There was also the animal self that lived in the terrestrial, changing world where you find the passions and the emotions. The knowledge of the celestial world helped the soul transcend the animal self and thus be a better person.

So in the crudest possible form, the *studia humanitatis* will make a man of you. Given that the Roman root *"vir"* or "man," is the gender term, *"humanis"* is the nongender term and is very different. "*Vir*" is the root word for *"virtus,"* which is virtue. Cicero's idea of how you obtained wisdom and virtue was that by having knowledge of the eternal realm, you would transcend and rise above your animal self, your emotions, and your passions.

Petrarch agreed with Cicero that we were still searching for wisdom and virtue via the *studia humanitatis,* and still held a hope of gaining mastery over our turbulent emotions and desires. But he added a few things that were not present in the ancient Roman world. He had a negative program as well as a positive program, and he offered a different set of disciplines as his recipe for how the young should be educated toward wisdom and virtue.

The negative program had to do with his view of the scholastic university of medieval times. According to Proctor, Petrarch was disdainful of this medieval university with its scholastic theology and the debased form of medieval Latin that was then in use. He argued that methods had driven out content; that cunning and cleverness had replaced the search for virtue and wisdom in that institution. His reform program was to return to the original Greek and Roman texts for several reasons. The first was to appreciate the lives and work of the ancients as exemplars of wisdom and virtue. Cicero was a particularly good subject for this. The other reason was to be able to think and write clearly and elegantly in pure classical Latin, which Petrarch was sure was much more ennobling than medieval Latin.

Petrarch also had little use for some of the most popular subjects in the scholastic, medieval university. He recommended that the studies should focus on literature, poetry, history, moral philosophy, and ancient languages. History is an interesting addition to this list. In the days of the scholastics, as in the days of Cicero, history was about what changes, and knowledge could only be about what was eternal. So knowledge of history was an oxymoron in the scholastic time as in ancient Rome. In contrast, Petrarch thought that studying the subjects of the scholastic university, such as science, math, law, metaphysics, and logic, would pollute the mind.

Is Petrarch's prescription basically a way to retreat from the world into a monastic, scholarly life, or is it a way of actively engaging in the world? And does this have anything to do with today's medical humanities?

Italy, in Petrarch's time, was seeing the rise of the mercantile and business classes, many of whose members were involved in civic affairs. The world was full of change and novelty. Ships were going to Africa and Asia, and eventually to the New World, and bringing back tales of things that were not part of anyone's prior knowledge of the world. As the old feudal order broke down,

effective, persuasive verbal or written communication became the most important social glue. A verbal contract, or article of incorporation, was starting to become the way society was organized and held together. Therefore, the importance of rhetoric, particularly as a subject of study, matched the needs of the practical world in which Petrarch's students found themselves. We are not talking about what today we call "mere" rhetoric, where I persuade you to do something against your better judgment with smoke and mirrors and verbal flimflam. What was meant by rhetoric, in the ideal sense, was a mix of reason, logic, and artistry, so that one both finds out what is right and is moved to do what is right.

In order to persuade others on whatever the subject, the Renaissance rhetorician needed to know all subjects. He couldn't avoid logic or metaphysics or science, because he never knew what might come up in a discourse or the dialogue that might ultimately persuade his audience about the right thing to do in a particular situation. So there was something very interdisciplinary and very wide-ranging in the knowledge base of the Renaissance humanist rhetorician.

In his essay, *The Culture of Renaissance Humanism,*[4] historian William Bouwsma traced what happened to Petrarch's ideal as we moved from the early to the late Renaissance. In his view, Petrarch's reform program actually carried the seeds of its own destruction. The contradiction that Bouwsma diagnosed in the Petrarchian tradition was that by showing how different pure classical Latin was from medieval Latin, for the first time the world became aware of the idea that Latin was a dead language. Ironically, in trying to bring classical Latin alive, in some sense Petrarch killed it.

The medieval scholars were able to say, "Ancient Romans spoke Latin. We speak Latin. Therefore, we speak the same language." But once they started studying classical Latin carefully and saw how different classical Latin was from the medieval version, they could no longer say they spoke the same language. Suddenly, classical Latin became a dead language, in contrast with the Latin that was actually used in the churches, law courts, and institutions of the time.

Along with this realization came the creation of the sense of self as "modern." According to Bouwsma, the Renaissance people for the first time thought of themselves as modern and different from the people of the ancient world. Because classicism seemed to belong more to the ancient than to the modern world, adherence to that aspect of Petrarch's program would risk condemning humanism to a sterile intellectuality and a disengagement from the issues of practical life. As people tried to study exactly how to decline the Roman nouns and conjugate the Latin verbs, they would inevitably be drawn away from the affairs of the world of the day. Within two generations, Renaissance humanism had come to resemble the scholastic curriculum against which Petrarch had rebelled. It was a question of too much focus on scholarly methods and rigor, and not enough on content.

Let's ignore the ancient humanities for a while and turn to a more modern subject. We can go back to the end of the 19th century and look at the work of Sir William Osler, arguably the greatest physician of his day and the first professor of medicine at Johns Hopkins University, which was thought to be the model for what a modern medical school should be. He was the last person to have the nerve to write a comprehensive single-author textbook of medicine—and it was a good one. He also reintroduced the tradition of teaching medicine at the bedside.

Osler taught medical students to carefully correlate what they saw of the living patient, what they could observe in the laboratory, and the changes they saw in the patient's body in the autopsy room. Widely viewed in his day as very compassionate toward patients, he was idolized by his students, and was seen as the ideal exemplar of the humanistic physician. A typical workday for Osler as described in Michael Bliss' recent biography, *William Osler: A Life in Medicine*,[5] included long hours at the hospital doing rounds, teaching, writing, reading journals, and working in the hospital or clinic. In the evening he would often invite his students and other faculty to his house to talk about medical topics. Before going to bed, he would read widely from the classics; his essays and orations were liberally sprinkled with quotations from these great works. If we look at our three definitions, Osler exemplified the boon companion model more than the other models, and even characterized that one passage of the *studia humanitas,* "haec studia . . . pernoctant nobiscum . . . ," or "they spend the night with us." Just before bed was when he wanted to read his favorite books—his friends.

The Oslerian model is amazingly alive today. Many people still view this as an important model for humanities, humanism, and medicine.

Why is this important? Because the Oslerian model is amazingly alive today in American medicine. In fact, the American Osler Society attracts a great deal of support because many people still view this as an important model for humanities, humanism, and medicine.

What about more recent history? Since the 1930s, reports have been written about the medical school curriculum. In the 1930s, learned medical educators got together, looked at the curriculum, and said, "There is too much science and not enough humanism." In the 1940s, another learned group of medical educators looked at the curriculum and said, "There is too much science and not enough humanism." And in the 1950s, a group of wise educators said, "There is too much science . . . ," and so on. The same report is written every 10 years. And every time one of these reports comes out, there is a half-hearted, short-lived

attempt to reinject humanism into the curriculum.

In the 1960s, one of these efforts involved Ministers in Medical Education, a small active group of ministers and religious scholars who were working in American medical schools. Their efforts led to the formation of the Society for Health and Human Values, which merged with two other bioethics organizations in 1988 to become today's American Society for Bioethics and Humanities. It is reasonable to assume that they saw their agenda as helping medical students to become wiser and more virtuous.

At about the same time, Penn State University created a new medical school at Hershey and established the first department of medical humanities. The model they chose followed the list definition. They hired a philosopher, a literature scholar, a religious studies scholar, and a historian, and said, "Go forth to the medical students and teach wisdom and virtue." But the faculty said, "We can't do that. The students would say, 'Who are you to teach us wisdom and virtue?' And besides, some of our colleagues in liberal arts, in humanities, are good folks, and some are not such good folks. But the fact is, we are no more wise or virtuous than the people in the math department. So why are you saying we should teach wisdom and virtue? We can teach history and literature and ethics. We can even do it in a way that is interdisciplinary. But we can't teach wisdom and virtue."

We can teach history and literature and ethics. We can even do it in a way that is interdisciplinary. But we can't teach wisdom and virtue.

Is there a danger that this model of the new humanities department will recreate some of the self-destructive features of Renaissance humanism? Some people today think that is what is happening, at least at the edges. In bioethics, for example, we focus on narrower and narrower issues. We have people now who specialize in neuro-ethics, and we have people who are solely interested in ethical issues in nanotechnology. We have more discussions of methods endless debates around principlism and narrative in medical ethics. There does seem to be some worry that cleverness and methodologic rigor will get in the way of content when it comes to at least some areas of the medical humanities.

Yet, there has been a steady increase in the humanities faculty in U.S. medical schools since the Hershey department was created in 1967. This past year actually seems like a bumper year for new jobs in medical humanities. There has been a slow but steady dispersion of the movement to other countries. If you look at the various efforts to reinject or to somehow resuscitate humanities in medicine, it is apparent that the medical humanities movement has been much longer-lived and more successful than most.

What about measurable outcomes in the medical curriculum and among our health professionals? There is little, if any, solid proof that teaching humanities to medical students produces better physicians. However, there also is no solid proof that teaching biochemistry to medical students produces better physicians. The simple fact is that a great deal of the modern medical curriculum is taken on faith. There is no solid knowledge that it actually makes better doctors. To have that knowledge, we'd have to be willing to have a control group. No medical school in the country would be allowed to have a control group that didn't learn biochemistry, and so we don't know. We're all in the same boat. We're no worse off than the other disciplines that are taught in the medical schools.

I believe that medical humanities today can make considerable contributions to medical student education. I also believe that we need well-educated humanist scholars to assume those faculty roles and to assist in a variety of different levels with this educational effort. Ultimately, we must address the challenge of helping students to become wiser and more virtuous. We cannot shirk that duty. And I would expand beyond wise and virtuous to socially just and socially aware.

I don't know that just reading ancient Greek and Latin in the original will make us wiser and more virtuous. I don't know that it will help us to be socially just and socially aware. I think we need another prescription for what is desperately needed today among physicians, nurses, and other health practitioners. We also must be aware of the competing historical traditions and ambiguity of the humanities, the narrative of this field, and how it relates to what we're doing today. Otherwise, we will just be repeating history.

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Bioethics and Human Experience

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The dominant way in which the medical humanities have contributed to applied ethics has been through the use of narrative, in general, and the notion of the life story, in particular. Rather than simply valorizing the narrative approach to medical ethics, I would like to point to some substantial theoretical problems that I think need to be addressed.

Let me begin with a prosaic example—the recounting of a story of a movie. For someone trying to find details about movies, the Internet Movie Database (IMDB) is an exceptional resource. At this Web site, one can find a film's full cast and crew, trivia, trailers, photo gallery, and writing credits. One can also find plot summaries. Interestingly, some films have more than one plot summary, for IMDB—in a manner typical of the anti-authoritarian leanings of the Internet—permits anyone to add a plot summary to a film's listing.

Look, for example, at two plot summaries for the film *Eternal Sunshine of the Spotless Mind.* One summary says, "A man awakes disheveled. Impulsively, he skips work, heading instead to the shore. On this chilly February day, a woman in orange, hair dyed blue, chats him up. She's Clementine. He's Joel, shy and sad. By day's end, he likes her. The next night, she takes him to the frozen Charles River. As he drops her off, she asks to sleep at his place, and she runs up to get her toothbrush. Strange things occur. Their meeting was not entirely by chance, and they have a history neither remembers. Our seeing how Lacuna came to be and their discovery of the memory loss take the rest of the film."

Here is another plot summary. "This is a story of a guy, Joel, who discovers that his longtime girlfriend, Clementine, has undergone a psychiatrist's experimental procedure in which all of her memory of Joel is removed, after the couple has tried for years to get their relationship working fluidly. Frustrated by the idea of still being in love with a woman who doesn't remember their time together, Joel agrees to undergo the procedure as well, to erase his memories of Clementine. The film, which takes place mostly within Joel's mind, follows his memories of Clementine backwards in time as each recent memory is replaced and the procedure then goes on to the previous one, which is likewise seen and then erased. Once the process starts, however, Joel realizes he doesn't really want to forget Clementine, so he starts smuggling her away into parts of his memory where she doesn't belong, which alters other things about his memory as well."

These two summaries are quite different. Although some overlap exists in characters and the themes of romantic relationship and memory loss, each of the authors relates the story in a distinct way. Such divergences have been accounted for by narrative theorists as having their origin in the differences between the basic story material, or what the Russian formalists referred to as *fabula,* and the particular presentational mode used within a specific narration, or *sjuzet.*

For narrative theorists, this distinction is particularly important when analyzing narratives that rely on their rhetorical effect by playing with the time sequence, as does the film *Eternal Sunshine of the Spotless Mind.* Thus, from a traditional narratological perspective, both tellings share an essential *fabula* and the deviations are simply the result of having different *sjuzets*.

Narrative theorist Wallace Martin notes that while conceptually such a distinction permits one to talk about the narratological rhetoric of a particular telling, it

"is achieved at a certain price: it implies that what the narrator is really telling is a chronological story—one that the reader tries to reconstruct in the right temporal order—and that the elements of narration are deviations from a simple tale that existed beforehand."[1]

This criticism of narrative theory has been most seriously presented by Barbara Herrnstein Smith. In her often cited essay "Narrative Versions, Narrative Theories," she notes that, "a lingering strain of naive Platonism" has been an ongoing feature of contemporary narrative theory.[2]

Such distinctions between *fabula* and *sjuzet* encompass a belief that there is a "basic story" or a "deep structure" that is "independent of any of its versions, independent of any surface manifestation or expression in any material form, mode, or medium—and thus presumably also independent of any teller or occasion of telling and therefore of any human purposes, perception, actions, or interactions."[2] In short, there exists somewhere a versionless version.

In order to naturalize narrative ethics, one must attend not to stories, but to storytelling.

Yet, Smith counters, the attempt by narrative theorists to find the deep structure of fairy tales is itself a fairy tale. She looks, for example, at the supposed unity of the various versions that have been cited for the story of Cinderella, which were at one time catalogued as having 345 variants.

The "basic story" of the narrative theorist is not so much a master narrative as it is a particular telling that is conditioned by the purpose of relating the narrative. Smith is not saying that there is no association between one story and another, but rather that there is little evidence to believe that there is some *fabula*, some basic narrative structure that exists outside of particular tellings.

It is my contention that in order to naturalize narrative medical ethics, one must attend not to stories, but to storytelling. That is, one must understand that stories do not exist to be "found," but are continually engaged in rhetorical work.

In *After Virtue: A Study in Moral Theory*, moral philosopher Alasdair MacIntyre argues that one of the essential qualities of the human animal to function as an agent is the ability to see oneself within a story.[3] Lacking the ability to construct such a narrative leaves one unable to make sense of one's actions as well those around one, so MacIntyre comes to conclude that the human agent is "not only an actor, but an author."[3]

The most important authoring that we can do is to be able to understand our life as functioning within a narrative whole. It is only with a narrative sense of the self—that is, one that maintains some degree of cohesion over time—that the self can be considered accountable for actions in the world.

Margaret Urban Walker, a philosopher and ethical theorist, points out that, "Narrative understanding of the moral construction (and reconstruction) of lives is central to understanding how responsibilities are kept coherent and sustainable over substantial stretches of life that, in important—but not imperial—ways, remain people's own."[4]

Lacking a life story, one would have what philosopher Charles Taylor refers to as the "punctual self," a person who has the ability of self-consciousness, but nothing else.[5] This Lockean notion of the self lacks a narrative sense of being in time and, thus, oriented to some good. A narrative self for Taylor permits an orientation within moral space that is analogous to our ability to be oriented in physical space. "We determine what we are by what we have become, by the story of how we got there."[5]

Although Walker is drawn to the utility of narrative in moral understanding, she finds the notion of "dominant identities" as simply too all-inclusive to represent accurately our moral lives. "There are . . . reasons not to assume that such story lines are, can be, or should be global or largely unified or strictly continuous. Can one imagine a totally or maximally unified life?"[4] Such a notion Walker finds to be either "desperately simple or intolerably suffocating."[4]

As the use of the personal narrative was translated from moral philosophy to the applied arena of medical ethics, the particular type of personal narrative shifted from a concern with the autobiography to the third-person genre of the biography. For the moral philosopher, the autobiography becomes a genre tool for responding to the questions, "What is the good? What narrative am I a part of? How should I live my life?" For medical ethicists, the question is not inward toward understanding personal authenticity, but rather outward in a more Levinasean manner toward authentically responding to the needs of another. The moral philosopher asks, "What is my story?" The medical ethicist asks, "What is this person's story?"

In 1990, the journal *Second Opinion* began a new series called "Case Stories." The editors of the series, Steven Miles and Kathryn Montgomery, began by noting that because "human understanding is grounded in narrative, ethics has always been in some sense a storytelling enterprise."[6] In a later discussion of these issues, Miles and Montgomery focus on storytelling as "the substance of communication within families and between friends, lovers, doctors, and patients. Telling, hearing, and interpretively retelling stories is how people come to understand themselves and each other and appreciate their duties to one another."[7]

The first case that they selected concerned a woman who died alone in a hospital. Miles begins his description by revealing his source.

"This is not a proper biography. I did not know Margaret Hull. I talked to no one who knew her, except for the brief professional contacts on the day of her death. I found her story by extracting data from the medical record. Her 'chart' took up six thick binders

describing 14 hospitalizations, 73 clinic visits, 21 emergency room visits, and innumerable laboratory reports and administrative procedures."

The lengthy collection of notes does not narrate a story. An astute medical student is the only person to record the notable onset of a potentially life-threatening cardiac arrhythmia seven years after the fact. A nurse notes the patient's fear the night before cancer surgery. These are recorded as data, not as human history. These moments suggest the outline of a coherent story. That Margaret Hull's story was lost at the medicalized end of her life shows how alienated medical conceptions of our duties to others have become.[6]

As Miles himself admits, there are no instances of storytelling from which he gains Hull's narrative. The data for his analysis come from the chart notes, which do not narrate a story. But there remains in Miles' account a belief in the existence of a particular story, a particular biography of Margaret Hull that has been lost by medicine.

Miles envisions that, like the narrative theorist's *fabula*, all these fragments are part of a disembodied story that lies in wait for his discovery. Miles is the teller, but also, from his perspective, the story he tells is simply the story he finds. In the end, we see from Montgomery's final discussion of their narrative ethics project that it is not storytelling that interests them or guides more reflection as much as it is a belief in a patient's life story.

Montgomery argues that our identity is itself the life story. She seems attentive to the way someone's story will be a particular interpretation of the events of his or her life, and this includes the moral problem that brings the person to the attention of an ethicist. Yet there lingers within her view a belief that there is a story to be found.

Returning to MacIntyre, we find that narrative exists outside of human construction. "Narrative is not the work of poets, dramatists, and novelists reflecting upon events which had no narrative order before one was imposed by the singer or the writer; narrative form is neither disguise nor decoration."[3] In her discussion of MacIntyre's approach, Hilde Lindemann Nelson argues that MacIntyre fundamentally misunderstands what a story is. That is, it is constructed "by selecting incidents and themes from the minutiae of our existence and explaining their importance by how we represent them in narrative form. Autobiography, then, isn't life."[8]

And neither is biography. MacIntyre is aware that there can be opposition to his position, and he quotes Louis Mink: "Stories are not lived but told. Lives have no beginnings, middles, or ends; there are meetings but the start of an affair belongs to the story we tell ourselves later, and there are partings, but final partings only in the story."[3]

MacIntyre responds by noting that the fact that there is death demonstrates that life naturally has a narrative ending. It is difficult, however, to see the event of the end of life as being the same thing as the end of a narrative. MacIntyre has an even more difficult time justifying how life has genres outside of a particular telling.

But within conventional storytelling activities, are the genres of biographies and autobiographies natural forms of storytelling? I'm using "natural" here not in opposition to unnatural storytelling, but rather as the social linguist William Labov and the narratologist Monika Fludernik use it—that is, in opposition to storytelling that is nonspontaneous, highly framed, and stylized. Fludernik observes that, "It is from this angle that some cognitive parameters can be regarded as 'natural' in the sense of 'naturally occurring' or constitutive of prototypical human experience."[9]

Although it may seem that natural narratives encompass all forms of oral storytelling, Fludernik confines the notion to spontaneous, conversational storytelling, which is distinct from formal oral telling genres such as folk tales and oral poetry. These oral genres "constitute a more literary (i.e., institutionalized) form of storytelling," and thus, they depend on "different kinds of competence and performance levels from those sufficient for everyday spontaneous conversation."[9]

Fludernik identifies three genres of natural narratives: experiential conversational storytelling, narrative report, and anecdotes, as well as three nonspontaneous types: folkloristic oral storytelling, epic poetry, and life story. The fact that she categorized life story as an institutionalized form of narrative and, thus, one that is not a natural form should be of particular interest to those who wish to use narrative in the analysis of moral issues.

> The moral philosopher asks, "What is my story?" The medical ethicist asks, "What is this person's story?"

Fludernik begins her discussion of the life story by noting that it can occur during "spontaneous conversation."[9] But her Norman Rockwell–like parenthetical example, which is, "Granny, I've always wanted to ask what happened to you during the war," is something I never said to my grandmother. It is clearly not an example of autobiography, but instead a type of memoir. Even in instances in which the life story is told in a very distinct institutionalized form as, for instance, the common activity in Alcoholics Anonymous of telling one's story, it is the experience of recovery that becomes the fulcrum that gives structure to the storytelling event.

Fludernik notes that the most common form of life story genre occurs in the very nonspontaneous genre of the ethnographic field worker trying to collect oral histories. Fludernik admits that, "The life story obviously is no complete autobiography. Very rarely, indeed, is there a situation in which people will be led to narrate their entire life from their birth to the present moment."[9] Instead, it is

the academic who creates a genre that in some manner pretends to be an example of a spontaneous storytelling genre.

Although many people may keep journals or diaries, I doubt many people write autobiographies without an intended audience outside of the self. In other words, life stories should be viewed as performative events that always involve an act of communication between people.

Naturalized narrative ethics must not simply attend to the story, but most also ask questions concerning the relationship between the narrative event and the narrated event.

In *The Wounded Storyteller: Body, Illness and Ethics,* Arthur Frank comes closest to analyzing a natural narrative of medical ethics.[10] Frank has been critical of how bioethicists, including those interested in attending to narrative, continually attend primarily to the stories of health care professionals rather than to patients. We have an ethical obligation, according to Frank, to listen to these illness stories. Frank sees illness itself as a call for stories. He means this in two ways. First, becoming ill demands that one recreate one's self-story, which can be profoundly damaged by the onset of the illness. Second, an ill person is literally asked to engage in storytelling to people around him or her. "Stories of the illness have to be told to medical workers, health bureaucrats, employers and work associates, family and friends. Whether ill people want to tell stories or not, illness calls for stories."[10] Frank recalls how, when he had an abnormal chest X-ray, he had to on one day tell a version of his illness story eight times.[10]

Frank's analysis focuses primarily on institutionalized storytelling of the memoir and the autobiography, which tend to be sites for narrative self-repair, rather than for natural storytelling events. Yet Frank is keenly attuned to the performative dimensions of storytelling. This can be seen in his notion of a narrative ethic that focuses on "thinking with stories," which entails, "allowing one's own thoughts to adopt the story's imminent logic of causality, its temporality, and its narrative tensions."[10] For Frank, this process "requires attending to how a story is used on several different occasions of its telling."[10] Stories are not merely told, but retold. And, in a Heraclitus-like manner, one never tells the same story twice.

A natural narrative ethic attends to the use of stories as a rhetorical tool, rather than simply as part of a general life story. In order to reveal the rhetorical features of storytelling within medical ethics, one must attend to such questions as, "What is the point of telling the story?" One must guard against the desire to create a single unitary narrative out of the storytelling performances, and, instead, keep the storytelling grounded in its rhetorical situation.

Medical ethicists who are interested in using a narrative approach tend to try to combine all the small natural narratives into a single master narrative. They tend to see the true narrative as simply lying "out there" waiting to be found and collected, rather than as entangled within social events. Naturalized narrative ethics must not simply attend to the story, but must also ask questions concerning the relationship between the narrative event and the narrated event—that is, reveal the rhetoric of the telling. Who told the story? When was the story told? Where was it told? What was the conversational frame in which the story was evoked? To whom was it told? What was the teller trying to do with the story? Has the story been told before? Does the story relate to other storytelling events?

By answering these questions, we begin to thwart any attempt at the construction of a single narrative. Instead, we keep the stories embedded in the ongoing social life of the people involved in the medical decision. It forces us to attend to the way stories are naturally evoked in medical ethics decisions.

These questions demand that we attend to the power struggles within the decision-making. When medical ethicists construct the patient story, they are themselves simply another part of this ongoing exchange of stories, for they are also engaging in a rhetorical move that attempts through a storytelling performance to alter the shape of the decision. It is only by moving from a concern with stories to an integration of storytelling that we can naturalize narrative medical ethics and thus bring it closer to human experience.

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Narrative and Healing, or Probing the Well-Dressed Wound

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Before healing, there are wounds. I begin with two metaphorical wounds. The first is described by a pregnant physician. "I cried there right in the middle of the hall with my white coat split down the middle and my belly sticking out... The surgeon came up to me,... and he ignored the tears and the belly and the baby kicking, so unprofessional...."

The second wound is described by a metaphorical physician, a Danish prince and a would-be avenger. He has diagnosed, and is trying to treat, his mother's hypocrisy. Her wound has closed prematurely: "Lay not that flattering unction to your soul," says Hamlet. "It will but skin and film the ulcerous place / Whilst rank corruption, mining all within / Infects unseen."

In each case, I'll show how the wound—and its narrative treatment—concerns the identity of a would-be healer. I want us to think about what it means to heal wounds, especially metaphorical ones, and to ask whether it should be the work of the humanities scholar to be a metaphorical doctor, offering therapeutic narratives to heal patients and doctors—and modern medicine. Or, if not, then what is it that we can offer?

My topic raises two challenges concerning the work of humanities scholars in medicine. First, the assumption that narrative *per se* is what we do, and that narrative is intrinsically a good thing, making better doctors, healing patients, and so on. And second: the meaning of the word "humanities" in the context of medicine has come to be linked, imprecisely, with a whole cluster of cognates—in particular, words like humanism, humaneness, and humanitarianism—and these words have been used as synonyms for metaphorical (and sometimes literal) healing.

Let's look at some words. Let's look "at" them, rather than using them to look at something else, which is what tends to be done—quite sensibly and usefully—in most other disciplines. I was given three words for my title: Narrative; And; and Healing.

Narrative. The term as it's used in the medical humanities, or in narrative medicine, is often not very clearly defined. One of the problems with the so-called "narrative turn" that has dominated a great deal of interdisciplinary thinking of late is that we have come to see narrative everywhere, forgetting perhaps that while "narrative" is a way of knowing, it does not describe all that is known. Not all language is narrative. Not all stories are narrated. A person's life is not a narrative. The narrative happens when the life is represented, its events recounted. Narrative is text (spoken or written) and always a construct, with some things chosen for inclusion and the vast majority—of possible words, events, impressions, and so on—left out. A narrative is an artifact.

As a way of knowing, "narrative" is also specific and usually individualistic. A narrator recounts particular events happening to particular characters in a particular setting. Narrative resists generalization, and it resists reduction to principles or precepts or probabilities. So how is it useful to medicine? As Kathryn Montgomery, director of the Medical Humanities & Bioethics program at Northwestern, has shown, medical knowledge is inherently narrative in structure. In the individual clinical interchange, the patient recounts a story, which the physician interprets, translates, and retells to the patient. Patients often describe their illness—to themselves as well as to others—in narrative terms, and, hence, experience both the illness and its treatment as subject to the rules of narrative.

Illness may mean that something has gone wrong with the plot. The ill person may think, "In this story I am the hero." Or, "My character isn't meant to be the one in a hospital bed." Or, "My story doesn't end before my children are grown up." Or simply, "This part doesn't make sense."

To this extent, "healing" (the next word in my title) may be understood as restoring integrity—wholeness. The doctor's role can be to collaborate in this process of integration. This is valuable in that it reminds the doctor that patients are imaginative beings as well as bodies, and that meaning imbues all illness or injury.

But beyond this framework for understanding the patient as a whole person, is there more that medical humanities—particularly literary studies—can contribute? This leads to the smallest word in my title, "and." Can it do more than suture the idea of stories to that of whole persons (which characters in narratives by definition are not)?

I worry about our imposing a benevolent but premature closure on the rather jagged edges where narrative and healing—or literature and medicine—touch. I want to suggest that the role of the humanities is to provide incisive, pointed and, sometimes, aggressive reading of narrative (and other representational texts that have come to be included under the term). The sharp and prickly adjectives are deliberate. It seems that medical humanities should work by deferring premature closure, by probing wounds, or by lancing boils. Our procedures may be painful, are always aesthetic rather than anesthetic, and may cause messy results. Critical procedures are invasive. Can they also promote healing?

> Illness may mean that something has gone wrong with the plot.

Let's return to the first of my wounded healers. Dr. Martin is the protagonist and narrator of a short story called "Laundry" by Susan Mates,[1] who is also a physician. We know the character is called "Dr. Martin" because she points to the name tag on her white coat that says so. She doesn't tell us the rest of her name.

In this passage, Dr. Martin has just refused—or failed, depending on your point of view—to persuade Mr. Dantio, a terminally ill cancer patient, to consent to a lung biopsy. First she tells him that "some studies show" that the procedure might enable them to lengthen his life a little. He asks her to "Tell me what you would do," and after a struggle she gives in: "Don't let them do it to you," she says and then bursts into tears.

". . . I couldn't stop the tears," she says. "I kissed you [she addresses her narration to her now-dead patient] and waddled out of the room and stood around the corner so your wife couldn't see me and I cried there right in the middle of the hall with my white coat split down the middle and my belly sticking out, the baby writhing like a snake making ripples in my navy-blue maternity dress with the little red bow on top."

Her white coat dressing cannot contain the leakage Mr. Dantio has provoked by calling forth her personal self, with its red bow. She continues:

"The surgeon came up to me, a young man, younger than me, so energetic and clean-shaven and he said did you talk him into it? and he ignored the tears and the belly and the baby kicking so unprofessional and I said no.

"No! he shouted at me and I said I know as a doctor I should have said do it but as a person I felt no no no and he looked at me and stared at me and finally said there is no difference between how I feel as a doctor and as a person . . ."

We have two doctors here. The surgeon, as he presents himself, is fully integrated. He is directed, sure of himself, unambivalent . . . and he is clean-shaven. Not hairy. His body is under control, just as his personal life maps neatly onto his professional one. As she observes a little later, "His clean white coat [is] buttoned down his flat front."

Our narrator is not buttoned down. Her body is not under control, and her identity as a person is in clear and explicit conflict with her identity as a physician. So clear that we can actually see the one bursting out of the confines of the other: the tears leak out of her face, and her white coat is "split down the middle." She has a significant wound in the fabric of her being as a doctor. Does she need to be healed? Why is it that the story seems to suggest instead that the surgeon needs to be wounded?

I believe this story is not just about women doctors, although it can obviously be read as such. There's more. Mates presents the doctor's body—or rather her person—a complete, materially present, psychosomatic entity—as overflowing the limits set by her professional role. To read the story as only about gender diminishes its meaning.

It is also about professionalism. Professionalism has recently become a significant focus in medical education, often as a catchall phrase for efforts to restore to medicine something that seems to be missing. Oddly, this seems to have led to shifts in the meaning of the word itself. The professional used to mean the opposite of the personal—as it does in Mates' story, where the doctor and the person are split apart. Yet current efforts seem to be trying to make professionalism do the work of restoring the personal to a profession that has become overly focused on surviving the impact of mega corporations, bottom lines, and a healthcare delivery system that seems at times designed to breed cynicism in practitioners. A "professional behavior" curricular competency includes the expectation that students learn to "deliver appropriate care regardless of patients' personal characteristics." To be professional is to submerge the personal. To be professional is to be fair, neutral, equitable—disinterested. That's why doctors don't treat their own families. Yet what if we ask what "appropriate care" means? What is dictated by the studies or what the doctor's interested, imaginative, personal engagement with the individual patient as a person leads her, sometimes in tears, to recommend? What kind of education can help doctors resolve this ambiguity?

The term "narrative professionalism" was coined by Coulehan in *Academic Medicine* to describe the use of stories about good doctors to inoculate medical students against the dehumanizing effects of their training.[2]

How would we choose stories for narrative professionalism? Does Mates' story offer this inoculation? She presents the biopsy option to her patient in two voices. As a doctor, Dr. Martin offers calculations based on statistics: the studies. The knowledge she offers is formalized and generalized. Science knowledge. As it should be.

But then, as a person, she finds herself imagining what it'll be like for him, a specific person: "I thought of you lying in the ICU with tubes in your mouth and arms . . . nurses ripping the sheet off . . . your eyes are like mirrors . . . your heart keeps going" and so on. She says what she thinks will lead to a happier ending: "Don't let them do it."

Is the personal better? She's honest, but she may be wrong. What evidence leads to the particular scenario she imagines for Mr. Dantio? What is the reader to make of this? Remember, it's a narrative, and a fiction—a made up thing. The author could have given Mr. Dantio a peaceful, dignified death, had she wanted to.

How does the story end? Endings are the most powerful way that stories impose order on the endless chaos of reality. The ending ties things up, provides closure. Is closure the same as healing? We want the story's ending to be happy, I think. Yet we're also pleased that it's not a simple, too-neat ending because that would be less plausible. Mr Dantio dies, and not well. The physician is still dubious about her role. The ending is messy. She is still folding newly laundered diapers. The baby cries, she picks him up to breastfeed. Milk leaks. "We're drenched, he and I, in a fecund shower." This messiness is positive, surely? It's a fertile mess: breast milk meaning love, nurturing, the kind of things we dream our doctors will do. Mother us, make it all better.

And maybe we also see a kind of closure that is often offered as comfort in the face of death: the neatly seamless and infinite circle of life. Dead Mr. Dantio, new baby, doctor-mother joining them both in a tear-stained milky embrace. We can do this.

Perhaps the story is itself doing the laundry, washing out the dirty diapers, folding them neatly, dressing the wound (with a small red bow?), trying to make us feel we have some kind of control? The sense of an ending is what makes a story make meaning—and making meaning is finally what stories are for. The ending needn't be happy, but it should create the temporary illusion that the world is orderly and meaningful. Stories should provide the illusion of healing.

Because oddly enough, a "whole story"—made whole, all loose ends neatly knotted up—is by definition never the whole story.

A trained reader must begin by seeing the illusion for what it is. A splendid creation, an image of life and the world that is better than life and the world. The trained reader, suspicious of the seamless, then asks how it's done. And then we ask what it does outside of the story, or we might apply some of the same splendid creating in life, in the clinic, if we can do so without simply leaning on comfortable self-delusion.

There's a third identity in "Laundry." Dr. Martin also wishes she could simply cure her patient. She says: "I want to be the hero." Not healer, but curer. All doctors want superpowers. But the word "hero" also works in a more complex literary form than Marvel comic books, and I want to shift to an altogether different kind of professionalism, in a fiction text less literally relevant to medical training.

Now on to *Hamlet.* Here the identity of healer is both figurative and yet absolute, a kind of ideal of professionalism, where personal identity and vocation, task, or purpose in life are inseparable. This is in the always-fictional, always-constructed, role of tragic hero. The King of Denmark is dead and his brother has taken both his throne and his queen. The prince has to figure out his own role in the play. Called on to avenge his father's murder, Hamlet struggles with the role of revenger, the role of tragic hero, and, importantly to us here, the role of metaphorical physician (or to be more historically precise, of surgeon and anatomist).

Something is rotten in the state of Denmark and Hamlet has been called on to treat the infection. The time is out of joint, and Hamlet is chosen—was born, in fact—to set it right, to rearticulate the dislocated bones of his family and his government. This can't be done by making nice. Hamlet's therapeutic role requires him to be a killer, but before he can do that he must be diagnostician. He must, above all, be critical. Incisive, even violent, in his investigations, he enacts a kind of "radical hermeneutics" on his family and his society. I want to focus on one piece of therapeutic violence: Hamlet's figurative vivisection of his mother, Queen Gertrude. This is where he demonstrates the danger of the neatly sutured wound, of premature closure.

> The time is out of joint, and Hamlet was chosen . . . to rearticulate the dislocated bones of his family and his government.

He has confronted his mother in her private rooms and accused her of complicity in his father's death. More important, he needs her to acknowledge her part in Denmark's disease, and this requires inward attention. "You go not," he says, "till I set you up a glass [a mirror] / Where you may see the inmost part of you." She is terrified, for she takes him literally. But rather than pay serious attention to his objections, to the content of his speech, she tries to make him into the patient. She says he is mad—he is sick. We've heard some of his reply: "Mother, for love of grace, / Lay not that flattering unction to your soul / That not your trespass but my madness speaks." Her denial is a "flattering unction"—a soothing ointment that glosses over the flaw. It is bad medicine, for "It will but skin and film the ulcerous place" —make a clear surface over the wound, closing it off—"Whilst rank corruption, mining all

within, / Infects unseen." Beneath the healed exterior, the wound is festering.

As critic and diagnostician, as vengeful healer, as hero, Hamlet works as a lancet. He opens wounds. He lets blood (which was at the time therapeutic for a great many illnesses). Hamlet's methods prove effective. His incisiveness is educational. Gertrude acknowledges her guilt in his medical terms: "Thou turnest mine eyes into my very soul, / And there I see such black and grained spots / As will not leave their tinct," and later, "O Hamlet, thou hast cleft my heart in twain." What follows, this being a tragedy, is a very complex kind of healing: in assisting Hamlet and trying to protect him, she is of course herself killed.

To be more critical is, for the medical humanities scholar, also to be more ethical.

It's important that the kind of wound-draining presented here is not identified with airing of grievances, unreflective emotional disburdening. Claudius is denied the relief of confession, and Gertrude doesn't feel better now that she has apprehended her inner lesions. She dies by taking into her body the poison intended for Hamlet. So is there healing in the play? Or, does Hamlet heal? Tragedy, as a fiction, as life remade as artifact, is, like narrative, always more tolerable than suffering in a meaningless abyss. In response to a question Howard Brody asked in his 1994 article on fixing broken stories,[3] a tragic story is no less healing than a comic one. But much may depend on one's rules for genre and one's expectations of healing.

To be more critical is, I believe, for the medical humanities scholar, also to be more ethical. But the name of our disciplinary field continues to place on us the expectation that we will join torn edges together. The "human" has come to be the word used most to bridge the gap between profession and person. A published definition of the medical humanities captures the burden this conflation of terms can place on our work. Stephen Pattison, professor of religious studies and a leader in medical humanities in Britain, gives a fairly representative—and representatively imprecise—account of what many in medical education expect of the field: "a humane contribution to the humanization of health and health care in the broadest possible way. It would affirm common, if diverse, humanity. It would aim to enhance and affirm human existence and to remain relevant and accountable to humanity understood in the broadest sense."[4] Pattison does not define what he means by "humane," "humanization," or "humanity."

The difficult circularity of these terms makes me suspicious. If we turn to *The Oxford English Dictionary,* to humanize means, most simply, "to give human characteristics or qualities." But we, being human ourselves, pick the admirable characteristics. The second meaning is given as: "to make humane; to civilize, soften, refine; to imbue with gentleness or tenderness."

Stephen Pattison goes on to say what, in his opinion, medical humanities should not be—and I confess that here I feel a little wounded myself. He says that medical humanities "must avoid becoming exclusive and elitist, disaffirming of what people are already doing, dismissive of non intellectuals and nonprofessionals [those who are not professors], or indeed dismissive of professionals [those who are doctors]. It must avoid both becoming 'expert' dominated, narrowly academic, burdensome in its expectations and demands, and imposing an extra compulsory part on an already overcrowded healthcare syllabus. It must not be selfserving or selfperpetuating to justify the existence of some academic groups" and must not be led by "professors of medical humanities who communicate in esoteric jargon." We must personalize and humanize. We dare not professionalize.

But what about the ending of *Hamlet*? Just before the final scene—the one where just about everybody dies—Hamlet finally decides that he will take on the identity of avenger, and dress himself in whatever passes in such tragedies for the white coat—figuratively, at least, the bloodstained garb of the surgeon—but he does so in full acknowledgment of his uncertainty. In fact, the value of his role lies in the uncertainty itself and in his willingness to articulate it. In terms that directly contrast with the hypocrisy he had to cure in his mother, he says to his best friend, Horatio: "Thou wouldn't not think how ill all's here about my heart."

He even likens his forebodings to an infirmity that might affect a doctor, one with a body like Dr. Martin's: "It is such a kind of gainsaying as would perhaps trouble . . . a woman." But despite his uncertainty he proceeds, saying, "the readiness is all."

In the bloodbath that follows, it is Hamlet's apprehension of the complexity and contingency of all action—a perspective unusually self-reflexive in the Renaissance tragic hero—that makes possible the play's final and very conditional optimism about a future, less corrupt, and a healthier world.

And perhaps in that stubborn struggle to find—or make—meaning lies the value of medical humanities. Perhaps it's in acknowledging the way in which well-read texts resist closure—and narratives, even when they end well, are never quite the whole story—that the humanities in medicine can approach a more realistic kind of healing.

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Public Health, Technology, and Culture

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I am a journalist who believes in narrative journalism, which means I spend a lot of time talking to people and getting their stories. I will confess upfront, I do that in part because I think it's interesting. It's a great way to make a living. People open their lives to me. I get to take down notes and listen to them. I get to be part of their lives for a while, and I get to tell other people about it. It's a terrific privilege. It's wonderfully educational.

But I also believe in it because I believe that you cannot understand the world without talking to people. Statistics alone do not tell us the way the world is. That's particularly true in public policy.

It is one thing to hear somebody tell you that there have been studies to show that people who cannot afford their medical care skimp on the medical care they need. I don't think you can really understand what that means until you've listened to a woman who is a widow tell you about her husband's final months, how the two of them would trade off who took the pills that week because their insurance had run out, and how finally at one point he just stopped taking his pills because he was too proud to let his wife go without her medication and too proud to go to the clinic and beg for his medication. I also think that it's important to tell narratives because it makes a connection with the audience.

If you've listened to any news accounts of the health care debate recently, you've heard these numbers: 18,000 people a year, according to the Institute of Medicine, die because of inadequate health care because of health insurance limitations; 45 million people are without health insurance, or 42 or 47 million depending on which number you believe; and 16% of the Gross Domestic Product is spent on health care.

If you are a reporter and you do narrative journalism, you have a responsibility to be honest. And I don't know that all reporters understand exactly what that means. Honesty has two components. One is to be honest about what you see. It's very easy to listen to somebody tell you their story, take down what they said, and write it down. That is not journalism. If you're a journalist, if you're doing narrative journalism, you have an obligation to figure out whether what you're being told is true.

That's not because people lie, although sometimes they do. People have selective memories. They see one part of a picture. As a journalist, you're doing the first draft of history, and you want your first draft to be good. So you try your best to get different versions of that same truth. You ask for proof. You ask for confirmation. You talk to other people.

The other part of being honest is about context. This is where statistics come in. The truth is if I interviewed every one of you reading this, I assure you I would have at least one story to validate any point in the world on health care policy. I also assure you that there is not one single person whose story perfectly encapsulates any one point. People are complicated. Real life is messy.

So honest journalism gives you context; it presents stories that are emblematic of broader trends, and then it presents those stories with their complications. You don't run away from the inconvenient facts; you embrace them. And when you do that, you get stories that really do tell you something. You get an example, a picture, a poster child who can connect with people and actually make a point and make people think about politics.

You may have heard that we are having a debate in this country now about whether to authorize a program called the State Children's Health Insurance Program (SCHIP). This is a program that was established in the

1990s to give publicly funded health insurance to people—mostly children—who were too poor to get it on their own, but not poor enough to qualify for state Medicaid programs. Congress passed a bill that would have not only renewed the SCHIP program, it would have expanded it. President Bush said he would veto the bill and then he did.

There is a fair amount of opposition among conservatives who argue that the expansion is a deviation from what the program actually stands for. SCHIP was a program meant for poor children only; now the program is expanding to include more people who are better off, who we don't want to be giving assistance to, and who we don't need to be giving taxpayer assistance to.

Every week there is radio address in response to President Bush's weekly radio address. Earlier this year, a 12-year-old boy gave the address. His name was Graeme Frost. A couple of years ago he and his sister were in a very severe car accident and both sustained serious injuries. As a result, they had very high medical bills, which their family could not afford because they could not afford private health insurance. Fortunately for them, they were able to get coverage under Maryland's SCHIP program. So Graeme told his story and said, "Please, this program has helped me. Please renew this program and please expand it so it can help more people."

> Millions of Americans who "play by the rules" . . . are being locked out of the health insurance system.

For whatever reason, Graeme Frost struck a nerve. Within a few days, some of the people who disagreed with his perspective and the political perspective of the people who wanted to expand the SCHIP program began to dig into his family story. They began discovering facts that they said were a little inconvenient, like, "Did you know that the Frost family owns their own home?" If these people are so destitute that they need government health insurance, how do they own their own home on a block where a house recently sold for $300,000?

Somebody else started looking through the public information available on this family, and it turned out that Mr. Frost owns a woodworking business. He is a successful small business owner from the looks of things. What's he doing on the taxpayer dole?

Somebody else found out that the Frost family enrolled the two children in an expensive hoity-toity best-private-school-in-Baltimore school, a $20,000-a-year private school. What are these people doing on government assistance?

Then a conservative columnist named Michelle Malkin, who became famous for writing a book defending the internment of Japanese during World War II, decided that she would look into the story. She flew to Baltimore, drove by the Frost's home, and saw that there were three cars in the driveway, including a new SUV. Three cars? Why are these people on the government dole?

And finally, somebody who wrote a blog about health insurance said, "I went and priced policies in Baltimore to see how expensive they are. A family could buy a policy in Baltimore for $400 a month. This family is making $40,000 to $50,000 a year at least. They can afford that. What's going on here?"

Of course, if you're going to look into the facts, you need to look at all the facts. Somebody finally did talk to the Frost family and here is what they found. The Frost family does have three cars. One is a beat up old truck that's about 20 years old. Mr. Frost uses it for his woodworking business to haul things around town because, frankly, it's not strong enough to go longer distances. The SUV was a gift. After the car accident, the kids were traumatized. They couldn't go in a small car. So a group of families in the neighborhood got together and bought them a new SUV. They also arranged to have the kids sent to private school on scholarship because the children needed special attention.

The house was bought 15 years ago for $50,000 in an area that was a drug neighborhood. It has since cleaned up, it has gentrified. But they still owe a mortgage on the house. But the fact that they had some money wasn't really an issue. They tried to buy health insurance. But Mr. Frost was a small business owner and Mrs. Frost had a part-time job, so they had to buy it on their own. If you know anything about the individual insurance market, you know that people with preexisting conditions usually can't get insurance. Preexisting conditions? Well, meet the Frost children with their lingering injuries from the car accident. Nobody wanted to insure them.

It turned out that most of the things that were being said about them were wrong, but not all of them because, you see, this was a complicated story. The truth is the Frost family of Baltimore was not destitute. They were not dirt poor. They were not starving. They did own their own house. They did work. They were living an okay, working-class life. But they couldn't get health insurance. And that is the problem we have today.

We have a situation where millions of Americans who "play by the rules," as Bill Clinton used to say, are being locked out of the health insurance system. The story of the Frost family is actually a very good window into what's happening in America. Unfortunately, the story of what happened to the Frost family politically is a very good window into what's going to happen in this political debate.

In my book, *Sick: The Untold Story of America's Health Care Crisis—and the People Who Pay the Price*,[1] I try to tell the story of that debate through a few stories of actual people. Let me mention one at the top, the one about Janice Ramsey.

Janice is a real estate entrepreneur in Florida. She and her husband started a business. When he reached retirement age, they sold the business and she continued to work for it as a consultant. A self-made woman, she

put herself through college taking night classes after her children had grown up. She worked very hard. She prided herself on carrying herself like a professional, even though she grew up in a blue collar family and it took her a while to learn all the tricks of the trade. She is a real spark plug of a woman too, a real go-getter, very fiscally conservative. She paid every bill on time and had a perfect credit rating.

Janice had just one problem: she was diabetic. She learned this at a relatively late age, and when she learned about it, her insurance policy was cancelled. They said that she had concealed the fact. She had switched policies because the one she had was very expensive, as often happens when you buy insurance in the individual market.

Janice didn't conceal anything. She had no idea she was diabetic. She actually had the right to challenge the cancellation of her insurance under Florida law but she didn't know it. She kept trying to look for new insurance. She had the money and was ready to write the check. She wanted to get insurance, but no one would sell it to her, until finally she found a policy through a local association of realtors.

They said, "Here, we have a group. You can get insurance through it." The people who sell the insurance came to her house. They had beautiful brochures. They plugged her into all the nice doctors and hospitals in central Florida; they would cover her diabetes, and it was not too expensive.

Janice was thrilled. She signed up. She paid her premiums. Eventually she started getting calls from the hospitals she had been to. They hadn't been paid. So she called the insurance company and said, "Please, you've got to pay this bill." They said, "Oh yes, we're just reviewing it."

She finally got a call from a bill collector, so she decided to get the state authorities involved. She said, "Please can you do something? My insurance company won't pay." The state had to break the news to her: "Ma'am, your carrier is fraudulent."

Now the good news for Janice is that she had lots of company. This was a nationwide scam. It was the third such wave of scams since the 1980s—all of them targeting people like her who were having trouble finding insurance in the individual or small business market, promising good insurance to people, even if they had preexisting conditions. There was $250 million in unpaid medical bills from this one scam alone. A lot of these people now found themselves saddled with five-figure medical debt, uninsured all over again, and back to square one. This is the nature of our insurance system today.

There is actually a good deal of agreement that at any one time the number of Americans without health insurance is 45 million. It is true that not all of them are uninsured for the whole year. But it is just as true that in up to a 2-year period, 80 or 90 million Americans will at some point go without health insurance. We're talking about more than one-fourth of the American population. And not all of these people are hapless victims. In fact, nobody is a hapless victim. One of the complications of life is that everybody makes mistakes and does things they shouldn't have done. There are people who should get health insurance, could afford it, and just don't get it. But there are also people who cannot—not by any reasonable standard anyway.

And this is going to continue. All the trends that we're seeing are going to continue. Costs will keep going up. The safety net is going to keep weakening. The good news is that as we get a better understanding of genetics and what diseases you're predisposed to, we'll be able to treat you way in advance. The bad news is that the insurance companies will know way in advance what your risks are and will be able to deny you coverage if you apply on an individual basis.

If we turn over our health care decisions to the for-profit sector and don't give them any rules for what they may do, we shouldn't be surprised when they try to make money the way they do. That brings us to the political debate we're having now. The emerging political debate basically looks like this. We have what I would call the mainstream conservative position: it's the lawyers, it's the malpractice lawsuits. Anyone who tells you that solving the malpractice problem will solve the affordability of health care either doesn't understand the problem, or is lying. The studies on this are virtually unambiguous.

At any one time, the number of Americans without health insurance is 45 million.

The big complaint that you'll hear from conservatives is that we have too many mandates on insurance. One of the things they'll say is that it's unbelievable for a state to mandate that Medicaid cover wigs. The state that covers wigs is Minnesota and the wigs are for chemotherapy patients. Wigs are expensive, but Minnesota decided, "You're going through chemotherapy. You should be able to get a decent wig. Many private health insurance programs cover wigs. Why shouldn't Medicaid?" Some mandates are egregious. A lot of them are there to protect the people who need them.

We also hear about consumer-directed health care or, as we like to call it in the health care business, "show us some skin." If you talk to anyone in the corporate sector you will hear these buzz words: "We need people to have skin in the game," which means they think people aren't paying enough for their health care. They consume too much. When I'm in front of a corporate audience, there is always some guy saying, "My grandson had a sore throat, it turned out to be nothing, but they took him for a strep test because it was free. If they had charged for that strep test, he wouldn't have gotten it. This is the problem with health care."

Believe me when I tell you, too many strep tests is not the reason we have expensive health care. Most of the money spent is concentrated on the 20% of people who are really, really sick. The idea of giving people more

exposure to costs really doesn't affect them. Usually the way it works is you say, "You have to pay the first $5,000 of your expenses as a deductible and then insurance kicks in." Well, really sick people pay $5,000 in 2 weeks. They're acting the same as they did before.

The one thing we do know, however, is that people will skimp on medication they need. There have been many studies on this, going back to the original Rand studies in the 1970s. A 2006 study in the *New England Journal of Medicine*,[2] based on data from the Medicare drug benefit, found that if you charge people more for their hypertension pills, they don't take their hypertension pills. Then they show up in the hospital with heart attacks. It's a lot more expensive to treat the heart attack than it would have been to give 100 people cheaper hypertension pills.

That's not to say that having consumers take on some cost is not good, because it probably is. A good health-care system does make everybody pay a little bit. But you should have to pay what you can, not more than you can.

> There is a relationship between a nation's culture and the kind of health care system it has.

So what is the alternative? The alternative is universal health care. What does universal health care mean exactly? It can mean almost anything. I think of it like a Chinese restaurant menu. You can have delivery options. You can have a public plan, a choice of multiple private plans, or a combination platter of public and private plans. You can have taxes or mandates. You can try to get money through efficiency. You can try to regulate prices. And you can design the benefits you want. You can make everybody pay nothing and have completely free health insurance. You can make everybody have lots of cost sharing. You can do it in any sort of way.

However, the common elements are that insurance is available to everybody, it's affordable for everybody, and everybody has to have insurance. You do that and you pay for it in a reasonable way. The benefits are that at some decent level, you have universal health care.

When I talk to experts I often hear, "Universal health care is not going to get rid of medical errors and it won't do much right away to control costs." Well, no, it won't. It won't solve global warming either. What it will do is create a simpler system where nobody faces severe financial penalties because they're seeking medical care. That's a pretty big deal. If it does only that, it will be the single biggest piece of social legislation in this country since the 1960s and maybe even since the 1900s.

You can say, "Yes, but if we go to universal health care, how do you know we'll be like France or Germany or Switzerland or one of those countries that covers everybody, but doesn't ration services, like they do in England?" In England, they do rationing. They scrutinize treatments heavily. People wait on long lines.

There is a relationship between a nation's culture and the kind of health care system it has, for better or for worse. The British spend a lot less than we do. Frankly, the British get a lot more for their money than we do. Maybe it's not worth spending all that money on health care. Maybe it is. Either way, that's the British sensibility. They are a low-spending country. They always have been and they always will be. We'll always be a high-spending country, for better or for worse. Universal health care won't change that, not right away.

People here talk about bioethics. Maybe that's a place where we do need to change things. Maybe we do need to stop throwing the health care kitchen sink at everybody late in life. We have to think about what we want to do and what we don't want to do.

But that's going to take time—and when you look at the severe economic and medical hardships that people without insurance face, time is something we don't have. Universal health care would mean a guarantee of economic security and access to the best medical care we have to offer—not just for a privileged few, but for everybody. That would be a pretty big accomplishment.

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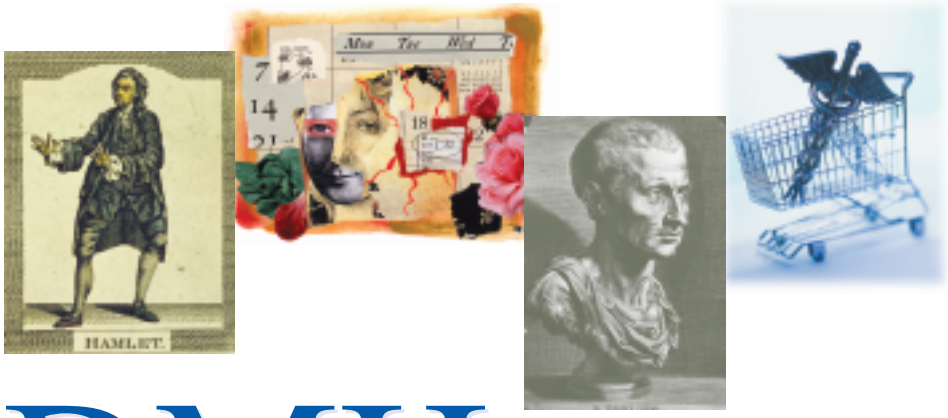

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