About the Cover

“All rational thought ended for me at 8 a.m. on January 12th, 2006 when the nurse couldn’t find my baby’s heartbeat, even though it was my due date, my water had broken and I was obviously in active labor,” the mother on the cover, Lynda, writes. “I just was being swept along by the actions of the hospital staff as they put IV’s, told me what would happen next and asked me if I knew of a funeral home I wanted to use. Then someone said they were going to call a man named Todd and that the hospital offered bereavement photographs to pictures of stillborn babies. I couldn’t speak, but I remember vaguely wondering: ‘Bereavement photographs? What are those?’ I never heard of that. You mean someone is going to come in and take pictures today?” My doctor said “Trust me, you may not think you want it now, but in a few months from now or a year from now you will be so glad you have them.”

The infant on the cover, Joshua, died in utero at forty weeks because of a cord accident. Bereavement photography is a service hospitals like Northwestern have begun offering to people confronting loss, and Todd Hochberg made this family photo of Lynda, Stephen, and their stillborn son Joshua to help them navigate their grief. Mr. Hochberg doesn’t pose photographs; he works in a documentary style and strives to elucidate the emotional and spiritual energy in the room.

“To be honest, Stephen didn’t want Todd to come to photograph Joshua’s birth,” Lynda writes. “It didn’t seem like the type of experience that one would want pictures of… You don’t use soft light on that kind of precious and often short time can help. ‘We rely on photographs to build and pass on our social support and connection.’ Mr. Hochberg also works with hospital bereavement programs, palliative care programs, and hospices to make photographs and legacy videos for people struggling with serious illness or grieving the death of a child or adult.

Bereavement photography isn’t new. A 1664 painting of a deceased baby is among the earliest known American ‘mortuary portraits,’ and postmortem photography was a significant part of the work of nineteenth century photographers. These images were made of people of all ages, and they were displayed in parlors, put in family albums, mailed to relatives. In the twentieth century, changing social attitudes to death and the possibility of amateur photography virtually eliminated professional postmortem photography, until some deceased baby is among the earliest known American ‘mortuary portraits,’ and postmortem photography was a significant part of the work of nineteenth century photographers.

“People think the day your stillborn child is delivered must be the worst day of your life,” Lynda writes. “But I think an equally horrible day is the first day after you return from the hospital waking up in your own bed but your belly is empty and your child is not in the house…. Day after day after day I’d wake to a panorama of the hole in the floor where the concrete that served as a toilet.

I came away from these experiences with a strong sense of injustice regarding the inhuman conditions in which the mentally ill were treated (“held” is a more accurate term). That sense has only intensified with subsequent experiences around the world that convince me the mentally ill are among the worst treated sufferers globally.

Medical journal reviewers told you the photographs of human rights abuses you wanted to publish were “unshakable” in some sense. What was their rationale, and why don’t you share their point of view? VP: Images have been used in public health on many occasions. Perhaps the most evocative examples of such use of images are conflicts (e.g. in Darfur), famines (e.g. the chronic images of dying children in Africa), and HIV/AIDS. Such images, when used sensitively and for the explicit purpose of advocating for people in similar
circumstances, have had a powerful impact on public policy. It was in this spirit that we wished to use images of persons with mental disorders in contexts where their basic rights were being denied. The images were collected from a wide variety of reputable sources (from international

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priests to medical doctors) and the identity of the subjects was masked. Yet, we were surprised at the strong negative feelings about the use of these photos. One commentator, apparently from a patient group, said “I would be very distressed if that was a photo of me—even of my arm, without my permission—I would know absolutely that it was me—others might know—would that have their picture published if this was published. Would make me feel even more degraded and shamed.” It appears that the concern was that consent was not obtained; how exactly one can obtain consent for photos of persons chained in a hospital, of course, remains unclear. Furthermore, we wondered why such ethical principles should apply to these photos but not to the images of hunger in Darfur or HIV/AIDS in southern Africa? We haven’t found a satisfactory answer as yet to this apparent dissonance.

One reviewer proposed that there is likely to be another side to the story, and I don’t doubt there are explanations for such disregard. However, the concern we expressed is that such images might damage colleagues and psychiatry in general, and the notion that such images should be obtained if there is any doubt. For example, masking the eye region in photographs of patients is inadequate protection of anonymity. If photographs of persons are used, other subjects must not be identifiable or their pictures must be accompanied by written permission to use the photograph. Where possible permission for publication should be obtained.*

* International Committee of Medical Journal Editors, Uniform Requirements for Manuscripts Submitted to Biomedical Journals (Updated October 2007): “Patients blandly stated to have a right to privacy that they should not be identified or unidentifiable or unsanitized types of view.”

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Imagery is one in which mental health is never effectively prioritized nor a recipient of major resources. Societal responses to mental health represent a marginalization and an inexcusable therapeutic, and not to undermine.”

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Other Peoples’ Troubles Are My Business

Ted Chambers, PhD

Why don’t we talk about research ethics in the medical humanities?

Since the 1960s social scientists have attended to the ethics of their practice. They have taken seriously the inherent voyeurism in their methods, their past relationship to colonialism, and their capacity to use people as objects. In medical sociology, Charles Box has been notably insightful about the moral issues that can arise while doing sociology in the clinical setting. I have found his reflections on his own identity in relation to genetics health care professionals to be particularly revealing.

Yet medical humanities scholars have generally not attended to the moral issues that surround using the personal stories of patients as part of their scholarship. I have rarely found much concern over the ethics of presenting other people’s stories. Of course, especially for literature-and-medicine scholars, fiction provides data with few if any moral quandaries. I have never felt much guilt in being shown the inner life of Ivan Ilych. And Howard Breyer uses this approach quite nicely in Stories of Sickness. The realm of the pathography may have moral quandaries—as in the case of John Bayley’s memoir of Iris Murdoch’s dementia—but they are usually not our quandaries.

We should question, however, the morality of studying writings by physicians that use their interaction with patients as the subject for their material. These writings may or may not have been published with the permission of patients, and I think medical humanities scholars must begin to demand the status of these works be made more explicit. In Complications, Atul Gawande illustrates the ambiguity of the permission status in these works: “To the patients and families who go named and unnamed in this book, I wish to extend a great and special thanks. Some I am fortunate to still keep up with. Others I was never given the chance to know as well as I wish I could have” (268). And I admit to being uncomfortable with John Lantos’s use of Priscilla in Do We Still Need Doctors?

Even these odd liminal entities, the fictionalized versions of actual interactions, should give us some pause. Are Richard Selzer’s stories fact or fiction? If they are purely fiction, then my evaluation of “Brute” changes significantly; still a racist story but unlike most of our humanities colleagues, the subject of our research are vulnerable and require protection. We will in turn have to subject ourselves to the same scrutiny that social scientists and oral historians endure, who themselves have been having some difficulty accepting that IRBs can serve an important role in ensuring that their research is morally acceptable. We must step out from the crowd of physicians, take off the white coat (literally or figuratively), and at times identify ourselves not as teachers or healers but as researchers.

M.G., MD

Psychiatry has no set standard for deciding how much information is considered sufficient to treat patients beyond a clinician’s own sense of completeness. Unlike internal medicine, where pathology can often be quantified and even visualized, in psychiatry one’s depth of inquiry is frequently guided by a gestalt sense that one has reached totality. That’s not to say that we don’t have access to psychometrics and all of its sophisticated ways of helping diagnose and monitor emotional disruption. But when it comes to things like heartbreak and loss, there’s little to assay. I don’t know whether the details that bring patients’ stories into Technicolor, like what they wore to their sentencing or the look on their face before they threw the lit match, will have any impact on treatment. Yet these are the details I always want to hear.

Psychoanalysis refers to this mode of listening as “vicarious empathy.” What if I’m just plain old nosy? Because the truth is this: in the midst of hearing another human voice tremble with the fireworks of what it means to be awake and alive, I sometimes forget what it is I’m exactly listening for. Sometimes I assume, as the clinician, as the altruisit bastion of magnanimity that I market myself as, find myself becoming entangled. I don’t mean “entertained” in the typical sense of simple pleasure or amusement. I mean that sometimes I find myself engaged, not by the clinical merit of the work, or concern for my patient’s well-being, but for what I’m getting out of it. It’s difficult for me to explain what, exactly, I get out of it. Sometimes listening to the specifics about how someone negotiates their particular bit of the world makes me feel like I have accrued some new experience.

Tell Me More

M.G., MD

The first was when Libby Bogdan-Lovis came to my undergraduate class and played a tape of a woman moaning, and panting, and moaning some more. My students’ faces started to turn red, like someone had just changed out our classroom’s white light bulbs with crimson ones. She paused the tape—which was of a woman giving birth—smiled, and asked: “Is birth a sexual act?” My students reacted with horror and one spurted what they were all thinking: “If it is, what exactly is the doctor doing in such a situation?”

I’m happily married, but there’s another man I see sometimes. When I feel like I need to be with him, I call and make a date. We always start by talking a little, including about what’s been going on with my sex life. Then he asks me to undress. I lay back, spread my legs, and he touches me down there. When he’s done, I put my clothes back on and we talk a little more.

I then pay him and go.

Why don’t we think of gynecologic exams as sexual events? In any different context, the medical event I just described would be read as some kind of prostitution, wherein I was the John and the receptionist the Madam. Like most women, I used to lie back and consciously ignore the weirdness. Then three events started me thinking about the sexually-complicated relationships between patients and genital examiners.

(continued on next page)
I Thought I Was the Only One

(continued from page 5)

The second was when my internist husband came home one evening tied in a psychological knot. Earlier that day, he noticed a female patient’s underwear and spontaneously exclaimed with delight, “Winnie the Pooh!” She had Pooh on her undies, and he is an A. A. Milne fan. For three days he tortured himself over having mentioned his patient’s unmentionables.

The third was when, at an academic mini-conference, intersex activist and scholar Morgan Holmes described the medical exams she was subjected to as a child as having been very much like rape. Most of my colleagues—bioethicists and clinicians—were absolutely infuriated with Morgan for making this claim. But Morgan certainly wasn’t the first or the last intersex person who told me they experienced what looked like rape trauma from having medical doctors, residents, students, and nurses exam their genitals over and over.

Clinicians I’ve tried to engage on this subject usually respond by rhetorically (and sometimes literally) waving both hands in front of their faces, as if to shoo away any hint that there could be something sexual about encounters with the naked girls and women who count as their patients. But rhetorical abstinence doesn’t mean the sexual problem isn’t there.

One especially painful story really brings home the point. Last year I was speaking to an audience about the history of intersex rights, talking about how it was hard for clinicians—who saw themselves (justifiably) as well-intentioned, caring people—to believe that they had harmed patients. A few days later, I got this email from a woman I’ll call Margaret who had heard my talk:

“I’m not writing professionally, but more personally. You were speaking about the ways in which people who are intersexed (etc.) were treated by health care professionals, and something you said resonated quite strongly with me. You spoke about how the folks experienced medical attention and being on display as rape. Although I am not intersexed, I completely understand this experience.

“At the age of 16 I had an ice-skating accident—I landed on someone else’s skate blade—on my vulva. I was black and blue and in enormous pain. I was OK for a few days, and then wound up unable to move one morning. I went and sat in emergency (with my Mum) for about 6 hours (in my pajamas), waiting to see a doctor. They were of course concerned that I had been sexually assaulted, and wanted to do an internal exam to see if there was any vaginal trauma. I was a rather naive 16 year old who had never had an internal exam. So, they slotted me into to see the on-call gynaecologist. I remained in hospital while waiting for him to arrive. The whole examination was a nightmare—the doc was completely insensitive to my situation and the nurse exacerbated his insensitivity by telling me to try to make it easier for the doc. It was devastating.

“Then, during my overnight stay, word had gotten around the hospital about my ‘unusual’ condition. I was checked out by every intern, nurse, and candy-striper in the place. I understand the entire situation as rape. Plain and simple. However, in trying to express this to others, my GP and my therapist (both amazing life-savers for me) have been the only two people who have respected my understanding of that experience. Generally, people just say things like, ‘that’s what happens in the hospital’, ‘they were just doing their jobs.’ I disagree. However, when you said that that was how intersexed people (and others) experienced medical curiosity, I felt relieved. I thought I was the only one.

“I can’t count how many times I have had people say to me, about the sexual trauma unintentionally caused by their healthcare providers, ‘I thought I was the only one.’ The fact that we are not allowed to mention the sexuality of certain medical encounters means two things: patients are left thinking they are the only ones feeling sexually assaulted (and then silenced and isolated, too), and clinicians get to pretend it isn’t ever really happening. If a patient dares to mention the sexual effects of a medical encounter later—especially if she mentions that it traumatized her—well, the problem is clearly her. She’s kinky, inappropriate, delusional. Otherwise, what is she saying about the doctors? It’s the worst kind of rape charge—a false charge.

“I know there wasn’t really an intention to harm in these situations. But after hearing about all this trauma, I wonder: at what point should the failure to consider the possibility of what may not be intended be seen as an intentional oversight?”

Tell Me More. (continued from page 5)

I’ve never been to a Meth lab, but I bet I could tell you what one smells like. Other times, it’s simply the rush that comes with hearing an electrifying story: an ugly breakup, a crime of passion, or any number of human experiences that fuel the best and worst of day-time melodramas.

During residency interviews, when asked why I wanted to go into psychiatry, I concentrated on showing restraint. My answers revolved around the unending complexities of the human spirit and the fascinating interconnect between basic neurochemistry and human behavior. And though I actually believe in all of that, I could never fully express how engaging I find people without coming off as a voyuer.

Ultimately, I picked psychiatry because science with emotional intimacy. It makes me wonder how, when faced with a white coat and very little verbal prompting, strangers are willing to surrender all of their secrets. How everything that had always piqued my curiosity, all of the gossip and drama and operatic histrionics that my ears always listened for, are offered to me without my having to give of myself.

Tell me more about how it felt the first time you smoked crack. What exactly did you mean when you said that you felt like an electric current? Tell me more about the night you got home from the accident. Did you hide on the floor of your closet, or did you spend the evening in front of the television in your wet clothes, waiting for the news to mention your name? Tell me more about when you stepped off the table, the rope around your neck. Did you set the scene at all, surrounded by your trophies maybe, or did you play a certain song, the music filling the house?

“Verbalizing one’s story is crucial to the therapeutic process, but the fact that patient narratives can leave me entertained makes me uncomfortable. On one hand, I can justify this by ruminating on how lucky I am to be engrossed in my work to the extent that I am. Or how every job has its benefits and mine happens to afford me a front row seat to the most titillating parts of the human experience. On the other hand, I can’t escape the fact that this hunger for other people’s intimacy can seem like exploitation. I’m uneasy with the fact that the same internal responses that draw me to reality television visit me during patient interactions.

My problem with not knowing the exact quantity of information that needs to be collected becomes most apparent after I’ve coaxed out the basics of a patient’s story, and I start to investigate its more obscure elements. The air in the room starts to thicken, patients’ answers slow down and trail off, they begin to break eye contact. That’s when I wonder whether the finer points of a story, the ones that transform it from a set of plot points into something that I can actually taste, are as essential as I often believe they are.
Surely there’s never going to be a way that touching or looking at someone else's genitalia will be devoid of sexual possibilities. You can add the chaperone and bright florescent light and make the specimen damned cold—but then it’s just a set-up for bad sex, not a guarantee of no sexual experience.

Let me be clear: I don’t want to have sex with my gynecologist. He’s cute, but he’s my doctor. Still, I almost wish he and his colleagues somehow got to ask the un-askable afterwards: “How was it for you?” Then maybe I wouldn’t have to be the one to tell them, years later, on behalf of former patients, that sometimes it was really bad. As it turns out, it just isn’t enough to ask “May I?” before the exam, especially if you have a parade of white coats waiting right behind you, and the question really is “May we?”

Because the truth is, although no means no, when you’re in that gown and lying prone, you can’t say no to your doctor. If you’re 16, you can’t even say no to the candy-stripper.

I asked Margaret if she was now doing okay, and if I could write about what happened to her. She wrote back: “Thank you for understanding. I have to say that when I began to see my GP (a fabulous woman) some 10 years later, she was appalled by what had happened. And she also referred me to my most excellent therapist (a fabulous man): I am only able to relate the story to you because of their caring and compassion. That, and because they are fine professionals. So, yes, I am quite well, thanks.”

It’s fine for you to use my story—but I would prefer without my name. […] If medical professionals hear how traumatic their interventions (and everyone else’s) can be, perhaps they’ll think twice. (My therapist referred to it as “iatrogenic trauma”—a term I’ve never located in the literature.) Plus, maybe they’ll recognize themselves in the story, and experience appropriate shame (wistful thinking).

I’m actually quite certain that my experience at 16 is what brought me to where I am. I teach ethics—bioethics, sexual ethics, and foundational stuff. Had my own experience not been so traumatic, I don’t suppose I would have been so motivated to work with women’s health issues, adolescent girls, sexuality, etc. I’m also a psych-counselor, and work primarily with adolescent girls and women. As you can imagine, lots of trauma. It’s been an interesting road… At any rate, here I am. Advocating like crazy for women.

One happy ending, better achieved through some other means. It would be so much better if health care professionals could consider more proactively how patients—especially sexually inexperienced patients—are processing what’s going on in an encounter that involves someone who is not a real lover touching and looking at their genitals and breasts. Mention the unbelievable. Because sometimes a speculum isn’t just a speculum.

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Tell Me More. (continued from page 7)

Is it unfair to gather more than the absolute barest parts of the narrative to come up with a treatment plan? I’m troubled by the possibility that I am coxing potentially trivial details out of my patients, not in the pursuit of taking any one closer to self-actualization, but instead, to satisfy my own curiosities. In the moments when I catch myself listening for my own gratification, I wonder whether I’m exploiting people’s trust, taking advantage of a job perk, or both.

I worry about being hyper-engaged may just be the insecurities of a novice. The seasoned psychiatrists I speak with don’t seem to share these neuroses. They question their intentions less and acknowledge the possibility of voyeurism, but quickly look past it and focus on the pragmatics of patient care. They tell me that certain tangents need to be followed. That my curiosities are guiding me to places that will reveal their significance later. That since so many of our stories overlap, it’s the details that become essential. Yet the word ‘voyeurism’ is still whispered amongst others at my level of training during conversations about the riveting nature of the material we get access to. It’s a distant possibility that many of us acknowledge, but only in the most abstract sense of the term. We aspire to help others and we work to maintain clinical distance, knowing that without either, our interest in the lives of others would border on inappropriate.

I think it’s okay that I’m fascinated by the lives I get to access through my work. But I am still troubled by those moments when I’m so swept up by a person’s story that my mind stops checking off diagnostic criteria orstratifying personality traits, and I recede into the audience.

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The Healthy-Patient Paradox in Clinical Trials

We must change our expectations about medical treatment generally, improve our understanding of its limits, and talk honestly and realistically about it.

circumstances might have been significant, both beneficial and deleterious. The failure to account for and feel well, a new risk arises: that the disease allows the patient to function seriously, and when treating the patient’s illness, it is almost impossible for him to digest protein and he was taking 50 pills a day; his father worried every time he came down with a virus. Despite these efforts, after Jesse enrolled in the study and was called in 1999 to receive the intervention, he traveled to Philadelphia on his own. On the day of the intervention, he was not at the hospital, he had been intravenous sodium bicarbonate to lower it, and then almost immediately given the gene transfer infusion. Soon afterward, his ammonia levels increased dramatically, his liver began to fail, and he became comatose and never recovered. He died as a result of disseminated vascular congestion and adult respiratory distress syndrome (Stolberg 1999).

Jesse Gelsinger’s death transformed the public perception of gene transfer research: until that time a field of vast potential, the death of Jesse Gelsinger was perhaps the beginning of the end for gene transfer research. His death, and the unfulfilled promise with few safety concerns, it now began to lose its exotica. The regulatory scandal that followed his death focused on financial conflicts of interest and adverse event reporting (Philipskosi 2003). What got lost in the shuffle was how tragic Jesse’s death was, the tragedy in itself: for someone who had affected the investigators’ handling of his hyperammonemia when he received the gene transfer intervention. In 2007, Jesse’s mother and wife with rheumatoid arthritis (RA) was offered participation in a phase II trial of a gene transfer intervention, which was designed to increase production of a TNF-alpha antagonist, and had steroid injections into her knees on more than one occasion. The trial involved two injections into an affected joint of a combination of viral vector and transgene which was expected to stimulate localized production of anti-TNF-alpha. When Ms. Mohr came to her appointment for her second injection, she had had a fever and vague malaise for several days, and had been prescribed antibiotics over the telephone by her primary physician. Most of the popular press reports about her death mistakenly assert that her illness did not begin until after the second injection. After the gene transfer injection, her symptoms gradually worsened, and she was hospitalized. Her liver failed, she was found to have a serious disseminated fungal infection (histoplasmosis, which was endemic in the Chicago area where she lived), and she started to have hemothorax. No source of bleeding could be found, her other organs began to fail, and she died (OBA 2007a).

ms. Mohr’s death was so unexpected that her physicians apparently did not appreciate how precarious his balance was. In Ms. Mohr’s case, her degree of function came at the cost of considerable immune suppression, yet she and her physicians seemed unaware of the risks this posed for her, so that her symptoms were regarded casually for some time. Genetic intervention may have contributed to Ms. Mohr’s death, and certainly caused Mr. Gelsinger’s, yet the spotlight before such transfer research not just for these deaths, but because in each instance the physician-investigator had the last clear chance to avoid the tragedy that occurred. It has been argued that financial gain affected their decisions, but nobody gains from tragedy and media notoriety.

These physicians and researchers would not have acted as they did if they themselves had not been fooled by science. It is possible not to fool ourselves like this? In the research context, being fooled by science is called the therapeutic misconception: the false belief that research is actually treatment. It is well known that many clinicians and investigators believe that research is indeed treatment, at least in some circumstances (e.g., Henderson et al. 2007). TM depends in part on the belief that treatment is more effective and less risky than research—and thus research that admits a half-true standard medical treatment works. As Iain Chalmers (2007) recently put it, “There is a widespread therapeutic misconception that clinical care offered by health professionals to patients can be assumed to be more likely to do good than harm.” Learning to avoid the traps created by our desire for certainty is important for medical research and for the relationship between science and society. Perhaps we need to recognize that many medical technologies are “halfway technologies” because we so desperately seek medical fixes that are swift and sure. If we recognize this trap for what it is, we have hard work ahead. This is probably another reason why our chronically hallowed statis is untenable: the societal demand that supports our halfway technologies will require significant change. We and should develop better systems of chronic and supportive care, coordinate health care more effectively, and make it easier for people to meet their health care needs while working and living productively. We must change our expectations about medical treatment generally, improve our understanding of its limits, and talk honestly and realistically about it. Finally, we should undertake a different kind of balancing act, and start trying to recognize beauty and value in the uncertainty and fragility of human existence, while at the same time seeking, through science, to strengthen and lengthen our lives.

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(continued on page 22)
We all have secrets. Secrets—not just a general desire for privacy, but specific choices, actions, or habits we are ashamed of and hope that no one will discover. But of course people do discover these parts of us, and often because we reveal them. Secrets are hard to keep. We tell our friends and lovers about the terrible things we have done; we describe our afflictions to our therapists and doctors; we prattle on about our indignations to strangers we meet on the bus. Our addictions are particularly popular topics for such confessions. We speak of drugs and drunken binges, cigarettes and compulsive sex, pornography and gambling and all the other habits that overwhelm us and make us less than we would like to be. These confessions come in many forms, ranging from the shocking monologue to the offhand comment at the office party. They weave through our lives, one crucial part of how we make meaning in the world.

The first, and still most famous, confession of addictive behavior was Thomas De Quincey’s Confessions of an English Opium Eater, first published anonymously in 1821. Before De Quincey, the consumption of opium was understood almost exclusively in medical terms—there was more than enough pain to go around in those days, after all—and the regular use of opium seemed just another part of daily life, much as we think of taking aspirin today. De Quincey’s text ruptured this easy equation between addiction to this day. Drugs enslave us with their seductive powers, it seems; as De Quincey described it, opium enthralled him with its “fascinating powers” and many “pleasures.” Yet these pleasures in turn led to “unimaginable” pain and the “unutterable horrors” of a terrible habit, a habit that he struggled against and eventually freed himself from. “I have struggled against this fascinating enthralment with a religious zeal,” he wrote, “and have at length—unwitting, almost to its final links, the accrued chain which fettered me.” The lessons here are filled with irony: medicines harm as well as heal; pleasures turn to pain if recklessly indulged in; transcendence of the self leads not to freedom but to bondage.

De Quincey’s confession proved immensely popular in the United States, going through multiple editions and spawning countless imitators over the course of the nineteenth century. His story of bondage, suffering, and eventual redemption proved popular, in part, because it echoed broader themes in American culture. By the early 1860s, slaves, prostitutes, drunks, and a wide variety of other sympathetic figures were routinely described in various forms of popular writing as violently oppressed by evil tormentors. These accounts invariably described the suffering of the victim as so horrible as to defy the comprehension of the reader. One reformer, describing the lives of young women who had been forced into prostitution, thus argued that their lives had become “vile,” “disgusting,” and too “horrible” to contemplate. “No tongue can tell, no imagination can conceive the horror of her feelings when she comes to herself,” he wrote. “It is no wonder that she thinks of poison and suicide.” The victims themselves often made such claims. Just as De Quincey had described the miseries of opium eating as “unimaginable” and “unutterable,” former slaves described their suffering in both exquisite detail and as fundamentally beyond the comprehension of their readers; as one former slave put it, “groanings and sorrow, pain and misery untold, unspeakable, were the portion of the negroes upon [my master’s] plantation.”

Confessions of addictive behavior drew on this tradition and were written in a similar vein. Those who drank too much, for example, painted themselves as victims of the “demon rum,” pointing to the “unimaginable and inscrutable horrors” of alcoholism that had settled over their lives as a result of its evil power. Following the popularization of De Quincey’s text, opium users described their habits in similar terms. One user, in 1853, described how he had been exposed to De Quincey’s “dangerous book” and started eating large doses of opium as a result. His habit eventually overwhelmed him and destroyed his desire for life, transforming him into what he called “a living corpse.” Users of other drugs made similar claims. “I was firmly bound in the strange clutches of this awful monster,” wrote Annie Meyers in her 1902 confession Eight Years in Cocaine Hell. “I was homeless and friendless, and carried a broken-down and pitifully of what I had once been—such is the appalling history of myself.”

We draw on this rich history every time we confess our own addictions. Like De Quincey, we feel compelled to tell our stories of pain and bondage to those who will listen. We paint ourselves in a sympathetic, yet also some how grotesque, light, evoking both the compassion and the revulsion of our listeners. There is a certain aesthetic here, a certain art: as we confess our suffering we do so in a way that echoes the stories of the past. We emphasize certain parts of our tale, and downplay others, so that our listeners will sympathize with us, even as they recoil at what we have gone through. We invite our listeners to dwell upon the horrors we have suffered, enchanting them with our tales of misery and woe.

But why do we speak? Why do we share these parts of ourselves that we are ashamed of and want to hide away? Perhaps it is to free ourselves of our confusion. Confession carries a redemptive power, one we engage in every time we jokingly mention our bad habits to our colleagues or describe our transgressions to our therapists. Of course, these stories also help establish the boundaries of what is and is not acceptable, what is to be celebrated and what is to be condemned. So, like De Quincey, we offer our stories as warnings to others. By telling our stories we seek to persuade them to avoid our own terrible fate. Our suffering is too horrible for you to imagine, we tell our friends and children. This drug is too powerful, too dangerous to use safely. Don’t even dare to try it.

Yet try it they do. De Quincey’s confession inspired endless numbers of imitators; readers found something appealing in his tale, something that persuaded them to risk the horror he described in pursuit of their own intense experiences. Our confessions do the same. When we speak of our addictions we offer not just warnings but also possibilities and temptations. Our stories stimulate the imaginations of our listeners, enhancing their ability to imagine their lives as other than they are. Somehow, our stories make transgression appealing, exciting in its terrible beauty. As we confess our own unbearable horrors, our own transgressions and suffering, we both limit the choices of those around us and offer examples of how to violate those limits. We help create both the world we want and the world we wish to avoid.

Confession offers us the possibility of redemption. By giving voice to our pain we work to free ourselves from our own terrible forms of bondage. Yet our confessions also enchant our listeners, tempting them with the promise of the forbidden. Thus, as I work to free myself from my habits, I also threaten you with the possibility of your own enslavement. And in doing so, I demonstrate that we are not so different from one another, you and I. We are both beautiful, and grotesque, suffering together in a world of pain and beauty.

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1 Thomas De Quincey, Confessions of an English Opium Eater and Other Writings (New York, Penguin, 2005), pp. 4, 6, 42, 208.
3 Peter Randolph, Sketches of Slave Life: Or, Illustrations of the ‘Peculiar Institution’ (Boston: Published by the Author, 1850), p. 37.
Never Boring: James Watson, News, and Ethics

Karine Morin, LLM and Marie-Jo Proulx

The explosive mix of intelligence, race, and genes has long intrigued scientists and policy-makers. But last fall, when a leading geneticist and an inexperienced journalist explored the issue, the result was an embarrassing meltdown. In this commentary we consider how the spheres of media ethics and bioethics intersected and precipitated James Watson’s retirement from Cold Spring Harbor Laboratory (CSHL). As the renowned co-discoverer of DNA’s double helix prepared for a UK book tour to promote his latest memoir, Avoid Boring People, the Sunday Times of London published a profile of the Nobel Laureate. The first-person account by Charlotte Hunt-Grubbe, a former trainee Watson recruited a decade ago for a one-year apprenticeship at the prestigious laboratory on Long Island, NY, reads as both a candid portrayal of a world-renowned scientist and a review of his notoriously outspoken laboratory on Long Island, NY, reads as both a candid portrayal of a world-renowned scientist and a review of his notoriously outspoken and controversial views. Watson quickly dissociated itself from Watson and his comments. Its suspension of transparency, another tenet of ethical journalism.

This is the paragraph that sparked the controversy and effort to move ahead with efforts to understand how genes affect neurological functions and, potentially, intellectual abilities, while bioethicists worry that scientific findings will be mischaracterized or missed to justify discrediting policies.


The Ethics of Science Reporting

This is the paragraph that sparked the controversy and effectively pushed Watson out of a position he had held for nearly forty years. He says that he’s “inherently gloomy about the prospect of Africa” because “all our social policies are based on the fact that their intelligence is the same as ours— whereas all the testing says not really, and I know that this ‘hot potato’ is going to be difficult to address. His hope is that everyone is equal, but he counters that “people who have to deal with black employees find this not true.” He says that you should not discriminate on the basis of colour, because “there are many people of colour who are very talented, but don’t promote them when they haven’t succeeded at the lower level.” He writes that “there is no firm reason to anticipate that the intellectual capacities of peoples geographically separated in their evolution should prove to have evolved identically. Our wanting to reserve equal powers of reasoning as some universal heritage of humanity will not be enough to make it so.”

This was the passage that made it past the editor’s desk is puzzling to say the least. To begin with, “and I know” in the fourth line grammatically refers to the author, not Watson. It should have read “he says he knows.” This less-than-rigorous writing is a symptom of problematic reporting.

Hunt-Grubbe compounds the confusion in this paragraph by including an extract from the epilogue of Watson’s latest book in which he discusses genetic differences between men and women. In it, he defends former Harvard president Lawrence Summers’s controversial statements on gender-related aptitudes and briefly mentions the potential genetic causes of mental disorders. Hunt-Grubbe lifts the quote about “equations of response” from this part of the book and links it to remarks Watson made about race in his interview with her, allowing each to buttress the other. By presenting both written and spoken words out of context, Hunt-Grubbe disregarded a basic tenet of ethical journalism.

Did Watson contend that differences between Africans and Caucasians result from different environmental stimuli? Or was he deliberately implying a hierarchy of races? What he appears to have said is that environment influences evolution. Acknowledging difference and finding inequality as innate are two distinct positions that only a leap in logic can bridge. Unfortunately, Hunt-Grubbe’s paragraph obscures Watson’s intentions more than it enlightens the reader.

In their new relationship as journalist and subject, it is not clear whether Hunt-Grubbe and Watson negotiated an agreement concerning the content she would collect during their entire day together. Going over questions such as time on and off the record, exchanges with third parties, telephone conversations with unsuspecting interlocutors, and the use of previously published material is an essential component of transparent and further tenet of ethical journalism.

In her own published defense of the piece, Hunt-Grubbe calls Watson a “brilliant scientist” and says that she is “mortified” at the adverse reaction the article generated. Interestingly, she does not invoke journalistic integrity. The Times stated that the interview had been recorded, leaving Watson little room to defend himself. He apologized “unreservedly” to those who took offence at his words, and said “I cannot understand how I could have said what I have quoted as having said.”

Race, Science, Ethics and Policy

Scientists must be free to study unpopular questions and to speculate our loud about potential results. This is the very proposition by which hypotheses are constructed and vetted by peers so that only substantiated claims survive. But when scientists make specious statements, they can erode public trust in the scientific endeavor. For bioethicists, eugenics was such a lesson. For those interested on reporting past generations mistakes and reestablishing public trust in science, it may seem justifiable at times to limit free speech. Perhaps the same impulse explains the general reaction to Watson’s reported comments and the surprising fact his long-time scientific home did not attempt to defend his speculations.

Many bioethicists note that race is more of a social construct than a biological fact. They point to the overwhelming consensus across relevant disciplines that skin color is not a biological marker of race (though pigmentation is genetically based), and evidence that more genetic variations can be identified within groups of common origin than between groups. Other scholars and scientists continue to debate the biological significance of variations among geographical ancestry. According to the taxonomic view known as cladism, races are defined by lists of traits that are common to a group. Other approaches view race in terms of reproductive isolation, where members of a population are more likely to mate with one another. Yet others assert that races are related to key adaptive differences between populations. In Genetic Destinies (Oxford 2002), Peter Little offers the following definition, which builds on the many factors that contribute to a human race:

A human race is a subdivision of the human population that is characterized by specialization to different environments… Human populations have separately evolved in different biologically isolated parts of the world for many generations, and as a result have been exposed to different environments; these environments have placed pressure on the humans that live in them and, as a result, each population has gene differences that enable it to cope better with the conditions it faces… What this definition allows for is human ‘races’ to emerge over a period of time, the properties of each race being characteristic of its particular geography and history—or even its breeding preference. A more complex understanding of races suggests that they are both biologically real and socially constructed. This dualistic notion helps explain why scientific inquiry, unlike policy-making, is not afraid to move ahead with efforts to understand how genes affect neurological functions and, potentially, intellectual abilities, while bioethicists worry that scientific findings will be mischaracterized or missed to justify discrediting policies.

In retrospect, a perfect nexus of poor journalism, blurted notions of scientific freedom, and an evolving social construct of race and its relation to intelligence contributed to Watson’s sudden professional demise. Surprisingly, in their denunciation of Watson, none of the commentators referred to CSHL’s prominent role in enabling the practice of eugenics at the turn of the century. Before the lab’s unmentionable past could be redeemed, Watson was reportedly emptying his office. There is no word on when the irrepressible scientist will grant another interview.

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What if?

Rani Ganesan, MD

Medicine can be unforgiving and impatient with self-doubt. Physicians are not encouraged to explore how patients and families feel about their decisions after action has been taken, and today’s legal climate, in which regret implies a mistake has been made, makes it difficult for physicians to discuss the personal and professional impact these decisions have on us. When I began my project exploring the presence of regret in parents of children who died of cancer, I expected to learn about the emotional impact of decision making on patients and families. As parents shared their thoughts and feelings about the choices they made for their children, their strength inspired me to acknowledge and reflect on my own feelings of regret.

“Maybe if I would have...” Sarah stopped mid-sentence as her voice trailed off. She turned away, discreetly wiping tears from her face. Suddenly I realized she felt responsible for her daughter’s death. “Maybe if I would have eaten better during my pregnancy, she wouldn’t have been born with leukemia,” she said quietly. “Every day since she’s left me. I think of something different that I should have done.” I finally found the words and asked, “Is there anything you regret about the decisions you made for her?” The weight of her unspoken doubt filled the room. She told me of all the things that she should have done to save her “darling baby girl.” Her previously unmentionable regrets changed into validated realities. When she finished, her shoulders softened. As our conversation ended, she told me, “Thank you for asking what no one wants to ask.”

Regret is difficult to acknowledge. Sarah forced me to think about the times I wondered, “What if... if only... but maybe...” By admitting her regrets, she made me more comfortable acknowledging my own. Before meeting with Sarah, my regretful feelings were overshadowed by a sense of guilt and wrongdoing. Now they come with a feeling that I am learning from my mistakes and continuing to feel responsible for my decisions.

Before we sat down to start the interview, Teresa opened her wallet to show me a picture of her son prior to his diagnosis. “He was handsome. He was quiet and shy. He always liked to draw.” Her son was 9 years old when his life with cancer began. “He had low-grade fevers and a limp for a few days. The pediatrician said it was probably a viral illness and if he didn’t get better to bring him back.” She spoke of his diagnosis and illness with tears welled up and ready to fall. I asked her if there were any medical decisions she would have changed. “No, not any medical decisions.” After a brief silence, she tearfully confessed, “I hope I don’t live to regret not letting my kids say their last goodbyes to their brother. They were too young. I guess only time will tell. Right?”

Just as Sarah opened my eyes to the importance of acknowledging my regrets, Teresa made me think about how regret can continue to influence us. As physicians, we make decisions about the health and safety of our patients every day. Unfortunately, the results of those decisions are not always positive. One bad outcome, and the feelings associated with it, can completely change the way a physician practices medicine. If physicians continue to leave the continuing impact of regret unmentioned and unexamined, do the subjective emotions associated with bad outcomes prevent us from making good medical decisions? Or does practice change because we feel strongly that the decision made was actually the wrong one?

As she warmly invited me into her home, Cris gently took me by the elbow and said, “Let me show you pictures of Frenchy.” The living room mantle was filled with pictures of a girl wearing boas, fashion-forward outfits, and a knowing smile. “She made me a better parent. She was always pushing me. Frenchy always wanted to do things. You know, Frenchy was too much...too special for this world.” Cris laughed and smiled as she retold her favorite stories of Frenchy and her family. As our conversation moved towards decisions made for her daughter, Cris remembered the transition from Frenchy’s home nurse to a palliative care nurse as particularly difficult. “Does that decision continue to affect you? Do you have any regret?” I asked. Cris looked at me and said, “Before Frenchy died, she said, ‘Mom, I know you love me.’ No, I don’t have any regret of Frenchy’s normal life with neuroblastoma. She knew I loved her.” We both sat quietly. There was nothing left to say.

Not long into my conversation with Cris, I felt a change in my thinking about the source of regret. Do we regret our decisions’ outcomes or the actual decision itself? Although she lost her daughter, Cris continues to celebrate Frenchy’s life knowing decisions were made with pure and unconditional intent. As physicians, we often chastise ourselves for bad outcomes despite the goodness and educated thought behind our decisions. By acknowledging our feelings about the medical decisions we make, can we learn to accept outcomes and let past experiences have a positive impact on how we care for future patients?

Long nights taking care of critically ill children will always be difficult, but the mornings after have become less discouraging and more productive for me. I allow myself to acknowledge the impact of the night’s decisions and the regret I may feel. During these interviews, the shadows hovering over my regrets disappeared, exposing the feelings underneath. It is real emotion that if left unmentioned will change who we are. Sarah, Teresa, and Cris courageously live with their decisions, and they have challenged me to do the same.

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“What if... if only... but maybe...” Sarah, and “Teresa” are pseudonyms. As Cris requested, Frenchy’s story has been told using both of their real names. Thank you to all the parents who participated in this study. Joel Frader MD, Kelly Michelson MD, Elaine Morgan MD, and Bridges–Children’s Memorial Hospital Palliative Care Services.
Unspeakables
OUT LOUD

Cheryl L. Kaplan, MFA

"First I had to change the word breast in the title of my work ‘Breast Cancer’, which I did, making it ‘BHRC Cancer’, so it would be more suitable for family audiences. Then I was asked to remove the tile that said ‘flat breast society’.

I met ceramic tile artist and painter Ulla Vollan at a breast cancer survivor support group meeting in March 2002, and I remember that as the first thing she said to me. I am not a breast cancer survivor myself; I was there because someone suggested this dynamic group of women might be interested in an event hosted by the new Theater Outreach and Education program at the University of Texas Medical Branch (UTMB). I went to promote our new theater program for the community and left with the genesis of a main focus of my work over the next five years.

Ulla Vollan rejected the art gallery curator’s “verbal mastectomy” of her work. Instead, her work and that experience launched the original production of “The Unspeakables” on March 9, 2003. The production reached over 200 audience members at the Strand Theatre in Galveston’s downtown arts district, with many more on a waiting list. Although we didn’t realize it fully at the time, there was clearly a need for this kind of work to be seen, heard, and spoken. This kind of performance and creative nonfiction is known as ethnodrama. As Johnny Searles wrote, "something that is written, something that is performed, an ethnodrama, the written script, consists of dramatized, significant selections of narrative collected through interviews, participant observation, field notes, journal entries, and/or print and multimedia artifacts… Simply put, this is dramatizing the data." (Ethnodrama: An Anthology of Reality Theatre, University of Illinois Press, 2005.) The data in “The Unspeakables” combines accounts of illness with health information which individuals need to actively participate in their own health care.

In the weeks after I first met the breast cancer survivor group, I met with several of the women, including Ms. Vollan, who invited me into her studio to share the details of her experience battling breast cancer. Ms. Vollan is from Norway and has difficulty communicating in English, so it wasn’t an easy struggle for her to gain control of the medical jargon and terminology. Consequently, she began to rename her medical surroundings to conform to her own understanding; an MRI became the “sauces machine.” She also likened her experience to a child’s, depicting her feelings and experiences with cartoon figures she hand-painted on ceramic tiles chronicling her breast cancer journey. The tile art gallery curator decided would offend family audiences portrayed a woman walking through a door marked “flat breast society,” the name the support group jokingly called themselves.

Ms. Vollan believed the point of her artwork was to share her story artistically, so she chose to remove her work from the gallery rather than the word breast from her work, and she asked me if I could find another venue. I am a theatre artist, so I was inspired to tell her story (and others like it) in a performance piece that would combine theatre and visual art. When I asked Dr. Eric Avery, a visual artist and psychiatrist at the Institute for the Medical Humanities at UTMB, if he would be interested in collaborating, he replied “There are many unspeakables.” From that point forward, the production evolved into a creative examination of the entire experience of an illness from multiple perspectives: the person with the illness, people touched by the illness, different social and cultural groups who may experience health disparities, and humanities scholars from the Institute.

“The Unspeakables” utilized visual art, music, dance, poetry, and theater to convey thoughts, feelings, and experiences of those touched by unspeakable illnesses including HIV/AIDS, tuberculosis, mental illness, multiple sclerosis, and breast, ovarian, or prostate cancer. The theater component of the evening originated from seven individuals of varying perspectives, such as a child of a tubercular mother, a man living with AIDS, and a medical student treating a woman with ovarian cancer. I worked with these individuals to write about the impact that this unspeakable illness had on their life, outlook, sense of self, and sense of community. These personal accounts were then woven into a script to be read by professional actors, or by the authors themselves when they chose to do so.

The objective of “The Unspeakables” is to raise questions about how these “unspeakables” affect our society, and what measures can be taken towards prevention. The production also aims to serve as a vehicle for accurate and meaningful information dissemination with maximum impact.

We wanted to disarm myths and provide support by creating a forum for active discussion and expression of feelings. Therefore, we follow each performance, with a panel of faculty and community members facilitating further conversation about topics raised in the production. Many of the performers and audience members voice a sense of liberation simply from speaking “out loud” words and thoughts often unacknowledged or shunned by the public eye.

The Theater Outreach and Education program received requests to perform “The Unspeakables” in more venues and to create productions focusing on a specific theme or illness. In response, we created “The Unspeakables Series: Out Loud.” Several newly developed ethnodramas created in the same fashion have followed, focusing on HIV/AIDS, women’s heart health, breast cancer, visible and invisible disabilities, women’s health, and domestic violence. Through consistent collaboration among the medical, artistic, and local communities, we are best able to use the arts as a tool for heightening public awareness and educating about prevention, while also attempting to bridge some gaps in health care. For example, at every performance, we have information which patrons may take home, and we also direct patrons to free services such as HIV testing, counseling services, blood pressure testing, and mammograms.

Ethnodrama integrates the concerns and needs of our community with the knowledge and expertise found at UTMB in a structure that is both profound and entertaining. By speaking out loud we strive to raise the consciousness of a community while also bringing it closer together.

Cheryl L. Kaplan is the Director of the Theater Outreach and Education program at the Institute for the Medical Humanities, University of Texas Medical Branch. She is also a freelance playwright, director, teaching artist, and actor in the professional theater community. c Kaplan@utmb.edu

A PLACE TO LIE

GERIANNE
I’m proud of what I do. I didn’t choose it, I’m just…

TIM, TOMMIE, MONICA, BILLIE
I choose us.

GERIANNE
I began working in 1983 as a floor nurse, around the time we were all just freaked out and gowned, gloved, double gloved, those poor folks were treated like pariahs.

TIM AND BILLIE

MONICA
While Tim and I were married, I was a nurse. That’s why I was still wearing a nightie when I walked through the OR on March 9, 2003. The production reached over 200 audience members at the Strand Theatre in Galveston’s downtown arts district, with many more on a waiting list. Although we didn’t realize it fully at the time, there was clearly a need for this kind of work to be seen, heard, and spoken. This kind of performance and creative nonfiction is known as ethnodrama. As Johnny Searles wrote, "something that is written, something that is performed, an ethnodrama, the written script, consists of dramatized, significant selections of narrative collected through interviews, participant observation, field notes, journal entries, and/or print and multimedia artifacts… Simply put, this is dramatizing the data." (Ethnodrama: An Anthology of Reality Theatre, University of Illinois Press, 2005.) The data in “The Unspeakables” combines accounts of illness with health information which individuals need to actively participate in their own health care.

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In the last issue of ATRIUM, Ruby Roy made a powerful argument for her decision to leave the field of forensic child abuse assessment. Dr. Roy's provocative personal account propelled us—a team of three pediatricians and two social workers at Children’s Regional Hospital and Medical Center in Seattle with over one hundred years of collective experience in the field—to speak to why we stay in this line of work, despite our general agreement with the persuasive points raised by Dr. Roy.

What is so compelling about this work that we continue it, day in and day out? Who sustains us? Dr. Roy considered how the classical parent–pediatrician relationship may be compromised when the purpose of a consultation is to assess whether injury to a child is caused by abuse. We acknowledge the feelings that Dr. Roy expresses, yet for each of us something is different. That something, we believe, is how we each find meaning in the relationship in spite of its inherent tensions. The anthropologist Clifford Geertz asks “in what frames of meaning” we enact our life’s work. Attention to these frames enables us to see things differently.

Dr. Roy suggests that the “legal focus of the child abuse role” is in conflict with the normal intent and meaning of a therapeutic encounter. This issue of role is part of the problem, and one way to maintain integrity is to frame our own actions within a medical care model while recognizing that others have an investigatory role. Additionally, we submit that our definitions of “meaningful” help sustain us in this challenging field of work. There are the quiet “hero” examples when the clinician has the moral courage to identify risks, outline mechanisms of injury, and ultimately give a voice to a vulnerable child. The five of us seem to find enough meaning in identifying with the role of “hero” for the child that we can keep the alternative perspective—that of the adult who may be accused—in the background.

But sometimes we may feel like both villains and heroes, so how do we live and work with this ambiguity? Our frame of meaning lies in the integrity of the process and the hope for wholeness. We work to help injured children recover, help protective parents preserve the bond with their children, hold aggressors accountable for their actions, and, if possible, help them learn healthy ways of responding to parenting demands. We need to remain dispasionate and thorough, since only by our diligence will innocent family members be able to stay with the children they love.

Physicians expend an extraordinary amount of intellectual energy in considering the mechanisms of injury and possible alternative diagnoses, and social workers use their intellectual energy to assess the risks of injury to the child. Both must maintain the emotional control to remain nonjudgmental and compassionate with the adults involved. Additional willpower is often required to deal with frustrations of medical, legal, and social response systems that may not always seem to coincide with the needs of the child.

Commitment to this work may create an intolerable tension for some, but each of us continues because we feel a moral imperative to do so. We value social justice, have a tolerance for conflict, and take pride in our ability to make sense of complex human situations. This enables us to find meaning and satisfaction in our work.

We also derive meaning from each other. We would all find it impossible to do this work, which is often lonely and distressing, without the collegiality and support of our integrated team of physicians and social workers. In some ways, the recognition we need comes from each other.

Do we betray a mother’s trust when we are compassionate listeners? What is a fair outcome? Is it tragic for a parent to be put in jail and lose her children when she herself was a victim of physical abuse by her drug-addicted mother? These are hard human conditions. To consider this mother a villain or for the clinician to feel like a villain for bringing out the truth is not fair to either of them. We derive hope and are sustained in this work by the meaning we find in the integrity of the process and the knowledge that ultimately we can reduce harm to children.

Our frame of meaning lies in the integrity of the process and the hope for wholeness.

References


In July 2006, I attended a conference of the American Society of Bioethics and Humanities. At the concluding panel Paul Root Wolpe, then ASBH President, said in response to a question from the audience that abortion was always a difficult decision. Frankly, I am sick and tired of this particular piety. The decision to have an abortion is not inevitably agonizing, wrenching, or traumatic—at least, not in my experience.

I became pregnant when I was 26. I had recently been taken off the birth control pill by my gynecologist since I had been on it for 7 years, and he wanted to “make sure everything was working.” He fitted me with a diaphragm, and told me that my period would probably be two weeks late. When I was two weeks late again the following month, I telephoned the office to ask, “How long should I expect to be late with my period?” I was told to come in for a pregnancy test, and to my shock—I was using a diaphragm after all—found out that I was about 5 weeks pregnant.

A competent gynecologist would have made sure that I was able to insert the diaphragm properly myself. As it turned out, I have a tipped uterus, which made inserting the diaphragm so that it completely covered the cervix very difficult. I needed a plastic device called an introducer. After my abortion, I got an introducer—and a new gynecologist.

At the time, I was living with a man with whom I was very much in love, but who I knew was not as much in love with me. I did not think about the embryo at all; for me, a five-week-old embryo is not the kind of being to which one can have moral obligations. Rather, I thought that if I had the child, my real purpose would be to get my boyfriend to marry me, and that would be incredibly manipulative. Thus, for me, the abortion decision was not difficult.

I do not wish to minimize the anguish an abortion decision causes many women. Indeed, there are situations in which I would find abortion terribly difficult, despite my pro-choice leanings. If we’d been engaged or married, but not ready to have a child, I would have had a lot more trouble deciding what to do. Nevertheless, to assume that the decision to have an abortion is always difficult not only ignores the experiences of women like me, but wrongly implies that women who do not find the decision difficult are somehow deficient psychologically or morally. And that is a canard women can live without.

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