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ATRIUM

The Report of the Northwestern Medical Humanities and Bioethics Program

Unmentionables

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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 was just being swept along by the actions of the hospital staff as they put in 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 parents of stillborn babies. I couldn't speak but I remember foggily wondering: 'Bereavement photographs? What are those? I've 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 usually take pictures of horrible things in your life.… Now, however, Stephen will readily say that he is so glad that he didn't protest on that day because of the importance of the pictures to both of us."

It's difficult to talk about the death of an infant, but Mr. Hochberg finds that images of this precious and often short time can help. "We rely on photographs to build and pass on our family histories," Mr. Hochberg writes. Documentary photographs offer parents an "illustrated narrative of 'their story' for themselves and the loved ones they choose to share it with, fostering greater social support and connection." Mr. Hochberg also works with hospital bereavement programs, palliative care programs, and hospices to make photographs and legacy video for people struggling with serious illness or grieving the death of a child or adult.


BEREAVEMENT PHOTO, 19TH CENTURY

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, and mailed to relatives. In the twentieth century, changing attitudes toward death and the possibility of amateur photography virtually eliminated professional postmortem photography, until some hospitals began offering this service in the early 1980s. (See generally, *Secure the Shadow: Death and Photography in America* by Jay Ruby, MIT Press 1995.)

"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 awake to a panicked emptiness. It took me time each morning to believe that what happened wasn't just a nightmare, that it was real. It got to the point where I dreaded mornings because I knew how I'd feel when I opened my eyes. Then, all of a sudden, we were given a gift, Todd's album. We saw our time with our son laid before our eyes. It's as if the [photographs] spoke to us saying 'It was real. You did hold him. You did kiss him. You are a family.' When I awoke the morning after we'd been given the album instead of having that usual panicked feeling I felt such a sense of peace."

ATRIUM is grateful for Lynda and Stephen's permission to share their story and photograph. Touching Souls Bereavement Photography is funded entirely through donations. Cover photo © Todd Hochberg. www.toddhochberg.com

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Worth a Thousand Words?

A Conversation with Arthur Kleinman and Vikram Patel

"Hidden Away: Stigmatized, abandoned, often locked up, Asia's mentally ill are left to inhabit a living hell" —that's the headline of the "Lost Lives" cover story that appeared in the Asian edition of Time *magazine on November 3, 2003. The article and an expanded photo essay on the* Time *website include many photographs of identifiable children and adults in squalid conditions in mental health institutions. In contrast to the approach of the news media, a medical journal objected when medical anthropologist and psychiatrist Arthur Kleinman and psychiatrist Vikram Patel sought to illustrate an academic article on human rights abuses of mentally ill people in Asia with photos from* Time *and other sources. In this conversation with* ATRIUM*, Doctors Kleinman and Patel discuss difficult questions of privacy, justice, and ethical obligations across borders.*

Katie Watson: What drew your attention to the lack of mental health care in Asia?

Vikram Patel: My attention has been focused on this issue ever since I returned to work in India in 1996. I have researched the burden, social determinants, and the current care received for mental disorders since then, and based on this work begun to experiment with alternative models of health care for mental disorders through community and primary care delivery systems. The *Time* article in 2003 and the National Human Rights Commission report in India in 1999 both drew my specific attention to the issue of human rights of persons in mental hospitals in the region.

Arthur Kleinman: When I was in Taiwan in 1975-76 I visited mental hospitals in and around Taipei. In one small family-owned hospital, a young woman with bipolar disease, but now no longer psychotic, was (like other patients) chained to a bed. She pleaded with me to get her out. The owner's wife explained that this woman would be in the hospital a long time because her family refused to accept her, and they also did not want her roaming the streets, at least until their other children had married. They feared the powerful stigma associated with mental illness would otherwise interfere with their prospects and bring disgrace on the family. I offered to pay for her release, but to no avail. The same set of visits put me in contact with other groups of patients with serious mental illness who were locked in cages at home, abused in a mountainside shrine, and locked up in small hospital rooms: naked, with filth on the floor near the hole in the cement 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 "unshowable" 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 iconic 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

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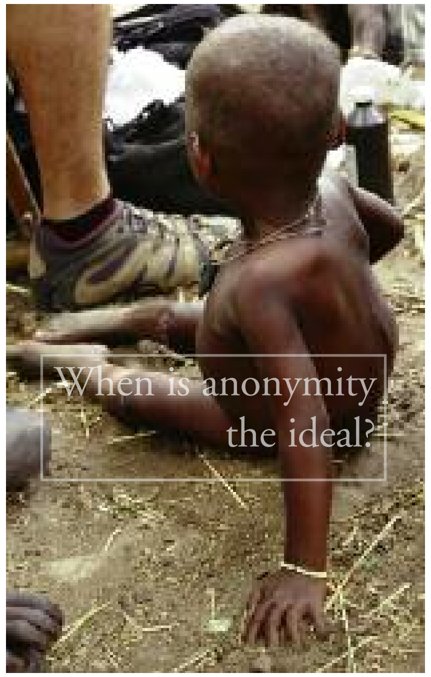
circumstances, have had a powerful impact on public policy. It was in this spirit that we wished to use images of persons with mental disorders in contexts where their basic rights were being denied. The images were collected from a wide variety of reputable sources (from international press agencies to human rights advocacy groups) 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 know that it was me—others might know—would loathe the fact that 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 from someone 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 children dying in Darfur or of HIV/AIDS in southern Africa? We haven't found a satisfactory answer as yet to this apparent dissonance.

One reviewer proposed there is likely to be another side to the story, and I don't doubt there are explanations for each of these images which may help attenuate our outrage. However, there is no justification for the kinds of practices we are criticizing based on cultural relativism because ethical relativism is simply unsustainable in the area of human suffering and care-giving. Furthermore, there is evidence that advocating for the human rights of the mentally ill is an effective tool in their defense to improve services. One commentator was concerned that such images might damage colleagues and psychiatry in developing countries but our goal is not to undermine psychiatry (indeed, both authors are psychiatrists); instead, we seek to demonstrate that an evidence- and rights-based psychiatry is in fact part of the solution, just as it is starting to be in developed countries. Another reviewer was concerned that our article would abet those who, with varying political motives, seek to undermine medical and psychiatric services that people with mental disorders and disabilities need: our response would be the same as to the previous concern.

As authors, we believe it is critical not to deny the reality of the tragedy these photographs capture; the real ethical issues are contained in the content of these images.

Dr. Kleinman, you say "held" is a more accurate term than "treated," which suggests perhaps the ethical analysis should consider the subjects of these photos more like prisoners than patients. Dr. Patel, you draw an analogy to the ethical status of photos of victims of conflicts, famine, and disease, yet those subjects generally aren't "patients" photographed in clinical settings, and their photos are mostly in newspapers. Journalistic ethics doesn't require consent for photos of news events (though investigative reporting can push the limit of this definition)*, but medical journals require consent for photos of identifiable persons. All this leads me to wonder—are the two of you essentially arguing for a new category in the medical literature that would be judged by different standards than traditional clinical articles about "patients"?**

* National Press Photographers Association Code of Ethics: "[I]mages can reveal great truths, expose wrongdoing and neglect… Photographs can also cause great harm if they are callously intrusive…." Photojournalists should "[t]reat all subjects with respect and dignity. Give special consideration to vulnerable subjects… Strive to ensure that the public's business is conducted in public… Strive for total and unrestricted access to subjects… and work to show unpopular or unnoticed points of view."

** International Committee of Medical Journal Editors, Uniform Requirements for Manuscripts Submitted to Biomedical Journals (Updated October 2007): "Patients have a right to privacy that should not be infringed without informed consent.… Identifying details should be omitted if they are not essential. Complete anonymity is difficult to achieve, however, and informed consent 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 people are used, either the subjects must not be identifiable or their pictures must be accompanied by written permission to use the photograph. Whenever possible permission for publication should be obtained."

VP: Images of people dying of, say hunger or HIV/AIDS, have been used in medical journals, for example in *The Lancet.* I am pretty sure none of those whose images were used gave written consent for this use. Furthermore, the human rights issue is not based on the setting where the photograph was taken but on the violation of rights. Thus, if the rights question related to how a patient was being treated or 'held' in a hospital, how else could one visually convey this other than through a photo of a patient in that hospital? I think both recommendations you cite provide a strong ethical basis for the use of such photographs. I think a critical point in the second recommendation is "Whenever possible permission for publication should be obtained"; receiving consent of a person in chains in a hospital is clearly one of those situations where such permission is virtually impossible.

AK: I agree with Vikram. Pictures are crucial in advocacy and mobilization. If we are to tell the global human stories of injustice, discrimination, and abuse among the seriously mentally ill, then we must see the real people in real conditions. The unwillingness to do so, often defended in the name of ethical protection of human subjects, is tantamount to silencing those with the greatest suffering and need for help. Refusing to project disturbing images of real people with mental illness is an example of misplaced value that fits the comfortable conditions of ethicists in rich societies, where the stark danger of being treated as inhuman is not an everyday reality as it is in poor and middle income countries.

Here the best is the enemy of the good. It would be best to receive permission from the people pictured in these photos before they are displayed in a medical journal. Obtaining that permission, in this instance, is not possible. Withholding the photos, however, defeats truth, criticism of the abuses pictured, and the possibilities of using public understanding to build a global movement that will bring about reform. It keeps us from doing good in the world for people who have no voice, no presence, and no possibility of changing the abuses to which they are systematically exposed.

I believe if medical journals and the press did more to expose the intolerable conditions of the mentally ill, more would be done to improve those conditions. My colleague Amartya Sen has long argued that where there is a free press, there is no famine. Criticism from the press forces governments to make food available to those in greatest need. In the 1990s, in several South American countries, large numbers of hospitalized chronically mentally ill patients routinely died of starvation. Pictures of their conditions created an international outcry that resulted in reform of mental hospitals. Much the same happened in the U.S. in the 1950s and 1960s. I believe medical journals should accept the ethical responsibility of the newspapers whose investigative reporting has done more to call attention to this human tragedy than psychiatry has.

I am not unaware of the misuse of images[1], and I appreciate medical ethicists' concern for protecting patients. But in this case the wider claims of social justice and the need to address the worst of health disparities require that readers of medical journals be exposed to an on-the-ground reality that needs to be seen to be appreciated.

What obligations do clinicians in one country have to patients in another? How would you respond to a Western clinician who says of course she's sympathetic, but she's too busy caring for patients and dealing with shortcomings in her own country's mental health care to take action on behalf of psychiatric patients in Asia?

AK: Of all the medical specialties (in the U.S. at least), psychiatry has the lowest profile for advocacy for patients in poor societies, and the smallest footprint of global health action programs. The ethical issue is the almost complete failure of psychiatrists to take a moral position on mental health in poor countries, to set out and advocate for a global agenda, and to develop programs. At this very moment there is a huge wave of student interest in global health and the development of a national moral movement for global social justice, yet the problems of aging, psychiatry, and mental illness are largely absent from the international agenda.

VP: I completely agree with Arthur. This is a tricky question for which I don't have a pat answer. While I don't see that clinicians in one country have any tangible obligation to the care of persons with mental disorders in others, I am ambivalent towards the view that we can do nothing about injustice in a globalizing world because we are too busy with our own lives. If the reason was 'I don't care', that is honest and perhaps I can accept that more. But to say 'I don't have time' is to deny your own conscience an avenue to react. It does not take much time, for example, to vote for a president of your professional association who vows to challenge injustice, or to write a letter to a human rights agency protesting what the photographs display, or to give a donation to a user group in a developing country, or to spend part of your holiday in an exotic country supporting local advocacy efforts.

Did the reporting and photography in the Asian edition of *Time* (www.time.com/time/asia /covers/ 501031110/story.html) trigger any improvements?

VP: The impact on policies has been minimal. These horrific conditions remain the norm in many hospitals, and the most distressing reality is the complete silence of the psychiatric associations in these countries in response to this tragedy.

AK: I concur. Each year, it seems, publications will highlight abuses of the mentally ill in one setting or another. After this happens there tends to be something locally that is done with the intention of improving matters. But it is most often neither systematic nor substantial. The situation is rather like the global mental health field generally. There are plenty of small demonstration projects, but very few are ever evaluated and almost none are scaled up and implemented at a more substantial level. There is no governmental or substantial private sector buy-in. Over time the inadequacy of these responses tells a story. That story 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 inefficacy that my colleagues Veena Das and Margaret Lock and I had in mind in our book *Social Suffering* when we pointed out that governmental responses themselves become a significant part of the creation and maintenance of suffering. I see no escape from this tragic circle, until that time when the global prioritization of mental health is robust enough to command substantial resources and systematic large-scale reform.

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[1] See Arthur Kleinman and Joan Kleinman, "The Appeal of Experience; The Dismay of Images: Cultural Appropriations of Suffering in Our Times," *Daedalus* 25 (1), 1996. Reprinted in Arthur Kleinman, Veena Das, and Margaret Lock, eds. *Social Suffering* (Berkeley: University of California Press, 1997), pp. 1-24.

Other Peoples’ Troubles Are My Business

Tod 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 Bosk 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 Brody 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 those 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 perhaps in the analytical structure of Wayne Booth there is a moral distance between the implied author and the narrator. But, if it were true, then am I contributing to the objectification of this man by continuing to use his story? What is the fictional status of William Carlos Williams’s tales?

We need not only be concerned with the use physicians’ tales, but also the manner in which we non-physicians have been given the privilege of access to patients stories. For many of us, the line between insider and outsider, educator and scholar often becomes blurred. Just over the past week I have learned in a variety of settings, from patient visits, to ethics conferences, to conversations with physicians and chaplains, an extraordinary number of tales of suffering, failure, disenchantment, moral lapse, and disturbing family secrets.

Those engaged in the medical humanities need to understand that our position standing with physicians, nurses, and other health care professionals grants us access to personal narrative and thus confronts us with complex moral positions that the rest of our humanities colleagues rarely have to consider. I believe that in general we have been sloppy in our ethics and have not taken seriously the need for a moral firewall between our research and our pedagogical activities. Scholars of bioethics have begun to concern themselves with the ethics of bioethics, but this seems far more related to the construction of a new professional identity (the “bioethicist”) than to the traditional professional identity of academic.

The time has come for medical humanities scholars to attend seriously to the moral problems that arise when we use patient narratives gained during teaching or observing physicians in hospitals. We must recognize that unlike most of our humanities colleagues, the subjects 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.

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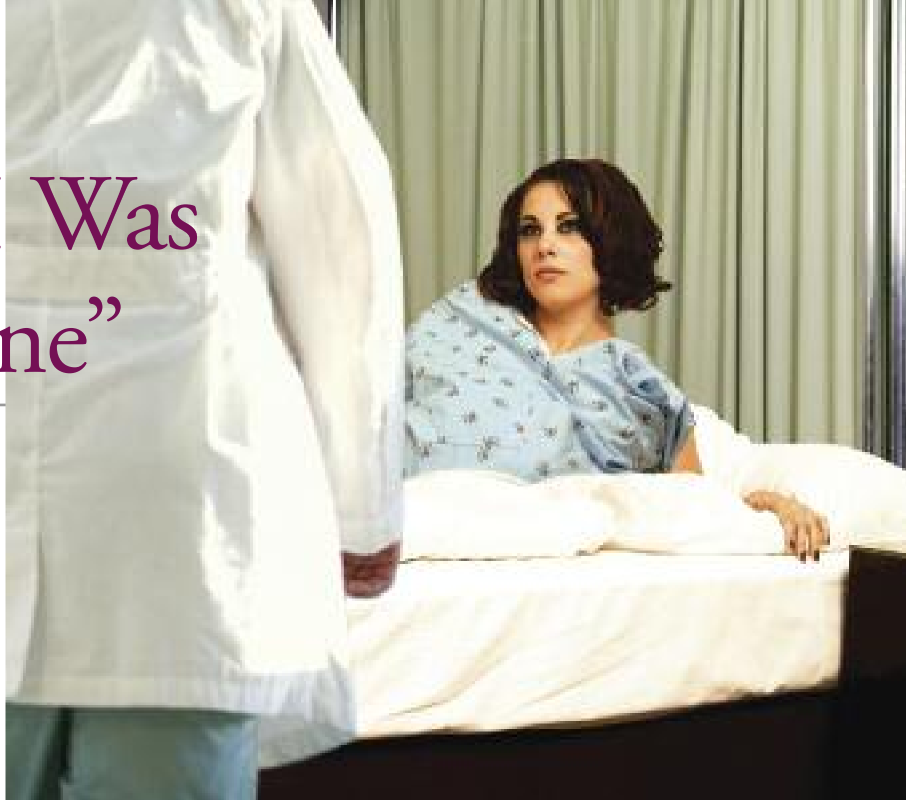
“I Thought I Was the Only One”



Alice Dreger, PhD

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. Then I 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.

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 sputtered what they were all thinking: “If it is, what exactly is the doctor doing in such a situation?”

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Tell Me More.

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 nosey?

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 as the listener, as the clinician, as the altruistic bastion of magnanimity that I market myself as, find myself becoming entertained. 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.

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"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 Mom) 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 in to see the on-call gynecologist. 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?

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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 voyeur. Ultimately, I picked psychiatry because it married science with emotional intimacy. It never ceases to astonish me 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 curiosities, 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 obtuse 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.

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“I Thought I Was the Only One”

(continued from page 7)

Surely there’s never going to be a way that touching or looking at someone else’s genitals will be devoid of sexual possibilities. You can add the chaperone and bright florescent lights and make the speculum 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-striper.

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 (wishful 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 unmentionable. 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 coaxing potentially trivial details out of my patients, not in the pursuit of taking anyone 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.

My worries 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 or stratifying personality traits, and I recede into the audience.

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The Healthy-Patient Paradox in Clinical Trials

Nancy M. P. King, JD

Medicine fails people. Research fails people. Most medical technologies are “halfway technologies” (Thomas 1974). These three rarely mentioned truths address only part of what is unsaid about medical progress and its effects on people who are also patients and, at times, research subjects too.

Everyone knows that many medical treatments are not “cures.” Drugs to lower blood pressure or cholesterol don’t preclude heart attack or stroke or even completely normalize those measurements, transplantation replaces failing organs with chronic immune suppression, and so on—the examples are legion. Nonetheless, our faith in medical progress is profound. Much of the lure of breakthrough medical technology lies in the hope that this time, the fix will really and truly work. This hope affects those who participate in technological advances in some unexamined ways.

The deaths of Jesse Gelsinger and Jolee Mohr in early-phase gene transfer research studies have raised pressing questions about safety, efficacy, and design, as well as questions regarding subject selection in early-phase clinical trials, the therapeutic misconception, and financial conflict of interest. However, their deaths also highlight the paradox of medical progress. They were members of an increasingly large yet unacknowledged constituency: those for whom medicine has proven imperfect and whose stories therefore have become incompatible with the narrative of scientific success that has so captured the modern imagination.

This group consists largely of those for whom science has simply come up short. A recent example is provided by the story of Carl and Clarence Aguirre, the Filipino craniopagus conjoined twins who were surgically separated in New York in 2003. Their surgery is generally described as a striking success. It is; that’s just not the whole story. Both boys need extensive follow-up services, ranging from additional surgeries to intensive physical therapy to home health assistance and financial support; ensuring access to these less high-profile services is an ongoing challenge for the twins’ mother (Santos 2007).

Another set of craniopagus conjoined twins illustrates a second consequence of the perceived success of science. Ladan and Laleh Bijani were adult sisters who sought separation in order to pursue separate careers and lives. They chose to undergo a difficult and risky surgery, and did not survive it (King 2003b). Their surgical team may have drastically overestimated the possibility of success, in part because they relied on the images provided by a novel software program. This program built a 3-D image of the twins’ skull and vasculature from a collection of conventional scans, which did not reveal several hidden anatomical details. These details became apparent during surgery and could not be overcome.

For the Bijani twins, belief in novel technology fell short more drastically than for the Aguirres. Yet both of their

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stories demonstrate the consequences of inattention to the possibility of less than perfect outcomes from medical advances. Mr. Gelsinger and Ms. Mohr show us something new, I think. They had very different diseases and very different lives, but were alike in an important and increasingly common way: they both had significant disease but were not ill. Like the classic "healthy volunteer" subjects in phase I drug trials, Mr. Gelsinger and Ms. Mohr both enrolled in cutting-edge early-phase research that was not expected to benefit them. The failure to take account of technological imperfection can be seen not only in that research, but—much more consequentially—in the standard treatment regimens on which they relied every day.

The disease-illness distinction used to be taught in medical school in order to humanize physicians, to help them recognize the differences between lab data and lived experience. But modern medicine may have rendered that lesson too well-learned. When physicians are taught to take the patient's illness experience seriously, and when treating the disease allows the patient to function and feel well, a new risk arises: that the underlying disease, not cured, might at critical times be forgotten. Both these research subjects regarded themselves as healthy, and both were viewed by physician-investigators as sufficiently healthy to be enrolled in early-phase research. Both lived apparently normal lives by adhering to medical regimens involving significant medications with significant effects, both beneficial and adverse. Both were given an experimental intervention although symptoms and lab values categorized them as not sufficiently healthy. Proceeding in these circumstances might have been appropriate with research subjects who genuinely qualified as healthy volunteers; instead, in both cases it led to their deaths.

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

Here is the imperfection in experimental gene transfer technology: instead of attempting to correct the mutated genes that give rise to disease (that is, doing "therapy" on genes), gene transfer introduces large numbers of non-mutated genes into the research subject's system, almost always using genetically altered viruses to penetrate cellular defenses (King 2003a). The effects can be insufficient for clinically significant or long-term changes, or so much that the immune system is swamped, or both. Important as this imperfection is, it's not the elephant in the room this time; take note of how easily it hid the elephant in two tragic stories.

Jesse Gelsinger was not yet 18 in 1998 and aching to be independent. That's when he first learned about the first-in-humans trial of an experimental gene transfer intervention for ornithine transcarbamylase (OTC) deficiency, the rare metabolic disorder which made it almost impossible for him to digest protein and with which he was still coming to terms. He did not inherit his disease; it was caused by a spontaneous mutation. OTC deficiency results in an excess of ammonia in the system; untreated, it leads to coma and death. There are not many adults with the disorder—it is most often diagnosed in an infant during a hyperammonemic crisis. Growing up, Jesse had several serious crises, but his drug and dietary regimens, though burdensome, kept improving in effectiveness. He had a job, a tattoo, and a motorcycle, and when he turned 18 and was re-contacted about the study, he decided to "help the babies" (Gelsinger 2000). The investigators said Jesse had only 6% of the normal capacity to digest protein and he was taking 50 pills a day; his father worried every time he came down with a virus. Despite these factors, 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, his ammonia level was higher than permitted for study enrollment, so he was given 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 intravascular coagulation 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 and unfulfilled promise with few safety concerns, it now began to lose its exceptionalism. The regulatory scandal that followed his death focused on financial conflicts of interest and adverse event reporting (Philipkoski 2003). What got lost in the shuffle was how precarious Jesse's health was, and how that may have affected the investigators' handling of his hyperammonemia when he received the gene transfer intervention.

In 2007, Jolee Mohr, a young wife and mother 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 in affected joints. RA is a relatively common chronic and progressive auto-immune disorder with a range of serious symptoms, including inflammatory responses that erode joints. TNF stands for tumor necrosis factor, an inflammatory agent that is produced normally in the body but is overproduced in people with RA, causing joint damage. Standard treatments for RA include TNF-alpha antagonists, corticosteroids, and methotrexate—all of which can suppress immune function and increase the risk of infection. Most patients are on multi-drug regimens, as each category of agent works in a different way.

Ms. Mohr was a person who was unlikely to be recognized as sick. She played tennis, cared for a young daughter, and maintained an active lifestyle. She was also far from asymptomatic—she took methotrexate and 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 symptoms 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 is endemic in the Chicago area where she lived), and she started to hemorrhage. No source of bleeding could be found, her other organs began to fail, and she died (OBA 2007a).

Extensive follow-up testing suggested strongly, but not conclusively, that the effects of the gene transfer injection were not the straw that broke the camel's back. The immunosuppression associated with Ms. Mohr's overall treatment is thought to have given histoplasmosis its foothold, with the gene transfer almost certainly playing a very small role at best (OBA 2007b). As in Mr. Gelsinger's case, questions were asked about financial conflict of interest because the investigator who enrolled Ms. Mohr in the study was her rheumatologist, conducting gene transfer research as part of his private practice (Weiss 2007a-c). Some people also wondered, as they did in Jesse Gelsinger's case, why Jolee Mohr had been asked to participate in research from which she herself was very unlikely to benefit. (This is a bad question, because research is supposed to be for the next person, not for the subject; the enrollment of research subjects in trials from which they cannot benefit is common and often very informative.)

Finally, as with Jesse Gelsinger's death, both of these issues have obscured the possibility that Jolee Mohr, her family, her primary care physician, and her rheumatologist had such confidence in the safety and effectiveness of her standard treatment regimen that nobody thought a possible infection dangerous in a person taking the drugs she was taking, and she was given the second injection despite her fever and other symptoms.

Modern medicine makes it possible for people with serious disease to not have to be sick, to live normal, well-functioning lives. Nobody wants to mention the balancing act that is required for this to work. In Mr. Gelsinger's case, the picture of his disease was unusual, and the investigators 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 belongs on gene transfer research not just for these deaths, but because in each instance the physician-investigator had the last clear chance to avoid the tragedy and did not act. 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.

Is it possible not to fool ourselves like this? In the research context, being fooled by science is called the therapeutic misconception (TM)—in other words, mistakenly believing 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 it rests on a prior misconception: that 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 fail 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 hoodwinked state is unmentionable: becoming a society that supports our halfway technologies will require significant change. We can 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)

UNSPEAKABLE HORRORS:

Addiction and the Art of Confession

Joseph M. Gabriel, PhD

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 indiscretions 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 *mea culpa* 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 opium and pain control. He described his drug use in terms of sensory pleasures and transcendent visions, thereby creating a new category of consumption that today we rather dismissively call "recreational." Yet De Quincey also described his opium habit as a fall from innocence, a terrible form of bondage characterized by physical suffering, a growing alienation from the rest of society, a habit filled with terrifying visions which overwhelmed his daily life.

DeQuincey's remarkable text established the basic framework that we use to conceptualize 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 enthrallment with a religious zeal," he wrote, "and have at length…untwisted, almost to its final links, the accursed 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.[1]

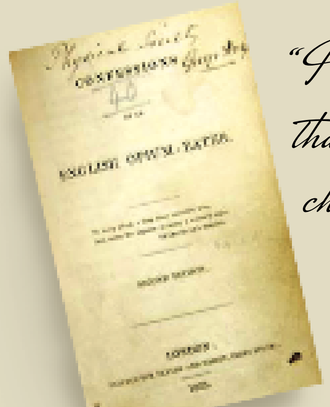
De Quincey's confession proved immensely popular in the United States, going through multiple editions and spawning countless imitators over the course of the nineteenth century. His story of bondage, suffering, and eventual redemption proved popular, in part, because it echoed broader themes in American culture. By the early 1840s, slaves, prostitutes, drunkards, 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."[2] 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."[3]

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 indescribable horror of darkness" that had settled over their lives as a result of its evil power.[4] 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 slavery of this awful monster," wrote Annie Meyers in her 1902 confession *Eight Years in Cocaine Hell.* "I was homeless and friendless, degraded and frenzied, insane, a broken-down and pitiful wreck of what I had once been… such is the appalling history of myself."[5]

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 somehow 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 them. 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 horrors 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 unspeakable 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.


CONFESSIONS

ENGLISH OPIUM-EATER

LONDON

"It cannot be supposed that any man can be charmed by its terrors?"

—THOMAS DE QUINCEY

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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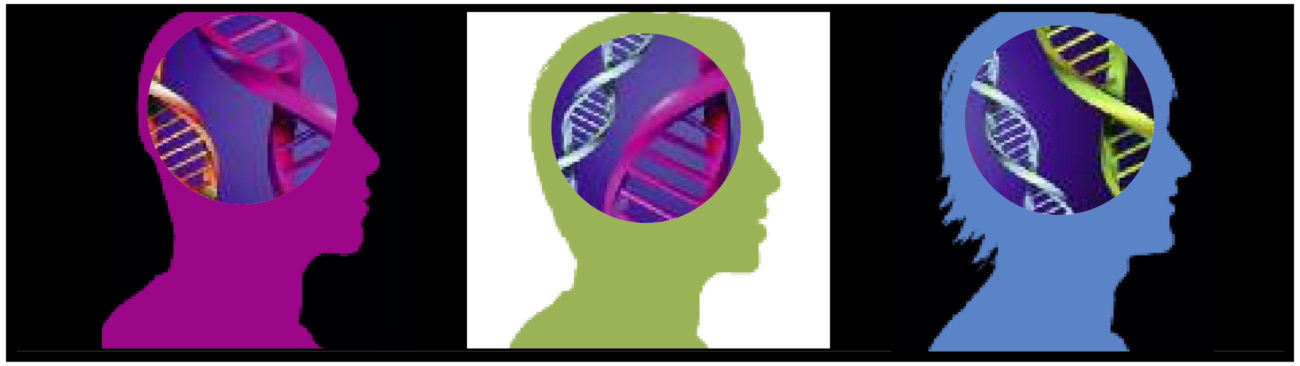
[1] Thomas De Quincey, *Confessions of an English Opium-Eater and Other Writings* (New York: Penguin, 2003), pp. 4, 6, 42, 208.

[2] *First Annual Report of the Female Benevolent Society of the City of New York, Presented January 13, 1834* (New York, 1834), p. 22.

[3] Peter Randolph, *Sketches of Slave Life: Or, Illustrations of the 'Peculiar Institution'* (Boston: Published by the Author, 1855), p. 37.

[4] Robert Carlton, *Something for Everybody: Gleaned in the Old Purchase, From Fields Often Reaped* (New York: Appleton, 1846), p. 178.

[5] Annie C. Meyers, *Eight Years in Cocaine Hell* (Chicago: Press of the St. Luke Society, 1902), p. 68.



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 portrait of the man and a review of his notoriously outspoken musings on science and life.

Within days of its publication, the article triggered condemnations of Watson on both sides of the Atlantic. British institutions and fellow scientists quickly dissociated themselves from him. The Science Museum in London and the University of Edinburgh cancelled scheduled presentations by the esteemed guest who was already in the country.[1] The Federation of American Scientists accused Watson of using "his unique stature to promote personal prejudices that are racist, vicious and unsupported by science."[2]

In a 140-word press release, CSHL unambiguously distanced itself from Watson and his comments.[3] It suspended him as Chancellor four days after the article's publication and announced his retirement less than a week later.

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 is "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 reason as some universal heritage of humanity will not be enough to make it so".[4]

How this convoluted passage 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 and *"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 "equal powers of reason" 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 defining 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 transparency, another 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.[5]

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 am quoted as having said."[6]

Race, Science, Ethics and Policy

Scientists must be free to study unpopular questions and to speculate out loud about potential results. This is the very process 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 intent on repairing past generations' mistakes and rebuilding 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.[7] 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 across geographical ancestry. According to the taxonomic tradition known as cladism, races can be defined as sets of lineages that share a common origin.[8] Other approaches view race in terms of reproductive isolation, where members of a population are more likely to mate with one another.[9] Yet others assert that races are related to key adaptive differences between populations.[10] In *Genetic Destinies* (Oxford 2002), Peter Little offers the following definition, which builds on these many features:

> [A] human race is a subdivision of the human population that is characterized by specialization to different environments.… Human populations have separately existed in geographically 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.[11] 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,[12] while bioethicists worry that scientific findings will be mischaracterized or misused to justify discriminatory policies.[13]

"I cannot understand how I could have said what I am quoted as having said."

James Watson, October 19, 2007

In retrospect, a perfect nexus of poor journalism, blurred 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 denunciations of Watson, none of the commentators referred to CSHL's prominent role in enabling the practice of eugenics at the turn of the century.[14] Before the lab's unmentionable past could be rediscovered, Watson was reportedly emptying his office. There is no word on when the irrepressible scientist will grant another interview.

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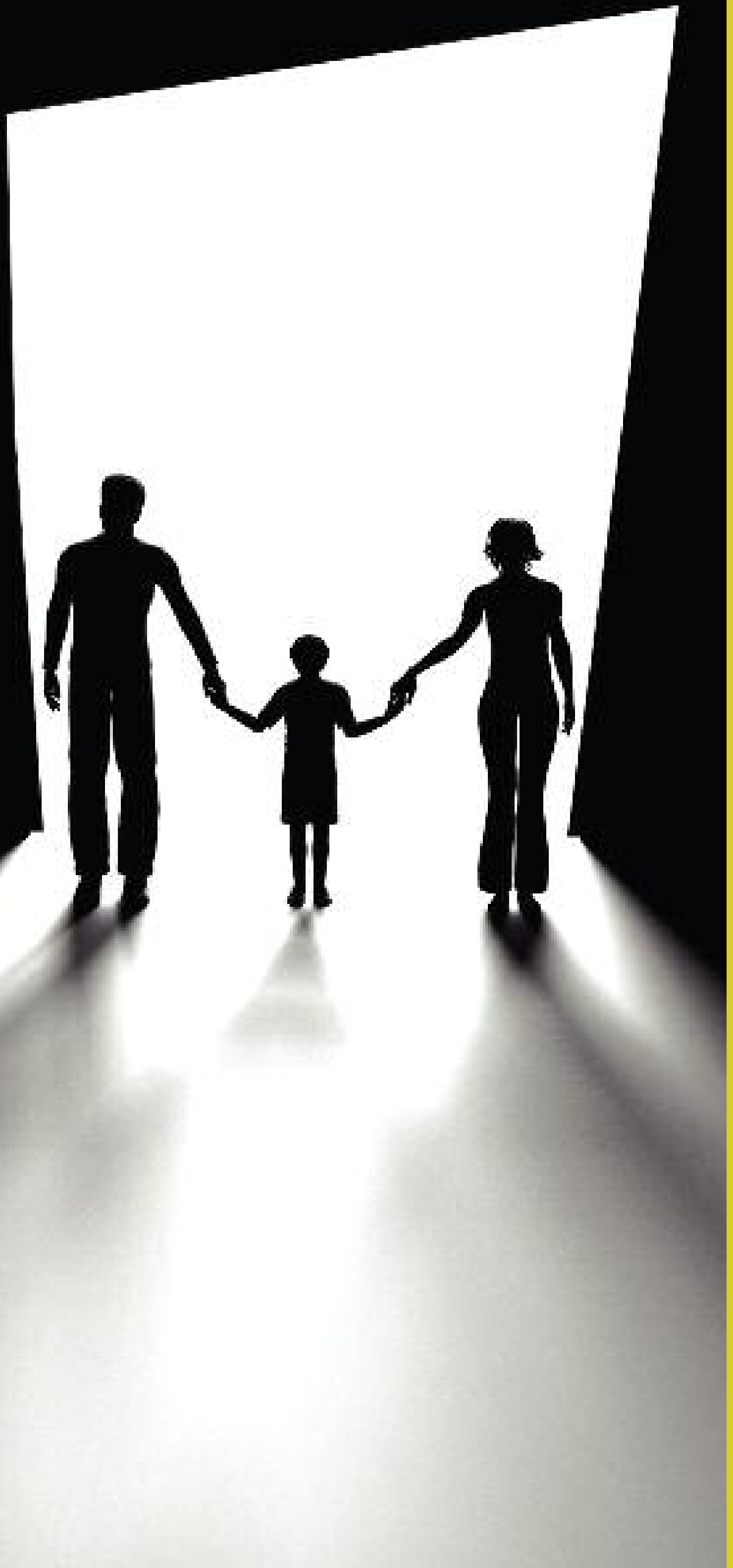
What if?

Thanks for asking

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, discretely 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 said to 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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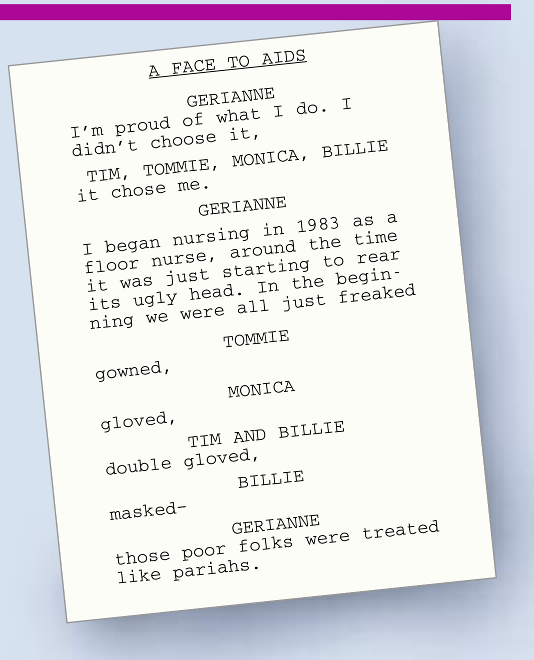
"Sarah" and "Teresa" are pseudonyms. At Cris's request, Frenchy's story has been told using both of their real names. Thank you to all the parents who participated in this study, Joel Frader MD, Kelly Michelson MD, Elaine Morgan MD, and Bridges-Children's Memorial Hospital Palliative Care Services.

Unspeakables
OUT LOUD



A FACE TO AIDS

GERIANNE
I'm proud of what I do. I
didn't choose it,

TIM, TOMMIE, MONICA, BILLIE
it chose me.

GERIANNE

I began nursing in 1983 as a
floor nurse, around the time
it was just starting to rear
its ugly head. In the begin-
ning we were all just freaked

TOMMIE

gowned,

MONICA

gloved,

TIM AND BILLIE
double gloved,

BILLIE

masked-

GERIANNE
those poor folks were treated
like pariahs.

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 Saldaña explains, "an ethno*drama*, the written script, consists of dramatized, significant selections of narrative collected through interviews, participant observation field notes, journal entries, and/or print and media 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 was an enormous struggle for her to gain command of the medical jargon and terminology. Consequently, she began to rename her medical surroundings to conform to her own understanding; an MRI became the "sausage machine." She also likened her experience to a child's, and depicted her feelings and experiences with cartoon figures she hand-painted on ceramic tiles chronicling her breast cancer journey. The tile the 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, a discussion follows 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 Unspeakable 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.

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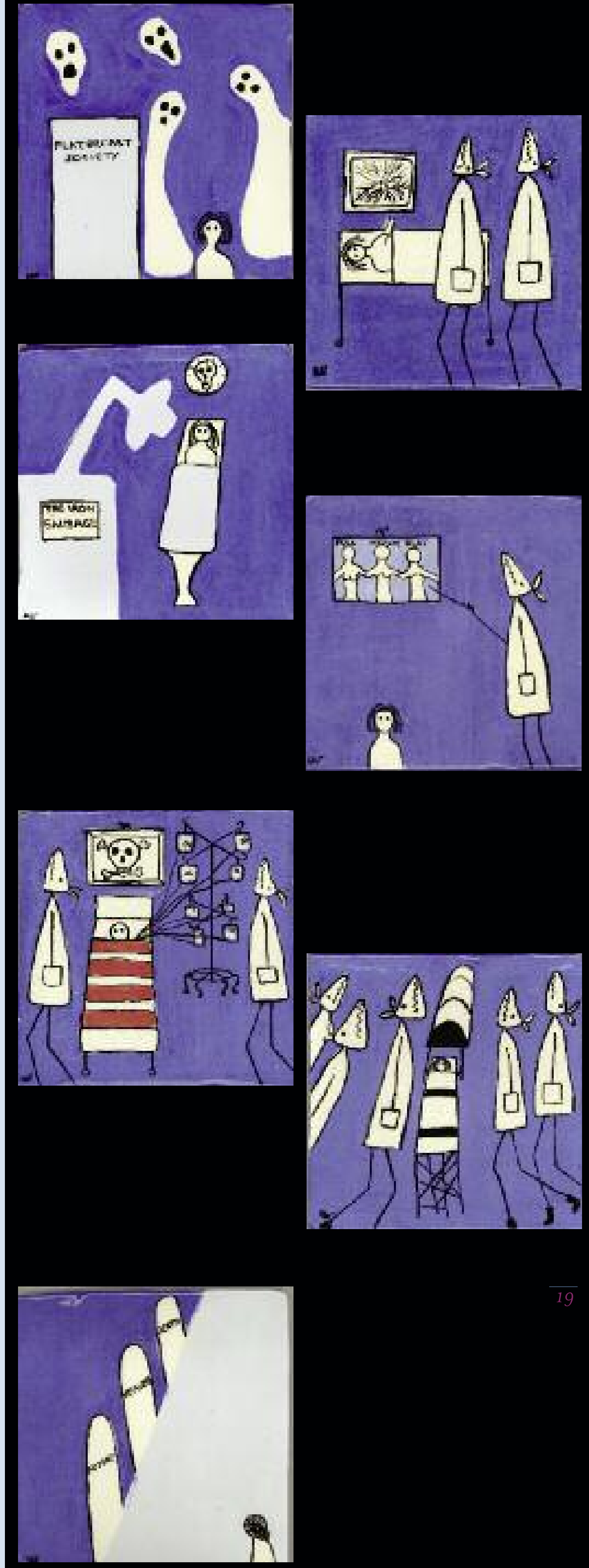
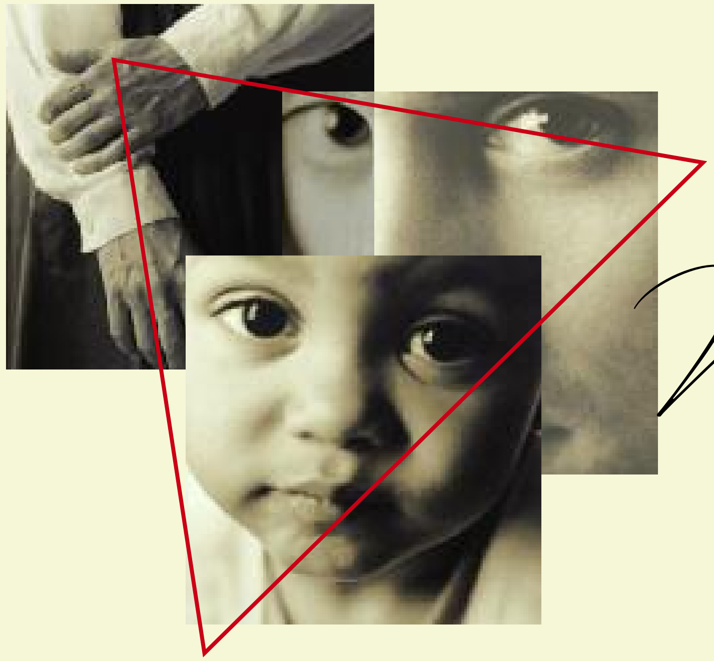


Tile Art © Ulla Vollan, 2002



Why do we keep at it?

A Response to "Villains and Victims" (*ATRIUM*, Summer 2007)

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? What 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 dispassionate 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.

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

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.

Ken Feldman, MD, Naomi Sugar, MD, Becky Wiester, MD, Jackie Brandt, LICSW, and Ana Brown, LICSW, the Children's Protection Program at Children's Hospital and Regional Medical Center of Seattle. The authors would like to thank Ruby Roy, MD, for her 15 years of professionalism in the field of child abuse and neglect and all of the other professional, quiet heroes who do this work everyday.
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John Ford, senior marketing executive for Parke-Davis, speaking to medical liaisons:

I want you out there every day selling Neurontin.… We all know Neurontin's not growing adjunctive therapy, besides that is not where the money is. Pain management, now that's money. Monotherapy, that's money. We don't want to share these patients with everybody, we want them on Neurontin only. We want their whole drug budget, not a quarter, not half, the whole thing.… We can't wait for them to ask, we need to get out there and tell them up front.… That's where we need to be holding their hand and whispering in their ear Neurontin for pain, Neurontin for monotherapy, Neurontin for bipolar, Neurontin for everything…I don't want to see a single patient coming off Neurontin until they have been up to at least 4800 mg/day. I don't want to hear that safety crap either, have you tried Neurontin, every one of you should take one just to see there is nothing, it's a great drug.

David Franklin, PhD was hired by Warner-Lambert's Parke-Davis Division as a "medical liason," an expert field scientist who answers prescriber questions. He reported this comment from Mr. Ford in his whistleblower lawsuit alleging illegal off-label marketing of Neurontin. FLIP (Formulary Leveraged Improved Prescribing) is a collaboration between Cook County Hospital and the University of Illinois at Chicago College of Pharmacy and College of Medicine funded by a grant from the U.S. Attorney General made possible by the $430 million settlement of Dr. Franklin's Neurontin case. FLIP's goals are to use the formulary process as a means to educate clinicians and students, to encourage critical analysis of evidence from drug companies, and to promote rational prescribing. For more information on the Neurontin case or the work of FLIP, see www.uic.edu/com/dom/gim/FLIP/.

(continued from page 11)

The Healthy-Patient Paradox in Clinical Trials

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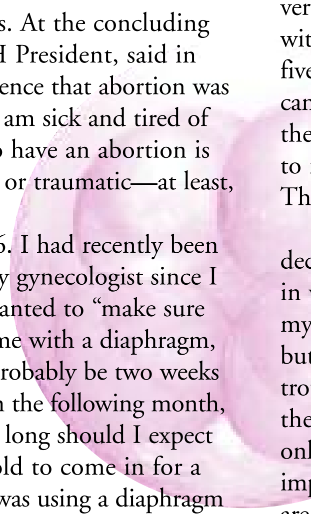
WHY ABORTION DECISIONS ARE NOT ALWAYS DIFFICULT

Bonnie Steinbock, PhD



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 worse, 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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ATRIUM welcomes unsolicited submissions. The theme for the next issue (Winter 2009) will be "HAUNTING."
For more information, visit www.bioethics.northwestern.edu/atrium.
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