

Issue 9

# ATRIUM

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The Report of the Northwestern Medical Humanities and Bioethics Program

## BLACK AND WHITE



## About the Cover: THE WHITE CROW

A third-year medical student (M3) recently emailed a clerkship director: “After the ethics conference last Thursday, I see that (like all things in ethics) there really is no right answer.” The clerkship director says he hears this from M3 and M4 students all the time, and I struggle to understand why. By pushing medical students to see the gray, do we blind some of them to the black and white?

William James was a Harvard professor who studied and taught medicine, psychology, and philosophy. In a lecture in 1890



James said, “To upset the conclusion that all crows are black, there is no need to seek demonstration that no crow is black; it is sufficient to produce one white crow; a single one is sufficient.” (James was investi-

gating whether the living could ever communicate with the dead. He referred to Leonora Piper as his “white crow,” the one medium who confounded the conclusion that all mediums are frauds.)

I didn’t know white crows existed until a colleague mentioned James’s assertion. I’ve only seen black ones—or perhaps I *have* seen a white crow, but since I didn’t know they existed I didn’t recognize it as a crow, and categorized it as a different bird altogether.

Intransigent ethical dilemmas are the black crows of medical school; flocks of them roost in ethics syllabi. But following James’s logic, we only need to show one ethical question that has a “right answer” to debunk the M3’s blanket statement “In all things in ethics there really is no right answer.”

What’s the white crow of ethics? Actually, there are many, but they’re not always recognized as crows. When ethics concepts become deeply entrenched and widely accepted they stop feeling like “ethics.” Consensus shifts topics like confidentiality or informed consent into categories like “law,” or “standard medical practice.” Yesterday’s ethics controversies are today’s multiple-choice questions: 30 years ago students might have left an ethics discussion of whether granting a terminally ill patient’s request to disconnect the ventilator was mercy or murder thinking, “there’s no right answer.” Today that’s more a question of good medicine, communication, and procedures, and the ethical debate has shifted to physician-assisted dying. But does that mean a competent patient refusing lifesaving medical care is no longer an “ethics issue”? They stop looking like crows when they turn white.

From a practice perspective, I think this is great—when ethics becomes ordinary, ethics wins! From a pedagogic perspective, it may be contributing to a category error in which ethics is only associated with controversy. We teach consensus concepts, but as soon as the rule is introduced many of us focus on cases that provide challenges or exceptions to the rule, because that’s the interesting stuff. But maybe we should be more careful to point out the white crows before unleashing the black ones.

The clerkship director’s interpretation of “there really is no right answer in ethics” is that some students believe “all answers in ethics are equally right.” We try to teach there are always wrong answers, there are often best answers, and (as I’ve argued above) occasionally even right answers in ethics, yet some students are still swinging from rigid rule application to unfettered relativism.

Perhaps ethics consultation should inform ethics teaching. Ethics consultants debate whether or not their consults should end with recommendations, and I’m on the “yes” side of that debate. When decisionmakers ask people with professional expertise for counsel, I think we owe them the firmest conclusion we can offer and transparency about the reasoning that led us there.

So why don’t I use the same approach when I’m teaching medical students? Pondering this M3’s email, I realized I rarely offer physicians-in-training my own conclusions, either on the broad topics we study or the narrow cases we use for illustration. I push students to articulate their own arguments and conclusions because I think it’s enlightening for them to hear how differently peers sometimes view the same thing, and I often choose reading that conveys divergent expert perspectives. The only conclusion that seems to be off-limits to me in these discussions is my own. But by failing to disclose which student or expert arguments and conclusions I find most persuasive, by failing to model reasoning-to-recommendation in ethics, I may have unwittingly contributed to a hidden curriculum teaching that in ethics “there really is no right answer.”

The provocation of “Black and White” drove many of this issue’s authors to complexity instead of clarity, and that makes sense—sophisticated thinkers are often drawn to the gray. But let’s not let the challenge of the gray completely eclipse the pleasure, and the necessity, of the black and white.

—Katie Watson, Editor

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**The Northwestern MH&B Program is pleased to announce it has received an endowed chair. Congratulations to Kathryn Montgomery, Julia and David Uihlein Professor of Medical Humanities and Bioethics.**



“Heart of Darkness” sketch by Ben Walker

# Speaking of Black and White

Kathryn Montgomery, PhD

At the heart of Joseph Conrad’s *Heart of Darkness* is a blinding, incapacitating whiteness. It’s fog: impenetrable, unrelenting, and, above all, terrifying. Out of its menacing presence comes a warning attack on the steamboat carrying Marlow, the novel’s storyteller, up the Congo River and into the ambiguities of light and dark, white and black, that make up Western colonialism (Oxford World’s Classics [1899] 2008, pp. 143-47).

What’s not ambiguous, however, is the Manichean imagery Conrad draws upon. It pervades our culture. An ancient Persian religion, Manicheism posited a struggle of the forces of light and goodness against those of darkness and evil. In the fifth century CE, Augustine imported this light-dark duality into Christianity, where it fit well with neoPlatonism. There it’s been ever since—through the Dark Ages (a label now discredited), through the Enlightenment (a label under intellectual suspicion)—deeply embedded in our language and imagery. It’s as little discussed as race, with which it’s very much entwined.

Manichean imagery is central to John Milton’s *Paradise Lost*, where Satan, the apostate angel cast out of heaven, first glimpses hell:

A dungeon horrible, on all sides round,  
As one great furnace flamed; yet from those flames  
No light; but rather darkness visible....  
(1667, I, 61-3)

Less spectacular but no less powerful is our everyday use of light and dark. My morning meditation exhorts me to inhale life and light, exhale death and darkness. Villains are said to have “dark purposes,” to have gone over to “the dark side”—unless, of course, they “see the light.” A look at the *New York Times* on a random day turns up an article headlined “Gangsta Folk” and subtitled “Keren Ann sings softly... of the dark side” (March 13, 2011 p. 24). In addition, the pedestal to which women historically were consigned is engraved with Manichean light and its extension, whiteness. Look at the three generations of Isabel Allende’s heroines in *The House of the Spirits* (1982): Clara, Blanca, Alba. And this isn’t only a Latin custom. In other languages, other cultures, there are Alina, Blanche, Eleanor, Helen, Lana, Lucinda, Phoebe, Svetlana, Uma. Starlight stretches the list only a little: Stella, Esther, Estelle. All are children of light.

Perhaps most surprising, until we remember the Augustinian Christian connection, is Martin Luther King, Jr.’s use of Manichean imagery. In his 1963 *Letter from a Birmingham Jail*, racism, segregation, and prejudice are all imagined as darkness. Dr. King laments “the dark depths of prejudice and racism” and “the stinging dark of segregation” and commends “bruised and weary Negro men and women [who] decided to rise from the dark dungeons of complacency to the bright hills of creative protest.” Even though *Letter’s* intended audience was the Southern clergy, none of these uses has any explicit Christian reference. They are the customary, color-struck uses of American speech.

(continued on next page)



The use of light and dark for epic purposes did not end with the Civil Rights movement. Since then, *Star Wars* has given two generations in the U.S. and beyond both the death-dark Darth Vader (voiced by the African American actor James Earl Jones) and lightsabers, about which the film's Web site states, "To carry a lightsaber is an example of incredible skill and confidence, dexterity and attunement to the Force" (<http://www.starwars.com/databank/technology/lightsaber/>; accessed December 13, 2010). Harry Potter's universe is only slightly more nuanced. It is, after all, the Dark Arts he must learn to defeat.

We think with images of light and dark, especially when we aren't particularly thinking *about* them, and extend them all too easily to a binary symbolism of black and white. Good guys wear white hats, bad guys black ones; angels are robed in white, devils cloaked in black. There are "black markets," "little black clouds," the workings of "black magic." Lies and lists are "black" or "white." Consciences and hearts—even souls—are described as black with wrongdoing or pure as the driven snow. In Spike Lee's 1992 film, *Malcolm X*, the conversion of the future leader of the Nation of Islam begins when a wise older inmate points out the implications of the black-white dichotomy for African Americans. "Did you ever look up the word 'black' in the dictionary?" he asks, and the screen fills with words as Malcolm reads. White is "pure...free from spot or blemish, innocent without evil intent, harmless, honest...." Black is "destitute of light...soiled, foul, hostile, forbidding, savage...outrageously wicked, indicating disgrace, dishonor or culpability," all illustrated with "blackmail" and "blackguard." Malcolm's astonished, life-changing conclusion is, "This was written by white folks!"

These days, that black-white binary seems to be as taken for granted as the Manichean one it has become a part of. "Black Friday," for instance, is no longer the October day in 1987 when the stock market crashed but the annual shopping day after Thanksgiving. Because that single day constitutes a "thirteenth month" that can keep retailers out of the red, the label originally was an almost literal reference to a store's sales ledger. But what with crammed malls, impossible traffic, and a salesclerk trampled to death, the term has taken on a Manichean meaning—so much so that its red-ink opposite is often forgotten.

The evil of blackness and the beauty of whiteness are embodied not only by the swans in the nineteenth-century ballet *Swan Lake* but also in differing contemporary views of dance itself. Is ballet an ethereal evocation of the human spirit or an obsession that damages the psyches as well as the bodies of its performers? The title of Jennifer Homan's well received history of ballet *Apollo's Angels* (Random House 2010) suggests the first, while *Black Swan*, the recent film starring Natalie Portman, portrays ballet's "dark side." Debate may rage about the meaning and value of the art form, but no one questions the colors used to conduct it.

If you've read this far, you've surely thought: But wait! Those images (and certainly the names our parents gave us, the names we give our daughters) aren't meant to be racist! And you're right. But the black-white duality nevertheless

works in a racist way. I've seen dark-skinned people object to its implications and light-skinned people take offense at the suggestion that the imagery is racist and decide that dark-skinned people are too sensitive. Get over it! A light-skinned person might be tempted to say. Focus on my intention, which was never racist! But "sticks and stones may break my bones, but words can never hurt me" is a wishful defense, for in truth words shape belief, condition behavior and, even in the absence of explicit intent or purposeful behavior, possess the power to crush the spirit.

Yet how can we possibly avoid imagery that is inextricably part of our culture? I've puzzled over it since I first taught Nathaniel Hawthorne's "Young Goodman Brown," whose Puritan hero is led at midnight to a witches' Sabbath by a mysterious "sable form." Always beneath the black-white binary lies the contrast of night and day—scary dark and clear sunlight—a diurnal arrangement that (unless you live near the poles) is not going to change much. But artificial lighting may have exaggerated our aversion to the dark. Historians of medieval European have fascinating accounts of the lively social activity that went on before we lit up the night (see, e.g., A Roger Ekirch, *At Day's Close: Night in Times Past*, Norton 2005). Dark then was distinguished from day by freedom from physical labor. That era's "good night's sleep," unlike ours, was segmented, interrupted by neighborly visits, storytelling, courtship, and games.

But even if the light-dark duality is in some sense "natural," the links we assume between light or white and goodness and between darkness or black and evil are not. And nothing authorizes the link between Manichean imagery and skin color. From Herodotus to hip-hop, the meaning of the black-white dichotomy has often been reversed. In ancient Greece northern Europeans were pale and savage while Egyptians and other Mediterranean people were dark and civilized. For darker-skinned people, white is often the color of death. Jews carried that association into the diaspora; Hindu widows wear white. In *Harper's Weekly* in the mid-nineteenth-century, Thomas Nast's cartoons caricatured Americans of African descent right along with everyone else, but depicted the recently arrived Irish as savage apes. (Nast himself was a German immigrant, part of a group then poised precariously in the "white" column.) A century later, James Baldwin took note of the evil inherent in Roman bishops blessing Mussolini's Italian troops as "forces of light" as they set out to conquer Ethiopia (*Notes of a Native Son*, Library of America 1998 [1955] pp. 307-08). A white friend reports that as a Peace Corps volunteer in midwestern Nigeria he was taunted by children gleefully calling him "oyibo"—"peeled man"—at every opportunity, while Jay Allison, the master narrator, has described radio storytelling as "dark and intimate." Above all, black was declared beautiful in the late 1960s and so it became.

Still the links persist. Cultural shifts in the symbolic meaning of other colors have been more successful. Is it because, although value laden, they have nothing to do with good and evil? Or nothing to do with race? Victorians dressed boys in warm colors, including pink, and girls in cool ones, often blue. However that gendered

color scheme came to be reversed, the current version was initially applied primarily to infants' clothing. The wall-to-wall pinkification of girls' toys and clothes occurred only after a valiant attempt to introduce same-sex gear in the 1960s. A far more surprising color-shift is the designation of Republican states as red and Democratic ones as blue. How did this happen when so many people still alive still associate red with the Communist party?

The attempt to alter the meaning of black and white imagery is political, of course, because the equation of white with good and black with evil is a public as well as a private concern. But reversal does not work very well because it continues the narrowness of binary thinking. Elijah Muhammad, founder of the Nation of Islam, taught that white people were created as "a devil race—a bleached out race of white people" (*The Autobiography of Malcolm X* as told to Alex Haley, Ballantine 1984 [1964] p. 165). Indeed, the assassination of Malcolm X may have been motivated by his turn toward a more inclusive, multi-racial Islam. The far more successful assertion that black is beautiful was achieved without denigrating whiteness. Yet fundamental change, or even acknowledgment of the complexity of the terms, never quite takes hold, perhaps because so many of us don't talk about the use of color symbolism—or deny that it matters when we do.

The odd thing is that most people, especially in the United States, are neither black nor white. African Americans confront this whenever they visit Africa; in Arthur Penn's 1970 film, *Little Big Man*, nineteenth-century Native Americans describe them as "black whitemen." Lately I've been noticing the progressive "people-first" label "person of color," borrowed from the pre-1870 census category "free person of color." Certainly the term is useful, pleasant to the ear, and more inclusive than "black." And maybe it makes sense: with skin that hardly ever tans, I've certainly felt my relative colorlessness. It's a condition best described in Mark Twain's *Huckleberry Finn* as "fish-belly white" (Penguin Classics 2002 [1884], p. 30). But isn't that a color? Like Cyril Fielding, the English protagonist of E.M. Forster's *Passage to India*, those of us not "of color" might devise a more accurate description of ourselves—although Fielding's attempt alienates him from his fellow colonialists:

The remark that did him most harm at the Club was a silly aside to the effect that the so-called white races are really pinko-gray. He only said this to be cheery, he did not realize that 'white' has no more to do with a colour than 'God save the King' with a god, and that it is the height of impropriety to consider what it does connote. The pink-gray male whom he addressed was subtly scandalized; his sense of insecurity was awoken, and he communicated it to the rest of the herd (Penguin Classics 2005 ed. [1924], p. 57).

This is important to our understanding of Fielding's character and to the novel's conclusion, but to people who are not "of color" it's likely to seem trivial.

Yet if pinko-grays are not people of color, then "white" goes on being the uninflected norm from which everyone else deviates. It's like the 70-kilogram man that served as the "normal" human being in clinical research and medical textbooks for so many years that the designation often was left unstated. The rest of us—thin men, fat men, all women, all children—were deviants, special cases, and as a consequence were scientifically neglected and sometimes poorly cared for. "White studies," the shockingly named academic inquiry that at first sight seems to portend battle-flag waving racism,

attempts to de-normalize whiteness by studying the history and sociology of its construction. Besides reading Nell Irvin Painter's eye-opening study, *The History of White People* (Norton 2010), what are we to do? I have two ideas, both of which involve a more conscious use of language.

The first is precision. We can avoid a thoughtless default to the black-white/dark-light binaries when other words are more exact or more vivid. When the impulse to call something "dark" or "black" arises, we can ask whether the thing described is gloomy, forbidding, or desolate. Is it destructive or false? Perhaps it is threatening, grim,

or frightening? Mysterious, unknown, or unexplored? Or is it simply evil? Say so! Our writing and our conversation can benefit from considering whether that "little black cloud" that follows us around occasionally really might be gray or heavy. To default to "black" may be useful shorthand—but for what? Our own sadness or depression? A sense of doom?

Likewise, when something seems white or light, what is it really? Innocent? Good? Open to scrutiny? Does it represent knowledge, understanding, beauty? An ideal or the sacred? Whatever it may be, it surely it deserves a more precise description.

And is the thing described really black or white? "Black eyes" are often purple, then interestingly yellow and greenish. "White lies" are no color at all, nor is the register of economic institutions in good international standing in any real sense a "white list." Likewise, the "black market" isn't black—and sometimes it's not even a market: "underground economy" is both more precise and a livelier, less clichéd description. "Black humor" is more accurately and therefore more suggestively labeled "gallows humor." The one admirable thing about Richard Nixon's vengeful record-keeping is that what it produced was called "the enemies list."

Now I'll admit that precision isn't always desirable; as every reader of poetry knows, indeterminacy can be useful. Take Carl Elliott's excellent *White Coat, Black Hat*, an account of the pharmaceutical industry's corruption of U.S. physicians in more ways than we knew (Beacon 2010).

(continued on page 23)



Gustave Doré, *Depiction of Satan, the antagonist of John Milton's Paradise Lost* c. 1866

# Thinking in Color

Greg Loeben, PhD

Forget your perfect offering,  
there is a crack in everything,  
that's how the light gets in.

—Leonard Cohen, *Anthem*

When I look at old pictures or films I sometimes have to remind myself that the world wasn't actually black and white—that the people in those images lived in color just as we do today. It's odd, but when I remember this something about the images and the people in them changes. They become more alive, more whole. Actually, it's something about me that changes. Something I thought I knew, some type of certainty dissolves and my thinking becomes richer and more open.

Most of my students see medicine in black and white when I first meet them. I teach ethics to a wide range of health professional students: occupational and physical therapists, pharmacists, perfusionists, podiatrists, dentists, physicians, and physician assistants. There is no single type of person that enters these programs, though in the early didactic portion of their training the majority share a common perspective: there are facts and there are values. Facts are real, values are something else; facts are provable and scientific, values are personal and there is no correct answer about them. Of course, it goes deeper. Most assume that disease, illness, and health are essentially factual biological categories. They believe that medical education will teach them the truth about these things. They know that truth is something real, to be discovered and/or known independent of perspective. They find it hard to believe that standards of practice can be inconsistent across geography, that we don't have good evidence for many things we do, that powerful economic forces drive and shape the medicine they are learning. And so on. They are fond of the saying that medicine is both a science and an art, but they see medicine and their education primarily as science, and they see science as factual, objective and neutral.

Why? For one thing, it's what they've learned—or haven't learned—in school. Many of them have little experience with courses that require deep critical or creative thinking, communication skills, or conceptual analysis. Their undergraduate educations are primarily science-based, and many have taken only one or two meaningful non-science classes that might explore these issues. They haven't had courses, or even discussions, about the nature of science or medicine. They are very good at memorizing and reading to memorize. They are good at looking for facts, for pieces of information that they need to repeat on a test, but they are not as familiar or as comfortable with analysis, interpretation, discussion, and argumentation. They want to know the right answer and they are uneasy with learning that explores shades of gray.

Sadly, little in their current programs requires them to deviate from this model. The information they are required to learn is certainly complex and there are amazing quantities of it. But little requires or encourages creative critical thinking. Routines dominated by PowerPoint lectures, memorization and multiple choice tests almost require them to function in black and white. Most perceive shades of gray as a diversion they do not have time for.

In ethics class, I ask what they think about the readings and they aren't sure what I'm asking. They are uncertain about what they've read and what they are supposed to remember. I tell them to read for understanding not memorization, to look for meaning, to see if they agree or disagree with the points being discussed. They aren't confident about what to say because they aren't sure what counts as a good answer in this context. I tell them to rethink what makes a good answer. There are better and worse answers to even the vaguest of questions. Is your answer interesting? Does it capture anything important? Does it have any depth? Does it shed light or expose confusion? Does it require you to understand yourself or others better? Does it play or tease or dance with the reading?

I give them Billy Collins' "Introduction to Poetry."

I ask them to take a poem  
and hold it up to the light  
like a color slide

or press an ear against its hive.

I say drop a mouse into a poem  
and watch him probe his way out,

or walk inside the poem's room  
and feel the walls for a light switch.

I want them to water-ski  
across the surface of a poem  
waving at the author's name on  
the shore.

But all they want to do  
is tie the poem to a chair with rope  
and torture a confession out of it.

They begin beating it with a hose  
to find out what it really means.

The transition is not easy. They want information that has obvious clinical application and it is tempting to show them my relevance with lots of facts that I can test for. Some of this is important of course, but too much and most will be discarded with the rest of their short-term memory. They need something different, something challenging that will remain, seeds that will continue to grow after the too short time we have together in class.

I have them read Michael Pollan's article, "Unhappy Meals," in which he discusses the way we think about food and nutrition, and how our views are shaped by powerful social, economic and political forces. Most are surprised how they never thought about it from that perspective. I ask them if medicine is similar and together we see that in many ways it is. Some color seeps into their thinking.

I ask what it means to say that medicine is both science and art and we read "The Misdescription of Medicine" by Kathryn Montgomery. We talk about medical power and read "I Thought I Was the Only One" by Alice Dreger and "Authority" by David Hilfiker. We discuss autonomy and choice and read "Shopping for Long-Term Care" by Deborah Stone. We consider whether



illness is fundamentally biological or social and read Carl Elliott's "A New Way to Be Mad." Each article and discussion pushes them into unfamiliar territory. I say that while these readings might not provide obvious answers to clinical dilemmas, I want them to be chefs rather than cooks. Where others enter the kitchen and see eggs or mustard or onions, they should see ingredients, flavor profiles and cooking techniques. We want a deeper understanding so that we can be as flexible as possible with whatever components the case presents. The metaphor throws light and the color grows richer.

So I push further. The point about black and white thinking, I tell them, is that it's about categorization, our need to put things into boxes by which we understand them, make sense of them, and make them more manageable. Humans are remarkably adept categorical organizers and it contributes powerfully to our success and flourishing as a species. Huge amounts of thinking can be bypassed with a good classificatory scheme, and we can create layer upon layer of categories. But despite this complexity, it is still essentially black and white thinking because it is the imposition of discreet borders upon what is essentially continuous. Black and white may give way to red, yellow, orange, green, purple, but these are just alternative categorizations. More subtle and complex perhaps, but still likely to limit, constrain or distort the reality they seek to make sense of. There is always more to be seen and understood than the categories admit.

Of course, categorization is essential to our survival. It imposes a structure that benefits us immeasurably, and it captures something meaningful and important. But for health professional students overly accustomed to and dependent on such categorizing, there is great value in seeing that it often also imposes something limited and incomplete, a rigidity and certainty that is at odds with what it seeks to capture. That categories are sometimes simply inaccurate.

We read "Yes to Blue" by James Haba:

Yes to blue after trying  
to separate green from yellow  
and hoping that everything  
will get simpler each time  
you bring an idea closer

to the light which is always  
changing always being  
born  
day after day  
year after year  
again and again  
now.

Slowly, students begin to evolve. It is growth, a form of maturation. They are developing emotional and intellectual abilities necessary to deal with the complexity they will face in the world of medicine. And it connects them with that world. It enhances their understanding of the clinical context in ways that many of their other didactic courses do not. They feel closer to being a practitioner, which makes learning and memorizing the scientific information of those other classes easier and more meaningful by helping to provide context for it. I tell them the greatest limit on their ability to explore the ethical dimensions of medicine is the assumptions they barely notice and rarely challenge. I want them to question what they think they know. I confront them, disagree with them, argue with them. At first, many find this uncomfortable, destabilizing. They are surprised by the limits of the way they think and see things, by their inability to communicate their thoughts clearly. It is painful for them in some ways, but I remind them over and over again that this will help them be better healers.

We read Katha Pollitt's "Lilacs in September" and I tell them to think of the experience of illness, though I know they will see themselves in it as well.

Shocked to the root  
like the lilac bush  
in the vacant lot  
by the hurricane—

whose black branch split  
by wind or rain  
has broken out  
unseasonably

into these scant ash-  
colored blossoms  
lifted high  
as if to say

to passerby  
*What will unleash  
itself in you  
when your storm comes?*

Growth in the face of adversity. Illness as opportunity for growth. A few comments and suddenly we are discussing the need to challenge what one thinks in order to make room for new understanding. This too becomes a lesson and a component of the transition in their thinking. Color is breaking out of their black branches. Will it hold and continue to mature? For some it will. For others, the roots might not be deep enough and their time in this light may be too short. But for many there is no going back. "It was like seeing in black and white" more than one has told me. But then something changed, something they thought they knew. Some type of certainty in their thinking gave way, and what seemed so simple and clear blossomed into something richer and more open.

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# ECONOMY

*“My accounts, which I can swear to have kept faithfully,  
I have, indeed, never got audited,  
still less accepted, still less paid and settled.”*

(Henry David Thoreau, *Walden*)

Joanne Jacobson, PhD

My mother can drive to the doctor or the grocery store, but she cannot drive at night or in snow. Probably she shouldn't be driving at all, but she can't agree to give up her independence.

My mother can go on every day, even when she feels tired or chilled or discouraged—dressing herself and taking medication for the arthritis in her hip and back and neck and for high blood pressure—but she cannot beat back completely the respiratory infections that keep recurring and turning into pneumonia, more serious each time.

My mother cannot leave her apartment without an oxygen canister, but she can breathe on her own wherever she goes if she sits in a chair or on a sofa.

My mother cannot hear the conversation at the dinner table if she doesn't wear her hearing aids, and she cannot follow what others are saying unless they speak slowly and loudly and are prepared to repeat. She cannot wear hearing aids when her oxygen apparatus is hooked over her ears.

My mother cannot bend down to tie her own shoes, but she can make vegetarian chopped liver and cream of broccoli soup, and she can bake raspberry squares from the recipe that she's been using since I was a kid. She cannot always keep her grandchildren's birthdays straight, but she can still manage the old Scrabble strategies, coming up with six-letter words and boosting her score by building across the board on the colored double-letter and triple-word squares.

My mother can go to my sister and brother-in-law's house and sit drinking seltzer under the grape arbor they just built in their backyard, but she cannot stay outside if there's wind. And she cannot fly alone from Chicago to spend the month of January in warm Phoenix again with her lifelong friend Clarice.

My mother can watch the birds shift with the seasons through the picture window in her living room, but she cannot return to Costa Rica, where we were lucky enough to catch sight of the Resplendent Quetzal through a field telescope—*Can a bird draped in green, thick and lush as ermine, be real?* we asked one another in wonder—or to Sanibel Island, where we watched flocks of anhingas and gulls jam the scarlet, low-hanging sunset sky.

My mother can have Thanksgiving dinner with my sister's in-laws, an hour's drive from her house, and she can spend Passover at her nephew's, a mile away. But she cannot catch all the words of the Four Questions chanted in the reedy, hesitant voice of the youngest at the Seder table. And she cannot any longer travel to Minnesota for the weddings and birthdays and bar and bat mitzvahs of her nephews and nieces, or to lay flowers on the grave there where they buried her sister thirty years ago at the age of fifty-two after ten long, killing years of cancer.

My mother can never visit me in New York again. My mother cannot understand why my sister and I don't use coupons at the grocery store; why her downstairs neighbor blocks the driveway when she parks or her upstairs neighbor has so many packages delivered; why American politicians don't tell the truth—or why her own twin sister hardly ever calls her yet continues to complain that my mother doesn't call her! But she understands that her daughters are worried. She knows that we're measuring the strength of her voice over the phone, that we're checking with one another about her, that we're not completely convinced that she's okay.

My mother can arrange to have her apartment redecorated, she can select paint colors for four rooms and she can order fabric for new floor-to-ceiling drapes, but she cannot ask her doctor the hard questions: *Why doesn't your office return my phone calls? Will I be able to go outside this winter?*

I can fly home when my mother ends up in the emergency room, straining for air, but I can't provide the patience for the long process of recovery from pneumonia—for the labored three-minute walks from her hospital room to the nurses' station with which she must slowly start, even though only a week before she was pushing her own cart through the grocery store. I can help my mother sort her bills into piles, paid and unpaid, on the dining room table: her monthly condo fees and electricity and water and heat; the contributions that she makes to her synagogue and to agencies committed to rebuilding progressive politics in Israel and to combating hunger all over the world. But she won't let me show her a better way to organize the pills that she deposits each morning into a discolored plastic container top on her kitchen counter, where they roll around the rim like a children's puzzle.

How can it take so long for my mother to get ready to go outside? I try not to count the minutes as she showers and decides what to wear; as she pulls up her socks with the long shoehorn on which she depends because of her arthritis; as she puts on her plastic mask and inhales medicated mist; as she makes breakfast and eats it; as she puts all the dishes in the sink and she wipes her placemat; as she fills her oxygen tank and she grabs the stamped mail; as she braces for her first cautious breath of chill, hurting air. My mother is no longer strong enough to clean her apartment, and she claims that she doesn't have the time to look for help or the money to pay for it. I try to convince her otherwise—she has plenty of both!—first reassuring and then squabbling with her, until both of us are weary although nothing is settled; until it's hard to remember love.

*Joanne Jacobson's writing has appeared in such publications as Fourth Genre, New England Review, The Nation, BOMB, and Iowa Review. Her memoir Hunger Artist: A Suburban Childhood appeared in 2007, and she is currently working on a creative nonfiction project about her mother's chronic respiratory illness and end-of-life issues. She teaches American literature, American studies and creative writing at Yeshiva College in New York City. jacobson@yu.edu*

**Confidentiality & Consent Disclosure:** The author has withheld the name of the family member described and quoted in this article, but no details have been altered. The author has told this family member that she is featured in the author's ongoing memoir project, but the author chose not to ask this family member permission to publish this essay. The author understands this to be her story as well, and therefore believes permission is not required.



# *Negotiating the Gray:*

## Contemplating Zones of Possible Agreement in Clinical Ethics

*Mathew David Pauley, JD, MA*

The job posting for my current position as a clinical ethicist listed “tolerance for ambiguity” as a prerequisite for competitive candidates. I noticed similar language in other ethicist job descriptions: hiring institutions stressed being “able to work in uncertainty,” and “comfortable in the gray” as a crucial trait for their ideal applicant. Presumably, hospitals are looking for clinical ethicists who are comfortable in gray areas so ethicists can help others navigate out of them. But that navigation often requires more than clarifying ethical issues and communicating hard-to-digest information. Ethics consultants must be able to provide guidance not only when there are opportunities for mutual agreement, but also when the interests are so black and white that agreement will not—and should not—occur. This requires recognition of basic negotiation principles.

The clinical ethicist is like a sailor in the crow’s nest of a ship lost in fog. Thorough investigation gives the ethics consultant a far-reaching perspective on the patient’s undeniably rocky hospital course. The sailor in the crow’s nest wants to help the ship’s captain make it through the fog with as little loss as possible; yet the sailor also bears the responsibility of letting the captain know when the peril of continuing the journey is too great. Value conflicts often operate the same way. The difference between the rocky-yet-navigable moral conflict and the uncompromising dilemma can be understood in terms of Zones of Possible Agreement.

*(continued on next page)*

## Negotiating the Gray:

Contemplating Zones of Possible Agreement in Clinical Ethics (continued from previous page)

A Zone of Possible Agreement, or ZOPA, is the range between the least that one person is willing to accept and the most the other person is willing to give. Futility conflicts take this form: patient surrogates demand a minimum level of treatment, and physicians decide whether this goes beyond what they consider appropriate. Provider-patient bargaining zones can be represented as follows:

Figure 1

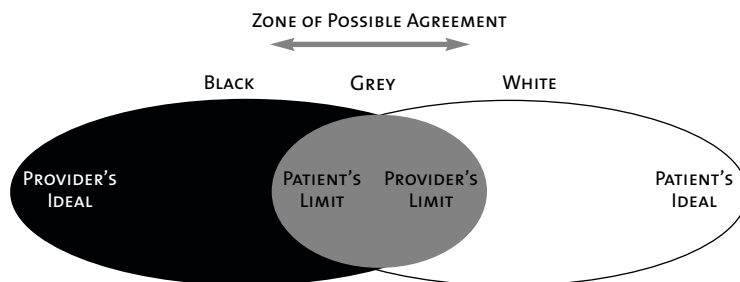
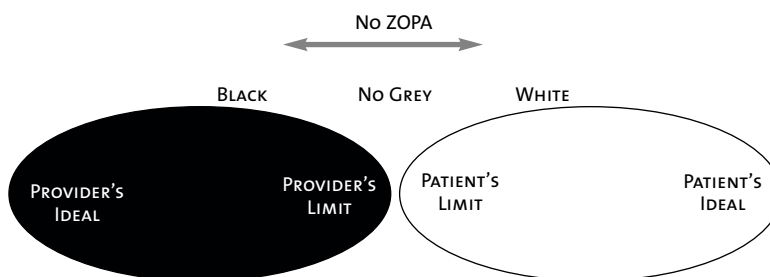


Figure 2



In an ideal world, people recognize which of the above situations they are in and choose accordingly: when room for agreement exists people bargain back and forth, moving further from their ideals (but not beyond their limits) until a compromise is reached, or they recognize that no overlap exists and walk away from the table. The problem I notice frequently in ethics consultation is that either: 1) people in a Figure 1 situation can't see a way to agree and, consequently, do not agree; or 2) people in a Figure 2 situation do not recognize that agreement is impossible (or, rather contrary to one or both persons' interests) and in the end agree to something that they simply should not. This can occur for a number of reasons, such as one party's inability to articulate their views, fatigue caused by disagreement, desire to appease, and so forth.

Agreeing to something against your interests is just as problematic as remaining divided when everyone's interests could have been met. I consider both these results "negotiations gone wrong." Negotiations gone wrong are process errors that can yield distressing results with real moral impact upon clinicians, patients, and family members. Moreover, there are tie-ins to substantive ethical principles. When patients or surrogates agree to an arrangement that falls outside their interests, ethicists should raise flags of paternalism, coercion, and power disparities. When ethicists intervene, they can mitigate the process error, or they can become complicit in exacerbating that error by pressing for agreement. I consider complicity in such a process error a moral harm.

Ethicists have opportunities to intervene within these gaps and overlaps to positively affect bargaining between provider and patient. Moreover, I believe there is an imperative to do so. If clinical ethicists are going to encourage people to negotiate differing moral perspectives, ethicists should help them negotiate well.

Being aware of ZOPAs requires that ethicists be attuned to the difference between positions and interests in bargaining. Positions are people's stated desires (e.g. I want \$100K salary), while interests are the underlying reasons the positions are stated (e.g. salary correlates with self-worth and respect). Interests can often be addressed in a broader variety of ways than positions. "Do everything for my mother" is as much of a bargaining position as "I want \$100K for my starting salary" is a bargaining position. Whether ZOPAs exists in those situations can be immediately identified: in the case of the patient "everything" includes dialysis and the physician is either willing or unwilling to provide dialysis; in the case of the job applicant, the employer wants to extend a job offer and is either willing or unwilling to pay \$100K salary. Eliciting interests (e.g. "I want to feel I did right by my mother") can reframe positions in ways that close gaps of disagreement and allow contentious issues to seem less black and white.

Reframing positions as interests won't solve everything—there will still be frequent occasions when stakeholders' limits will never overlap and agreements should not occur. In these cases, clarity and action are both important. Irreconcilable differences need to be acknowledged and negotiations should cease—and in fact the ethicist should consider encouraging them to cease. Instead of seeking agreement, stakeholders should be employing alternatives to agreement. Failure to act on a patient's behalf because of indecision is itself morally problematic. Clinical ethicists have an obligation to go beyond clarifying morally acceptable options—they need to create movement for the stakeholders to get to those options, even when the stakeholders disagree.

If an agreement cannot be reached at the table, clinical ethicists can take three steps: 1) stop; 2) separate; and 3) advise. Stopping a negotiation is a recognition that agreement at the table has, or should have, failed. Stopping respects the stakeholders' autonomy and personal conscience. Stopping also supports trust by providing a more transparent process. The second step, separating, is not meant to distance the stakeholders who are at odds—relationship-building and open communication should always be fostered. Rather, by "separate" I mean that ethicists can divide their approach by supporting the stakeholders in identifying and proceeding down their divergent paths. Advice should be provided to all parties to the consultation: physicians could be advised to invoke the hospital's futility policy, for example, and family members could be directed toward legal resources to respond. (Of course there may be better alternatives.)

The purpose of this piece is not to provide guidance on how to approach moral conflict or how to provide ethical analysis, but rather how to move out from the uncertainty that accompanies disagreement. My primary goal is to highlight the importance of respecting disagreement, a respect that is sometimes lost as we focus on communication and mediation skills. I have been guilty of allowing people who still had a ZOPA to walk away from a negotiation, and I have been guilty of encouraging individuals who lacked a ZOPA to agree to something beyond their limits. Having spent hours working to build consensus in irreconcilable futility disputes, I can certainly understand the powerful pull that "consensus" creates. In response to my own struggles, I remind myself to reflect on my role in the consultation. From atop the crow's nest of a ship lost in the fog, the sailor needs to assess the situation, be decisive, and give direction—"Yes Captain, we can reach shore," or "No Captain, if we keep on course we'll crash and sink." Having someone able to instruct others what to do when things are foggy and vague is why they put a basket up there in the first place.

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Roger Fisher, et al., *Getting to Yes: Negotiating Agreement without Giving in* (Houghton Mifflin 2nd ed. 1991).



# Telltale Purple Lesions

Colleen Farrell

On the last page of his 1990 book *Surviving AIDS*, AIDS activist Michael Callen wrote, “I have a very clear vision of myself free of AIDS. My immediate goal is to see the lesion on my right wrist that I hate so much (because it is a constantly visible reminder that I’m sick) gone by January 1, 1991.”<sup>1</sup> In Callen’s personal account, his Kaposi’s sarcoma lesions were both a literal and symbolic reminder that he was living with AIDS.

In its early stages Kaposi’s sarcoma (KS) appears as purple lesions. This previously rare form of skin cancer was an especially common manifestation of AIDS in gay men prior to the advent of effective antiretroviral treatment for AIDS. Before a test for HIV became available, many gay men searched their bodies regularly for KS as a sign that they had AIDS. Mark King, who lived with AIDS during the 1980s, explained in a recent interview with *The Body*, “Oh my God, it was a daily ritual for every gay man at that time to check every place on their body they could possibly see in the shower and look for a spot. They did so with great trepidation and fear. We were checking ourselves all the time. We were checking each other.”<sup>2</sup>

Many gay men, especially those in San Francisco, Los Angeles, and New York City who followed the epidemic and knew others who were sick or already dead, knew what the “telltale purple lesions,” as AIDS activist Cleve Jones called them, portended.<sup>3</sup> Many other personal accounts of KS tell a terrifying story in which a dark lesion on the body becomes the kiss of death.

In her 1997 memoir *Hospital Time*, Amy Hoffman captures the foreboding significance of a new KS lesion while also offering a glimpse into what makes KS lesions such a potent marker in representations of people with AIDS. She writes of her friend Tim, “small KS lesions had broken out on his face. He was next.”<sup>4</sup> The way Hoffman structures this description of Tim, it is as if KS lesions are situated at the border between life and death. The invocation of KS situates Tim as the *next* to die and next to—or bordering on—death. It is in part the lesions’ location on the skin, visible signs at the boundary between the internal body and the external world that enables such narrative possibilities.

Though the mass media often ignored the plight of gay men in the AIDS crisis, when articles did appear about gay men with AIDS, being gay was frequently equated with dying and death.<sup>5</sup> KS lesions often functioned as a synecdoche for AIDS in depictions of gay men with AIDS, as Michael Callen’s experience with a *Newsweek* photographer demonstrates:

When [the photographer] arrived, he looked me over and then snorted contemptuously: “Where are your lesions? I need someone with lesions!” This was before I had developed KS, and when I told him I didn’t have lesions, he stormed out, cursing the writer who had given the photo editor my number.<sup>6</sup>

Without KS as a visible sign that he had AIDS, Callen could not fulfill the mainstream media’s expectation for what a person with AIDS should look like.

The dramatic possibilities of KS were not lost on Hollywood. In the 1993 film *Philadelphia*, the KS lesions on Andrew Becket, a gay lawyer with AIDS played by Tom Hanks, drive the action of the movie. The partners of his law firm suspect he has AIDS when they notice a purple lesion on his forehead. In the climax of this courtroom drama focusing on Becket’s wrongful termination at his firm, his lawyer asks him to unbutton his shirt and show the courtroom his lesions. The lawyer, played by Denzel Washington, announces: “We’re talking about AIDS; we’re talking about lesions. Let’s see what we’re talking about!”

The discourse around AIDS in the 1980s frequently hinged on stark dyads of heterosexual/homosexual, pure/deviant, healthy/diseased, and living/died. *Philadelphia* uses KS to dramatize each of these intersecting dyads. At one point in the film, one of the senior law partners says to another, “Andy brought AIDS into our offices, into our men’s room. He brought AIDS to our annual cocktail family picnic!” In this exclamation, Andy is positioned as a lesion on the heterosexual, familial sphere. The law firm partner suggests that Andy’s presence will lead to social decay, just as the film depicts the KS lesion in relation to Andy’s body.

Here again, the KS lesion serves as a way of marking boundaries and borders. KS enables the solidification of each of the borders (visually represented by the /) in the above dyads as Andy becomes definitively located as homosexual, deviant, diseased, and for all practical purposes, dead. In upholding these dichotomies, the invocation of Andy’s KS lesions marginalizes queer identities, conflates HIV infection with immoral behavior, and disempowers people with AIDS by casting death as their definition.

In *Philadelphia*, as well as other depictions of gay men with AIDS, KS functions like the Scarlet Letter, a mark upon the deviant. Nevertheless, KS cannot be dismissed as merely a visible stigma. Rather, what is so challenging about unpacking its significance is the role it played in individual lives, as reflected in so many narratives. And yet, without discounting the lived experiences of those intimately and painfully affected by KS, it is important to examine how widespread cultural discourses of an illness shape an individual’s understanding of that illness. Thinking about race and gender in connection with KS offers insights into questions of experience and representation, and how those categories are mutually constitutive.

AIDS was originally thought of as a gay male disease (it was first called Gay Related Immune Deficiency (GRID)) and KS emerged as a key facet of AIDS in medical, public health, activist, and media writing. But the importance given to KS as an element of AIDS did not fully reflect the experiences of all people with AIDS, especially people of color and women.

A 1985 medical review article reported that “males outnumber females with [Kaposi’s sarcoma] by a 50-to-1 ratio.”<sup>7</sup> Nevertheless, KS was seen as a key facet of AIDS in early CDC definitions of the disease. As journalist Gena Corea, author of *The Invisible Epidemic: The Story of Women and AIDS* (1990) explains, “The first definition was based on what was observed in a minuscule number of mostly white gay men. The conditions considered to constitute an AIDS case for national reporting were [*Pneumocystis carinii* pneumonia], Kaposi’s sarcoma, cryptococcal meningitis, and certain lymphomas.” The early CDC definitions did not include certain gynecological conditions common among women with AIDS. This had material consequences for many women. For example, doctors were much slower to identify AIDS in women as it was not perceived as highly probable.<sup>8</sup> Without an official AIDS diagnosis, a person with AIDS would not qualify for certain assistance programs designed for people with the disease.



Courtroom scene from *Philadelphia*, focusing on the wrongful termination of a lawyer with AIDS after a KS lesion is apparent.

Melinda Singleton explained her experience with AIDS in the 1990 book *Women, AIDS, and Activism* published by ACT UP. “We don’t fall into the categories that the gay men do; our illnesses are somewhat different... no I don’t have KS and some of the other things that most people think of as the signs of AIDS. But that does not mean that I’m not having problems.”<sup>9</sup> Not only was Singleton coping with the physical effects of AIDS, she also had to defend her experience as authentic because of a widespread misunderstanding about the prevalence of KS in people with AIDS.

Emilio, a gay Latino man with AIDS, explained how his experience with KS diverged from the dominant image of KS in an interview for *Surviving AIDS*. “I was biopsied and diagnosed with KS in ’84, but as early as November of ’83 I had noticed lesions. The only thing is, I didn’t recognize them as KS because the Gay Men’s Health Crisis and all the gay papers said KS spots were purple; but mine were brown, so I thought they were moles.” As Callen reflected on this interview he wrote, “I learned how subtle racism can be... I wondered how many other people of color have ignored strange lesions because white gay-boy AIDS organizations have been telling everyone that KS lesions are purple or pink.”<sup>10</sup>

While Emilio and Callen attribute the unrecognizability of Emilio’s KS lesions to the negligence of the Gay Men’s Health Crisis and other similar groups, the relative silence around the appearance of KS lesions on people of color may also be tied to the symbolic potential of KS lesions. The ability of KS lesions to invoke and uphold the aforementioned dyads relies in large part on the contrast between the dark lesions and the fair-skinned body, a symbolic contrast less readily available when representing people of color. In upholding these false dichotomies, representations of KS lesions also upheld a racist logic where white—and therefore light-skinned bodies—is equated with purity, health, and life, and dark colors—and therefore dark-skinned bodies—are equated with deviance, disease, and death.

Dramatic representations of dark lesions on white gay bodies were one element of larger discourses that defined AIDS as a gay disease and defined gay existence by AIDS, while simultaneously obscuring the experiences of women and people of color with AIDS. While representations of KS were in part grounded in the reality of KS as a physical manifestation of AIDS, these representations were also infused with cultural fantasies surrounding sexuality, illness, morality, and death. The resulting chiaroscuro picture of AIDS in the U.S. in the 1980s overshadowed lived experiences of people with AIDS and maintained false dichotomies between heterosexual/homosexual, pure/deviant, healthy/diseased, and living/dead. In their street protests, politically-infused art, and other forms of resistance, people with AIDS and other AIDS activists fought back against not just AIDS, but against this interpretation of AIDS that devalued their relationships, communities, and lives. Their stories demonstrate that questions of representation and meaning are also questions of survival.

Colleen Farrell received her BA in Women’s and Gender Studies from Williams College in 2010 and is currently a research assistant at the Hastings Center in Garrison, New York. Her senior honors thesis, “Epidemic Politics: Representation and Resistance in the First Decade of AIDS,” examined gay men’s experiences with and responses to AIDS in the 1980s. 10cmf@williams.edu

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# Race, Civil Rights, and Psychiatry:

## A Conversation with Jonathan Metzl, MD, PhD

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**John Franklin:** In *The Protest Psychosis: How Schizophrenia Became a Black Disease* you pierce the scientific veneer of medical diagnoses unaffected by cultural, philosophical and political movements of the day. Specifically, your book bears down on a 20th-century historical analysis of the diagnosis of paranoid schizophrenia in this country. Why do you deem it the Protest Psychosis? How did this diagnosis come to signify a different meaning to white and black America?



John Franklin, MD, MSc



Jonathan Metzl, MD, PhD

**Jonathan Metzl:** Let me begin by saying that, as a practicing psychiatrist, I feel strongly that many clinicians attempt to help their patients in ways that are entirely genuine. At the same time, attempts to help people are sometimes impeded, or even thwarted, by social, cultural, or individual forces that can, in extreme examples, inject forms of racial or gendered bias into clinical interactions. For instance, inchoate cultural anxieties about the civil rights movement in the 1960s and 1970s influenced the ways in which psychiatrists diagnosed and treated African American men.

The title of my book comes from a 1968 article that appeared in the prestigious *Archives of General Psychiatry*, in which psychiatrists Walter Bromberg and Frank Simon described schizophrenia as a “Protest Psychosis” in which black men developed “hostile and aggressive feelings” and “delusional anti-whiteness” after listening to the words of Malcolm X, joining the Black Muslims, or aligning with groups that preached militant resistance to white society.

Advertisements for new pharmaceutical treatments for schizophrenia in the 1960s and 1970s depicted similar themes. For instance, advertisements in leading psychiatric journals for the antipsychotic medication Haldol showed angry black men with clenched, Black Power fists in urban scenes, whose symptoms of social belligerence required chemical management.

Meanwhile, mainstream white newspapers in the 1960s and 1970s described schizophrenia

as a condition of angry black masculinity, or warned of crazed, black, schizophrenic killers on the loose.

These and other representations had tremendous negative implications for the relationship between psychiatry and African American men. The era saw vast racial differences in the diagnosis of schizophrenia, for instance. And many of our present-day stigmatizations of schizophrenia as a violent disorder saw their origins at that time.

The purpose of the analysis I did in my book is not to lay blame for individual racism because I feel that such blame-games oversimplify what was going on. Many of the doctors

I study genuinely wanted to help their patients. At the same time, my evidence shows how even the most scientific diagnostic criteria can reflect the social environments in which they are produced, a process I discuss through the language of structural or institutional violence.

**JF:** In our “enlightened” 21st-century approach to the concept of schizophrenia, we now think of it as a brain connectivity disorder with origins in polygenetic risk factors interacting with multiple pre- and post-natal environmental factors such as infection, psychological stress, and urban inflictions. But as you and others have noted, in the past counter-transference may have led to schizophrenia being over-diagnosed in African-Americans. How has the diagnosis of schizophrenia changed over the last 50 or 60 years, and how does that impact your thesis?

**JM:** To be sure, counter-transference is key, but I also focus on how structural factors shaped doctors’ observations, and particularly the ways that our assumptions about the volatility of schizophrenia morphed over time. One key piece of evidence that helps explain the shifts is the changing language associated with the official psychiatric definition of schizophrenia. Before the 1960s, psychiatry often posited that schizophrenia was a psychological “reaction” to a splitting of the basic functions of personality. Official descriptors emphasized the generally calm nature of such persons, in ways that encouraged associations with middle-class housewives. But the frame changed in the 1960s. In 1968, in the midst of a political climate marked by profound protest and social unrest, the second edition of the *Diagnostic and Statistical Manual (DSM)* was published. That text recast the paranoid



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### Usually leaves patients relatively alert and responsive

Although some instances of drowsiness have been observed, marked sedation with HALDOL (haloperidol) is rare. In a report on a study with criminal psychotics the investigator states, "The patients remained alert and more amenable to psychotherapeutic intervention."<sup>7</sup> Another investigator reports that HALDOL "normalizes" behavior and produces a sensitivity to the environment that allows more effective use of the social milieu and the therapeutic community.<sup>8</sup>

### Reduces risk of serious adverse reactions

HALDOL (haloperidol), a butyrophenone, avoids or minimizes many of the problems associated with the phenothiazines. Hypotension is rare and severe orthostatic hypotension has not been reported. There is also less likelihood of adverse reactions such as liver damage, ocular changes, serious hematologic reactions and skin rashes.

The most frequent side effects of HALDOL (haloperidol) — extrapyramidal symptoms — are usually dose-related and readily controlled.

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McNeil Laboratories Inc. 1974

*Haladol Advertisement, Archives of General Psychiatry, Volume 31, no. 5, 1974, pp. 732-33.*

subtype of schizophrenia as a disorder of masculinized belligerence. "The patient's attitude is frequently hostile and aggressive," *DSM-II* claimed, "and his behavior tends to be consistent with his delusions." This language—particularly terms such as "hostility" and "aggression"—was used to justify schizophrenia diagnoses in black men in the 1960s and 1970s.

Diagnosis can become politicized even in the best of circumstances if it is not accompanied by awareness of social and political context. To be sure, we psychiatrists want to know what causes mental disease, and present-day science offers promising clues about nosology. But we are not there yet. We do not diagnose schizophrenia (or depression, traumatic stress, or a host of other illnesses) solely through x-rays, brain scans, or specific laboratory tests. Instead, we query, listen, observe, categorize, and expertly surmise. Thus, even in an era dominated by neuroscience, diagnosis remains a projective act, one that

combines scientific understanding with a complex set of ideological and political assumptions. Sometimes, cloaking our observations under the seemingly objective rubric of science renders these ideological functions all the more difficult to discern or critique. That is not to say that science is not important, just that we need always to be aware.

**JF: In the late 60s and early 70s, I was a young black man growing up in Detroit—a place that plays a prominent role in your book. That time closely followed the gains of the civil rights movement, King's assassination, the Detroit riots and the Black Power movement. There was a sense of change, impending revolution in the air. The government, FBI, and segments of white America feared certain black political voices, feared a black backlash and violence. Do you think this has somehow lead to prisons being today's "new" asylums?**

**JM:** Well, I can certainly say that fear about black political violence shaped the ways that schizophrenia was constructed as a violent disorder in the 1960s and 1970s. Articles like "The Protest Psychosis" directly claimed that African American men who participated in civil rights protests were driven to violent forms of insanity. In the present day, negative perceptions of persons with schizophrenia as being unduly hostile or violent still thrive in American society, even though these persons are exponentially more likely to be the victims than the perpetrators of violent acts. Meanwhile, as you suggest, persons diagnosed with schizophrenia in the present day reside more often in penal than in psychiatric care facilities. While many complex economic and social factors contribute to such issues, their current composition also depends on a racialized logic that comes directly from the 1960s and 1970s, whereby schizophrenia represents both a mental illness and a threat to civilized society.

*(continued on next page)*

JF: The book describes how the early psychiatric “split mind” concept of schizophrenia resonated with the public. You highlight how black leaders like Dubois, King, the Panthers and others spoke of a derivative of schizophrenia as an adaptive response to institutional racism. To them, accepting the status quo of disparity and projected self-hate is insanity. This self-defensive attitude of the “crazy nigger” certainly resonates with me, and, I think, with many black youth today. Can you expound on this for us?

JM: Absolutely. At the same time that schizophrenia became a racialized diagnosis, it also became a complex metaphor for race. This process appeared at many sites in culture, the most important of which was within the rhetoric of civil rights itself. Here, schizophrenia functioned as a way of debating the implications of violence in response to injustice—a debate that split the leadership of the movement itself.

For instance, Dr. Martin Luther King Jr.’s address before the 11th constitutional convention of the Transport Workers Union of America in October 1961 used the examples of “schizophrenia” and “madness” to urge workers to psychologically “maladjust” themselves in the name of nonviolent protest. Such language was not unusual for King, a thinker and rhetorician who often used psychological binaries to preach nonviolence. In his famous “Unfulfilled Dreams” sermon, his soaring, elegant, final address at Ebenezer Baptist Church, King described the psychic split as follows:

[T]here is a civil war going on in your life. And every time you set out to be good, there’s something pulling on you, telling you to be evil. It’s going on in your life. Every time you set out to love, something keeps pulling on you, trying to get you to hate. Every time you set out to be kind and say nice things about people, something is pulling on you to be jealous and envious and to spread evil gossip about

them. There’s a civil war going on. There is a schizophrenia, as the psychologists or the psychiatrists would call it, going on within all of us. And there are times that all of us know somehow that there is a Mr. Hyde and a Dr. Jekyll in us... There’s a tension at the heart of human nature. And whenever we set out to dream our dreams and to build our temples, we must be honest enough to recognize it.

In these and other instances, King’s use of the term schizophrenia implied an ethical, spiritual divide that was at once universal to mankind and particular to the African American experience. As a universal archetype, the split mind signified the timeless tension between good and evil, chaos and community that humans have faced since the beginning of time. Those who wished to find salvation were to resist the allure of Satan, the pull of hate, the anger of the body, and to instead walk the path of Christ, who turned the other cheek. As a specifically black term, schizophrenia functioned as a powerful metaphor for King’s articulation of the conflict at hand.

In his formulation of Civil Rights, African Americans were always and already divided, their minds split both because of racism and segregation and because of the choices they faced in their attempts to change the system. Persons who acted with anger or violence (rioters, Black Panthers, Black Power agitators, Malcolm X, Huey P. Newton) lived on the side of the unbridled id. But those who felt the allure of anger yet reacted with the measured, civilizing response of the superego walked down the “right road.”

Conversely, in the rhetorical circles of Malcolm X, Stokely Carmichael, Robert F. Williams, or H. Rap Brown, schizophrenia was an ethical response to racism in which violence was the only sane treatment for an otherwise insane problem. In this context, the language of paranoia, psychosis, and schizophrenia became a means of pathologizing white society while justifying aggressive self-defense.

To be sure, schizophrenia was a particularly complex term for Black Power, Black Nationalism, Nation of Islam, and other groups advocating non-passive resistance or armed self-defense. Many of the movements’ leaders had been spuriously diagnosed with the illness by the Federal Bureau of Investigation as a way of highlighting the insanity of their allegedly militant revolt against the United States.

Perhaps it is not surprising, then, that leaders of Black Power and other movements located insanity not within the minds and bodies of persons who fought back against unjust social systems, but within racists who perpetuated them. In his influential text *Negroes With Guns*, Williams turned his alleged schizophrenia diagnosis (“...In describing me as schizophrenic they do not say who had psychoanalyzed me. Do they mean I was analyzed as being schizophrenic by Monroe’s semi-illiterate chief of police?”) against his white oppressors. In the section of the book titled “Minds Warped by Racism,” Williams sets up his argument for the creation of a “Black Militancy” by arguing that “We have come to comprehend the nature of racism. It is a mass psychosis.”

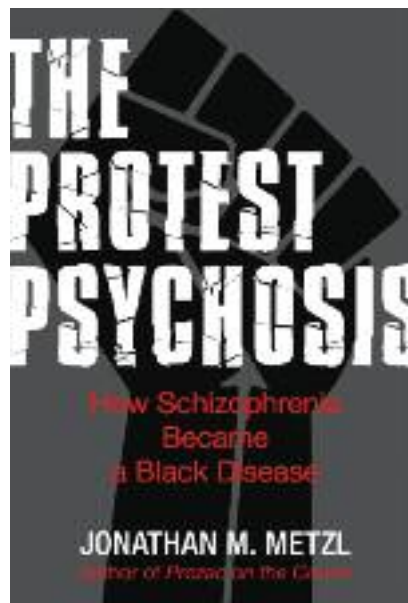
Other voices argued that African American violence reflected the natural psychological consequences of violent American racism. The leading 1960s-era advocates of this position were the African American psychiatrists William Grier and Price Cobbs, whose Malcolm X-inspired book, *Black Rage*, became a national best-seller in 1968. In *Black Rage*, Grier and Cobbs depicted schizophrenia as a condition of survival for black Americans. Paranoid schizophrenia, they wrote, was a potentially violent state that emerged when black men were pushed into a split between adhering to the mores of white society and fighting back against them in order to stay alive. Like King, Grier and Cobbs believed that schizophrenia was a healthy adaptation in addition to a mental illness, even if in their formulation it potentially resulted in hostility.

JF: You speak eloquently about the concept of remnants, and the related way our minds attempt to forget and/or bury unpleasant historical dispositions and biases. Psychologists and popular authors like Malcolm Gladwell speak of two distinct ways our minds process information: 1) a fast, instinctual, gestalt assessment of approach/avoidance/threat, and 2) a slower, language-based way of knowing. Prejudice most often works at the first level. Biases and prejudice affect physicians' diagnosis and treatment, and they contribute to health disparities. Importantly, your work also highlights structural and political effects on disparities. How do you now view cultural competency training in light of your work on this book? Can you describe the concept of cultural humility?

JM: The so-called cultural competency approach represents medicine's most sustained recent attempt to impart clinical understandings of the cultural and cross-cultural aspects of health care. In 2000 the Association of American Medical Colleges (AAMC) instructed American medical schools to teach students the skills of "understanding the manner in which people of diverse cultures and belief systems perceive health and illness and respond to various symptoms, diseases, and treatments." Around that same time, virtually every professional health care provider organization added cultural competency to its list of requisite clinical skills. The American Psychiatric Association outlined sets of core "Cultural Competencies for the Clinical Interaction" for its members. Hospitals and clinics subsequently required cultural sensitivity training for all employed personnel. Meanwhile, leading physicians such as Abraham Verghese argue that "bias in health care must be corrected not by medical ombudsmen, or by legislation, but by a focus on the individual—individual patients and individual doctors."

Learning to talk across cultural difference is, of course, vital. At the same time, there are problems with current cultural competency approaches. For one thing, the discourse of cultural

competency often assumes fixed definitions of culture, or conflates culture and race. Medicalized race categories are exceedingly complex: a person's racial identity may or may not be the same as the race category ascribed to that person by a doctor or a medical chart. Moreover, the tensions inherent in an interaction between a doctor from Cleveland and a patient from Thailand are not the same as those that arise between a white, American doctor and an African American patient, and the two scenarios require different sensibilities.



And research in cross-cultural psychopharmacology often uses social categories of difference, such as those derived from the U.S. census, to make biological claims about variances in drug metabolism among racial groups. This type of research often overlooks how census categories are comprised through self-identification rather than genetics, while at the same time positing that knowing what is happening to a racial group biologically tells us something about what is happening to them culturally. As researchers Jamie Brooks and Meredith King Ledford aptly put it, race-based genetic research thus constructs "biological reality" out of "social reality."

Another concern is that, for understandable reasons, cultural competency presupposes biomedical interactions as the framework for interpersonal ones. Patients describe,

while doctors listen, analyze, diagnose, and treat. Cultural competency shores up this framework by in effect empowering doctors to make another diagnosis when they enter the room: that of the patient's race, ethnicity, or culture. If not handled well, a cultural competency approach risks conveying the notion that professional sensitivity training enables one person to achieve competent mastery over the beliefs, family structures, practices, or attitudes of another person. By so doing, cultural competency interactions oversimplify the complex ways in which people negotiate difference, a process that is based on the intersubjective responses of two participants rather than the diagnostic observations of just one.

Importantly, as you say, critics note that cultural competency's unidirectional flow reinforces racialized power grids while leaving the culture of the doctor free from diagnostic scrutiny. Medical educators Melanie Tervalon and Jann Murray-Garcia rightly argue that cultural competency should be replaced by "cultural humility," a phrase that emphasizes respect across cultural boundaries along with the humbling premise, first developed by the philosopher Emmanuel Levinas, that the other always lies beyond the comprehension of the self.

Anthropologist Linda Hunt writes that in the cultural humility approach, "the most serious barrier to culturally appropriate care is not a lack of knowledge of the details of any given cultural orientation, but the providers' failure to develop self-awareness and a respectful attitude toward diverse points of view." Picking up this theme, pediatrician Sayantani DasGupta asserts that doctors who assume their reading of a patient's narrative is the "definitive interpretation" risk closing themselves off to awareness of the patient's "valuable nuances and particularities."

Perhaps my most important concern about the cultural competency approach is the idea that cultural differences can be resolved through individual interactions at all. My central argument in the book, however, is that racialized assumptions and biases are historically embedded in health

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care delivery systems, and shape interactions and outcomes long before the participants appear on the scene. I believe that focusing on the individual obscures the impact of the structural, while putting undue pressure on even well-intentioned patients or doctors to solve problems in ten-minute office visits that have taken decades or even centuries to evolve.

Therefore, I think clinicians might be encouraged to develop skills of what I call “structural competency”—an awareness of how structural forces can shape interactions but remain elusive to the interactants, or an expertise required to understand the biological in the context of the structural or the historical or the political.

**JF: Great response. Speaking of cultural humility, what drew you to this particular work at this particular time? And what was it like as a “white” psychiatrist and social scientist to research and write about this specific “black” experience?**

JM: Good question. On a personal level I grew up with a deep sense of social responsibility, and my family imparted an awareness of the potentially pernicious effects of unchecked state, economic, racialized, or gendered forms of power. (My father and my late grandparents came to the United States in the aftermath of the Second World War having lost everything they owned and everyone except each other.) At the same time, I want to be clear that I am not speaking “for” any particular person, race, or ethnicity. I reproduce quotes verbatim to attempt to allow characters to speak for themselves as much as possible. I make no claims about “black” interiority or experience. Mine is a book about the ways that race is constructed in medical discourse and through an oft-invisible set of categorical assumptions. As such, it’s as much about what might be called “white” projections or anxieties as it is about anything else.

**JF: My understanding is that the DSM-V schizophrenia workgroup is leaning towards eliminating subtypes**

**of schizophrenia, including paranoid schizophrenia. The proposed definition for schizophrenia seems to increase the inclusion group. For example, delusions no longer have to be bizarre, and one might meet the criteria for schizophrenia without delusions or hallucinations. How much do you think the history you exposed in your book contributes to the proposed revisions? How much do you think the process is driven by science versus cultural politics?**

JM: On one hand, I have to say that there is something admirable about a profession that is willing to throw its entire diagnostic system up for grabs every fifteen years or so, and to seriously consider each and every word of its diagnostic bible. I also think that psychiatry has made great strides toward understanding the causes of mental disease, so in this sense the revision of the DSM represents progress on many fronts.

Yet history teaches us to be wary of language that might broaden diagnostic categories (or, in this case, might pathologize risk in addition to illness), especially when that broadening is not supported by clear-cut scientific facts. Even in an era dominated by neuroscience, diagnosis remains a projective act—one that combines scientific understanding with a complex set of ideological assumptions.

I believe that vigorous debate is good for psychiatry—both from outside the profession, and from within it. In previous eras, critics adopted a so-called antipsychiatric stance that advocated the near-overthrow of the profession. And to be sure, important critics still advocate for massive change. We know all too well from plagues past that the rhetoric of mental health and mental illness can become effective ways of policing the boundaries of civil society and of keeping undesirable persons always outside.

But today you also see increasing numbers of scholars like myself who believe in the therapeutic and even potentially liberating promise of the profession. My work is in no way meant to suggest that mental illness is socially

fabricated or, worse, that people’s suffering is somehow inauthentic. I strongly believe that persons diagnosed with schizophrenia and other mental illnesses benefit from various forms of treatment or social support, and that our society should invest more in the care and well-being of the severely mentally ill. Still, scholars like myself remain deeply concerned about such issues as the impact of the pharmaceutical industry, the stigma surrounding diagnosis, and the expanded use of psychotropic medications, to name but a few.

I would like to think that books like mine help us understand how tensions that seem timeless or eternal in fact result from particular decisions made at specific moments in time. As I write in the book:

[O]nly during the civil-rights era did emerging scientific understandings of schizophrenia become enmeshed in a set of historical currents that marked particular bodies, and particular psyches, as crazy in particular ways. The tensions of that era then changed the associations that many Americans made about persons with schizophrenia. Ultimately, recent American racial history altered more than the meaning of mental illness: it changed the meaning of mental health as well.

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# THIN LIKE ME

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*April Michelle Herndon, PhD*

In a *Saturday Night Live* sketch called “White Like Me,” Eddie Murphy “goes underground” to examine the question of whether there is a White America and Black America. The Black actor hires a top-notch hair and makeup team to make him look White, he reads Hallmark cards and watches episodes of *Dynasty* so he can speak like a White person, and he practices walking with his butt “real tight” in hopes of passing. After all his preparation, he finally manages to walk the streets of New York as a White man and see what it’s really like in White America when no Black people are around: another White man gives him a newspaper without charge, a bus full of White people break into Big Band dancing when what they presume to be the only Black man on the bus exits, and as a White man Murphy learns he can get a loan for an undisclosed amount without filling out any paperwork. Murphy concludes that the situation was “worse than he expected.” Murphy’s spoof manages to offer a sophisticated account of racism, racial inequality, and the aspects of privilege that it’s one thing to have knowledge of, and another to be a part of.

This year Murphy’s sketch took on new meaning for me. I recently dropped 100 pounds, and my weight loss immersed me in a world of privilege that was new to me, the world of

thin (or at least thinner) people. I currently walk the world in a very different body than I once possessed, a body that has given me a set of new experiences not unlike those Murphy sends up in his routine. As a Fat Studies scholar and a self-identified Fat woman, I certainly knew thin privilege existed, but my experiences of feeling like I’m in disguise in the last year have given me a whole new perspective on the psychological issues surrounding large embodiments and people’s reactions to them. When I stepped into the privileged class of thinness, I learned that—even as a Fat Studies scholar—I wasn’t always prepared for those experiences. My body became, in some very tangible ways, unbelievable to me and to others. People’s reactions to me, my struggles to work through their reactions, and my own response to suddenly being thrust into this world of privilege have been both difficult and enlightening.

People may wonder why a self-identified Fat woman and a Fat Studies scholar would lose so much weight. To tell the truth, I didn’t set out to do it. My mom, who has always been thin, has type 2 diabetes. After witnessing diabetes march across her body, I knew I needed to take my high blood glucose readings seriously, so I saw a dietician to help me regulate my blood sugar. She put me on a plan similar to one that someone who had already been diagnosed with

diabetes would follow, and I thought I might lose ten or twenty pounds as a side effect of eating smaller portions of carbohydrates and more exercise. I had no idea I’d lose 100 pounds without really trying to lose weight, but along with regulating my blood sugar came pretty drastic weight loss.

Slipping into the world of thin privilege and feeling like I’m in disguise has been especially hard for someone like me, a person who hasn’t bought the traditional narrative of why people are fat. I have always eaten plenty of fruits and vegetables and I have always exercised, so I knew from personal experience that it was possible to eat healthy food, move and still be a large person, and I’ve always believed large people who say they

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Losing this much weight caused many changes in my body and my life, and I haven’t been prepared for them all. I certainly wasn’t ready to become a member of the privileged class of thinness and discover a harsher reality than I’d imagined.

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eat healthy foods and exercise and still maintain their weight. I have watched people in my family, especially my father’s family who are large people, work hard all day in the coal mines and come home and pull weeds out of a garden or pick beans all evening, so I knew fat people weren’t lazy by definition. I have a PhD and see people of all shapes and sizes in the academic community, so I knew all fat people weren’t stupid.

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Yet losing weight seems to have signaled to those around me that I must have always or must now believe these stereotypes of fat people; my weight loss also seems to have suggested to them that it's now okay for them to admit they believe those stereotypes. Numerous people have said to me that I must have lost so much weight because I'm eating right, as if they didn't believe me before, even though some of these people have personal knowledge of at least some of my eating habits since they've seen what I eat for lunch for several years. Others have said to me that it's amazing that exercise could make that much difference, implying that I wasn't exercising before, yet these are people I regularly see in the exercise rooms, pool, and locker room of the YMCA where I have a gym membership. All of this smacks of claims that fat people fail to realistically represent their diet and exercise habits and aren't to be believed. Remarkably, no one had made these sorts of comments to me until I was thin like them.

Having spent 38 years as a Fat woman, I have an impressive repertoire of comebacks for people who make negative comments about my body or fatness, but I was unprepared for these comments. These people were trying to praise me, but it felt hurtful and wrong and I wasn't sure how to respond. Perhaps the most challenging comment came from a colleague during a conversation about my weight loss when I said if I were betting in Vegas I'd bet that I would gain some or all of the weight back. She asked what I meant, and I told her that I was a Fat Studies scholar and knew the literature says there's a 95% chance I'll gain some or all of the weight back, and I wasn't sure I was special enough to beat those odds. She said to me, very sincerely and without a hint of malice, "April, you're too smart to gain the weight back." I left the conversation wondering if she believed all large people were dumb or if I had somehow been the exception. I wasn't happy with any option I could come up with for what such a statement implied about large people.

During similar conversations over the last year, I've confirmed another truth about how people think about weight and weight loss: those who claim their concern about weight is all about health are fooling themselves. Although I've been very clear that this process was about regulating my blood sugar and the weight loss has merely been a side effect, no one has asked about my blood glucose levels.

and opinions about my scholarship to light, ideas I didn't know people held. One colleague told me that I could no longer call myself Fat and that she supposed I'd find something else to write about now. I explained to this colleague that I did still consider myself Fat identified, but my scholarship wasn't about my personal identity. Most scholars, I told her, have written work that is both related to their



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A few people have congratulated me on having good numbers after I've told them that my blood glucose is regulated and I now feel much better, but no one has ever asked about it. When people have approached me, they've asked about how much weight I've lost now and about how I lost the weight. My body is being read apart from my goals and wishes, and there's very little I seem to be able to do about it. When I tell them that the weight loss isn't important to me, they look at me as if I can't possibly be sincere.

The change in my embodiment has also brought problematic notions

identity and not. I, for example, don't have an intersex condition but have published on that subject and worked for the Intersex Society of North America. Besides, I told her, there's still lots of fat discrimination in the world that needs to be acknowledged and addressed, and I still plan to be a part of that difficult and important work. I wondered if somehow people had been thinking of my scholarship as personal therapy rather than rigorous academic work with the goal of social justice. I wondered what they thought of me as a scholar and colleague, and if they'd ever really understood my work or seen its merit.



Another colleague said to me that my arguments about weight were probably more on target twenty years ago, implying that I was behind the times. She'd never said this to me before, even though we'd talked about my scholarship many times and she'd heard many of my on-campus talks. It made me wonder if my weight loss enabled her and others to say what they'd been thinking all along: that my scholarship wasn't valid. Perhaps they'd been afraid to say this to me before because they believed it would have been personally insulting, but now that I was thinner their comments would only be about my scholarship? Maybe now I could have the distance from fatness to see that I'd been wrong to argue against simplistic understandings of large embodiments?

Throughout this last year, I've struggled to find support for my difficulty in feeling at home in my scholarship or in this instantiation of my body. When you lose weight, people act as though you've won the lottery. When you suggest that maybe winning that lottery hasn't been the easiest thing for you, they react as if you've lost your mind or are just too ungrateful to appreciate your good fortune. The truth is, though, that losing this much weight caused many changes in my body and my life, and I haven't been prepared for them all. I certainly wasn't ready to become a member of the privileged class of thinness and discover a harsher reality than I'd imagined.

The master narrative about losing weight is that it always makes one's life better. Almost no one talks about the complications that it also creates. After 38 years, this body feels foreign to me, and it looks different than I'm used to. I have loose skin in places that used to be firm; I have half the breasts I used to have. I have muscles in places I didn't before, and sometimes I stare at my own hands, marveling that they're actually mine with all their visible veins and sinews. I've had to learn to dress myself all over again and figure out what stores have clothes that fit me, which has been time consuming and expensive. When I've told people

that the weight loss has been a big adjustment and not always a comfortable one, they brush my concerns aside, as if I'm just being silly. I should just enjoy my lottery winnings and not whine.

In spite of all these changes in my body, I still feel like the same person, and this also contradicts the master narrative of weight loss. My Fat self was not hiding my Thin self. Recently my dietician, whom I genuinely like, asked what I'd done with all of my clothing that no longer fits. I told her I'd had some of the clothing altered and packed the rest in boxes. She insisted that I either sell or give away all my larger clothing so that I wouldn't be holding on to my old self. She said I needed to burn that bridge. To me, this replicates the notion that fat is only ever loathsome. In most people's understanding of weight loss, body fat is an enemy to be isolated and destroyed. But I never lived that kind of existence with my fat. I was always very aware of my fatness and comfortable in my own skin. When I described myself as fat, I meant it as an objective description of how my body existed in the world, not an insult or a symbol of sloth or stupidity. In a world of thin privilege and fat prejudice, I understand why some larger women talk about living from the neck up, but I'd never been one of those women, and so I didn't see my "old self" as a problem. I don't see my fat as an enemy lurking on the other side of a bridge I needed to burn, and I'm not afraid that boxes of clothing will drag me back to a loathsome fat self.

In spite of the changes, I'm still very much Fat identified. To me, this feels similar to my identifying as Queer by choice. To say that one chooses to be queer contradicts the master narrative of queer life being fraught with peril, joyless, a life no one would choose. Yet, I did start dating and continue to date women by choice because I see life as a Queer person as more than pain and prejudice. I see it as freedom to date whomever I choose, the ability to have a community around me, and the pleasure of wearing comfortable shoes and still being considered sexy. Hearing that

someone identifies as Fat probably feels the same to people. If a person believes that Fat means being lazy, stupid, out of control, or any of the other stereotypes rife within American culture, then it would be difficult to understand why anyone would choose to identify as Fat. But I've never had those associations with fatness. I still weigh 185 pounds, obese by medical definitions if one wants to think of it that way, still fat by many people's standards of bodies, and still Fat in terms of my political commitments and intellectual endeavors.

A few nights ago I was trying on clothing that no longer fits, trying to figure out what I could wear to get me through this semester of teaching, and talking to my partner about how difficult this journey has been. I've felt so misunderstood by so many people, and knowing what people in my life were really thinking of me before will make it hard for me to face them if and when I do regain some or all of the weight. It even makes it difficult to face them now, as I seem to be continuing to lose weight. I told her I worry that if I do regain the weight I will have done myself more harm than good psychologically and physiologically because I also know the medical literature on the negative health effects of yo-yo dieting. My partner said she thought if I had known I would lose this much weight I probably wouldn't have even started this. She's probably right, and that's just another part of my now unbelievable body.

Much like Eddie Murphy in his sketch, the knowledge I've gained during my time in the privileged class is both oddly comforting, because it means that as a fat person I wasn't imagining what was happening, and also disconcerting, because it says to me (as Murphy's experiences said to him) that things are worse than I thought.

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# PHYSICIAN-WRITERS:

Jay M. Baruch, MD

When physicians write about patients and clinical encounters, are they bound by the same bedside obligations to respect privacy and confidentiality? Physician and narrative-medicine scholar Rita Charon suggests that patients own their stories, and for physicians to write about a patient encounter informed consent must be obtained.<sup>1</sup> The physician-writer Richard Selzer expresses an alternative viewpoint: his life takes place in the “hospital or an operating room or the bedside of a patient and therefore, to ask me not to use the material would in fact [be] to censor me, to silence me as an artist.”<sup>2</sup> Journals have a range of informed consent and permission requirements as a precondition to submission and publication of medical narratives involving potentially identifiable patients.<sup>3</sup> As a writer and a physician, I’ve struggled with how best to balance my dual and dueling duties to patients, readers, and the creative work.

Some physician-writers believe they’re respecting privacy and confidentiality by changing identifiable features, rendering patients functionally anonymous. Informed consent and the de-identification of patients through descriptive plastic surgery both strike me as well-intentioned, specific, but alas, superficial “treatments” for an issue that isn’t so black and white.

Medical stories serve many purposes and come in a range of genres, including essays, fiction, nonfiction, creative nonfiction, graphic novels, and poetry. The online bookseller Amazon offers 667 titles under the heading of “medical memoir.”<sup>4</sup> The growing number of clinical experiences penned in medical journals as well as media outlets like *The New York Times* illustrates that physicians are writing about their experiences for publication, and a wide and eager readership exists. Blogs and social networking sites offer an expanding range of venues for publishing these narratives.

Paradoxically, the ubiquity of medical stories comes in the decade following HIPAA legislation and tightening reins on patient privacy.<sup>5</sup> Perhaps the time has come to reexamine rigid conceptions of privacy and confidentiality as applied to writing about patients, and take a more honest and difficult angle on the question of how physician-writers work with and around these obligations.

We shouldn’t be surprised physician narratives have been the subject of greater ethical examination the past few years if we consider the broader genre of non-fiction and the ethical questions facing professional journalists. “It is hardly possible to write about the real world without taking a few steps into a slippery slope,” write journalists Mark Kramer and Wendy Call. “As writers who delve into

other people’s lives, we can’t stand on the edge of that slope prissily avoiding it. We are *there*. To operate ethically we must begin by acknowledging that.”<sup>6</sup> Rewards of narrative writing, they believe, are possible only when writers accept ethical responsibility. They acknowledge that a journalist may violate a subject’s privacy when gathering material. Journalist Isabel Wilkerson writes, “Narrative writers must strike a careful balance, caring about our subjects without sacrificing our narratives, with caring about our narratives without sacrificing our subjects...good journalism and empathy can go hand in hand.”<sup>7</sup>

The teller of any story has great power. The relationship with the subjects is not an equal one. “The moral imperative lies with the writer.”<sup>8</sup>

## The physician-writer and the patient-subject

The physician-patient relationship, even at its most ideal, teeters with questions of inequality and power independent of any physician’s desire to write about it. To be sick, one enters an anxious, vulnerable, and exploitable state, one characterized by exposure. Not only is the flesh revealed, but charged intimacies—fears, worries, failings.

The patient is dependent upon the physician’s expertise and specialized training, and trusts the physician will use this information only to restore or improve her health; that whatever is revealed travels no further.<sup>9</sup> Physicians, in turn, are duty-bound to honor and protect what’s told to them. Medicine has foundations as a moral community dedicated to something other than self-interest. Patients should not be used by physicians as means towards personal ends. The journalist building a narrative using particular subjects comes pre-packaged with his or her intentions on full display. When physicians write about encounters involving patients, it might be argued they are operating as clandestine operatives.<sup>10</sup>

## Violating privacy and confidentiality without getting caught

Privacy is “characterized as freedom from intrusion or exposure to others,” and the focus of this discussion is informational privacy, the prevention of disclosure of personal information.<sup>11</sup> Confidentiality is violated if a person to whom information was disclosed in a confidential relationship fails to protect that information, or makes a disclosure to a third party without consent.<sup>12</sup>

Altering identifying details obtained in a strictly defined professional relationship doesn’t alter any moral breach because it doesn’t change the condition under which the information was obtained; the physician-writer simply reduced the risk of being caught. And stripping identifying features is a precarious business—even the

# Dual and dueling responsibilities

most diligent efforts can leave fingerprints, and people can figure it out. So let's be honest about the practice of de-identifying: it might cloak a patient's identity, but it still violates privacy and confidentiality.

Certain legal and ethical privacy and confidentiality protections feel like window dressing in today's clinical world. The army of individuals constituting the health-care team (not even including various third parties from quality improvement to insurance companies) makes for a porous firewall when it comes to healthcare privacy. Almost thirty years ago, predating the internet and the push for electronic medical records, physician-ethicist Mark Siegler called patient confidentiality a "decrepit concept."<sup>13</sup> In our confessional age of memoirs and reality television, blogs and Facebook and Twitter, normative lay conceptions of confidentiality and privacy have taken seismic steps towards becoming public commodities.

The physician-writer must first recognize the tension: the physician's moral duty to protect patient privacy and honor confidentiality may conflict with the writer's duty to his or her creative work and, ultimately, to the reader.

When I consider physician-writers whose stories and essays cross the threshold into literature—William Carlos Williams, Richard Selzer, and Oliver Sacks serve as a few examples—the possibility that they might have breached patient privacy and confidentiality doesn't trigger the same type and degree of moral outrage in me as less accomplished writers do. Their transgression is met by a shameful ambivalence on my part. Their willful exploitation of the doctor-patient relationship feels like an unfortunate but unavoidable trespass necessary for generating important, powerful narratives. The physician in me holds a strong position regarding the obligation to respect patients' confidentiality and privacy. But a thoughtful, balanced, well-written reflection piece published in a respected peer-reviewed journal *feels* less morally culpable than a feverish rant posted on a physician blog, even if both writers breached patient confidentiality in the process. The quality of the work, as well as the skill, sensitivity and responsibility of the writer, strike me as morally relevant when judging any breach.

The writer in me is well aware of the instinctual tendency of writers to be magpies. They'll feed on anything if it nourishes their creative work. The writer's ears and eyes are always primed, and this reflex in the physician-writer when doctoring can create a slippery slope that might be difficult to recognize, negotiate, or control until too late. The physician-writer must be first, and foremost, a physician.

## It's my story; no, it's mine

Charon has written beautifully on the idea that patients own their stories, so what is revealed to physicians can be used for other purposes only with their consent. I agree with her in principle, but in practical terms consent feels like a moral spare tire: it will get you safely home now and then, but it's not terribly practical for varied day-to-day driving. It feels disingenuous to claim that patients own their stories when physicians are situated as prominent characters in the story or experience, when physicians are integral to these stories. I don't discount the importance of privacy and confidentiality, only posit that such duties are not absolute or inviolate. They are *prima facie* duties, subject to being overridden by stronger competing moral claims; examples include imminent threats to identifiable others, and mandatory reporting of child abuse, gun shot wounds, and certain communicable diseases.<sup>14</sup>

Rather than take an idealized conception of story ownership, a more realistic and sincere approach to physician-writers' dual and dueling responsibilities would involve trying to dissect this notion of ownership into identifiable parts. Perhaps we could decide upon the types of narrative details we might consider the rightful possession of the physician or the patient, what information deserves shared custody, and what fragile or intimate details should be left off the table completely.

Such a dissection poses challenges. But casting the light away from consent and anonymization forces us to examine whether our unease with certain narratives really emanates from abuses of privacy and confidentiality, or whether it's from the relationship of these breaches to the overall quality of the work.

## Informed consent for inspiration?

Conceptually, consent works well in particular situations—specific moments, strong pre-existing relationship, and a straightforward narrative. But in practice consent can be suspect even when obtained. Let's say my internist asks me if he could write about an experience we shared as patient and doctor. He's ushered me through a few serious illnesses, and he knows my complicated medical history and more vexing personality. I can refuse his request. But I'm indebted to him and wouldn't want to offend him or dent our relationship because excellent internists are like diamonds. So I'd "consent," fully aware that it isn't completely voluntary. And let's say he gives me Botox on the page; it's not just "not bad," I emerge a better figure than I am in real life. Still, a cautionary tug might accompany my next history and physical. I might edit what I say, holding back sensitive information in a way that might not serve my best health interests.

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The consent process is further muddled by the many potential uses of information for which consent is obtained. Sometimes it's simple: Can I write about your battle with cancer for an essay in a medical journal? But what if I want to use part of an experience, a shard of what the patient told me, a conversation I overheard between the patient and her husband, those large teeth, that groin arrow tattoo pointing one way.

Patients with compromised decision-making capacity are poorly equipped to provide true informed consent, so requiring consent also seems to limit or remove from narrative concern unique stories about patients suffering from mental illness, drug and alcohol abuse, serious trauma, and dementia.

I write fiction to avoid many of these conflicts, but I can't escape them. Even fiction writers aren't absolved from responsibility. Writers invent stories by finding them, and find them by inventing them.<sup>15</sup> Joyce Carol Oates said, "To write is to invade someone else's space."<sup>16</sup> Transgression and exploration are essential to the process. How should consent be incorporated when the physician-writer hasn't a clue about how specific information will be used? The lifted pieces serve as a nidus for something unimaginable at that moment, to be processed and morphed in the writing at a date far in the future, and ultimately fashioned upon characters not yet created. The artistic process involves chasing ideas into these crazy places, letting your imagination wander. But the idea you chase might start with a breach of patient confidentiality and privacy. Can patients give valid consent for details used in a manner that one might define, for lack of a better term, as inspiration?

Selzer sits on one end of the spectrum. "I feel that I have as much right as any writer to use my life experience. To suppose that there was an ethical or moral question in the selection of that material would be dangerous territory. If constraints were to be placed in that way, I think that would be too bad."<sup>17</sup> Too bad for the writer, and the writer in me agrees. But what about the physician's moral responsibility to his or her patients?

Coulehan and Hawkins invoke the concept of "relational ethics," the potential for such writing by physician-writers to both benefit and damage the physician-patient relationship.<sup>18</sup> Jerome Groopman paints a similar perspective on these dual, or dueling, moral responsibilities, situating the physician-writer as a trusted ambassador to the medical experience. "I was a physician writing about people I cared for, and who trusted me," writes Groopman. "So to succeed meant more than the usual. It meant that the writing could not be divorced from practice of medicine, and that it would be judged by its effect on my relationship with my patients and their loved ones."<sup>19</sup>

### Caring for patients and readers: what next?

A voyeuristic element is integral to the beauty of medicine. William Carlos Williams said his medical badge "was the thing which gained me entrance to those secret gardens of the self."<sup>20</sup>

I admire and crave the work of colleagues who take the trafficked physical and emotional terrain of medicine and infuse it with a fresh palette. Critical evaluation of physicians' published writing about patients—in print and online—should honor these aspirations: respect patients and readers, produce truthful and engaging work, commit to transparency, and acknowledge that privacy and confidentiality are sometimes compromised in published narratives. I can't bring myself to give up what would be lost by stepping out of this conflict, and I can't reason it away, so accepting the tension may be justified. I ask my detractors to troll their bookshelves and syllabi for their favorite books, essays, and stories and consider whether privacy and confidentiality was breached, whether informed consent was obtained. Did those concerns even cross your mind? What might be lost if restrictions prevented these works from taking shape and finding publication?

Physician-writers negotiate an uneasy alliance. As physicians, we are bound by moral codes distinct from other professions. We're deceiving ourselves if we believe that informed consent is the answer, or that patients alone own clinical stories. Using instruments like informed consent serves a purpose for a narrow range of writings, but it might be the wrong or misapplied tool for others. This shouldn't discount the use of consent, but we should be wary of its shortcomings. And stripping identifiable features feels disingenuous to me if the exercise deludes the physician-writer into believing that patient confidentiality wasn't breached. We must be honest about the many ways medical experiences are connived onto the page, and be mindful of other bedside obligations when writing. These include veracity, trustworthiness, and compassion.

Physician-writers must be sensitive to moral landmines when writing medical narratives, and rigorously question themselves and their work. Were possible breaches of privacy and confidentiality minimized or eliminated? Did the situation satisfy conditions that make genuine consent possible, and was it obtained? Was the reader informed whether the narrative is fiction or non-fiction? Is the work excellent and original? Medical journals rarely publish studies that have already been done, that don't add at least a new wrinkle to the literature. Medical narratives must be interpreted similarly. The medical profession, editors, physician-writers, and laypersons from the worlds of publishing and patient advocacy should take the lead in this arena. The quality, intention and respectfulness of the written work has moral resonance for me, and such writing should be considered different from medical narrative porn, the willful display on the page of voyeuristic behavior, actions, or findings. I recognize that judging the worthiness and quality of art is a subjective beast, but I trust that open and respectful dialogue can lead to a consensus on what counts as responsible work.



A simple, imperfect test might have the physician-writer imagine how the patient would respond to the work. Not whether the patient would grant approval, but would he or she consider the work fair, thoughtful, the best it could possibly be. And, would the patient still respect you as a physician?

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<sup>1</sup> R Charon. "Narrative medicine: form, function, and ethics," *Annals of Internal Medicine* 2001;134:83-87.

<sup>2</sup> R Selzer. "Physician-writers in dialogue," *Literature and Medicine: A Claim for a Discipline*. D Wear, M Kohn, S Stocker eds. (McClean VA: Society for Health and Human Values, 1987) pp. 77-94.

<sup>3</sup> The degree of permission ranges in scope. For example, *JAMA's* "A Piece of My Mind," requests a signed patient permission form if the patient is identifiable in the manuscript. Interestingly, the editors state that "omitting data or making data less specific to deidentify patients is acceptable, but changing any such data is not acceptable." The *Annals of Internal Medicine* does not require signed permission from the subjects of essays, but requires authors to state in writing whether they obtained the subject's permission. If not, an explanation for the absence of permissions should be included in the cover letter. The *Annals of Emergency Medicine* states that permissions may be required if patients or other identifiable persons are described.

<sup>4</sup> <http://www.amazon.com/> Accessed on March 19, 2011

<sup>5</sup> <http://www.hhs.gov/ocr/privacy/hipaa/administrative/privacyrule/index.html> Accessed March 17, 2011.

<sup>6</sup> M Kramer, W Call. "Introduction," *Telling True Stories*, Kramer & Call, eds. (New York, NY: Plume 2007) p.164.

<sup>7</sup> I Wilkerson. "Playing fair with subjects," *Telling True Stories*, p. 172.

<sup>8</sup> Wilkerson, p. 172.

<sup>9</sup> ED Pellegrino, DC Thomasma, *The Virtues in Medical Practice*. (New York: Oxford University Press, 1993) p. 155.

<sup>10</sup> I want to narrow this discussion to writing aimed for publication in written form or numerous online venues, and not writing exercises that are becoming more common in medical education or writing which is private or personal.

<sup>11</sup> JC Moskop, CA Marco, GL Larkin et al. "From Hippocrates to HIPAA: Privacy and Confidentiality in Emergency Medicine—Part 1: Conceptual, Moral, and Legal Foundations," *Annals of Emergency Medicine* 2005; 45:53-57.

<sup>12</sup> TL Beauchamp, JF Childress. *Principles of Biomedical Ethics*, 6th ed. (New York: Oxford University Press, 2009) pp. 302-310.

<sup>13</sup> M Siegler. "Confidentiality in medicine—A decrepit concept." *New England Journal of Medicine* 1982; 307:1518-1521.

<sup>14</sup> Moskop et al.

<sup>15</sup> S Koch. *The Modern Library Writer's Workshop* (New York: The Modern Library, 2003) p. 58.

<sup>16</sup> Koch, p. 28.

<sup>17</sup> Seltzer, p 77.

<sup>18</sup> J Coulehan, AH Hawkins. "Keeping faith: Ethics and the physician-writer," *Annals of Internal Medicine* 2003;139: 307-311. Rita Charon (see citation 1 above) eloquently describes the profound impact of sharing her medical narratives with patients and their families.

<sup>19</sup> J Groopman. "Physician writers," *Lancet* 2004;363:88.

<sup>20</sup> WC Williams. "From the Autobiography," *The William Carlos Williams Reader*. (New York: New Directions, 1951) p. 288.

Worn by a single symbolic figure on the book cover, the physician's coat and the bad guy's hat are meant to shock and accuse. Whiteness isn't cleanliness or idealism anymore, and we are left to consider whether that hat has been earned through blindness, stupidity, or pure evil.

A second idea is to use the binaries self-consciously: to play with them, interrogate them, or invoke them ironically. Shakespeare, who had the problem of writing sonnets to a dark-eyed brunette at a time when the poetic convention inherited from Petrarch demanded a pale, golden-haired lady fair, declares a new symbolic regime, one that overturns European sonnet conventions and the habits of language. So lovely is his "dark lady" that in Sonnet 127, black has become, rather shockingly, "beauty's successive heir" (line 3), and the poet is able to conclude that because of her "every tongue says beauty should look so" (line 14).

Light and dark images may be questioned too. William Butler Yeats uses them to complicate the reunion of long-ago lovers in his eight-line poem, "After Long Silence." For all sorts of reasons we are free to imagine, both lamplight (line 3) and night beyond the drawn curtains (line 4) are described as "unfriendly," and the tension prepares us for the poem's last two lines:

Bodily decrepitude is wisdom; young  
We loved each other and were ignorant.  
(1932, lines 7-8)

And there's Conrad's *Heart of Darkness*. That ominous white fog conceals the route to Kurtz's horrific realm. There Marlow finds a ritualized and murderous regime, reimaged in Francis Ford Coppola's Vietnam-era adaptation of the novel, *Apocalypse Now*. Its savage customs have been instituted by a man whose skin is white. Once safely back in England, Marlow begins his tale (and the novel) by looking out over the Thames toward London and declaring, "And this also...has been one of the dark places of the earth." Neither that observation nor the novel's compelling ambiguities were enough to mollify Chinua Achebe, the Nigerian novelist who found Conrad's novel racist—nor should they be. But they are evidence of a mind more open than most at the turn of the last century, a mind more aware of the power of imagery and the potential ambiguities of the Manichean binary than many of us are now. Achebe's pronouncement should not send anyone running for post-racial cover. It should prompt instead the important conversation about race that we have avoided so long.

*Thanks to Catherine Wallace, who is eloquent about the poverty of binary thinking, to Homer McEwen, who knew the meaning of "sable" in "Young Goodman Brown" before he asked, and, especially, to Barbara Katz and Chuck Perkins, conversational provocateurs most mornings at Café Rose Nicaud.*

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# WHITE COAT CEREMONIES

## —*Not so White (or Black)?*

*Allan Peterkin, MD*

Medical training has many symbolic transition points that call for discernment. White coat ceremonies and their analogues (like Donning the Stethoscope at The University of Toronto, where I now teach) have the potential to mark one early transition and to allow students to ask some important questions. They are putting on a uniform, a powerful, visual, non-verbal reminder of a particular social role, just as many professionals do. But the white coat is deeply symbolic for us and for our patients, and it represents more than one thing in society at large.

Last year I gave the “White Coat Address” at McGill University on a weekend that happened to be the 25<sup>th</sup> anniversary of my own graduation from medical school, so I was ripe for personal reflection. We didn’t have a formal white coat ceremony when I was at the University of Manitoba; I bought mine unceremoniously at the university bookstore. My main memory of that coat is all the objects I placed in its pockets. Even more so than my classmates (or so it seemed), I was weighed down with guides, manuals, notebooks, lab results and other scribblings alongside my reflex hammer, ophthalmoscope and other paraphernalia. In hindsight, I may have been building a suit of armor as a defense against uncertainty. Some days I wore my coat with tremendous satisfaction and even joy. Other days I hid behind it, using it as what some have called “a cloak of competence.” That little coat gave me instant status without having to prove myself. Looking back, I always felt its weight, and not just because of all those books.

Physicians first donned white coats to emulate scientists. In the mid 1800s science was becoming all-important and a new emphasis on empirical knowledge was unmasking many so-called doctors to be cranks, charlatans, or even cult figures.<sup>1</sup> Science offered new hope for humanity and scientists wore coats that became symbols of their credibility, their rigor in the lab, and their objectivity. Initially those coats were beige, but by the late 19<sup>th</sup> century, when doctors started wearing them, they became white. In contrast, the clergy wore black on the wards as they ministered to the sick and dying. Black signified an endpoint, and white seemed to suggest new hope.

The whiteness of physicians’ coats came to signify other things as well.<sup>2</sup> There was certainly a sense of purity and innocence. The uniforms were clean and infection-free like new bandages. Thanks to the miracles of science, the hospital had become a place to get better rather than a place to die. White also invoked religious references to Moses, Jesus and the saints, all of whom were described as being cloaked in white in their roles as spiritual leaders. The doctor who donned his white coat was reminded on a daily basis of his moral duties and responsibilities and of his commitment to both the science and art of medicine.

But the white coat and its loaded symbolism have been rejected by some. In the twentieth century, the white coat was abandoned altogether in Scandinavia by those who believed that it signified an authoritarian stance and underscored the difference between the doctor and the patient, especially in terms of a power differential. Pediatricians and psychiatrists worldwide have eschewed the white coat in order to “put their patients at ease”—when I started my own residency in psychiatry at McGill we were told not to wear lab coats or white coats at all, as patients would be more comfortable speaking to and confiding in us in the absence of that powerful clinical symbol. Unfortunately, the language of healthcare has been shifting too: “clients and consumers” didn’t want barriers from their “providers,” and a white coat seemed old-fashioned and hierarchical to some.<sup>4</sup>

White coat ceremonies became widespread in the U.S. in the early 1990s (much less so in Canada), and the literature contains a number of unsettling critiques of these rituals, particularly in ethics and education journals.<sup>3,5,6,7</sup> Ceremonies have been criticized for being quasi-religious and for setting up a type of false “conversion experience.” Some deem the rituals to be about self-promotion and self-congratulation, smacking of entitlement and “unselfconsciousness” (or lack of professional reflexivity). Others argue it is facile and false

to suggest that by merely donning a uniform that doctors or students should expect to be seen as competent or trustworthy. The ceremonies are said to codify and even celebrate attitudes related to privilege, hospital-based hierarchies, and the doctor's otherness, or at least being identifiable as "special" through their garb. Furthermore, these critiques elaborate, students in some settings are required to recite or compose oaths that are uninformed by real clinical experience, essentially pledging allegiance to concepts and practices they cannot possibly understand. (On a lighter note, physician writer Abraham Verghese has referred to the white coat and the stethoscope thrown cavalierly around the neck as boastful mating symbols for young medical students!)

As I read these critiques, I was reminded of the Canadian Broadcasting radio show of my friend and colleague Dr. Brian Goldman. The show is called "White Coat, Black Art" and it demonstrates quite provocatively, from week to week, that things are not always as they seem in the world of medicine. Our symbols and rituals are not always fully conscious, benign, or even beneficent, and our white coats are a perfect blank screen for multiple projected meanings and distortions.

When I spoke to (and then with) the students at McGill I did not encounter hubris, entitlement, or consumerism. Nor did I hear intimations of these in the thoughtful oath they had composed themselves for that day. Many of the post-modern critiques of this recently established medical ceremony seem to attack a basic human need for symbols and shared meaning-making, and for the rich reflection that can result from participation in traditions. We all need rituals to mark special life events and transitions, to affirm relationships, and to profess our ideals in front of witnesses. I also noticed that the critiques of the white coat ceremony were written, for the most part, by American scholars who do not yet work within a system of universal medical access, and issues of privilege, otherness, and assumptions about who merits care are even more trenchant (and charged) in that context. In other contexts, it makes perfect sense for future healers to make pledges in front of the very communities they will serve. Healers have always been held in trust by the sick. When I spoke to the McGill students, I reminded them that the white coat should remind us that daily we still have to earn that trust.

It doesn't bother me that the white coat ceremony could be a quasi-religious experience. Yes, some students will find a spiritual dimension in the proceedings and recitation of the oath, and their medical work (like that of McGill's own Sir William Osler) will be informed by religious and cultural traditions. Others will do their work guided by a profound secular humanism. Nonetheless, putting on the same short coat allows them instant access to a world where, side by side, they will be required to witness, interpret, and discuss human suffering and resilience.

When I was a medical student my beeper felt like a teleporter. One moment I would be eating lumpy macaroni and cheese in the cafeteria, then the ring of my beeper would transport me into another person's universe, their deeply personal reality. The beeper summoned me, but the white coat is what allowed me entry. The patients in those beds would tell me (a perfect stranger in a familiar uniform) things they might not have told to anyone else. People of different ages,

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racess, languages, social statuses, or physical realities allowed me to touch their bodies; they allowed me to take part in their life and death decisions. Did that make me feel all-powerful and arrogant, or even masterful? No. It made me feel honored, humbled, and sometimes terrified. Then the beeper would go off again and I and my coat would be transported to a completely other world with another patient.

I think medical students should mark all of the special events in their lives as healers in a process of lifelong learning. I encourage them to keep a journal of “firsts” during their

training: to write about their first delivery, the first time a patient dies, the first time they witness a serious mistake, the first time something they said or did made all the difference to a specific patient. I think they should tuck the letter they wrote to get into med school in their journal as an antidote to cynicism. A reflective stance throughout training, facilitated by reading and writing, can lead to useful questions about personal assumptions and privilege. In turn, such self-knowledge or discernment is precisely what can protect us and our patients from elitism, entitlement, or the exploitation of power. That insight should also protect us from denigrating attempts at meaning-making, or mistaking what is symbolic, layered, and evocative in a one-time ceremony for what happens in the real world.

By the time I retired my short white coat it was grayish, covered in four years of ink, sweat, and adrenaline. I wish I still had it. I invited the McGill students to keep their short coat and to think of it as a symbol that can change meaning over time for them, for their patients, and for the medicine-watchers and critics who remind us when we’re getting too comfortable in our uniforms. Being a doctor means understanding that words and symbols always have more than one meaning—nothing is black or white, or even stagnant, in human experience and meaning-making. Every day in our work we have to be able to tolerate uncertainty, complexity, and change. We constantly need to challenge our assumptions even as we honor the history, rules, and rituals of our ancient profession.

I reassured the students it was okay to feel proud of their accomplishments at a special ceremony on a beautiful Montreal autumn day, and to remember how privileged we all were to be there together. I insisted that the white coat ceremony was a potential “teaching-learning moment” just like any other in their training. Then I asked them to reflect on whether wearing that white coat, with all that it potentially represented, could deepen their humanism over time or, as the critics suggest, turn them into someone they no longer recognized.

That, I said, was up to them.

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*Many of the post-modern critiques of white coat ceremonies seem to attack a basic human need for symbols and shared meaning-making, and for the rich reflection that can result from participation in traditions.*

<sup>1</sup> Valerie A. Jones. “The White Coat: Why Not Follow Suit?” *JAMA* 1999; 281:478.

<sup>2</sup> Dan W. Blumhagen. “The Doctor’s White Coat: The Image of the Physician in Modern America.” *Annals of Internal Medicine* 1979; 91: 111-116.

<sup>3</sup> [http://en.wikipedia.org/wiki/White\\_coat\\_ceremony](http://en.wikipedia.org/wiki/White_coat_ceremony)

<sup>4</sup> M.B. VanDer Weyden. “White Coats and the Profession: Time to Rediscover the Symbol of Our Purpose and Our Pride?” *Medical Journal of Australia* 2001; 174:324-325.

<sup>5</sup> Robert M. Veatch. “White Coat Ceremonies: A Second Opinion.” *Journal of Medical Ethics* 2002; 28:5-6.

<sup>6</sup> P.C. Philip. “The White Coat Ceremony: Turning Trust into Entitlement.” *Teaching and Learning in Medicine* 2002; 14:56-59.

<sup>7</sup> Delese Wear. “On White Coats and Professional Development: The Formal and the Hidden Curricula.” *Annals of Internal Medicine* 1998; 129:734-737.





© Chicago Daily News Negatives Collection, DN-0086947, Chicago History Museum.

Figure 1: From the beginning of the twentieth century the general public was commonly exposed to “gruesome” crime scene photographs in the newspaper, and this photograph is representative of the era’s popular style. On December 17, 1928, a Chicago Daily News photographer was one of the first to arrive at the scene, and took this photograph in Nash’s Tavern on West Taylor Street. The victim, Ole Scully, had been called as a state witness in a kidnapping trial, but he was allegedly shot and beaten to death on the orders of Angelo Petitti, head of an extortion ring, before he could testify. A Chicago Police Officer is shining a flashlight onto the victim’s bloodied face. The police had no difficulty identifying Scully—they found a summons in his pocket requiring him to testify in court later that day.

## Picturing the Scene:

### Negative Emotions, Misperceptions, and Photographic Realities

*Paula Summerly, PhD*

Before Randal Rushing’s 2010 triple-murder trial, attorneys reviewed color photographs of autopsies and crime scenes at the Lackawanna County Court in Scranton, Pennsylvania. The hearing was to determine which photographs could be introduced as evidence in Rushing’s trial. The prosecutor argued that some of the photographs, including those depicting skull fractures allegedly caused by Rushing’s hammer blows, were necessary to demonstrate the force with which the victims were attacked. The defense attorney objected to most of the “gruesome” color autopsy photographs, questioning whether jurors would be unduly influenced by “all the gore.” Judge Vito P. Geroulo ultimately approved more

than twenty of the “gruesome” autopsy photographs for admission at trial, but only after requiring the prosecution to crop them, and/or convert them from color to black and white to make them less objectionable.<sup>1</sup>

Black and white photography took over a century to reach perfection. It bridged the gap between art and science, from still life to crime scenes. The merit of black and white lay in its capacity to record perspective, contrast, shade and texture. Critics argued black and white was abstract, and because it could only record color in shades of gray, that it did not represent reality. Black and white forensic photographs may not have captured or revealed the whole truth; perhaps, critics worried, vital evidentiary clues were concealed amid its tones and shadows.

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Color photography had one major advantage over black and white, the ability to reproduce subjects in natural color, exactly as they had appeared to the photographer's eye. Color film could capture and freeze a vivid image of a victim's bleeding wound or a developing bruise, and thus might provide a jury with "unique information" not evident in a black and white version of the same image.<sup>2</sup> As a result traditional black and white was almost obsolete in forensic photography by the late 1960s.<sup>3</sup> But color photographs of victims' corpses and bodily injuries run the risk of providing the viewer with too much "realistic" information, which can create sensory overload. Jurors have cried, vomited, or suffered post-traumatic stress disorder after viewing "gruesome" color photographs and being exposed to graphic evidence.<sup>4</sup>

Mock-juror studies have highlighted the persuasive powers of photographic evidence. Researchers have discovered that mock jurors who view photographs of a murder victim are more likely to vote "guilty" compared to those who do not see them.<sup>5</sup> And it's not just the existence of photographs that can change verdicts—whether a photograph is color or black and white can affect the outcome. Mock jurors who viewed "gruesome" color photographs were more likely to experience greater psychological and physiological arousal which impaired objective decision-making than those who viewed the same photographs in black and white.<sup>6</sup> Researchers also found that viewing "gruesome" color photographs made mock jurors more biased towards punitive sentencing than those who viewed the same photographs in black and white.<sup>7</sup>

As a result of such extreme reactions, color forensic photography may now be facing a backlash, and black and white forensic photography may be poised for a comeback. But "color or black and white?" is the wrong question. Although photographs have played an important role in the American courtroom for over 150 years, the legal profession is guilty of two important oversights. The first is that judicial analysis has focused on technical issues surrounding photography, while ignoring photographic theory and meaning. My research suggests that the legal profession's understanding and application of photographic theory is rudimentary at best. Photographs are admitted into evidence and authenticated under one of two theories: either as "pictorial testimony" or as "silent witness testimony."<sup>8</sup> In "pictorial testimony" the photograph is presented to the jury as part of a narrative—for example, when a medical examiner describes a victim's wounds and uses photographs to illustrate his or her description. In "silent witness testimony" photographs (taken from a surveillance camera, or by a third party) are treated as "self-authenticating," meaning no witness can authenticate the evidence recorded by the camera.<sup>9</sup>

Photographic theory and meaning are, however, much more complex. Attorney David Sternbach argues that "the nature of photographic representation is subject to conflicting and contradictory interpretations."<sup>10</sup> Sternbach notes that "when judges make decisions about

the admissibility or meaning of still or moving photographic images, their decisions are based on underlying theories of photographic representation—ideas about how photographs represent things and how visual meaning is communicated. These theories are often unexamined and are not usually a conscious or explicit part of the larger judicial decision making process."<sup>11</sup> Perhaps judges, attorneys, expert witnesses, and jurors should be cross-examined by photo-theorists on their knowledge of "semiotic, linguistic, cognitive and cultural critiques of photography."<sup>12</sup> If, for example, judges and attorneys adopted a social constructionist's approach—one that rejects the idea that meaning (or truth) is inherent in



Figure 2: This black and white photograph was taken by government officials for use as evidence of a crime, and it was presented in a homicide trial in Cook County, Chicago, 1950. The defense argued that this and other photographs of the victim were highly inflammatory and their gruesome appearance was calculated to inflame and prejudice the jury, but the objection was overruled. The Illinois Supreme Court ruled that the fact and cause of death, the number and location of the wounds, the manner in which they were inflicted, and the willfulness of the acts in question were all material to the offense charged. The Appellate Court explained that photographs tended to establish these facts and conditions, and under such circumstances their production as evidence was found to be a legitimate mode of proof. *People v. Jenko* 102 N.E.2d 783 (1951)

photographic images—what would the consequences be for jurors and the judicial making-process?<sup>13</sup> I am not advocating that the legal profession should adopt one particular theory, but I'd like to raise awareness of these theories' potential to increase and broaden our understanding of the impact of photographic evidence.

The second oversight of the legal profession is it has yet to address the concept of photographic meaning. Photo-historian and theorist Joel Snyder argues that "our notion of what is realistic and naturalistic is socially and historically conditioned."<sup>14</sup> Photographic meaning is greatly influenced by the viewer's (or in this instance, the juror's) age, sex, class, and social position. At the *voir dire*, or jury selection, attorneys could question prospective jurors on their knowledge and perception of photographic meaning and gauge whether the act of viewing "gruesome" photographs might elicit extreme reactions, and therefore potentially impair objective decision-making.<sup>15</sup>

Having an emotional response when viewing a "gruesome" photograph may be considered "normal"; however when the reaction it is extreme (e.g. induces tears, or vomiting) it may be the result of a common misperception. Looking at a "gruesome" autopsy photograph for example is clearly a very different sensory experience from

seeing the corpse with one's own eyes. The two-dimensional mechanical photographic representation is one step removed from reality. The photograph is remote and sanitized; thus it should be less emotionally charged than seeing it for "real." Our eyes are not free to track across the three-dimensional corpse, or see the wounds within the context of the body, for example. The photographer frames our view through his or her photographic choices.

Judges and attorneys should remind jurors of the obvious distinction between the photograph and reality, as the distinction may become lost or confused by some jurors. Jurors should be advised to take a clinical, studious and objective approach when viewing photographic evidence, no matter how challenging it may be.

The majority of photographic evidence is potentially powerful and emotive. Ideally, therefore, it should be accompanied by some form of testimony and standard interpretive guidance. Such guidance might minimize the risks of inducing an overly emotional response in jurors, particularly when the photographs are of a "gruesome" nature. Without directed viewing there are two risks. The first is "under-looking"—the risk some jurors will take one look at a "gruesome" photograph, have an extreme emotional response to it, and make a snap judgment. The second is "over-looking"—the risk that some jurors will become over-exposed or numbed to "gruesome" photographs, either by staring at one photograph or by seeing multiple photographs.

If the black and white photograph in Figure 2 were presented to a jury as part of a "silent witness testimony" it would be left to "speak" for itself. Without guidance, jurors may not get beyond the initial feelings of horror, disgust, and revulsion. Some jurors may wish they had not seen this photograph, and may choose not to look at it again (i.e. to "under-look"). Those who did look again (and who did not succumb to the risk of "over-looking") may read the text on the ruler, or consider the victim's identity, wounds, pain, and fate. Alternatively, if the photograph were presented as part of "pictorial testimony" the medical examiner, for example, would describe the size, severity, and nature of the victim's stab wounds to the jury. The prosecution may draw the jury's attention to the victim's chipped and dirt-filled fingernails and the defensive nature of the wounds, which the prosecution would argue attest not only to how much the victim fought for her life, but also the willfulness of the attack.

When Judge Geroulo instructed the prosecutors at the Lackawanna County Court to convert "gruesome" color photographs to black and white, they became less objectionable to the jury. Although this was not said explicitly, the implication of the judge's ruling is that black and white can not only mitigate color photography's emotional content, but it can do so without diminishing the photograph's legibility or accuracy. On October 5th, 2010 the jury found Rushing guilty of committing triple murder, and he was sentenced to serve three consecutive life sentences.

However, I'm concerned that reversion to black and white may have a negative impact on accurate and fair decision-making in the courtroom, no matter how subtle or extreme. The legal profession's consistent avoidance of photographic theory and meaning should stop. Photographic evidence requires testimony, and it should be accompanied by standardized interpretive guidance. Judges and attorneys haven't yet taken a sufficiently explicit systematic, methodological, and theoretical approach to photographic evidence. Once these issues are addressed, perhaps judges and attorneys will conclude that color photographs are technically more accurate than black and white, and could be admitted into court as evidence if they were coupled with interpretive guidance for the jury. This would not only put to an end to a common photographic misperception, but might also contribute towards more accurate and fair judicial decision-making.

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- 15 However, knowing when one's objectivity has been compromised may be difficult to self-assess or report.





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## Believing in Race in the Gene Age

*Dorothy Roberts, JD*

My birth certificate, issued in Chicago in 1956, states, "Mother—Negro; Father—white." It does not designate my race. Because of long-standing legal and social rules in the United States, it was an unstated given that I was born a Negro. Although a mulatto category was officially recognized until 1920, the system of Jim Crow segregation had settled the rule that one drop of black blood makes you black, even in Chicago. If I had been born in South Africa, I would have fallen into the category "Coloured," according to the Population Registration Act, passed in 1950 during the apartheid era. In the 1950s, anthropologist Harry Hutchinson found eight racial categories in between white (*branco*) and black (*preto*) in a Brazilian community, with *pardo* designating the children of the union of *brancos* and *pretos*.

Of course, my genetic makeup remains the same no matter where I was born. But my race, along with all the privileges and disadvantages that go with it, differs depending on which country I am born in or travel to, because race is a political category demarcated by invented rules.

A decade ago, the Human Genome Project proved that race could not be identified in our genes. But instead of hammering the last nail in the coffin of an obsolete system, the science that emerged from sequencing the human genome was shaped by a resurgence of interest in race-based genetic variation. Some scientists now claim that clusters of genetic similarity detected with novel genomic theories and computer technologies correspond to antiquated racial classifications and prove that human

racial differences are real and significant. Others are searching for genetic differences between races that can explain staggering inequalities in health and disease.

Why do most Americans cling to a false belief that biological races really do exist? Even many of my left-leaning colleagues balked at my book project challenging the re-definition of race as a genetic category. "Of course we should be working toward racial equality," they said, "but what if scientists are able to identify races genetically?"

People do not deduce that biological races exist from sound scientific evidence and reasoning. They were taught as children to have faith in race as a self-evident truth, like a traditional creation story that explains how the world works. Science has given racial folklore its superficial plausibility by updating its definitions, measurements, and rationales without changing what the tale is about: once upon a time human beings all over the world were divided into large biological groups called races.

The answer to the problem of race will not be found in our genes. Yes, human beings are remarkably similar at the genetic level. But what should link us together is not our genetic unity: we should be bound by a common struggle for the equal dignity of all of humankind.

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