

ATRIUM

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The Report of the Northwestern Medical Humanities and Bioethics Program



Gunsmile, photo by Michael Knaggs

POWER



Photo of Mat Fraser by Ashley

ABOUT THE COVER

Last spring the City of Chicago hosted “Bodies of Work,” a disability arts festival that appears to be the first of its kind in the world, and MH&B faculty member Kristi Kirschner was one of the driving forces behind this incredible week of performances, films and panels. Our cover features English actor, punk rock drummer, and martial artist Mat Fraser, who performed his one-man show *Sealboy: Freak* in the festival.

In *Sealboy*, Mr. Fraser interweaves the stories of two characters: Stanley Berent, a historical figure with phocomelia (missing or foreshortened limbs) who performed as “Sealo the Sealboy” in sideshows from the 1940s to the ’70s, and Tam Schrafer, a contemporary actor with phocomelia struggling to get hired. When Mr. Fraser plays Sealboy, his audience finds itself in the role of patrons at an old fashioned circus. It’s uncomfortable to watch Mr. Fraser clap his short arms like flippers, bark like a seal, and do “amazing tasks” like shaving as the charming, upbeat Sealboy; a bit of a relief when he shifts to the story of Tam. Yet when Tam delivers a moving monologue about his journey while he changes in his dressing room, it’s hard to deny being as interested in how he puts his pants on as in what he’s saying. *Sealboy* is a funny, confrontational piece of theater by a man who wants you to stare at him—as all actors do, but staring at this actor feels different, and that tension is exactly what Mr. Fraser wants us to explore. How different are we from the audience that went to see Mr. Berent? How different is Tam (or Mat) from Sealboy? In all his work, Mr. Fraser challenges the traditional framing of bodies like his, offering an alternative to lurid freak shows and objectifying photos in medical texts. His body of work represents an assertive reclamation of power and an insistence on individual voice and authority.

Several different stories of power are embedded in phocomelia itself. In 1962 Sherry Finkbine, a Phoenix mother of four and host of the children’s show “Romper Room,” took thalidomide just as its teratogenic effects were becoming known. Ms. Finkbine opened her quest for a legal abortion to the press, and when she had to fly to Stockholm to get one, the publicity generated some of the earliest open debate over abortion legalization.

Thalidomide ultimately caused birth defects in over 10,000 infants in 46 countries, but only 17 of those infants were in the U.S. That’s because Dr. Frances Kelsey’s first assignment as a new FDA employee in early 1960 was reviewing this drug that was already in use around the world, and most thought was harmless. But Dr. Kelsey had concerns and she resisted the manufacturer’s pressure for quick approval (Richardson-Merrill was eager to introduce the new sedative before Christmas, the best time for sales). She repeatedly asked for more safety data, and each new submission restarted a 60-day clock for approval. Then reports of birth defects in Europe began coming in. Germany pulled the drug in November 1961, and Richardson-Merrill withdrew its application from the FDA in March 1962.

Public fear of thalidomide and recognition of the FDA’s success in protecting most Americans from it propelled drug safety bills that had been languishing on Capitol Hill to passage. Under the Federal Food, Drug and Cosmetic Act of 1938, drug manufacturers only had to show that their drugs were safe. The 1962 amendments required manufacturers to show that new drugs were also effective, to advise physicians of risks in medical journal advertising, and to report any adverse reactions to the FDA.

Over thirty years later, thalidomide satisfied the rules it helped create. In 1998 the FDA made a controversial decision to approve thalidomide for treatment of the debilitating and disfiguring lesions associated with leprosy. (Uses for diseases such as HIV, lupus, and various cancers are also under investigation.) However, its approval came with a stringent mandatory program that attempts to insure patients won’t become pregnant or impregnate anyone while taking it.

—KW

For more information about Mr. Fraser’s work, visit www.matfraser.com.

The Medical Humanities and Bioethics Program

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METAPHYSICAL CONCEIT?

Toward a Harder Humanities in Medicine

Catherine Belling, PhD

“Death, Be Not Proud” is a sonnet by the seventeenth-century metaphysical poet, John Donne. Donne’s work is notoriously complex, spinning out analogies, or conceits, that use metaphorical language to test the depths of abstract concepts. “Death, Be Not Proud” is typical: in it, Donne finds power in a paradox. Cataloging the forms of death’s impotence, he ends by triumphantly pointing out that death itself, rather than the speaker-poet, is the one finally subject to death’s power—at least in the context of his Christian faith, and in the context of the poem’s own rethinking of the meaning of the word “death.” The poem turns language on itself to produce a statement of defiance.

As a humanities scholar trained in an English department but teaching in a medical school, I am interested and invested in what happens to a poem like Donne’s when the disciplines of literature and medicine interact. My concern is with the power of canon formation—the selection of a shared repertoire of texts recognized to have sufficient value that there is an imperative to read or teach them—and how this power is being translated in a new academic disciplinary context, in this case medical humanities. I am also concerned with what such a canon might mean for the institutional power of the field, and of humanities scholars in medical schools.

The case of “Death, Be Not Proud” may be illuminating here. Securely central in the traditional literary canon, the poem’s use in medical school reveals some of the ways the young and somewhat schizoid discipline of Literature and Medicine is still inventing itself and testing its power in the overcrowded, sometimes hostile, richly challenging context of the medical curriculum.

In an informal survey of colleagues teaching literature in medical schools, five of eleven respondents said they have never assigned “Death, Be Not Proud” as reading. Of the six who had, all but one of them used it as supplementary reading in sessions focused on another piece of literature, Margaret Edson’s 1999 play, *Wit*. In text, film, and performance, *Wit* is widely used by medical educators to teach and reflect on clinical skills and professionalism. Its plot concerns Vivian Bearing, a professor of English literature with advanced ovarian cancer, who endures intensive chemotherapy as part of a research trial. A brilliant and demanding teacher, she is profoundly isolated from other human beings, preferring books to friends, combat to conversation, performance to intimacy. In the play she “learns to suffer,” as she puts it, and in doing so finds that hard intellect, signified in the play by Donne’s poetry, is of limited use in the face of illness and death. The English professor, one might say, is punished both by cancer and by medicine for her pride. Only by accepting the compassion and companionship of Susie, a kind and courageous nurse who says “Guess you can tell I never took a class

on poetry,” does Bearing find a kind of redemption. *Wit*, then, seems to ally canonical literature—the John Donne sonnet—with misguided and inhumane arrogance.

At least this is one reading of the play. There are others. *Wit* is complex. Teaching the play or writing about it, I am surprised to find myself in a hall of mirrors—not least because, as a literature scholar transplanted to a medical setting, I cannot help but identify with Vivian Bearing. If the play is a kind of allegory about choosing between intellect and compassion, then, if I accept its logic, dare I bring the demands of rigorous textual study into my medical school classroom? Is it hubris to do anything but try to teach my students Nurse Susie’s kindness, and if so, what happens to the texts and methods I was trained to read and teach? Is there a place for literary studies as a discipline, or for the literature scholar as a professional, in medical education? And if not, what do I bring to medical humanities, and what should I be

...poor death, nor yet canst thou kill me.

—John Donne, “Death, Be Not Proud”

prepared to relinquish? As medical students sometimes say in their course evaluations when they object to our use of literature, “this is not an English course.” True. But what is it?

I don’t believe medical humanities scholars have yet articulated an adequately coherent teaching agenda, either to each other or to the deans and curriculum committees who make space for what we do. Yet we do have common primary texts, selections that reflect and determine the place of literature in medical education. In medical humanities we need to use literature to teach something other than literature. This instrumentality affects the canon we are forming. The texts we assign need somehow to be useful—and usable—in the training of physicians. It’s odd to me that what we teach is better defined than why or how we teach it; troubling that our developing canon is subtly yet powerfully shaping that “why” and “how,” rather than the other way around. Rita Charon’s valuable *Narrative Medicine: Honoring the Stories of Illness* (OUP, 2006) is the work of medical humanities most explicit so far in outlining a potential teaching agenda based in methods rather than texts.

On Doctoring (Free Press, 3rd ed. 2001) an anthology of poems, stories, and essays given to all new US medical students by the Robert Wood Johnson Foundation, is perhaps the *Norton Anthology* of medical humanities. Those who assign literary reading to medical students often begin with this useful book, not least because they can assume students already own it. Donne’s “Death, Be



Courtesy of Bill Fountain

Not Proud” is, since the decision to exclude Biblical extracts from the latest edition, the only piece in *On Doctoring* written before the 19th Century. *Wit* is not there yet, though I’ll be surprised if the next edition does not include extracts from the play. But why was Donne included?

“Death, Be Not Proud” is relevant to “doctoring” to the extent that it concerns death. But power over death belongs in it to God, not medicine. Perhaps the editors saw the poem as an instance of what some patients believe about dying, or as one culture’s view of medicine’s chief enemy. Or perhaps it was included simply because a collection like *On Doctoring* needs to contain at least one piece by one of the great—canonical—Renaissance writers if it is to be taken seriously as a literary anthology.

One of the first medical school classes I taught as a grad student was an elective called “*Hamlet* and Renaissance Medicine.” If I was going to teach literature

to medical students, I reasoned nervously, it had better be Great Literature. I soon found that I was not teaching *Hamlet*, even though the students read it, one act a week, and we discussed passages in close detail. If this had been an English class, *Hamlet* would have been analogous to a cadaver in Gross Anatomy. Here in medical school the play was more like a scalpel. I was *using* it as an instrument to help students explore other things: the historicity of scientific knowledge, the beautiful internal coherence of the humoral theory, once accepted as medical truth, and how the observation of bodies and attention to precision in language can be used in solving mysteries, both forensic and diagnostic. The play was the thing that caught their imaginations, but another play or author might have done as well, if a little differently. As I realized this, I felt I needed to distinguish a new agenda for what I was trying to do, something that had less to do with content than with a particular orientation towards knowledge and experience and embodiment that attended not just to the things of medicine—or literature—but to how those things are described and understood.

Using *Hamlet* also taught me about the social status of “hard” literature in medical school. At graduation, one of my students introduced me to his father, also a physician, who was clearly impressed by Shakespeare’s presence in his son’s medical education. The conversation was strange. What the son had learnt from reading the play was less important to his father that that he had read it, and had done so in a medical context, and that

this would say something about him as a doctor. It struck me that certain kinds of literature have the power to function in medical school as status symbols for those who have time left for reading after acing the science. Here, literature needs be perceived as “hard”—difficult, requiring elucidation by a professional scholar rather than accessible to the

I survived Bearing’s course. ... Hardest poetry in the English department. Like to see them try biochemistry.

—Jason Posner, in Margaret Edson’s *Wit*

amateur reader—in order to function as cultural capital. But this is at odds with the idea that the value of medical humanities lies in its perceived “softness.” Just as a metaphorical hard/ soft dichotomy haunts the relationship between science and humanities, then, it complicates the formation of a medical humanities canon.

When we choose reading, our primary criteria are often pragmatic. *On Doctoring* is a significant source of material because we know it's there. In this way we give its editors great power over our repertoire. (Another important source of teaching texts is the online *Literature, Arts, and Medicine Database*¹ but it is so extensive that I cannot speculate here about its role in canon formation.) Accessibility and relevance are criteria: we use texts that do not take too long to read and clearly have something to do with health care. This often translates into poetry (short) about medical situations (relevant) by doctors and patients (authorities on the subject matter). In the introduction to *On Doctoring*, its primary editors, physicians Richard Reynolds and John Stone, present their criteria for inclusion. They justify the predominance of poetry because of its "economy of form."

Independent deplored the play's "commercially canny combination of high-class cultural references and a reassuringly anti-intellectual bias."² Some might consider this a pretty good description of the kind of texts that work best in the medical school curriculum. I am not that cynical, but it is a view worth examining, if intellect is equated with hardness and the function of the medical humanities is seen as softening the edges of science.

But *Wit* is a fiction. Its stereotypically bad doctors are not unmediated examples of reality. They are constructs. *Wit* is not, as the physician reviewing it in *JAMA* says, an "exposé of the medical profession."³ It does not expose what's there. It presents an imagined version of health care that will, if examined closely, yield more than just negative role models. *Wit* undermines any simple claim that studying literature leads to better doctoring. The play's content seems to sabotage the use we want to make of it. In it, literary study is associated with selfishness and pride and the absence of compassion. Donne certainly counts as cultural capital: oncology research fellow Jason Posner, MD, is awfully pleased with himself for having studied the Holy Sonnets with his patient and research subject. "I survived Bearing's course," he boasts. "Hardest poetry in the English department." Metaphysical poetry, like biochemistry, is hard. Being a Donne survivor is a mark of prestige; he says the course "looked very good on my transcript... They even asked me about it in my interview for med school." Jason Posner's admissions committee might be impressed by his facility with metaphysical poetry, but he's a terrible doctor, as is his mentor, Dr. Kelekian. The doctors in *Wit* are presented as (hard) researchers rather than (soft) clinicians, failing to attend to their patient's experience, to read between the lines of her outward courage and tenacity and recognize her suffering. But their patient is as hard as they are—except that she's dying.

The content of *Wit*, then, is at odds with the view of the medical humanities that is often used to justify having medical students read literature like this play: that exposure to literature has a humanizing influence, enhancing reflection and therefore empathy. The *JAMA* reviewer is surprised by Vivian Bearing's toughness: "Despite her appreciation of fine English poetry, her humanity is not moved by her students' difficulties, and her demands on them are unceasingly exacting." He expects that being a connoisseur of canonical literature would make one compassionate and kind and, significantly, an undemanding and unexacting teacher. He also considers the argument between Bearing and her mentor about the difference between a comma and a semicolon in Donne's sonnet to be evidence of the play's "searing critique of academia." As a literature scholar, I don't agree with his assumption that such close attention to punctuation is self-evidently absurd. But the reviewer's larger point is lost on me as well: Why should exacting standards and precision be at odds with "humanity"?

His assumption emerges in part from a misapprehension of our disciplinary overarching term, the humanities—or perhaps our own misperception that medical humanities falls into that academic and professional category at all. In a special issue of the journal *New Literary History*

Resonances between [literature and medicine] offer us a unique view of the human condition that neither one alone can provide.

—Richard Reynolds, MD, and John Stone, MD, editors, *On Doctoring*

Poems (like Donne's fourteen-line sonnet) are short enough to read in class, rather than seeming to require advance preparation, and in poetry more meaning is usually compressed into fewer words. But the editors do not mention the trade-off that comes with this compression and density. Poems tend to meet with anxiety in the medical classroom, often seen as inherently challenging, as soft moral stuff hidden in hard language, rather than as engagements between writer and reader.

If poetic opacity is a problem, prose fiction is made too transparent. There is a tendency to see the kind of realist stories by doctors that predominate our reading lists (like Selzer's "Brute," Williams' "The Use of Force," Bulgakov's "The Steel Windpipe") as instances of clinical reality, rather than as textual representations. The authority and credibility of the physician-author can lead to a belief, stated or not, that every story about medicine written by a doctor is at some level autobiographical and hence not exactly fictional. The accessibility of realist fiction, where the language (on first reading at least) pretends to be a transparent window on actuality, supports this view that fictions can be read (or even better, watched in drama or film) as neatly packaged cases providing vicarious clinical experience.

Wit is easy to see as a realistic representation of one patient's experience of terminal illness. This is part of the reason for its popularity in medical education. Edson allows us to avoid its serpentine self-referentiality if we choose to. The play's allusions to Donne and Shakespeare (for *Hamlet* is in it too), along with the Pulitzer Prize it won in 1999, give it some of the caché of the canonical without diminishing its initial accessibility. A reviewer for the London

“hard literature”

humanizing?

on the “crisis in the humanities,” literature professor Jonathan Culler suggests that the term “humanities” should be abandoned because of its misleading etymological association with the philosophy and ideology of humanism. He says that “The *human* in the *humanities* risks leading us astray... our language proposes a strong link not just between the humanities and the human being but between *humanistic* thinking and even *humane* behavior, so that we imagine such terms must figure centrally in defenses of the humanities.”⁴

To the extent that humanities scholars in medical schools need to defend our presence, we need to work out how “medical humanities” is connected to the wider, perhaps harder, academic humanities and to claims like that of the *JAMA* reviewer, who not only links the appreciation of poetry with an empathic “humanity” but directly connects humaneness to the “softness” so often associated with literature teaching in medical school. He reads Bearing’s commitment to the accurate analysis of the “hardest poetry” as necessarily at odds with kindness or camaraderie, or even love, as if the rigorous application of intellect to difficult language somehow dulls the heart.

This makes sense if we accept as *Wit*’s moral message Bearing’s deathbed rejection of Donne’s poems in favor of a children’s book and a popsicle shared with her compassionate nurse, if we see in Vivian’s trial by chemo and cancer a fitting penance for her intellectual rigor, and as the basis for a salvation implicitly humanist as well as religious. But surely this is an ironic way to use a poem that is itself an intellectual account of the impotence of death? At the end of the play, Bearing appears to rise from her dead body, naked, into the light, as if she has fulfilled the promise of Donne’s poem, defeating death—but, in a paradox worthy of Donne himself, she has done this in part by rejecting Donne. This ending, cut from the film version, is certainly problematic if one seeks an educational message for medical students in the play, since her suffering leads to redemption. Hospital is her purgatory, the doctors her necessary demons. So, if hard literature fails to produce humane doctors, should we teach only easy literature? What would that be? *Wit* is far from easy once you start paying attention, and the humblest children’s story may be a profound allegory if you read it well. And reading well is what I’d like to teach.

“The human” figures largely in *On Doctoring*. The editors consider writing by doctors the most valuable—William Carlos Williams gets most space in the collection—because what the best physician-writers achieve, they say, is an understanding of the “frailties and strengths, the wonderment of the human condition.” The second-most important writer is the patient, who produces valuable “human documents.” The editors conclude their introduction by again invoking the value of “humanity”: “Resonances between these two disciplines”—literature and medicine—“offer us a *unique view of the human condition* that neither one alone can provide.” The book’s epigraph reinforces this, too. Taken from Frances Weld Peabody’s 1927 *JAMA* essay “The Care of the Patient,” a much-quoted classic, it states that “one of the essential qualities of the clinician is interest in humanity,” since this interest leads to “caring

for the patient.” This logic, moving from the literary to the human to the humane and caring, is also used to justify the medical use of *Wit*. Ken Rosenfeld, MD, of the *Wit Educational Initiative* makes it explicit: “*Wit* serves as a vital educational tool in depicting the problems with palliative treatment *because the arts introduce us to our own humanity*.”⁵ While literature is of course a valuable medium for self-reflection, we should be able to be clearer than this about its use. It’s not easy.

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.”⁶ Pattison does not define what he means by “humane,” or “humanization,” or “humanity.” His description is so broad in its laudable aims that it is difficult to refine into a guide for real educational or scholarly practice. The softness of this ideal comes into focus when Pattison goes on to say what medical humanities should not be: it “must avoid becoming exclusive and elitist, disaffirming of what people are already doing, dismissive of non-intellectuals and non-professionals, or indeed dismissive of professionals.

The human in the humanities risks leading us astray.

—Jonathan Culler, PhD. *New Literary History*, “Essays on the Humanities,” 2005

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 health care syllabus...It must not be self-serving or self-perpetuating to justify the existence of some academic groups” and must not be led by “professors of medical humanities who communicate in esoteric jargon.”⁷ Pattison’s central concern, it seems, is that an expert-dominated medical humanities will be “hard.” It may offer critiques that cause discomfort, speak in unfamiliar and anxiety-producing dialects, and make demands on those it seeks to teach; that it will cease to be humane in its dealings with health. Is he right?

Wit can be read to support him. Physician Peter R. Lewis, writing about using *Wit* to teach medical students and residents, sees Vivian’s humiliation and suffering as deserved and as necessary to her redemption: “through the trappings of these and other [medical] mistreatments,” he says, “Vivian is finally free (forced?) to see the pretenses and errors of her own ways as a ‘doctor of philosophy’.”⁸ The two characters in *Wit* who read Donne’s poetry—the English professor and the oncology fellow—are both con-ceited. Arguably, they are both punished for it.

But in holding up Bearing and Posner as examples of the deleterious effects of being good at hard literature, I

have fallen into my own trap. *Wit* is not simply the story of the edification and improvement by suffering of The Heartlessly Hubristic Intellectual, and we err if we hold up Susie as the only alternative. When her mentor E.M. Ashford tries to teach Vivian how to read Donne, she is bewildered: “Simple human truth, uncompromising scholarly standards? They’re *connected*?” Vivian never does quite work out the connection, but Professor Ashford, who teaches her the profound significance of choosing correctly between a comma and a semi-colon, is also the one who curls up with her on her hospital bed and reads her a tale about a bunny and his mommy. To one who reads as well as she does, that tale is also an “allegory of the soul,” and as such an account of the resilience of love—rodent perhaps, but also human and divine. More important, though, Professor Ashford is a construct used to complicate the simple hard-soft binary Edson seems to be setting up. If intellect should be exercised, rigorously, in the service of care—of love—then Donne’s poem, even if Vivian chooses not to hear it on her death bed, is inextricable from her education in suffering, humility, and kindness. And defiance against death (and cancer, and bad doctoring) is inseparable from precise attention to the language used to express that defiance. Jason Posner may survive Donne (with an A minus), but Edson roots his poor doctoring in linguistic ineptitude. Susie may know little about literature, but she questions Posner’s account of Donne as a puzzle. She wants solutions, and narrative resolutions: “Where does it end? Don’t you get to solve the puzzle?” Jason’s answers shows that he has misread both Donne and medicine: “research is just trying to quantify the complications of the puzzle.” If I demand precision of my students am I guilty of Vivian Bearing’s unkind conceit? I don’t think so. Is my role as a humanities scholar to teach humaneness by example? I hope I do that anyway, but is it my job more than it is the job of a biochemistry professor?

The community of humanities scholars teaching medical students will and should find themselves sharing a literature repertoire, but far more important than what’s on the reading list is what we teach our students to do with whatever is assigned to them. If we present them with stories as instances of reality to be used to reflect on reality, rather than on the mediation of reality by narrative and other representational uses of language, then we will limit our use of literature to its most literal. The humanities, and professors with specialized training in the humanities, can offer more than this. As well as role play and role modeling, literature can offer a different kind of practice, one essential in clinical interactions and clinical thinking: practice in the negotiation of meanings. The humanities bring our focus back to language itself, to the representation of reality, counterbalancing the risky trust in discursive transparency that is fundamental to bioscience and much teaching of clinical medicine.

Rather than a canon, with all that term conveys about exclusivity and the evaluation of inherent traits, we should first focus on developing a clear and shared sense of what use the methods as well as the texts of literary studies can be in the training of doctors. The philosopher Charles

Frankel defined what we do in this way: “The humanities are that form of knowledge in which the knower is revealed. All knowledge becomes humanistic when we are asked to contemplate not only a proposition but the proposer, when we hear the human voice behind what is being said.”⁹ When I use fiction or poetry (as well as most other texts) in class, I try to teach my students how to be better readers, to revel in diversity of meaning without slipping into unsupported free association, and to react to such multiplicity not with paralysis or anxious oversimplification but with careful analysis. I believe that such skills, though hard to do well, can underpin the attentive recognition of human voices that we have come to see as the softness so often missing in medicine.

Catherine Belling is a Research Assistant Professor of Preventive Medicine at Stony Brook University Medical School, and Associate Director, Institute for Medicine in Contemporary Society.

- ¹ Edited by Felice Aull, published online by New York University. <http://endeavor.med.nyu.edu/lit-med/lit-med-db/>
- ² Taylor, Paul. Donne in by a fear of over-complexity (review of *Wit*). *The Independent* 4/4/2000: 12.
- ³ Philip, Abraham, MD. Cancer patient (review of *Wit*). *JAMA* 2000; 283: 3261.
- ⁴ Culler, Jonathan. “In Need of a Name? A Response to Geoffrey Harpham.” *New Literary History*, 2005; 36: 37-42 (38).
- ⁵ <http://www.uams.edu/info/Updates/March01/play.htm>
- ⁶ Pattison S. “Medical Humanities: a vision and some cautionary notes.” *J Med Ethics: Medical Humanities* 2003; 29:(33-36) 34.
- ⁷ Pattison, Stephen. Medical humanities and cautionary tales. In Evans, Martyn, and David Greaves, ‘Developing the medical humanities’—report of a research colloquium, and collected abstracts of papers. *Journal of Medical Ethics: Medical Humanities* 2001; 27:93-98 (97).
- ⁸ Lewis, Peter R. The Wisdom of Wit in the Teaching of Medical Students and Residents. *Family Medicine* 2005; 37(6):396-8, p.396.
- ⁹ Quoted by Geoffrey Galt Harpham in “Beneath and Beyond the ‘Crisis in the Humanities’” *New Literary History* 36.1 (2005: 21-36), 26-27.



The Power of Emotion

Jonathan Marks, MA, BCL

Our emotions are deliberately exploited every day. Playing on fear and sexual desire, advertisers urge us to buy bigger cars, ask our doctors for expensive pills, and pay hard-earned cash for things we may not really need. After a few weeks of driving that new Hummer H3, we realize that it doesn't enhance our sex appeal, it just makes urban parking impossible—and that's when we begin to ask ourselves why we bought the huge gas guzzler in the first place.

There are a couple of reasons for our unwise purchase. The first is that, as numerous empirical studies have shown, we homo sapiens are very poor at predicting what will make us happy. The second and related reason—the one I will focus on here—is what psychologist George Loewenstein has termed the “hot/cold empathy gap.” When we are fearful, angry, desirous, or in any other “hot state” of emotional arousal, we tend to act in ways that we find difficult to understand once we have cooled down.

The power of emotion is not limited to individual behavior. Fewer than three thousand people died on 9/11. This was clearly a devastating loss. But every year, more than six times as many Americans under the age of 65 die prematurely for lack of health insurance. We have spent hundreds of billions of dollars in the “global war on terrorism,” much of it in an aggressive military campaign that most Americans now say does not make them feel safer. But we have not seen anywhere near the same level of expenditure to improve access to health care.

This can be explained—in part, at least—by our emotional responses to the vivid events of 9/11. One response was fear. That's why many Americans took to the roads in the fall of 2001, preferring to drive long distances than to fly. In retrospect, this was clearly a mistake. According to a recent study at Cornell University, these road trips resulted in at least 1,200 additional auto accident fatalities in the 15 month period after 9/11. Many now feel this fear has been exploited too. The color-coded terrorism

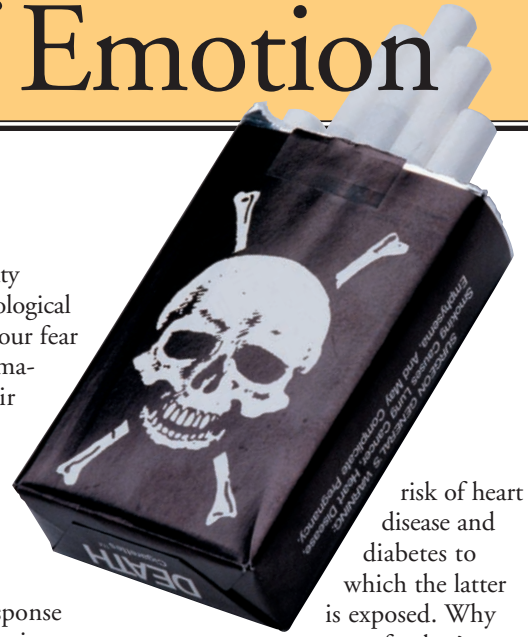
threat level system, which the Department of Homeland Security readily acknowledges has “psychological effects on the nation,” plays on our fear without providing useful information to help people modify their behavior. And claims like Condoleezza Rice's, that “we do not want the smoking gun to become a mushroom cloud,” undoubtedly fueled support for the Iraq war.

Another key emotional response to 9/11 was anger. America has since pursued an expensive and aggressive foreign policy which, in my view, we are likely to regret, just as many now regret the internment of almost 120,000 Japanese Americans during World War II and the prolonged conflict in Vietnam. The mistreatment of detainees at Abu Ghraib, Guantanamo Bay, and elsewhere is already a profound source of shame.

Since emotional “hot states” influence both our policy choices and our purchases, the ethical question is whether we should harness emotions and their sequelae for a different vision of the good.

My grandfather, a professional violinist, was a two-pack a day man. His love of cigarettes was only surpassed by his love of whisky. When he was sixty years old, his doctor told him to stop smoking or he'd be dead within the year. The prognosis was not strictly born of evidence-based medicine, but it had the desired effect. The doctor appealed to my grandfather's emotions by scaring him senseless, and his patient duly gave up smoking. My grandfather lived for another thirty-three years. Had the physician reasoned with my grandfather and admitted that the time of his demise was far from certain or predetermined, the outcome might have been a little different.

Similar, if somewhat more subtle, devices are still used today. A poster in the office of my daughter's pediatrician displays a picture of a skinny child and a slightly fatter child (with the same face) and warns of the increased statistical



risk of heart disease and diabetes to which the latter is exposed. Why not go further?

Perhaps public service announcements should counteract commercials with graphic warnings of the roll-over risks of SUVs, or shocking reminders that generic drugs have better known side-effects, so they may be less likely to kill or injure you than newer drugs.

Emotion could even be exploited in order to create support and build momentum for public policy positions that have the potential to radically improve public health, like universal access to healthcare. Television ads could remind viewers that every 30 minutes another American dies prematurely for lack of health care, or that health crises are a leading cause of bankruptcy in the United States, even for those who have health insurance.

I'm not eager to live in a world in which ads promoting universal health-care end like horror-flick trailers, with threatening voice-overs asking: “Who will be next? Will it be you?” But if we ignore a powerful tool for saving lives and improving public health because we'd rather leave the exploitation of emotion to those who would sell us cars, drugs, or war, we may have a great deal more to regret than a year-old Hummer.

Jonathan H. Marks is an Associate Professor of Bioethics, Humanities, and Law at Penn State University. A more thorough exploration of this thesis can be found in his recent article on emotion, public health emergencies, and human rights which appeared in the Columbia Human Rights Law Review (Spring 2006) and is available at <http://ssrn.com/abstract=896534>.

A BATTLE FOR THE SOUL OF MEDICINE:

MEDICAL COMPLICITY WITH TORTURE

Steven H. Miles, MD

It is abundantly clear that United States military clinicians were actively and passively complicit with the abuse of prisoners held in military prisons in Iraq and Afghanistan and at Guantanamo Bay.

Pathologists delayed finalizing death certificates that would have revealed deaths by severe beatings and asphyxia, and they remained silent as military officials concealed the deaths or falsely attributed those deaths to natural causes. In this way, they silenced a key early warning system that would have signaled that something had gone seriously wrong in the prisons.

Psychologists, psychiatrists, medics, and physicians helped design harsh interrogation plans that were designed to break prisoners down. In some cases, they even gave information on physical and emotional vulnerability from clinical records to interrogators. They monitored interrogations and made suggestions on how to amend interrogations in progress. They assisted harsh interrogation plans in violation of the Geneva Conventions; they assisted in breaking prisoners down and withheld psychiatric care and counseling from those who were broken. They treated broken bones, lacerations, heat stroke, and air conditioner-induced hypothermia, and returned the abused prisoners to their abusers. They failed to record signs and reports of injuries in medical records.

Above all clinicians were, with few exceptions, silent. Most objections to the harsh treatment came from seasoned investigators and the FBI.

The United States' civilian medical societies, except human rights groups such as Physicians for Human Rights, were largely passive as the scope of medical complicity with abuse became clear. The American College of Physicians unsuccessfully tried to arouse the American Medical Association. The AMA and American Psychiatric Association did not take significant action until 2006, two years after the Abu Ghraib pictures were released and three years after human rights organizations were reporting a pattern of abuses in the prisons.

Clinicians have a regular partnership with torturers. About 130 of the world's two hundred plus countries practice torture. More than half of the victims of torture see a physician complicit in the abuse. Such physicians certify prisoners' fitness for torture and treat wounds of torture in the prisons where the abuse then continues. Some prisoners never see the physician who falsifies the death certificate which says that victims of torture died of natural causes. Other prisoners never see the clinicians who design their abuse.

Clinicians have a choice to take another role. We could choose to play a key role in stopping torture. We could assume the responsibility of being front-line human rights monitors in prisons. After all, we are present

in prisons when the Red Cross is not, and we are there when it has gone. We see almost all of the prisoners. If we do not personally witness the abuse, our training enables us to see its signs, even when the injuries are crafted to be indiscernible.

The failure of United States medicine to resist and report human rights abuses in US military prisons has grave implications for the global

community. It allowed abuses to proceed that greatly damaged the moral authority that the United States needs to promote a civil society in Iraq. It has compromised our ability to argue that our POWs and imprisoned dissidents in countries like Uzbekistan be treated humanely in accord with the Geneva Conventions. And it has compromised the United States medical

community's ability to appeal on behalf of our courageous and endangered colleagues who are resisting torture in fascist countries.

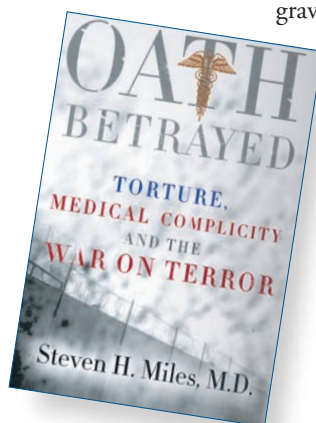
Abundant research shows torture does not yield information. By military intelligence estimates, 85% of the prisoners in Iraq were innocent or ignorant of insurgency or Al-Qaeda activities. At least 60% of the prisoners at Guantanamo are similarly not culpable of crimes.

Resistance to torture matters. Oona Hathaway studied 160 countries and found that a nation's signature on anti-torture conventions does not decrease the likelihood that it will resort to torture unless important domestic constituencies, like medical societies or the Armed Forces medical corps, forcefully call attention to discrepancies between commitment and behavior.*

Conscience matters. The medical profession must join its cultural, political and institutional power with the task of ending torture. In this case, we must call for independent investigations, rededicate ourselves and our professional societies to clear and enforceable standards of professional conduct, and press for transparency and reform in military prisons.

Steven Miles is a Professor of Medicine at the Center for Bioethics, University of Minnesota, and the author of *Oath Betrayed: Torture, Medical Complicity and the War on Terror*. Random House, 2006. miles001@umn.edu

* Hathaway OA. *The Promise and Limits of the International Law of Torture*. In *Torture: A Collection* ed Levinson S. Oxford University Press, 2004, New York.



THE POWER OF THE **media**



Glenn McGee, PhD



Glenn McGee, PhD

Balint Professor of Medical Ethics, and Director of the Alden March Bioethics Institute, the Albany Medical College, and Editor in Chief, The American Journal of Bioethics

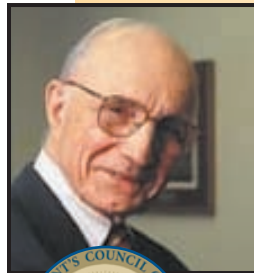
Bioethics' relationship with the media is paradoxical. We study technology, but we're not very good at using it. Even philosophers, the apocryphal turtle-neck-clad closet dwellers, make far more and better use of the Internet. Bioethicists, vilified by philosophers as superficial and media chasing, as Sagans-in-waiting, who suppose themselves to be poised to help society examine the intersection of *techné* and *phusis*, can talk on television. But television is a medium of 1995, not 2006. Bioethics scholars who bemoan or celebrate the appearance of their colleagues on television imagine an earlier era, when appearances on a news program translated into fame and book contracts. I can remember well when my former Dean at Penn said to me and my colleagues, through the PR office, that the dollar value of the number of minutes faculty in the school of medicine appeared on TV was equal to hundreds of thousands if not millions of dollars in advertising. Today there are twenty news channels, and as many people watch the news on their computers, iPods or by delay on Tivo. The "fireside chat" is dead as a doornail. Those who study bioethics would do well to focus not on how many times any of us talk to the media, but on the way in which that person-to-camera interaction and other more highly focused or technologically sophisticated modes of dissemination of bioethics commentary actually compare with one another, and whether they have the impact that is imagined. I suspect that we are just at the edge of a time when bioethicists will be less vicious to each other about "doing media" and more engaged in general with "talking to people in the world." I cannot wait for our Institute to begin its upcoming weekly Podcast, a round table discussion with different faculty members talking about what is going on in healthcare. I cannot wait to include Podcast Q&A with authors of *The American Journal of*

Bioethics' articles into the bioethics.net site. I counsel my friends in programs across the country to start digitizing the really good grand rounds they hosted, the conferences they sponsored, and so forth. A time is coming—soon—when it is possible to do media on your terms. The only problem is that most of us in bioethics are still trying to figure out whether or not you have to type the phrase "http://!" before a web address. It's time for dissemination boot camp for our field: we can't study technology and be oblivious to its use in communication.

Edmund D. Pellegrino, MD

Professor Emeritus of Medicine and Medical Ethics, Georgetown University, and Chairman of the President's Council on Bioethics

My best experiences with the media occur when the reporters take the trouble to request what I have written and ask informed questions. Sad to say, this occurs more frequently with foreign journalists than our own in this country.



"...many significant issues remain, ranging from the challenges of ensuring access to health care to meeting critically important needs in end-of-life care."

— Edmund D. Pellegrino, MD on his appointment as Chair of the President's Council on Bioethics



My worst experiences occur when I am asked to give a quick "sound bite" on a story in the newspapers reporting some "new" ethical or biotechnological issue. I reply that I do not comment on rumors or conflict-generating bon mots.

Carl Elliot, MD, PhD

Professor, Center for Bioethics, University of Minnesota

What's wrong with ethicists on television? It's not that television is junk. As Neil Postman pointed out over twenty years ago in his classic book, *Amusing Ourselves to Death*, the best thing on television is its junk. Television is most trivial, and most dangerous, when it presents itself as the vehicle for important cultural information. Nobody should feel threatened by an ethicist appearing on Oprah. What we should feel threatened by is an ethicist on a television news show.



“THE DRUG PUSHERS”

The Atlantic Monthly | December 2000

“A NEW WAY TO BE MAD”

Carl Elliot, MD, PhD

Television is a medium of images, not propositions. It is not designed for argument, conversation, or intellectual reflection. This is not to say that nothing intelligent can ever be said or heard on television. Occasionally a format will run against the biases of its medium, as Postman observed. Just as radio shows in the 1940s occasionally featured tap dancers and ventriloquists, television shows occasionally feature poets and philosophers. But what is spoken on television comes second to what is seen, and this is the problem for ethicists who believe that what they say on television will be taken seriously. To quote Postman: “It is the nature of the medium that it must suppress the content of ideas in order to accommodate the requirements of visual interest; that is to say, to accommodate the values of show business.”

Ethics as show business can be entertaining, of course. American television can turn almost anything into entertainment: political campaigns, evangelical sermons, natural disasters, criminal trials, the death of a pope or a vegetative woman in Florida. Ethics that is not entertaining will never make it onto television in the first place. And who would begrudge tired Americans their four-hour daily quota of televised amusement? The question is why anyone would watch an ethicist on PBS when they could be watching *The Office*, *The Sopranos*, or the NCAA basketball tournament.

In the introduction to *Amusing Ourselves to Death*, Postman drew a contrast between the dystopia of George Orwell’s 1984 and that of Aldous Huxley’s *Brave New World*. Orwell foresaw a world where the truth was concealed, while Huxley foresaw a world where the truth got lost in a forest of distraction. Orwell feared those who wanted to ban books, while Huxley feared that there would be nobody who wanted to read them. Orwell wrote about a future where people are controlled by inflicting pain, while Huxley wrote about a future where people are controlled by inflicting pleasure. In short, wrote Postman, Orwell thought that we will be ruined by what we hate, while Huxley thought that we will be ruined by what we love.

Huxley got it right, thought Postman, and it is hard to disagree. If anything, we have settled even more comfortably into the televised world since Postman published his book in 1985. The pressing question today is how older media, such as television, will be affected by the newer media, such as video games, blogs, and podcasts. But the sentence with which Postman ended his book is no less relevant today than when he wrote it. “[W]hat afflicted the people in *Brave New World* was not that they were laughing instead of thinking, but that they did not know what they were laughing about, and why they had stopped thinking.”

Laurie Zoloth, PhD

Professor of Medical Humanities and Bioethics and of Religion, and Director of the Center for Bioethics, Science and Society, Northwestern University

To do her work, the reporter needs the bioethicist to answer her question. In a way, this is a good thing—we have a free press, and a dedicated one. The science reporters who call are the same ones I rely on to tell me the truth about, say, physics, or global warming. Then the bioethicist as reader reads carefully what the expert says, and I think it is true, for after all, it’s in the *New York Times*. Moreover, many times, the question is an important one, a keen one, a troubling one—“what is good science?” asked an NPR reporter, or “who holds the patent on the new idea?” Sometimes, the question is not the best, or the most central, and I always want to chase down the issues of justice, the poor, health care reform, or the social disparities so often at the heart of the crises we confront in ethics.

A free and thoughtful press is the core of what democracy has meant, and its suppression the first sign of its failure. So why, then, the animus toward the media in bioethics? In part (discounting the issue of envy, long an issue in any academic field), it is because professors of philosophy and religion love nuance, subtle inflections, and long seminars. I try to give one to the good reporter, and she resists: “Dr. Zoloth, I have a deadline...” and she is right. In part, it is because so many people perform bioethics in the media, and then, via the strange alchemy that is American popular culture, simply become “bioethicists,” for they can be googled as such. In part we are anxious about being misquoted, which is a feature of the oral narrative form itself.

Because I like to teach, I am a friendly sort, and I had a best friend who was chair of the Journalism Department at the State University where I taught; because I have a philosophic commitment to the idea of “interruption” of my work by the inquiry of others, I always try to answer the question carefully. I think it is a good idea to do so—most especially if you cringe at comments made by others.



Laurie Zoloth, PhD on PBS' Online Newshour

There are some rules, I believe, common ones of civility: Don’t talk about things that are outside your area of expertise. Refer happily to your colleagues in the field, especially being careful to refer to colleagues whose views differ from yours. If you do not want to be quoted, you may ask to be allowed to give background, and that can benefit the field very well—Leroy Walters, one of the most

thoughtful commentators in bioethics, has taught many of us this. Learn from the people who do represent the field well, who are able to say one interesting and important thing in a clear way. Learn to know as real people the medical and science reporters in your city, read their work, and if you think they've made a mistake, privately tell them how it could be better. Never, ever lie.

Ethics is in the public arena as “first thoughts”—it has been the case since philosophers stood in the agora, since religious protests were nailed to Church doors, and the public arena in our time is the extended public media, in all its cacophony. As responders, we become a part of the actual event itself—the Heisenberg principle of bioethics. Does it help an academic career? No. But I believe it is our duty as those engaged in a scholarship that arises from reflection on the brokenness of the world. Words—conversation, argument and story—being what we have to offer.



Arthur Caplan, PhD

Arthur Caplan, PhD

Hart Professor of Bioethics, Chair of the Department of Medical Ethics, and Director of the Center for Bioethics, University of Pennsylvania

David Magnus, PhD

Associate Professor, Division of Medical Genetics, Department of Pediatrics, and Director of the Stanford Center for Biomedical Ethics

How often do you interact with the media on bioethics issues? Do you see it as a significant part of your job?

AC: Just about every day. It is a significant part of my job.

DM: I talk to media folks probably 2-3 times a week on average. It takes significant time and effort, but is an important part of the job.

How do you interact with the media?

AC: I get many press inquiries on breaking news stories. I farm them out first internally to Penn faculty and then to bioethicists at other universities and medical centers. Once a week I write a column for either a newspaper or msnbc.com. I much prefer writing my own columns. I control the content, there is no room for misquoting or quoting out of context, I have a bit of space to construct an argument and I can pick the topic.

DM: My interactions are all over the map. I regularly write op ed pieces, I speak with print reporters, I appear on radio shows and do some TV (mostly local).

Why should (or shouldn't) academic bioethicists talk to the media?

AC: Not all should. Some are not very good at this activity. But in general bioethicists should be talking to the media. When I consciously decided to push the field in the direction of engaging public attention with regard to bioethical issues in the early 1980s it quickly became clear that the media was the only tool available to undertake this task.

DM: I see my work with the media as an extension of our teaching function. Answering a question on a tv or radio show is not that different from answering a question in class. Speaking to a reporter is a lot like speaking to a student. A second, less noble reason is the value of media presence for the status of our center within the university.

Who should be identified as a “bioethicist” in the media?

AC: Bioethics in my view is not a profession. We don't license and we don't test. That said, those who claim the moniker should have the publications, experience and professional affiliations to back up the claim.

DM: We are fundamentally an academic field—that is what is behind our public presence. Therefore the standards should be the same as we would use in deciding who is appropriate to teach in the field. They should publish peer reviewed articles in the academic literature and be an active part of the field. In some cases, there is appropriate clinical expertise and experience that is relevant as well.

How would you describe the current relationship between bioethicists and the media?

AC: The media is growing somewhat in its sophistication in dealing with bioethics. It raises hard questions about the field itself, there is an interest in the politics of bioethics and in the financial ties and sources that bioethicists and bioethics programs have. There are also a growing number of people who interact with the media and that is a good thing. Younger people in particular are very comfortable with a bioethics that orients in part to the media—older people who do bioethics still a bit less so.

DM: The media often does not distinguish between experts who genuinely work in the field of bioethics and advocates who pretend to the role. In addition, TV tends to conflate balance with having two sides represented—even if 99% of a field holds one view, and a fringe minority holds the other. The fact that the media turns to us as experts at all though, is a good thing. Many philosophers have spoken of the importance of serving as a public intellectual—few actually are in the trenches doing it.

What is your goal in speaking with the media? Does it work?

AC: My goals are to provoke, challenge, provide context, offer alternatives, lay out possible scenarios and in general provide viewers, listeners and readers with some points to reflect upon.

It most certainly has worked—part of the reason bioethics matters is that the media has integrated discussions of ethical themes into many of the stories they write about medicine and the biological sciences.

DM: I do see the goal as educational—and I hope it works—just as I do in the classroom.

Who benefits from bioethicists appearing in newspapers and on television, and how?

AC: The public. Probably the group after that are high school and secondary school students who often are introduced to bioethics through the media (if my email is accurate).

DM: I hope the public benefits by being more informed and having their questions answered. Bioethicists and their institutions benefit as well—visibility can bring prestige and authority.

Has appearing in popular publications or broadcasts helped your academic career?

AC: Mixed. There is a tendency to dismiss the intellectual credibility of academics who appear in the media by some in academia. The media is no place for someone who has not established scholarly bona fides first. It is still dangerous to one's academic career to be seen as a popularizer. On the other hand, University Presidents, trustees, and deans are all grateful for publicity since it attracts students to apply for enrollment, helps boost alumni support, and is a concrete illustration of how the thinking that goes on at the university alongside the research and scholarship makes a practical difference in the world.

DM: It helps the Center more than the individual—as a Center Director, that means I am indirectly benefited by media exposure of myself and my faculty. But in the end, things like promotions and appointments depend on performance as a scholar and teacher.

A young colleague is considering doing his or her first bioethics commentary. What's your advice?

AC: Don't do it unless your scholarship is in great shape. Then try writing for local and regional publications in order to find your voice and hone your skills.

DM: Writing an op ed in a popular newspaper is actually a difficult skill to acquire. The first op ed I wrote was about genetics and ethics and at the time I was hosting an NEH Institute for University and College faculty. All of the faculty thought it was great, but at my wife's work (a public library) the folks couldn't get through it. "Eugenics? Huh? What are you talking about?"

Have you had any positive experiences in which you were particularly glad you commented on an issue?

AC: Many. For recent examples, I was very proud of the role I played in the national debate about the Terri Schiavo case. I also believe I have made a contribution to the public's understanding of the debate about embryonic stem cell research. I played a key role in some of the exposés of hypocrisy on the part of the administration about embryo adoption, the scurrilous practices of Miami-based SFBC (a huge CRO), the cover-up of problems with Viiox, heart defibrillators, and recycled medical products.



David Magnus, PhD

Going back in time I have tried to raise questions about the artificial heart, baboon heart transplants and xenografting, the stealing of embryos at UC Irvine to make children without consent, the intrusive practices of the Federal government with respect to Baby Doe laws, and reproductive technologies and human experimentation practices that I felt were overhyped or not receiving adequate regulatory scrutiny. And I've argued for more attention to ethical problems in nursing homes and in the futile care of patients, to name some examples.

DM: Yes, several times—commentaries have influenced individuals and policy makers, and I have had a great deal of feedback.

What was your worst experience? Anything you regret doing/saying in hindsight? Have you ever felt unfairly manipulated or misquoted?

AC: Getting quoted out of context just goes with the territory. People still come up to me and ask if I thought the key flaw with the Jesse Gelsinger case at Penn was that parents cannot give consent in emergencies. That was an issue but it was not my key worry about the case, which is how the press reported my position.

It is important to keep in mind that the media is not perfect, that opportunities do arise to correct misquotations and attempts at manipulation, that you can apologize for your most strident or zany statements, and that no single comment really shapes a bioethical debate—it may draw attention but a real difference in public understanding and public policy is only achieved if others in the field concur and at the end of the day the audience chooses to pay attention. Also there is no such thing as off the record or going on background. If you don't want something attributed to you then do not say it.

DM: Once I was thrown for a loop by something Bill O'Reilly said and I was having trouble framing the issues, and he wound up calling me a pin-head. The worst thing was when my wife saw it and agreed with him. Not my best performance. In general, you can tell when you are being used—most reporters and producers will let you provide input into how to frame the story. In the end, I care more about whether I've educated the reporter enough to do a good job on their story than if they attribute a good quote to me.

Alice Dreger, PhD

“I’m not a doctor, but I sleep with one.”

It was about five years into my work trying to change how doctors treat kids born with funny-looking bodies that I took to starting my grand rounds presentations with that joke.

“I’m not a doctor, but I sleep with one.” Those eight words set up the terms of our encounter: I know I’m not one of you, I’m just a PhD in medical humanities and bioethics. I’m not pretending to have the clinical experience—or, more importantly, the clinical *pain*—that you do. But I’m smart and interesting enough that one of your species is willing to sleep with me. So let’s talk.

I learned early on that I had to start with a joke. Most of the doctors I encountered didn’t want to hear what I had come to say—namely that the medical and surgical “normalization” techniques they were using on children born with conditions like genital anomalies, dwarfism, and conjoinment were ethically problematic and possibly ineffective. And they sure as heck didn’t want to hear that there wasn’t even any evidence of medical need for these interventions.

But it took me a while to realize why they didn’t want to hear this. It turns out, while I was saying, “What you’re doing is ethically and scientifically problematic,” they were hearing me say this: **You’re bad people.**

The self-identities of these doctors (in particular the surgeons) were completely wrapped up with their work. Being good, compassionate, beneficent pediatricians was absolutely central to how they thought about themselves. As a consequence, to them, criticizing what they were doing meant criticizing who they were, or at least misunderstanding who they were. It also meant I was calling their mentors bad people, a sign that I was crazy at best and really mean at worst.

The problem was that the doctors didn’t tell me this was what they were hearing. They thought it was obvious—after all, they thought it was exactly what I was saying. So I kept trying to engage them with ethics and science. I

would try to get them to articulate an argument back to me: “Tell me why your approach is not unethical the way I’m describing, show me the studies you have to counter the evidence I’m presenting to you.” But instead I’d get weird responses like, “My patients like me. They invite me to their weddings.” Or “When my patients come back to see me, their bring their Dr. Poppas doll.” These are not your usual longitudinal data points.

In retrospect, I should have figured out the disconnect sooner. After all, the part of my early talks for which the surgeons always sat upright was the part where I talked about which surgeon had discovered what important thing way back when. I knew how important their self-identities, their reputations, their legacies were to them. And I remember early on, when I encountered yet another surgeon who told me “What we’re doing is good, you just happen to be hearing from bad outcomes,” I groused a paraphrase of Winston Churchill at him—“History will vindicate me, and I will write the history”—because I knew that would make him think twice about digging in his heels.

Another reason I should have figured it out is because my self-identity is wrapped up in my work too, and of course it is hard for me to believe that my well-intentioned efforts might be misplaced or even harmful. Yet the very fact that these *were* (mostly) good, compassionate, beneficent pediatricians was why they couldn’t hear what I was saying.

So now I work differently from the way I used to. I start with those eight words—“I’m not a doctor, but I sleep with one”—and then acknowledge how well-intentioned everyone has been. I talk about what our shared goals are: patients who are physically, psychologically, and socially well. Then I move on to talk about sorting out what we know and what we don’t know. And I acknowledge how much easier it is for me to stand up and talk about these issues than it is for them to go back to the clinic and actually deal with them.

I’ve become pragmatic in this way, and, I like to think, more sympathetic and mature. But part of me—the part of me that earned a PhD in history and philosophy of science, the part of me that grew up at the Museum of Natural History in New York, the part of me that named my kid after the Copernican astronomer Johannes Kepler—that part of me keeps wishing we could all just be more scientific.

That instead of having to soothe the egos and feed the self-esteem of people who could not be higher in the game, maybe we could all just be rational, talk about this rationally, decide what to do based on reasoning and evidence, and not on personality and legacy and reputation.

But the reality is, nothing changes except by relationships. It’s all about who knows who. That’s why it works to start with my eight words. I should have realized this at the very start, in 1996, when Aron, the doctor I sleep with, joined me for a trip to go see Cheryl Chase, one of the founders of the intersex rights movement. We were sitting on a hillside at Point Reyes, overlooking the Pacific, having a picnic. Cheryl asked Aron, “How do you change medicine?” and Aron answered, “The first thing you have to know is that most doctors don’t read. You’re not going to change them by writing.” What he meant was something bigger: You’re not going to change them by speaking what you think of as the simple ethical and scientific truth.

Nowadays I spend a lot of time on the phone and over lunches and coffees. Sometimes I feel like I’m living in the early-nineteenth-century century, in a Jane Austen novel, because I ask this person to give me a written introduction to that person, and then I go see that person and have a bit of tea. I do what the late curator Gretchen Worden described to me as what academics do—“go sniff each other’s theses, and whatnot.” I ask former patients to gently and politely go tell their doctors what really happened to them. (I coach them on how not to appear too emotional, because if they’re too emotional, they’re scary.) I ask parents to write about how they experienced the visit with the specialist, and I read it to a group of specialists when I get a chance. And little by little by little, it’s changing.

Maybe. Because on my way out the door of the doctor whose practice I’m trying to change, I pass the drug rep who is on a first-name basis coming in to sell human growth hormone, and I pass the mother with her funny-looking kid in tow, the mother who just, at the advice of her friends and the morning talkshow host she loves so much, had her own face injected with Botox, and I pass the stooped-over beloved mentor whose life work was all about doing it the way I just said is wrong. And I go home and curl up in self-doubt next to the doctor with whom I sleep.

Growth Hormone Treatment for Short Stature: Inferences From FDA Decisions and Clinical Practice

David E. Sandberg, PhD

I'm 5'8", and as a male in the U.S., I suspect that fact will affect how you see me. Many associate height with power; our country likes its CEOs tall. Culturally speaking, height matters.

But in terms of psychological health and self-esteem, it matters less than you might think. Despite the risk of teasing and being mistaken for younger than they are, very short children and teenagers appear to function socially and emotionally as well as their peers, and there's no evidence that increasing their height increases their quality of life.

So why did the FDA approve rhGH for use in the shortest 1.2% of otherwise healthy children? And now that these children can take a hormone to add 2.0-2.5 inches in height, should they?



Hormone Therapy for Short Children

I began my research program on the psychosocial aspects of short stature in the late 1980s, during my postdoctoral training in developmental psychoendocrinology (i.e., hormones and behavior). "Short stature" (SS) is defined as a height at least two standard deviations below the mean for age and sex: approximately 5' 4" for men and 4' 11" for women. SS is a prevalent condition, whether as a feature of complex medical syndromes or as an isolated physical characteristic of otherwise healthy children.

At the time, clinical research on the psychosocial sequelae of SS was sparse and methodologically weak. Most studies focused on patients with classic growth hormone deficiency (GHD), inherited skeletal disorders, or chromosomal anomalies affecting growth, and they suggested that SS was associated with poor academic achievement and disturbed psychosocial adjustment. This view was so

pervasive that a brief statement that SS is associated with poorer psychosocial outcomes commonly introduced review chapters and research articles describing the clinical management of GHD. In this era, the only ethical quandary raised by treating GHD was equity in distribution, because until 1985 cadaveric pituitaries were the sole source. To conserve the supply, treatment was often discontinued in boys whose height reached 5' 5" and in girls who reached 5' 0".

The advent of recombinant human growth hormone (rhGH) was a watershed event in pediatric endocrinology. In 1985, the FDA approved Genentech's recombinant GH product, and this unlimited rhGH supply meant children with GHD could achieve an adult height well within the range of their genetic potential (i.e., mid-parental height).

Unlimited supply also made it possible to treat other pediatric conditions associated with SS. rhGH was never considered to be a treatment for the underlying causes of growth failure in these complex conditions; instead it targeted the visible impact of those conditions, short stature. The FDA approved rhGH for youth with Chronic Renal Insufficiency in 1993, Turner syndrome in 1996, Prader-Willi syndrome in 2000, and children born Small for Gestational Age in 2001. Being short, in and of itself, was considered a "disability" significant enough to warrant giving daily injections for 5 years or more with unknown long-term health risks. The early, methodologically marginal quality of life studies continued to be cited as justification for treatment.

The Psychosocial Screening Project

That literature began to change in the 1990s. After my post-doctoral training, I worked as a psychologist in pediatric endocrinology programs, where I developed a clinical service for all new patients who came for growth evaluations. The objective of our behavioral assessment at the point of entry to the growth clinic was to identify children and adolescents who were already experiencing difficulties, and to provide preventive information to the families of youths who were adapting well. This service also provided an important research opportunity because it involved standardized evaluations of large numbers of short youths whose growth problems were related to a wide range of etiologies, not just individual cases referred to mental health professionals during a time of crisis.

The *Psychosocial Screening Project*,^{1,2} the first effort of its kind, corroborated clinical impressions that SS is associated with teasing and juvenilization. But what surprised us was that youths with SS appeared to be doing as well as their peers with regard to social competencies, behavioral and emotional functioning, and self-esteem. Furthermore, the predicted relationship between severity of SS and children's psychosocial adaptation was not found: very short children or adolescents were no more likely to experience SS-related stressors or exhibit psychosocial problems than youth who were only mildly short. These conclusions held true for both clinic-based and community samples.³

Good news, right? These findings surprised me, but they are consistent with numerous studies documenting the psychological adaptation of children and adolescents with various medical conditions (some even life-threatening), and I ultimately came to accept their validity. The vast majority of children do well despite adversity as long as they have a reasonably supportive family environment and their medical condition has not compromised the brain, the machinery that allows us all to problem-solve our way out of difficult situations. And, subsequently, no controlled study has demonstrated a psychological benefit of rhGH treatment (in either the short or long term) for individuals with SS.

FDA Approval of rhGH for Idiopathic Short Stature (ISS)

Therefore, I was altogether surprised in 2003 when the FDA approved rhGH for children with Idiopathic Short Stature (ISS), the shortest 1.2% of children after excluding other causes of SS. By definition, these children are short and healthy, and findings on their lack of psychological problems had been published in peer-reviewed medical journals or had appeared in review chapters in pediatric endocrinology texts since the early '90s.

Eli Lilly's presentation to the FDA was logical, even elegant; there was little to no mention of the psychological "suffering" that children and adolescents with SS experience or the potential romantic and occupational disadvantages of being a short adult. Good thing, because the data would

not support such claims. Instead, representatives of Eli Lilly argued that since healthy children can be as short as those who receive rhGH when their height has been stunted by a medical condition, healthy children should receive the hormone for their appearance as well.

With GHD, we were replacing something that was missing—normal levels of growth hormone. With the second generation of indications, we were treating children whose reduced height was a symptom of their underlying disease. Now we're using rhGH for an essentially cosmetic procedure: making short and otherwise healthy children taller.

What happened?

It seems that the most meaningful endpoint for gauging the benefit of rhGH treatment, improvement in quality of life (QoL), is substituted with an objective physical measure, height. Many opinion leaders in medicine and the pharmaceutical industry are wary of the construct QoL as an endpoint in clinical trials, but in the case of rhGH for SS, this wariness could stem from the fact there was no evidence that the treatment accomplishes anything other than making the individual a little taller. In response to one question put forth by the FDA, "Should psychological or quality of life benefits be required outcomes of growth hormone treatment?", Dr. Charmian Quigley, Senior Clinical Research Physician at Eli Lilly and Company responded, "While this is a relevant question, I would point out that this has not been conclusively demonstrated for either growth hormone deficiency or for any other growth disorder that is currently approved for treatment." She was right—the FDA had descended the slippery slope years earlier by approving new uses for rhGH without identifying endpoints other than height for gauging success.

That rhGH adds inches to height is well established. But instead of just repeating the mantra of "evidence-based medicine," we should pay more attention to defining what constitutes meaningful evidence. SS isn't a disease in and of itself, so rhGH's effectiveness in promoting growth is irrelevant unless the child's height is a reliable and valid proxy measure for QoL. The weight of empiric data refutes that notion. Thus, the FDA approved what is ostensibly a cosmetic procedure for children and adolescents under the guise of "medical necessity."

I'm troubled that the FDA did not press the pharmaceutical company for evidence of efficacy beyond height gained. I'm also uneasy that the FDA was not more circumspect in approving rhGH treatment at supra-physiologic doses in healthy children when the long-term risks are unknown. What were the risk-benefit calculations? Is *any* risk to healthy children permissible when there is no evidence of benefit? Or is anything better than being short?

The FDA isn't the only one to confuse height and QoL; in my experience, parents, patients, clinicians, and the general public do it all the time. Although rhGH for SS is fundamentally a QoL intervention, an individual psychosocial evaluation is rarely done to determine if a child has problems that warrant that intervention. When a child with SS is in fact experiencing problems of psychosocial adjustment, height is commonly assumed to be the causal factor. But

Assumptions Underlying Growth-promoting Therapies

Research findings derive from the *Psychosocial Screening Project* and other independent investigations. A more complete discussion of the evidence upon which this table is based can be found in references 6 and 7.

Assumption Underlying Rationale for Treating SS with rhGH	Evidence
Patients with short stature experience chronic psychosocial stress	Supported by clinic-based studies
Patients with short stature exhibit clinically significant problems of psychosocial adaptation	Not generally supported
Short youths and adults in the general population (i.e., those not referred for growth evaluation) are similarly at risk for problems of social adjustment	Not supported in children, adolescents or adults
Stature-related social stress results in significant problems of psychosocial adjustment	Limited support: though teasing and juvenilization were related to behavior problems, overall psychosocial adaptation was equivalent to community norms
Increases in growth velocity and height induced by rhGH therapy result in improved quality of life	Not supported

identifying children who experience SS as a “disability” has proved a challenging task. Psychosocial stress is a common phenomenon in childhood and, by itself, does not imply psychiatric dysfunction or even significant problems of psychosocial adaptation. The fact that a young person experiences teasing or juvenilization or that the family is seeking a consultation with a pediatric endocrinologist regarding growth-promoting therapies is insufficient to make this determination. Because SS has the potential to serve as a lightning rod to divert attention from other stressors, clinicians must be watchful of misattributions on the part of the child, parents, or others (including themselves). These assumptions may direct attention away from prescribing psychosocial interventions for maladaptive coping.

Healthcare practices can be far from rational, and healthcare professionals are as likely to be influenced by negative social stereotypes as the general public unless specific steps are taken to disabuse them of these. Say a child is being bullied because of SS, and the bullying is associated with significant emotional distress. Are our actions saying that the most effective way of responding to discrimination is by altering your physical appearance? And given that the growth benefits of rhGH are quite modest and slow to accrue, what is the child supposed to do in the meantime? The majority of those treated will remain shorter than average even after treatment, so the bully would still be able to target the child’s height. Where is the evidence that making that child a little taller will yield any social benefit?

In addition to the absence of proven psychological benefit and the lack of data on long-term risk, I have several other misgivings about this treatment strategy, even if an individualized assessment showed problems and those problems were found to be height-related. The regimen of daily injections and regular visits to a pediatric endocrinologist may make a child feel “different” and may contribute to the perception that something is “wrong.” Currently, little to no consideration is given to the potential psychological harm that treatment could inflict on the child we seek to help. And by “treating” SS in healthy children, medicine is complicit with the social forces that maintain negative stereotypes about short people.⁴ There will always be individuals below any cutoff adopted to demarcate “normal” from “abnormal” height. Therefore, even if the individual with SS were to receive psychosocial benefit from rhGH (which has not been demonstrated), it is only because others remain shorter.

Finally, the estimated cost of rhGH treatment in ISS is \$52,000 per inch.⁵ Assuming that this is an intervention designed to improve QoL, we ought to first determine if there are less costly and invasive strategies to achieve the same goal—for example, a psychosocial intervention that addresses the specific social stressors. It’s frustrating that during a time of skyrocketing healthcare costs, the opportunity for profit has driven industry to expend substantial effort in researching and marketing rhGH (plus additional FDA oversight costs) without considering whether there is even a problem requiring treatment. In contrast, the psychosocial services in the pediatric endocrinology clinic I described were never reimbursable through health insurance.



Over time, there will be an increasing number of treatments that blur the distinction between what is considered medically necessary and what is cosmetic. The approval process for medications should consider a broader range of endpoints, in particular patient-reported outcomes pertaining to QoL. Nowhere should this be more true than in the treatment of minors who rely on parents and healthcare professionals to make decisions on their behalf.

Acknowledgement

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David E. Sandberg, PhD is an Associate Professor and the Director of the Division of Child Behavioral Health, Department of Pediatrics & Communicable Diseases at the University of Michigan (dsandber@med.umich.edu)

References

- ¹ Sandberg DE, Brook AE, Campos SP. Short stature: a psychosocial burden requiring growth hormone therapy? *Pediatrics* 1994; 94:832-840.
- ² Sandberg DE, Michael P. Psychosocial stresses related to short stature: Does their presence imply psychiatric dysfunction? In: Drotar D, editor. *Assessing Pediatric Health-Related Quality of Life and Functional Status: Implications for Research*. Mahwah, NJ: Lawrence Erlbaum Associates, 1998: 287-312.
- ³ Sandberg DE, Bukowski WM, Fung CM, Noll RB. Height and social adjustment: Are extremes a cause for concern and action? *Pediatrics* 2004; 114(3):744-750.
- ⁴ Sandberg DE, Colsman M, Voss LD. Short stature and quality of life: A review of assumptions and evidence. In: Pescovitz OH, Eugster E, editors. *Pediatric Endocrinology: Mechanisms, Manifestations, and Management*. Philadelphia, PA: Lippincourt, Williams & Wilkins, 2004: 191-202.
- ⁵ Lee JMM, Davis MMM, Clark SJM, Hofer TPM, Kemper ARM. Estimated cost-effectiveness of growth hormone therapy for idiopathic short stature. *Archives of Pediatrics & Adolescent Medicine* 2006; 160(3):263-269.
- ⁶ Sandberg DE, Colsman M. Assessment of psychosocial aspects of short stature. *Growth, Genetics & Hormones* 2005; 21(2):18-25.
- ⁷ Sandberg DE, Colsman M. Growth hormone treatment of short stature: status of the quality of life rationale. *Hormone Research* 2005; 63(6):275-283.

A Conversation with Mary Stainton: Power Dynamics and Informed Consent

Informed consent is usually framed as an expression of patient autonomy. Less addressed is the power that cultural expectations and the desires of loved ones have over these “individual” decisions. When a patient clearly expresses understanding and consent, does a physician have any responsibility to explore how other forces might be influencing his or her decision? Does that type of inquiry enhance autonomy or does it undermine it?

Mary Stainton is a writer who receives health care at Northwestern. As a teenager she assented to an elective hysterectomy, and her creative essay about that experience appeared in “A Piece of My Mind” in *JAMA* on September 27, 2006. Ms. Stainton spoke to *ATRIUM* about power, family, disability, and informed consent. —KW



Katie Watson: You had a hysterectomy when you were fifteen years old. Why was that?

Mary Stainton: My mother, doctors, and I were concerned about my lack of independence during menstruation. Having cerebral palsy meant my legs were very spastic, so I couldn't pull up a pad or insert a tampon by myself. Every time I had to go to the bathroom during my periods, I needed assistance. My mother felt like she had to be with me every minute, except when I was in school, where the school nurse assisted me. Doctors used drugs to stop or curtail my periods for a while, but they knew they couldn't mess with my hormones forever, so around 1970 or '71, when I was 12 or 13, we started talking about my having a hysterectomy. I argued and expressed doubts about giving up the ability to have children, but my mother's frustration—really, caregiver burnout—grew to the point where she blurted out one day that if I didn't have the surgery, she would commit suicide. I believed her and was terrified, so I stopped arguing, stopped expressing doubts, and had the surgery in November of 1973.

KW: So did you ultimately consent (or as a pediatric patient, did you give “assent”) to the hysterectomy?

MS: Technically, I suppose so. But I don't consider it consent as it was given under such pressure. I gave up fighting. I don't think giving up is the same thing as giving consent. Legally it might be, but beyond a strict legal sense, it isn't. I wanted my mother alive and for the tension in our family, which I felt like I caused, to end. It seemed like surgery was the only way that would happen. At the doctor's request, I wrote something saying what I understood they were going to do physically. I don't recall whether I actually said in that paper, “Yes, let's do this,” but if I did, it was because I didn't feel like my “No” had been, or would be, heard. “Consent” felt like the only way to alleviate the pressure.

KW: Is it fair to assume your physician didn't know about the power dynamics happening behind the scenes? And if so, how could he have found out your “yes” wasn't completely authentic?

MS: It's probably fair to assume that, and I'm not sure anything would have guaranteed his finding out that my yes was not real. But at some point, my mother told him I had reservations because our cats had just been spayed and I felt like that was what was going to happen to me. He addressed my concerns medically; told me for at least the second time they would not remove my ovaries. I wish he had checked with me to see if I really didn't understand the surgery, or if my concerns were something other than medical. Physicians need to recognize that emotional reservations do not always get articulated in emotional language, especially if authority figures do not appear to value emotions. They should ask how a patient feels, not just what she or he “thinks” about a proposed treatment. Take feelings seriously!

In my case, I think the assumption that there may be family pressure and caregiver burnout would have been the place to begin, given that I was medically healthy. Adolescents with disabilities are often particularly dependent on parents and medical personnel for their health and well being, so they may not feel safe expressing disagreement and may be particularly subject to coercion. Recognizing that my mother was the primary caregiver, he might have asked, “Have you ever expressed reservations to your mother? How did she respond?” Questions like, “Are you feeling pressured in any way to do this?” would have made a difference. Insisting that both my mother and I see a counselor and that I work with a physical therapist would probably have been helpful. I wish he had said, “If Mary has any reservations whatsoever, we will not do this.”

KW: It sounds like you were “performing” assent rather than really giving it. When a Jehovah's Witness is about to suffer harm by refusing blood, most physicians speak to the patient alone to explore to what degree his or her refusal is a response to community pressure, as opposed to an individually held desire. Did your physician ever speak to you about the hysterectomy without your mother in the room? And if so, did that help?

MS: Yes, he spoke to me alone sometimes, and no, it didn't help, because he only addressed the issue from a medical, technical information standpoint. If he had thought about possible stereotypes, prejudices, and family dynamics, as well as imagined my vulnerability as a teenager and a person with a disability, if he had attempted to address the emotional aspects of this situation—any of that would have helped. It IS absolutely necessary to speak to a patient alone, but the KINDS of questions you ask are determinative in circumstances like mine.

KW: Did you feel like your physician was a caring person?

MS: It may sound odd after all I've said about him, but yes, I feel—and felt at the time—that he was a caring person. In some ways, radically so. For all the dimensions of this that he dismissed, misjudged, or was blind to, I know he cared about me and respected me profoundly. More than any doctor had up until that point in my life. He was clearly impressed with my intellect. I remember once my mother told me to go wait in his waiting room while she talked to him and he looked at both of us and said, “No. I don't want to have a conversation about Mary behind her back.” My mouth almost dropped open! I thought, “Wow!” No doctor had ever shown that kind of respect for me; had ever said that to me. He was a very good man who made some mistakes, mistakes I hope this interview helps prevent. He underestimated or was honestly blind to some very important dimensions of this experience. His mistakes are sad, even tragic. And they are part of what made him human, with all the wonder and pain that being human implies.

KW: Have you discussed your feelings about your hysterectomy with your mother since the operation?

MS: Yes. About 10 years ago, with the help of a very good counselor, we sat together and I told her honestly how I felt about the surgery. I was very fortunate. She heard me. She said, “It was a difficult time. I'm sorry. I would not do that to you now.” She was a different woman. No longer responsible for, or judged by, how she raised me, she was able to see a dimension of what I went through which she could not acknowledge when I was 15. I would not wish my hysterectomy on anyone, but I would wish a moment like that with their mother on everyone! It was healing.

KW: I'm impressed with the way you've processed this experience and integrated it into your life! Do you have any residual anger?

MS: I'm angry at deeply imbedded cultural stereotypes and prejudices which have defined people with disabilities as less sexual, less alive, less deserving, and less able to be parents than non-disabled people. I'm angry at our over-emphasis on and narrow understanding of independence in the lives of people with disabilities. Independence is important, but it is not a god we should sacrifice our lives or the life of someone else to. Independence means “managing your own care,” not “being able to do everything by yourself.” I'm angry at a medical profession which trained (and to a great extent still trains) doctors to ignore or become blind to multiple dimensions of patients, patients' lives, and patients' needs. I'm angry at a society that fails to provide adequate resources like respite care, education, and other support to parents of adolescents with disabilities. I'm angry at the cultural sexism and ableism which so trapped my mother that they drove her to a moment of desperation where she threatened suicide, and which eventually silenced me. I am angry, and I am sad at the collective forces which imprisoned so many people that they made this story even thinkable, let alone true.



Sterilization of People With Disabilities Today

Last year MH&B faculty were involved with a sterilization case that illustrates one way contemporary legal and family power dynamics can play out on this issue.

Between the early 1900s and the 1970s, over 60,000 people were sterilized in the United States against their will. By the 1980s, the legal framework had changed: now people with physical disabilities make their own medical decisions, and medical decisions for cognitively impaired people are entrusted to guardians.

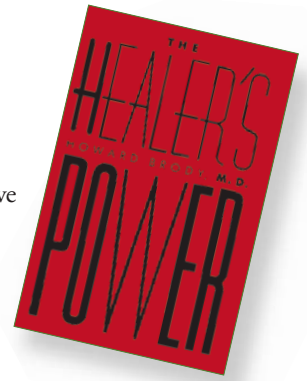
Transferring the oft-abused power of the state to individual guardians (often family members) is an improvement for many people with cognitive disabilities. But continued fertility is one medical decision in which the interests of wards and guardians might conflict. While some people with disabilities might enjoy parenthood, guardians may fear a new baby will become their responsibility. Or, in the case of congenital disability, guardians may fear the ward will “pass on their genes” to another family member. Ironically, these criteria—resources and eugenics—are exactly those used by the now-discredited state programs.

In 2005 Rachel M. (not her real name) was a cognitively impaired, sexually active, 26-year-old Illinois woman who had successfully prevented pregnancy for several years. (At the time, her guardian was helping her use the patch.) Ms. M was hit by a car as a child, and the resulting brain injury left her high functioning in some areas, low functioning in others. After her mother died, her aunt became her guardian. Ms. M called Equip for Equality because she hoped to marry her boyfriend over her guardian's objection, and her attorney found a petition her guardian had filed asking the court's permission to terminate Ms. M's fertility. The petition included supporting affidavits from a psychiatrist and an internal medicine physician stating doing so was in Ms. M's “best interests.”

Some states require judicial approval before guardians can consent to sterilization on behalf of their ward. Other states have no legal standards specific to sterilization, which allows

(“Sterilization” continued on inside back cover)

The Healer's Power...14 years later



In his *Essays* Montaigne tells of a South American tribe that punishes failed prophets and prognosticators with death, a striking instance of power matched by responsibility. We ask nothing like that of our physicians. Instead there seems to be an unspoken pact: we'll ignore the consequences and trappings of their power if they'll use it on our behalf when we or someone we love is ill. If medicine fails, we blame ourselves, our habits, our secret faults. Thus there was not much need to think about power in medicine, and even less need to bring it up in medical school. Howard Brody's *The Healer's Power* (Yale, 1992) broke the silence. He surveyed the field of bioethics, asking how considerations of power and the possibility of sharing it with patients might change the way medicine is practiced and ethical issues are viewed. He even (gasp!) wrote about money. It's one of those books that is still as important as the day it was written.

—Kathryn Montgomery



Howard Brody, MD, PhD

In *The Healer's Power* I tried to take seriously a suggestion from the philosopher John Ladd, that the central ethical question in medicine is, "How can physicians use their power responsibly?" I proposed that as a rough rule of thumb, power was most likely to be used responsibly when it was *owned* (the person with power acknowledged it and accepted accountability), *aimed* (the goal of the use of power was clear and the use of power was proportional to the goal), and *shared* (part of a relationship aimed at empowering the patient).

One goal of the book was to call for a bioethics that worked more closely in tandem with disciplines that take power more seriously—the social sciences and history. Some of this greater interdisciplinary collaboration has since occurred, but in my view, we still have a long way to go to involve bioethics in the ideal interdisciplinary mix. The fact that "bioethics" (human biology + ethics) seems by definition to be interdisciplinary has tended to distract us from an awareness of how bioethics can be impoverished by being practiced in a way that fails to take into account its natural affiliation with the humanities and social sciences.

As bioethics advances, a number of issues will require more sophisticated attention. These include concerns about multiculturalism, global justice, race and ethnicity in health, and disabilities concerns. Moreover, the current movement to enhance "patient-centeredness" in primary medical care illustrates that "respect for patient autonomy" has hardly triumphed to the extent that most of us fondly imagined. I would propose that the considerable advances made by feminist approaches in bioethics can provide a useful basis from which to address many of these concerns. The feminist approach seems to me to offer basic insights into how power looks different from the respective vantage points of those who have it and those who lack it. The vantage point of those with power is almost always the original point of departure for ethical analysis. The challenge to bioethics is

therefore to adopt the perspective of those lacking power, and to appreciate how differently the world appears to them. Certain assumptions that seem incontrovertible from the more privileged vantage point turn out to be radically in need of criticism as soon as one shifts one's gaze. I believe that this general approach has considerable utility, despite the obvious dangers of applying it in cookie-cutter fashion.

Arthur Caplan recently commented perceptively on the power of bioethics, and how a good deal of the recent anti-bioethics backlash has been triggered by the fact that bioethics now has some social and political power and has aroused the jealousy of other parties as a result.* Many of us, when training in this field, doubted that we would ever have any power in our role as bioethicists or that anyone of consequence would ever listen to us. This suggests that bioethics may have a problem in *owning* its own power. That, in turn, has important implications for what a "code of ethics for bioethicists" might look like, and what it would mean for bioethics to assume a *professional* role in society.

And what of physicians, about whom *The Healer's Power* was largely written? Do they have more or less power today, of various sorts, than when I first wrote? I think the self-pity of physicians dealing with the increasingly complex world of practice can be taken too seriously; physicians as a group still wield tremendous power, operate a good deal on their own say-so, and make a fair amount of money. That said, I have been struck in talking with medical audiences in recent years how pervasive is the sense of demoralization in our profession. It has reached the point where even if the perception deviates from the reality as others define it, the perception itself has become an ethical crisis. All of us who teach medical students know how many hands go up when we ask a first-year class, "How many of you were told *by physicians* that you were making a big mistake in coming to medical school?" This is hardly an issue solely of intra-professional belly-aching. No sensible patient wishes to be cared for by a physician who feels as demoralized, as burnt-out, as seems to be the case with many physicians today. The current focus on "professionalism" in medical education, assuming we can define satisfactorily what that means, will be incomplete if we cannot address that pervasive sense of demoralization in some helpful way. Doing so should not entail restoring physicians to the pedestal of unchallenged power that they enjoyed in earlier days. It will entail, I hope, getting more in touch with what makes successful and reasonably happy physicians feel that their work is meaningful and finding ways to share those lessons more widely with the entire physician community.

Howard Brody is the Director of the Institute for the Medical Humanities, a Professor of Family Medicine, and holds a John P. McGovern Centennial Chair at the University of Texas Medical Branch.

* Caplan AL. "Who lost China?" A foreshadowing of today's ideological disputes in bioethics. *Hastings Cen Rep* 2005; 35(3)12-13.

“Is There a Doctor in Greg House?”

Kathy Neely, MD

The professor of medicine is giving an inspired, interactive lecture. He asks the riveted students a question. One ventures an answer—turns out, it’s wrong. The professor scoffs. He nails another, who is too intimidated to speak. The professor turns his back on these two, and rails at the remainder in the auditorium, “They’re useless! But you’re worse! You know what’s worse than useless? Useless and oblivious.”

Meet Gregory House, MD. Millions of viewers tune in each week to watch the brilliant, unorthodox Dr. House handily solve cases that leave his baffled colleagues scratching their heads. It’s a satisfying journey, from the first devastating symptoms, through detailed patient histories and complex procedures, arriving at the correct diagnoses just in time to save the patient.

How did just another doctor show end up a runaway hit? Well, for starters, *House* is sexy and stylish, with weekly servings of life-and-death drama. But, unlike an ordinary soap, it comes off as “educational.” The technical accuracy is impressive: you’d swear those actors are truly intubating patients. Special effects allow the viewer to navigate through blood vessels and organs into a hotbed of pathology—ah, so that’s what a stroke looks like from the inside. It satisfies the voyeur—so that’s what it’s like behind the scenes of a hospital; that’s how doctors think. And, Hugh Laurie offers a stunning performance as a tormented, angry, conflicted physician, who, in spite of his failings, is always right.

I began watching *House* because my daughter loves it, but I’ve subsequently found that lots of us in medicine watch faithfully. Almost every student I’ve asked knows *House*, and besides being entertained, some claim to have picked up arcane facts that helped them pass the boards. A roomful of busy, forty-something clinicians will usually yield at least one *House* devotee. Unlike Dr. House himself, his physician fans I’ve encountered are usually some of the most sensitive, caring people I know. They typically laugh, a bit embarrassed, and admit *House* is sort of shocking, but—well—fun. One told me *House* gave him the vicarious pleasure of hearing a champion tell off the bad guys, something he wishes he could do but never does. (Of course he wasn’t referring to confronting patients or students, he quickly qualified, but giving pandering pharmaceutical reps and money-grubbing administrators a bit of what’s due them.) For me, it’s satisfying to see a doctor who is always right! And since much of what I do is mundane and sometimes seems

taken for granted, it’s gratifying to see my professional life glamorously showcased, even if not in exemplary fashion.

But by the time my daughter and I got to episode 5, I was pretty upset. It began with the language. Dr. House freely calls both students and patients “stupid,” “idiot,” “moron” and “bitch” to their faces. He rants about hating patients, but hungrily scoops up the “interesting cases.” Dr. House freely comments on patients’ breasts, including those of a 16-year-old and a nun; he invites a male colleague to consult regarding a particularly voluptuous patient, and both of them enjoy leering at her. He punitively shoves a Foley catheter up the urethra of a patient accused of drug seeking behavior. With aggressive application of what amounts to psychogenic trauma, and sometimes pharmaceuticals, he forces confessions from patients who haven’t told him the truth, buttressing his credo that “everybody lies.”

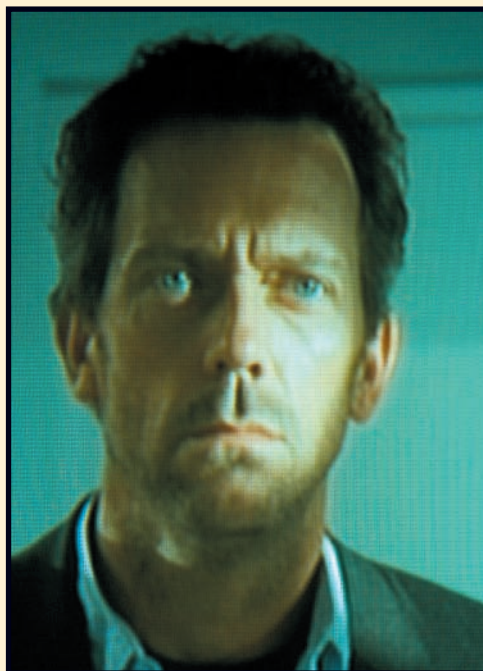
I kept waiting for a character to object. They occasionally disapprove in an off-handed way—Dr. House gets dragged before a few review boards, and once Dr. Cameron angrily quit (then came back for more punishment). But in the end, Dr. House gets away with all his breaches of professionalism, law, ethics, and plain civility because he is just too damn smart to let go. Perhaps his colleagues, who often collude with him in attitude and behavior, understand they’re swimming in this sea of cynicism and frustration together. If Dr. House is reprimanded or dismissed, their heads are on the chopping block next.

Unlike Dr. House’s fictional colleagues, my objections to his behavior were frequent and emphatic. “Outrageous!” I shouted from the couch when a doctor and surrogate collude to perform the very amputation the patient had clearly refused. “Impossible!” I scoffed when Dr. House lies to get his patient first on the transplant list. “No way!” I snorted when Dr. House comments to his boss about her “fun bags.”

“Mom, come on!” my daughter protested. “It’s just a story. Everyone knows doctors don’t act like that! Now please be quiet, I’m trying to watch.”

“You bet they don’t,” I muttered. “None of the doctors I know act like that. And if we lapse now and then, it gets noticed. And with any luck, formally censured.”

My daughter went back to watching, but I was churning. I hate sounding like a killjoy! I like a juicy drama, I know the difference between fact and fiction. So why does this show drive me crazy?



My daughter knows doctors don't act like that, but she was raised by two of them. Most people don't have her inside information; fewer than ever even have a doctor they've known over the years whom they can call "my doctor." I worry about what Dr. House, in my stead, is teaching my patients.

Gripping TV fiction can be powerful. Our professional organizations speak out against TV violence because it can negatively impact kids,¹ and research shows that television leaves viewers with incorrectly optimistic understandings about the efficacy of resuscitation attempts.² (No wonder our patients refuse a DNR status when TV has taught them that a simple little jumpstart would bring grandpa back to life.) So isn't it possible that a viewer who witnesses Dr. House's gleeful breast-ogling might put off having her suspicious lump checked? Or that *House* might convince a viewer struggling with substance abuse that doctors hate

medicine, or meet any doctors who model professionalism, *House* provides a powerful informal curricular message about what doctors believe and how they behave. Do medical students fear a *House*-like reaming when they can't come up with an answer? Might they be misled into believing that tight, low-cut clothing is appropriate for women doctors, and frank commentary on their appearance is an acceptable response from their male colleagues? Does the fact Dr. House scoped out a student by clandestinely reviewing her medical chart, then went on to date her, make them suspicious of their own professors? Could the show desensitize us to hearing patients called names, or watching physicians air personal disputes in front of patients?

Dr. House also champions an enormously dangerous inaccuracy. It is the professional who knows how to ask questions and listen deeply—MD, nurse, chaplain, social worker—who finally gets at the information that "solves the case." In real life Dr. House would pathetically miss most of the correct answers. Skilled clinicians know that even when you're feeling ornery and irritated, the disciplined practice of believing the patient and listening empathically will get you closer to answers than presuming patients lie. And even with the correct diagnosis, in real life Dr. House would miss the opportunity to treat. The glory of a great diagnosis is insufficient if the therapeutic relationship has been crushed and the patient has bolted. Bluster, insult, and cynicism make good drama, but they get us nowhere in our real lives.

Dr. House is right, oblivion is a state of mind to be avoided. That's why a central goal of medical education (which continues for all of us as life-long learners) is learning how to recognize, cope with, and hopefully overcome the dehumanizing features of medicine in the United States.⁴ We begin by naming the forces that get in the way,

and sometimes television is one of them. We need to be aware that television can subtly and powerfully invade the way we think about our patients and our profession, and the way our patients think about us. And that makes the task of creating trusting, therapeutic relationships even harder.

Kathy Neely is the Chair of the Northwestern Memorial Hospital Ethics Committee and Co-Director of the "Patient, Physician and Society" curriculum at Feinberg School of Medicine.

¹ American Academy of Pediatrics Committee on Public Education. Media Violence. *Pediatrics*. 2001;108:1222-1226.

² Diem SJ, Lantos JD, Tulsky JA. Cardiopulmonary resuscitation on television: miracles and misinformation. *N Engl J Med*. 1996;334:1578-1582.

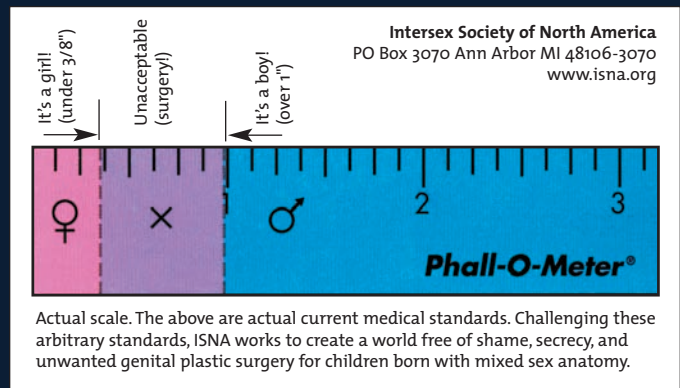
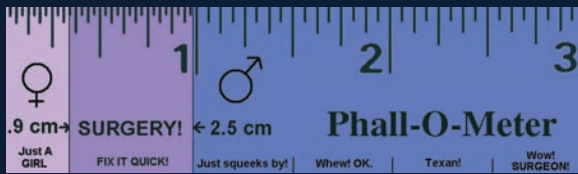
³ Hafferty FW, Franks R. The hidden curriculum, ethics teaching, and the structure of medical education. *Acad Med* 1994;69:861-871.

⁴ Coulehan J. Today's professionalism: engaging the mind but not the heart. *Acad Med*. 2005. 80:892-898.



addicts? Or that another kept waiting in the office might suspect his doctor is blowing him off, because *House* made it known that doctors consider patients insufferable idiots? The therapeutic relationship is the foundation of good medical practice. Under the best of circumstances it can be difficult to build; Dr. House seems intent on demolishing it.

I also worry about the way television drama affects medical students and faculty. During the heyday of *ER*, Emergency Medicine programs enjoyed a surge of residency applicants. Thousands of career choices launched by a TV show! Does *House* pack a similar, but negative punch? Medical educators understand that we are taught by both an explicit "formal curriculum" and an "informal curriculum" that's observed and tacitly internalized. The informal curriculum is far more powerful in shaping our professionalism than the formal curriculum.³ I worry that before medical students get any sort of context for the practice of



The Phall-O-Meter: Political Art and Visual Power

Art can play a powerful role in medical discourse. For example, in 1987 six AIDS activists harnessed art's ability to communicate a rhetorical point in a single glance by placing the phrase "SILENCE=DEATH" under a pink triangle. When ACT UP adopted the image, it served as both rallying cry and explanation for ACT UP's mission.

In the early 1990s, intersex activists began a movement of their own, working together to change the medical treatment of children born with sex anatomy different from that considered standard for males or females, and the Intersex Society of North America (ISNA) was founded in 1993. (MH&B faculty member Joel Frader is the current chair of ISNA's Medical Advisory Board, and Tod Chambers is a member.) In the mid-1990s feminist sociologist Suzanne Kessler suggested a simple visual aid to illustrate how surgeons decided which phalluses required "surgical correction." Kessler's idea inspired intersex activist Kiira Tria to create

the first "Phall-O-Meter," a laminated actual-size ruler satirizing surgical decisions to resolve indeterminate sex. "I wanted to make it sort of humorous because it is such a horrible, serious thing," Ms. Tria says. "I thought it would be easier for people to look at and think about that way." ISNA mass-produced Ms. Tria's rulers and distributed them far and wide. MH&B faculty member Alice Dreger remembers handing these out to surgeons, academics, potential activist allies, and perfect strangers on airplanes.

After a decade of work, intersex activists gained standing within the medical discourse and ISNA chose to tone down the original Phall-O-Meter. Around 1999 Ricki Wilchins designed a new version formatted as an ISNA business card. Several copies of the original Phall-O-Meter are now included in a Smithsonian collection on the intersex rights movement.

—KW & AD

("Sterilization" continued from page 19)

it to be treated like any other guardian medical decision. In those states, if the guardian can find a physician who agrees it's in the ward's best interest (or, sadly, can find a physician who will ignore this standard), the guardian can impose sterilization on a non-assenting ward without court approval.

Illinois is a state with no specific legal standard for sterilization of cognitively impaired wards, which means many cases like this begin and end in the doctor's office—just like Mary Stainton's back in 1973. However, some Illinois physicians and hospitals refuse to sterilize someone who can't give personal consent without a court order, a wise move that can add an extra layer of protection. Ms. M said if she were to marry a man who could help parent she would like to have a child someday, but her guardian persisted in her desire for a court-ordered tubal ligation. Equip for Equality represented Ms. M free of cost, and MH&B faculty members Katie Watson, JD and Kristi Kirschner, MD also volunteered their time to her case.

In an interim order the Probate Judge favored the guardian's position, ruling that it was in Ms. M's best interest "to have a permanent form of birth control." The judge was persuaded by several people who testified Ms. M would not be able to care for a child alone (despite the fact this means people with disabilities are the only group in America

who must submit to a "parental litmus test"), and that he believed Ms. M "would suffer irreparable psychological damage" if she had a child who was taken away because of her inability to care for that child. The only thing that prevented the judge from granting the petition for sterilization (as distinguished from "permanent" contraception, a murky distinction) was the testimony of Northwestern ob/gyn Cassing Hammond MD. In response to Dr. Hammond's testimony about alternate forms of long-term contraception, the judge ordered an evaluation by an independent gynecologist. Because that physician ultimately recommended birth control pills, the guardian's petition for sterilization was denied. Sadly, the cost of this resolution was a year of sometimes acrimonious litigation between family members living in the same house, and a bill from the guardian's lawyer that Ms. M had to pay—thousands of dollars of the award she received in the lawsuit over the car accident that left her impaired were taken out of her trust fund.

Equip for Equality and the MH&B Program hoped this case might create a legal standard governing involuntary sterilization in Illinois. It hasn't to date, but if the guardian appeals, it still could. The MH&B Program is also supporting Equip for Equality's investigation of legislative initiatives.

—KW

ALL BIOETHICS QUESTIONS SAVE ONE ARE MOOT

Tod Chambers, PhD

In the 1980s Jesse Jackson appeared in a *Saturday Night Live* sketch called “The Question is Moot.” Jackson played the host of an ostensibly pedestrian television game show, yet whenever the contestants tried to answer relatively benign questions, such as when Haley’s comet would reappear or who is on the one hundred dollar bill, Jackson would immediately respond, “The question is moot,” explaining that no one will ever see Haley’s Comet again because of the coming nuclear holocaust and that few Americans ever had the opportunity to see a hundred dollar bill under the Reagan administration.

I have noticed a form of “the question is moot” in bioethics. Inquire into the ethics of face transplants and you may be told that such concerns seem trivial when most people in the United States do not have access to basic health care. Ponder whether animals have rights and you may be told that one should first be concerned that most humans in the world are being denied fundamental civil rights. Ask about the status of the embryo and you may be told that one should be more interested in the needs of impoverished children already in existence. The appeal to social justice has become a powerful trump card in bioethics, a way of saying that regardless of the question, if it does not concern social justice, the question is

moot. As in the examples above, its rhetorical turn lies in creating a parallel construction that from its accuser’s point of view seeks to return the conversation to what is most important: we do not need enhancement technology for individuals but primary medical treatment for all, we should not be concerned with caring for potential children for the wealthy but for present-day children of the poor.

One could speculate that there resides in much of bioethics a profound guilt over the field’s neglect of that fourth moral principle. I suspect many American bioethicists would not even notice if the principle of justice were to give up and depart for another country. Yet curiously, for all its abuse, playing the justice card seems to possess the power to immediately silence the discourse on all other moral issues to which it has little to say. The use of justice in such examples entails a form of misdirection, and becomes like the guide in Robert Frost’s poem “Directive,” “Who only has at heart your getting lost.” The power of the call to justice in these instances resides in its belittlement of all other concerns in bioethics, its establishment not of a hierarchy of values but of a radical dichotomy between what is important and what is trivial, what is worth scholarly attention and what is simply navel gazing. Unfortunately, when used this way, the power of justice lies not in the principle, but in its rhetorical use to silence whole segments of our field.

Katie Watson, Editor. k-watson@northwestern.edu.

The next issue of ATRIUM will accept unsolicited submissions. The theme will be “Heroes and Villains.”

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Medical Humanities and Bioethics Program
Northwestern University
Feinberg School of Medicine
750 North Lake Shore Drive, 6th Floor
Chicago, Illinois 60611
www.medschool.northwestern.edu/mhb

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