

ATRIUM

2009

The Report of the Northwestern Medical Humanities and Bioethics Program

Snapshot

Ranjana Srivastava, F.R.A.C.P

“Fix my voice,” she says, sounding conspiratorial. “I want to talk to the kids. I want to answer the phone.”

“I know,” I answer glumly as I watch cancer ravage her body.

She undergoes chemotherapy despite my not-so-veiled attempts to dissuade her. “My kids must know that I tried.” Her husband squeezes her thin fingers, mute with grief. She can’t talk above a whisper, so she beseeches me with her eyes instead. Large brown orbs, widened with anxiety, fear, and questions—biggest of all, “Why my kids?”

I like her. She’s young, like me. She has children, like mine. My heart twists itself in a knot each time we meet. When I think of her at home with her kids, I see myself. I fret over how to save her while I curse the cruelty of her destiny.

She is admitted with pneumonia. Her lungs are drowning. Our eyes complicit, I send her home to her children. Her husband calls me in a panic. She is on the floor and can’t get up. Defeated, she is bundled back into the hospital. She dies, without her family.

I call him. “She made sure we had all gone home,” he says somberly. “Maybe she wanted it that way,” I console him. And as I start to say sorry I realize something horrible: I cannot remember her face. I saw her only a few days ago; this isn’t possible! I challenge my treacherous memory to conjure her face, but there is nothing. I came to know her so intimately, and every detail of her disease is still screaming at me, yet her face is replaced by a void. I associate her only with hoary whispers.

I feel betrayed by my mind. Without a face to attach it to, I find it impossible to file away her memory. At night, I try in vain to summon her features. What kind of doctor simply forgets? I have forgotten names and diseases before, but this is a different kind of forgetting, harder to accept. Did I not care about her as much as I thought? The harder I work to grasp her face, the more amorphous she becomes. I’m as fascinated by the process as I am maddened by the enigma.

I finally surrender the fight against my mind. Maybe it’s trying to protect me from the fragility of my own life, the vulnerability of my own children. Perhaps it is my subconscious way of avoiding questions about the role of God and faith when confronted with the gnawing pain of loss.

I run into her husband as he attends to unpaid bills. I selfishly hope that his fond recollections will breathe life into my memory, but it doesn’t work. Each time I see him it feels a little more inappropriate to ask the question I’m still carrying: “What did your wife look like?” The longer I leave it, the more wretched I feel. I flick through hundreds of pages of chart notes documenting her inexorable decline, a thorough paper memory, desperately incomplete like my own. I search for the photograph we never thought to take, the one thing that might have helped me put the patient to rest.

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ATRIUM welcomes unsolicited submissions. The theme for the next issue (Fall 2009) will be “Killer Apps.”

Deadline for proposals is April 16, 2009. For more information, visit bioethics.northwestern.edu/atrium.

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Haunting

William Utermohlen, *Head I* (2000)

About the Cover

Artist William Utermohlen was diagnosed with Alzheimer's disease in 1995 at age 61. He continued making art for seven years after his diagnosis, switching to drawing after painting became too difficult. Mr. Utermohlen stopped drawing in 2002, and he died in 2007.

The image on the cover is one of the last pieces of art Mr. Utermohlen made. In *Head I* (2000), the "artist has assimilated his drawing method to his destiny: to subsist while disappearing. ... The staring eyes are now like empty dark cavities fixed onto a head turning into a skull."¹

Mr. Utermohlen's primary focus during his career was painting portraits and murals, but after his diagnosis he mostly painted and drew self-portraits. These self-portraits are "unique

The Medical Humanities and Bioethics Program

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artistic, medical, and psychological documents. They portray a man doomed yet fighting to preserve his identity and his place in the world in the face of an implacable disease encroaching on his mind and senses. ... In most portraits there is an emphasis on the frontal lobe of the skull, where William knows the source of his illness lies. ... Continuity, as much as rupture, is evident in [Mr. Utermohlen's work]. The artist continued to think, observe, concentrate, and paint the facts of his existence even as the darkness closed in."²

From a clinical perspective, three members of a neurology department wrote in *The Lancet* that Mr. Utermohlen's post-diagnosis self-portraits "reveal a change commensurate and consistent with the deterioration in his cognitive state, particularly with respect to his visuoperceptual and visuospatial skills," yet his "creative impetus" wasn't impaired in the same way "the skills required to implement artistic intention" were.³

Pat Utermohlen, the artist's wife and an art historian, describes her husband's work differently. "William bravely began to paint himself, desperately trying to understand what was happening to his mind. ... In these pictures we see with heart-breaking intensity William's efforts to explain his altered self, his fears and his sadness. ... There is a new freedom of expression, the paint is applied more thickly, art-historically speaking the artist seems less linear and classical, more expressionist, and I see ghosts of his German heritage."⁴

Mr. Utermohlen's work raises profound questions of identity and its expression. His disease clearly deprived him of the ability to paint with precision, a precision Mr. Utermohlen sometimes sought: "His wife and his doctors said he seemed aware at times that technical flaws had crept into his work, but he could not figure out how to correct them."⁵ Yet there's no way to tell which elements of his post-diagnosis pieces are "flaws" dictated by his illness and which are deliberate choices. The neurology experts write as if Mr. Utermohlen was always attempting "accurate" self-depiction, and progressively falling short. In contrast, his wife writes that he was trying to "explain his altered self." Perhaps this evocative series expresses progressive alterations in how he saw himself; perhaps even in pieces like *Head I* he was adapting to limitations in form and finding new ways to successfully convey how he felt. Or perhaps these self-portraits are the visual equivalent of deteriorating speech, expressions radically distorted by the gap between Mr. Utermohlen's intentions and his ability to communicate them. It's impossible to answer these questions with certainty, but the conversation they inspire between medical professionals, humanities scholars, patients, and families is one of Mr. Utermohlen's enduring legacies.

—KW

"Portraits from the Mind: The Works of William Utermohlen—1955 to 2000," a touring retrospective of the artist's work before and after his diagnosis with Alzheimer's disease, was exhibited at the Chicago Cultural Center last summer.

ATRIUM thanks Patricia Utermohlen and Galerie Becket-Odille-Boicos for their generous permission to reproduce William Utermohlen's work.

¹ *Chicago Exhibit Catalogue*, 23.

² *Chicago Exhibit Catalogue*, 5, 22, 23.

³ Sebastian J. Crutch et al. Some workmen can blame their tools: artistic change in an individual with Alzheimer's disease. *The Lancet*. 2001; 357:2129-2133.

⁴ Pat Utermohlen, September 2006.

⁵ Denise Grady. Self-Portraits Chronicle a Descent into Alzheimer's. *New York Times*, October 24, 2006.

"How Could It Not Be Haunted?"

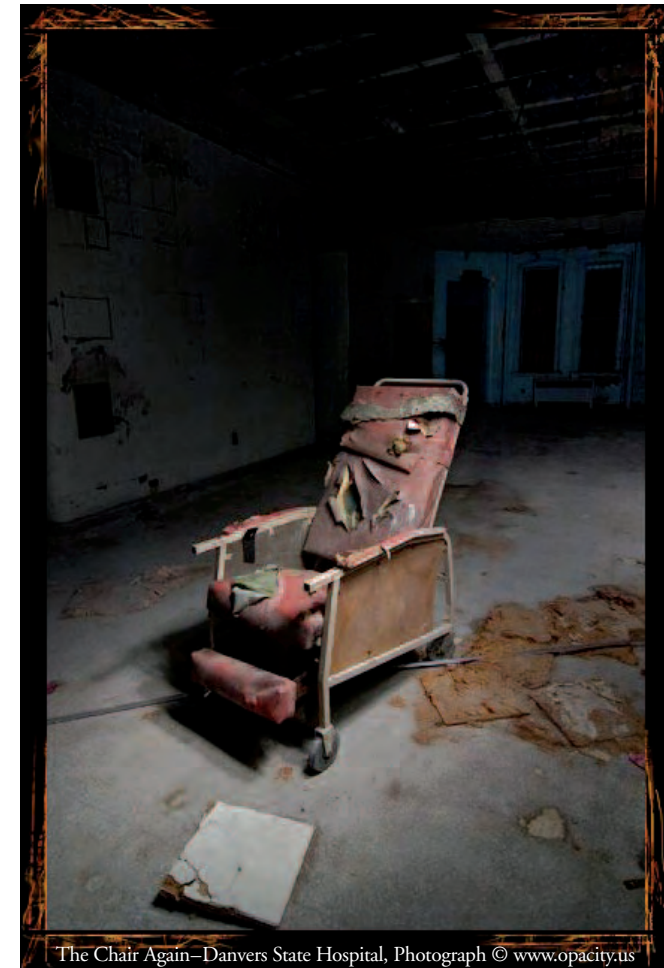
The Haunted Hospital as Historical Record and Ethics Referendum

Dayle B. DeLancey, PhD

"Haunted" hospital stories have been mainstays of U.S. television programs, feature films, and websites since the late 1990s. Medical ethicists and medical historians might be tempted to dismiss these depictions as mere vagaries of popular culture, but that would be an unfortunate oversight because haunted hospital lore memorializes historical claims of patient abuse, neglect, and maltreatment. Ethics breaches are common and indelible themes of haunted hospital stories, and repetition of these legends allows successive generations to engage with these alleged violations.¹ An increasing number of U.S. and European scholars embrace reputed hauntings as scholarly sources. Still, some academic folklorists argue that many academic disciplines are so wary of "ghost stories" that the entertainment media currently provides most of the existing analyses of haunting legends.² This is certainly true of "hauntings" involving hospitals.³ Yet the haunted hospital stories at the heart of these depictions often encapsulate not only genuine history, but also a record of public referenda on various aspects of 19th- and 20th-century hospitals—from their architecture and appearance to the new technologies and treatments employed within them.⁴

This conflation of the unethical and the uncanny is a central feature in several of the U.S.'s most celebrated hospital hauntings. Accusations of patient abuse were commonplace after Kentucky's Waverly Hills Sanatorium transitioned from tuberculosis treatment to elder care in the 1960s; today, "ghost hunters" often report encounters with the specter of a bloodied and disheveled elderly patient who weeps over her four-point restraints and begs visitors to free her. Similarly, former employees of Central State Hospital in Indiana have told lay folklorists that apparitions of the elderly and insane patients purportedly mistreated there during the 1970s roamed the facility's halls until it closed in 1994. Such tales are not limited to the U.S.: in England, for example, Yorkshire's High Royds Hospital has generated similar legends among former patients, staff, and local observers.⁵

Within this crowded field, Danvers State Hospital in Massachusetts offers an especially useful—and infamous—case in point. Opened as an insane asylum in 1878, closed to patients in 1992, and largely demolished in 2006, Danvers has generated over a century of legends that combine supernatural elements with public memory of very real allegations of patient abuse and neglect. It was in the 1890s that former employees and patients first began to allege that rampant overcrowding and understaffing had made Danvers a hive of patient ill-treatment. These early stories resonated with a local populace that, wary of the hospital's neo-gothic



The Chair Again—Danvers State Hospital, Photograph © www.opacity.us

Danvers State Hospital sat empty for years after it closed in 1992. The 2001 filming of *Session 9* at Danvers and local controversy about its future use raised interest in the "haunted" hospital, and 120 trespassers were arrested on the abandoned site between 2000 and 2005. A developer purchased the property after a long court battle with preservationists, and by 2007 the Kirkbride building was fully converted to a high-end apartment complex named Avalon Bay Danvers. Whether the hospital's graveyard of patient remains and numbered markers will be moved is still in contention. (The photo above was taken in 2005. For more photos see opacity.us/gallery97_dreary_skies.htm)

architecture and mindful of its location near a site central to the Salem Witch Trials of 1692, had already dubbed Danvers "The Witches' Castle." By the turn of the century, the public had begun to fuse these otherworldly understandings of the hospital with reports of patient abuse.⁶

As the hospital's staffing and funding crises continued into subsequent decades, so too did assertions of poor conditions and patient maltreatment, forming the crux of local supernatural lore. Some of these tales found expression in print, with local horror writer H. P. Lovecraft making a fictionalized incarnation of Danvers State Hospital the centerpiece of the nightmarish landscape of several short

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The Danvers State Insane Asylum—Kirkbride Complex, circa 1893

stories written in the 1920s and 1930s. The hospital was a fearsome place in Lovecraft’s cosmology. Writing just as reports of unprecedented overcrowding emerged from the hospital, Lovecraft combined Danvers’ dual reputations as the realm of the uncanny and as a place where patients were harmed with impunity. In the pages of Lovecraft’s stories, it was possible for a spirit-possessed visitor to shoot a “madman” in his cell, so lax were patient protections in this storehouse for the “poor[,] struggling bod[ies]” of the “violent and pitiable” insane.⁷

But it was folklore, more than published fiction like Lovecraft’s, that usually encapsulated eerie iterations of patient abuse and neglect at Danvers State. Local people told and re-told stories in which the supernatural memorialized and redressed the hospital’s alleged infractions against patients. These tales kept pace with developments at the hospital—hydrotherapy in the 1900s and lobotomy in the 1930s, to the renewed claims of patient ‘warehousing’ and neglect that engulfed the hospital in the 1960s and 1970s. When *Nobody’s Child*, the 1987 memoir of former patient Marie Balter, drew national scrutiny to overcrowding, neglect, and abusive treatment at Danvers (called “Sutton State Hospital” or “The Castle” in Balter’s book), local people not only folded the new events into updated ghost stories, but also contextualized them within the longer history preserved in existing haunting legends. As news of fresh scandals broke, locals opined that the latest patient maltreatment investigations merely underscored their belief

that “Danvers State Hospital was a place where evil things happened.”⁸

After the hospital ceased operations, the institution’s function as a flashpoint for local memory of reputed patient ill-treatment only intensified, with haunting legends now incorporating the ominous, abandoned site. *Session 9*, a 2001 horror film written about and filmed on location at the derelict Danvers State Hospital facility, was emblematic of this trend. When the filmmakers interviewed local people while drafting the film’s script, they observed that “ghost stories” about the hospital usually included details of the claims of patient harm that had dogged the hospital for over one hundred years. Long before *Session 9*’s production team decided to weave the hospital’s reputation for patient abuse into a macabre movie advertised with the slogan “Fear is a Place,” local people had commemorated and commented upon the topic in their tales of a haunted Danvers State Hospital. As one interviewee explained to the filmmakers, “How could a hospital where so many horrible things happened to so many people for such a long time *not* be haunted?”

If, as Gerald N. Grob argues, the public has consistently misgauged the prevalence of patient ill-treatment in 19th- and 20th-century hospitals, how should we view the persistent centrality of alleged patient abuse and neglect within historical and contemporary haunting legends about facilities like Danvers State Hospital? Recent scholarship on the cultural functions of haunting suggests an approach—especially when considered alongside Charles I. Stannard’s

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Graphic Brain-Imagining

Text and graphics: Catherine Belling, PhD

Graphic, adj.:

1. Of or pertaining to drawing or painting;
2. Producing by words the effect of a picture; vividly descriptive, life-like;
3. Providing or conveying full, unexpurgated detail; expressly stated or represented; explicit, esp. in the depiction of sex or violence.

Imagine a row of living human brains. Can you pick out your own brain? Such impossible self-reflexiveness is of course absurd: With what would you be doing the identifying, were your brain the object of observation? In what form would you exist, were your brain anywhere but concealed inside your skull?

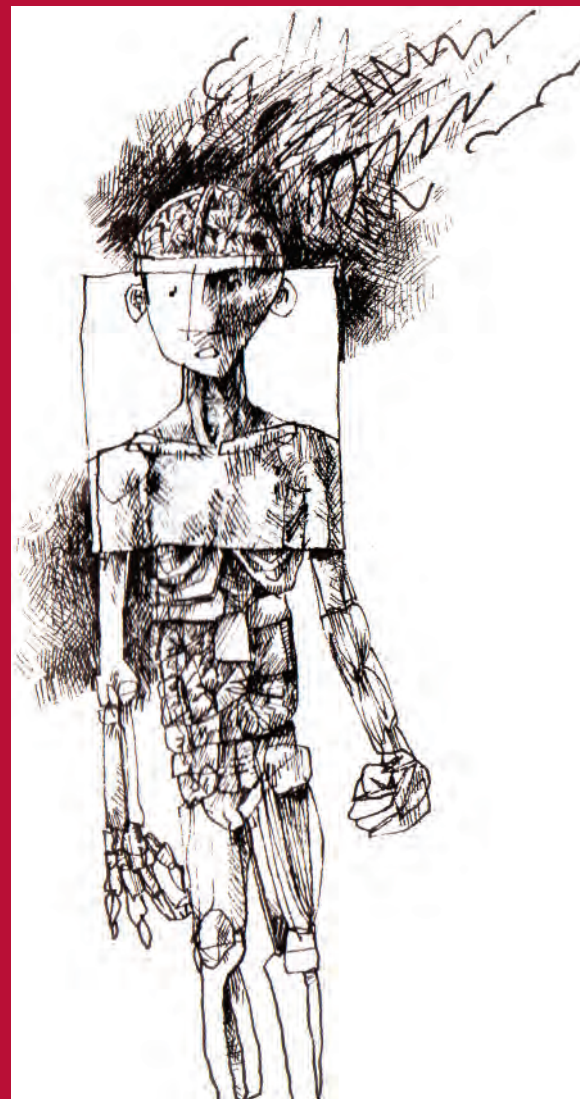
So an easier question: Can you actually imagine the living brain, complete and accessible, at all? Even for a neurosurgeon, this might pose a challenge. How much of a brain can be seen before it’s no longer alive? If you’ve had medical training perhaps you’ve held a human brain in your hand, and can imagine one now by remembering. But a cadaver brain is not a living brain. Perhaps you’ve looked at a CT scan of the head or a brain MRI, but that doesn’t help because I asked you to imagine those brains, not to picture them. When we imagine we often picture a picture, a representation of a representation. Computed Axial Tomography: drawing in slices. Technology’s images are, of course, not brains at all, but stylized graphics produced by tracking magnetic fields and electrons, not light, and encoded in colors that do not reproduce the grey matter, or the neurons, or sponginess and blood. As you read this, though,

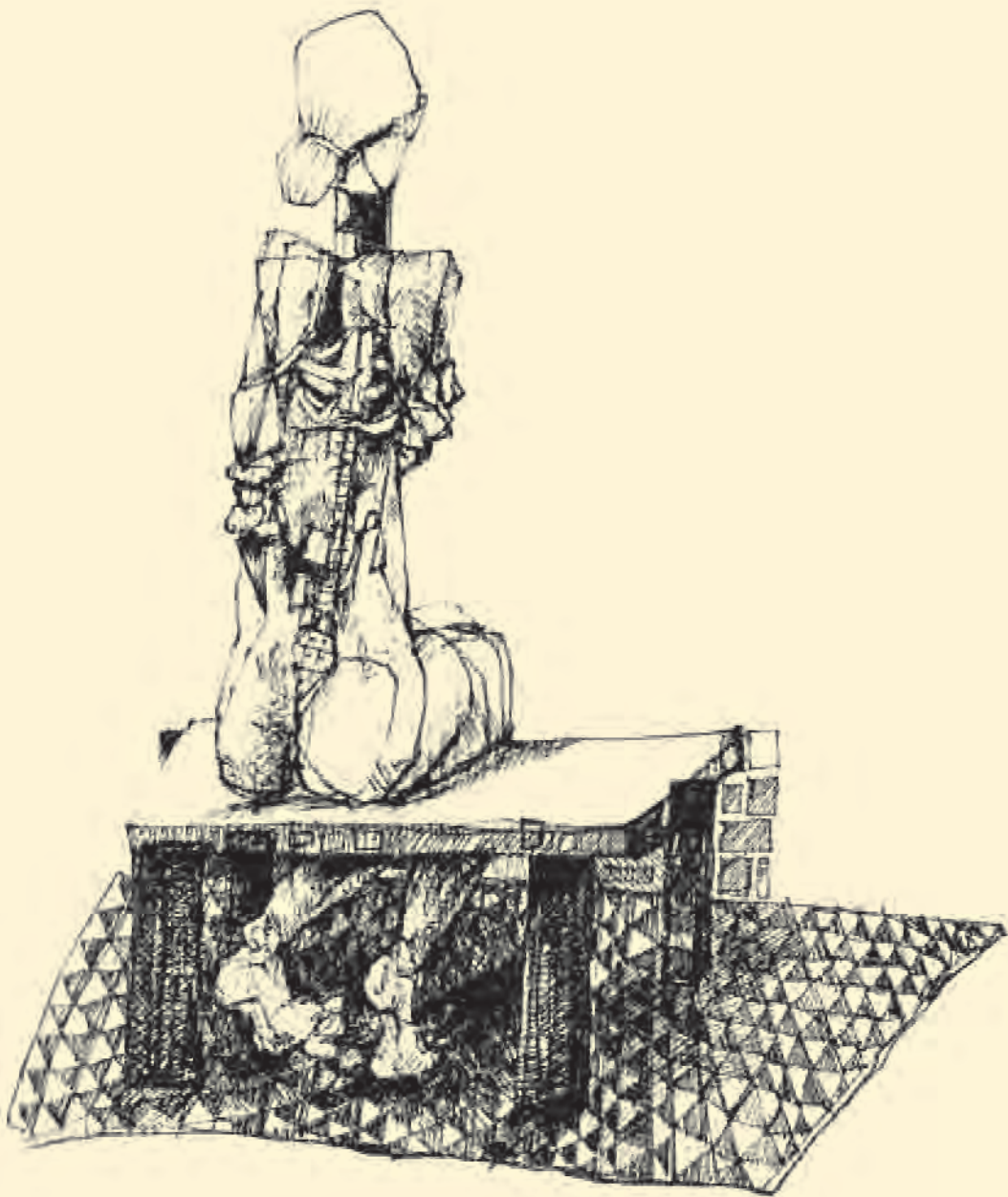
there is at least one live brain in the room with you. So instead of picturing brains, instead try to imagine your own brain on the surface nearest to you. On your desk? On the floor at your feet? (Don’t let it get too dirty.) Is it wet? Heavy? What does it smell like? How does its presence alter the room?

It’s odd that a material object so necessarily present at every moment is also so profoundly invisible, intangible, and inaccessible to us. It’s also absolutely necessary, the fundamental blind spot of all embodied beings. Perhaps this is why my thought experiment may seem disturbing, even obscene. We have such strong cultural injunctions against the revelation, and even the representation, of parts of the body that are hidden when the body is whole. There is a boundary to self-reflexiveness: the brain cannot perceive itself, or the mind cannot perceive the brain. We cannot encounter our inner organs directly, unless in the face of life-threatening violation of our bodily integrity. We tell ourselves that science reveals, where art represents (and the humanities study representations). We tend to trust that biomedical technology has found ways to reveal the inside of the body, but unmediated access is limited indeed. The internal organs, like fish, cannot survive for long at the surface. We have to imagine our own individual interiors rather than seeing them, and it is hard to imagine them without also imagining the violent, the gruesome, the graphic. And the medical.

When I was ten, I had an appendectomy. Afterwards, the surgeon gave me my sad little appendix to take home in a plastic bottle with a red screw-top lid. I kept it beside my bed and wondered whether the stuff still inside me

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Hypochondriacs do not want anything left to the imagination, for they imagine horrors inside them far worse than the graphic depiction of exposed organs.

Our fascination with these impossibly accessible bodies makes sense. Medicine teaches us, particularly in today's bioscientifically inflected, risk-averse popular culture, that to watch over the insides of our bodies is to take good care of ourselves. Or rather that it would be, if it were possible, and because it is not, we are inclined to pass the responsibility on to medicine, and are disappointed when doctors can't watch our insides either. In these thwarted expectations lie the seeds of clinical illness anxiety.

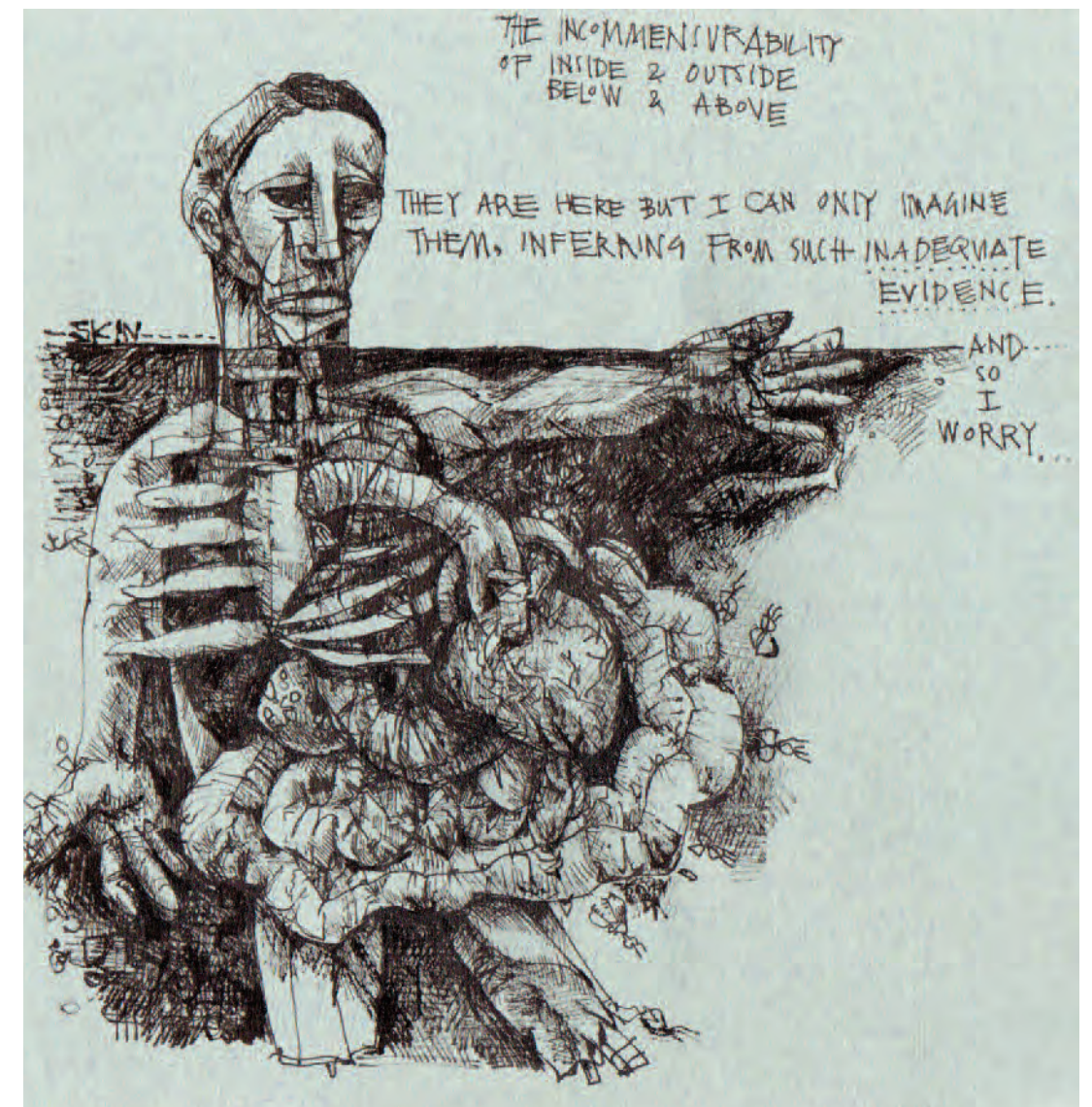
People who are anxiously vigilant over their bodies, who obsessively read signs and sensations as symptoms of hidden internal changes are usually diagnosed as hypochondriacs. I understand hypochondria as a problem of knowing and representing. Rather than irrational fear and neurotic grasping for attention, perhaps we should think of it as a quite rational unease about the limits of our ability to know our own bodies, with or without the help of science and technology. This is why hypochondriacs haunt medicine. But medicine needs hypochondriacs, for their resistance to reassurance denotes a fantasy that medicine and hypochondria share: the desire for continuous omniscience, for a benevolent panopticon that offers perpetual surveillance of the insides, detecting and arresting ominous changes as early as possible. Visual images are never adequate because they are static. Like the MRI or the CT scan or the lab values, visual images always capture a particular instant in the course of a dynamic organism. The still image kills. To interpret it is always a kind of autopsy, when what the hypochondriac wants (in theory at least) is an autopscope or auto-endoscopy: the ability to watch inside oneself in order to notice the moment one's death begins to stir. Hypochondriacs do not want anything left to the imagination, for they imagine horrors inside them far worse than the graphic depiction of an exposed brain.

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Graphic Brain-Imagining (continued from previous page)

was as fragile, little bits flaking off and sifting down through the increasingly murky formalin. I started drawing pictures of people whose brains or hearts or skeletons were visible. I realized that I knew what my nose looked like, but I'd never recognize my liver in a line-up. A teacher called my drawings "disturbing." I think this was meant as a diagnosis. To represent the insides is either to do something medical, or to be sick.

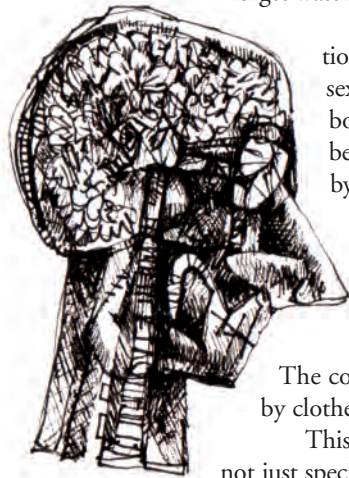
Vesalius's famous 16th-century study of anatomy, the *Fabrica*, includes figures drawn as if they were alive, in lovely landscapes, in some cases helpfully holding up flaps of skin and fat so we can see the structures beneath. These are not, I believe, pictures of animated corpses. These bodies are not supposed to be dead at all. They represent anatomy's ideal: to see what the insides of the living look like. (Similarly, Vesalius dissected live apes and pigs not to learn about apes and pigs but because human vivisection was—and is—prohibited.) Even flayed or pulled apart so far they must be held up with ropes, these people do not resist the opening of their bodies, or appear to feel it as pain. Their suffering seems existential, as if they are exposed not to violence and death but to a knowledge of themselves as vertiginously complex. They are signs, fictions, despite the scrupulously observed accuracy of the drawings of their organs.



That brain you have there with you right now: if you could look at it (even in the mirror), we'd know there was something seriously wrong. The prohibition against seeing internal organs is not that simple, though. It is also existential, spiritual, moral. To see what we have inside, directly, would be to know ourselves as flesh machines, our vulnerable material parts working beautifully together but finally just objects in the world. Self, spirit, soul: from such demystification these flee.

Surgery is the closest we come to watching the living body's interior. It is, strictly, a form of human vivisection, permissible of course because of its therapeutic purpose and effective analgesia and anesthesia. Yet the brain must be handled carefully indeed, and when it's probed, the surgeon relies on the patient's verbal reports more than on visual cues to guide the operation. The Welsh physician-poet Dannie Abse wrote a poem, "In the Theatre," about brain surgery. The patient is conscious, the surgeon's "fingers . . . , rash as a blind man's, inside his soft brain." Suddenly the patient speaks in a different voice, otherworldly and "arctic," as if his body is a ventriloquist's dummy for some other source of speech, a voice that keeps repeating, as the patient dies, "leave my soul alone. . ."¹

Surgery opens us up but we ourselves are kept from watching. Even for the physician, drapes help to bracket a surgical site off from the rest of the living patient. Breaches of such protocols are shocking. A friend who saw her own C-section reflected on the surface of a light above her told me she will never forget watching as her uterus was set beside her, like a handbag, on the operating table.



The meaning of the word "graphic" has come to signify not just representation, but specifically the depiction of what is supposed to be hidden. "Graphic sex and violence" describes actions involving the body, especially parts of the body not routinely available to view, exposed (and then represented) only because of sexual activity or violent damage. Such exposure is also facilitated by medical examination and intervention. The 1930 Motion Picture Production Code was the set of restrictions which (until the MPAA began in 1960s) controlled what could and could not be shown in American movies. As well as sex and violence, the list of banned "repellent subjects" included "surgical operations."² Details of surgery were described as "objectionable and offensive" and classed along with "brutality and possible gruesomeness."

The concept of nudity goes beyond the surface; body parts usually hidden either by clothes or by skin were taboo.

This has changed. Televised surgery—real surgery (though edited) on real bodies, not just special effects—is accepted largely because it claims to be educational rather than entertaining. And fiction film seems to have no limits at all. In *Hannibal*, a sequel to the serial killer thriller *Silence of the Lambs*, Hannibal Lecter drugs a US Justice Department agent named Paul Krendler, seats him at the dinner table, and performs a craniotomy on him. When his colleague Clarice Starling joins them for dinner, Lecter removes not only Krendler's baseball cap but also the top of his skull. In a parody of neurosurgery Krendler converses, slurring somewhat, with Starling, while she and we look at the top of his living brain, undraped and contiguous with his wakeful face. (Or rather we look at the special effects department's representation of brains remembered and recorded in actual surgery.)

Krendler does not exactly see his own living brain. What happens next is notoriously repellent, the far edge of perverse self-reflexiveness. Lecter slices off part of Krendler's cortex and sautés it in butter. Krendler mentions how delicious it smells. This is a kind of indecent exposure—or at least the indecent representation of imaginary exposure. Or maybe it's the context of the representation that makes this indecent: the purpose of showing us the character's brain is not to fix this brain or teach us about brains but to shock us with the gratuitously graphic and grisly. The graphic is what leaves nothing to the imagination. That we do not want to see Krendler taste his own brain—do not even want to imagine the act—suggests not just that we are against violent crimes, but that secure identity depends on the blind spot, on the unimaginability of this apprehension of self. The mind shudders and turns away from its own gruesome brain.

The image on the cover of this issue of *ATRIUM* is one of William Utermohlen's last self-portraits. This drawing records the progression of his Alzheimer's disease as it nears complete destruction of his ability to draw. But until that point, Utermohlen kept re-drawing himself, even as the alterations in his brain changed how he drew himself, and even (as far as we can tell) how he saw and imagined himself. His self-portraits mediate and represent what medicine could not apprehend directly. They are a symptomatic record of the condition of his living brain, the organ itself out of reach until after his death, when it could finally be handled and examined by others. An earlier work is titled *Self Portrait (With Saw)*.

From the Chicago catalog of a retrospective exhibition: "In 1997, William learns that only at autopsy will his doctors be able to definitively diagnose his Alzheimer's disease. This notion haunts him, and he speaks of it constantly to those close to him. The saw is an open allusion to this distressing fact, and to the artist's consent to have his brain dissected after death." In the painting, Utermohlen juxtaposes the ornate image of a bone saw with his utterly smooth yellow forehead, flattened out in contrast to the rough paint surfaces all around it, a solid helmet suggesting behind it a brain that is accessible only through craniotomy.

William Utermohlen was not, to my knowledge, diagnosable as a hypochondriac. The physical changes in his brain were incontrovertibly real, and his concern with the prospect of autopsy was based in his doctors' explicit accounts of what they knew, and could not know, about what was happening inside his skull. Yet he imagined his brain and he tried to represent it in the same frame as his own outward appearance, symbolically and literally. Another self-portrait, a black and white charcoal drawing, contains a vivid, and clearly brain-shaped, blotch of pink paint covering the top of his head.

There are at least two ways of seeing Alzheimer's disease. There are outward signs that we interpret to mean something has changed within—behavioral changes, described experiences, self-reports, and portraits of various kinds. Then there are the physical changes in the brain itself—the atrophied cortex, an odd spreading of the grey surface, more space, less material, enlarged sulci, channels expanding between the shrinking gyri. At the next level (for medicine can look closely indeed at a dead brain) its microscopic texture is thrown into chaos by sticky amyloid plaques and tangled neurofibers. How does the person with a family history of dementia but no diagnosis or symptoms imagine his or her brain? Does a moment of normal forgetfulness produce a horrible sense of trouble inside the skull, of nervous tissue disrupted by disease? We would never suggest this person be given the psychiatric diagnosis of hypochondriasis. Yet I believe that such anxious imagining is continuous with the kind that, because it keeps asking medicine to reveal all the truth, good or bad, is considered pathological. The pathology lies, then, not in the fear or the imagining, but in the expectation that medicine should always be able to provide access and answers.

Maybe William Utermohlen, as the disease progressed, was haunted by the knowledge that he would not be there at autopsy, to see for himself the part of himself that had turned against him. Or maybe it was the actual, anticipated exposure of that hidden brain, alive or dead, that preoccupied him.

The violence needed to reveal the embodied fact of the illness had become part of his self-imagining. The fine-toothed blade of the saw is set beside his living head, prepared already to remove that flat yellow skull mask. It is an icon of medical violence, necessary and illuminating, and it seems both feared and desired.

This ambivalent thinking about our most intimate and inaccessible interiors is something I believe we all do at some time in our lives, when we realize there are things happening in us that are important yet out of reach. It is why many of us go to the doctor and why some of us struggle to accept the limitations of what the doctor can know. Perhaps we all, at some point, imagine ourselves as William Utermohlen did, the saw beside the skull, ready to expose a body turning against itself, but prevented by the body's defensive need for concealment. Medicine can only ever offer an occasional glimpse. The vigil is impossible. Instead, we imagine, and often we represent, in whatever ways we can.

Catherine Belling is Assistant Professor in the Medical Humanities and Bioethics Program, Feinberg School of Medicine, Northwestern University. She is currently at work on a book exploring narrative approaches to hypochondria. c-belling@northwestern.edu

¹ Dannie Abse, "In the Theatre." *Collected Poems, 1948-1976*. London: Hutchinson, 1977.

² Susan Lederer. Repellent Subjects: Hollywood Censorship and Surgical Images in the 1930s. *Literature and Medicine*. 1998; 17(1): 91-113.



My Shadow Uncle

Kristi L. Kirschner, MD

“Why did you become a rehab doc?”
I’ve fumbled with incomplete answers to this question for years: “I’m interested in holistic medicine,” “I value longitudinal relationships,” “Human and civil rights issues have always interested me,” etcetera. Though these are all true, I always knew there was a missing link. Recently, I’ve realized what that link is, and why it’s been missing—because it’s my “shadow uncle,” Uncle Bobby.

I call my Uncle Bobby a “shadow” because until I began researching his life, I knew of him only in the sketchiest of terms. He was my father’s youngest sibling, born in 1932 in the midst of the Great Depression. When Bobby was just a year old, his 34-year-old mother Lillian died of rheumatic heart disease. When Lillian was found dead, Bobby—still attempting to nurse—had to be taken off her breast.

By all accounts Bobby was a “beautiful, normal baby” up until Lillian’s death, but in the following year his growth and development dramatically changed. Family lore had it that “he was never right after his mother died because he had drunk the poisons from her dead body.” I had a fuzzy picture of Bobby. They said, “he made sounds but didn’t talk,” he was slow to walk, and when he did walk it was “kind of funny, sort of on his toes.” His sister Phyllis took to carrying him everywhere she went, even when he was an older child, because it was faster.

My grandfather resisted the attempts of several sisters and sisters-in-law to remove the children from their home after my grandmother’s death. Instead, my grandfather, my father, Bobby, and their sisters muddled through, piecing



Bobby Kirschner and the author's father at the Missouri State School and hospital circa 1941.

together enough food and coal to get by in the small farmhouse. Bobby required constant supervision, so my father and his sisters took turns staying home from the one-room schoolhouse they attended with all the other farm kids in the Lake Contrary area to care for him.

That changed in 1939. At the age of seven, Bobby was placed in an institution in Marshall, Missouri. He lived there for ten years, then he died at age seventeen of mysterious causes. According to family lore, “his body

was too fragile to withstand the transition from adolescence to adulthood.”

As a young child, all I knew about the institution Bobby lived in was that it was a frightening place, and my father and aunts didn’t really like to talk about it much. The one story I recall my father telling about the Marshall institution was of seeing a child with hydrocephalus whose head was so massive that he couldn’t lift it. The image was burnished in my father’s memory—and subsequently in mine as well. Marshall was a good distance from Lake

Contrary, and in the days before they had a car, family visits to Bobby were few and far between.

That was pretty much all I knew, but as I grew my own practice of patients, some of whom have developmental disabilities, my thoughts increasingly turned to Bobby. What was his diagnosis? What was the Marshall institution like and how did he end up there? What was his day-to-day life like? And why did he die? For the last several years I’ve embarked on a personal journey to fill in the details. I tracked down his medical records (only 20 pages for ten years!) and his death certificate, and I visited the current facility—it became the Marshall Habilitation Center in 1983, but before that it was the Missouri State School and Hospital in Marshall, and prior to that the Missouri Colony for the Feeble-minded and Epileptic. I toured their archives, talked to two retired staff members, and pored over the biannual reports the Superintendent submitted to the state of Missouri for the ten years Bobby lived there. I also spent time interviewing my father, my aunts, and several of their first cousins.

As I pursued my inquiry, it began to dawn on me that this uncle I never met had profoundly affected my life. I began to recall early formative lessons about disability, both spoken and those left unspoken. When I was twelve, my 37-year-old mother was unexpectedly pregnant—much to my delight and much to my father’s despair. He was terrified she would have a child with a disability. They had “rolled the dice three times and been lucky—why press it?” The tension in the house throughout the pregnancy made me miserable and defied my understanding. I recall the palpable collective sigh of relief when she delivered a beautiful baby boy with ten fingers and ten toes.

My Uncle Bobby wasn’t just a fuzzy figure in my mind; I believe he was a psychological “shadow” in my father’s life, and by extension mine as well. Psychiatrist Carl Jung describes shadows as the unconscious forces of

our lives that can impel us in powerful ways. Often these shadows are painful episodes or thoughts we believe we can’t endure, so we dissociate from them or submerge them. Invariably, though, they reappear in the subterranean of our minds, unconsciously affecting our decisions and behaviors. I believe that’s what happened to my father. The tragedy of losing his mother, the complex feelings he had about his brother, and the horrific images of institutionalized disabled children created reactionary, and largely uncon-

scious, fears that permeated my family’s life. In turn, I absorbed these lessons of disability-as-tragedy to assimilate, ponder, and eventually question.

THE DIVISION OF HEALTH OF MISSOURI STANDARD CERTIFICATE OF DEATH											
FILED DEC 28 1949		REG. DIST. NO. 14		PRIMARY REG. DIST. NO. 1007		Registerer's No. 325		State File No. 43356			
1. PLACE OF DEATH a. STATE Missouri b. COUNTY Buchanan				2. USUAL RESIDENCE (Where born, raised, or lived, if institution, certificate before)							
3. CITY OR TOWN Rural				4. LENGTH OF STAY (In this place)				5. CITY OR TOWN Rural			
6. FULL NAME OF DECEASED Robert Edwin Kirschner				7. DATE OF DEATH (Month) (Day) (Year) Dec. 19, 1949							
8. SEX Male				9. AGE (In years) (Month) (Day) Mar. 10, 1932 17							
10. MARRIAGE STATUS never married				11. BIRTHPLACE (State or foreign country) St. Joseph, Missouri				12. CITIZEN OF WHAT COUNTRY? U.S.A.			
13. FATHER'S NAME Oscar Kirschner				13a. MOTHER'S MAIDEN NAME Lillian Vaughan				14. NAME OF HUSBAND OR WIFE none			
15. WAS DECEASED EVER IN U.S. ARMED FORCES? no				16. SOCIAL SECURITY NO. none				17. INFORMANT'S SIGNATURE OR NAME Official Records			
18. CAUSE OF DEATH Enter only one cause per line for (a), (b), and (c)				19. DISEASE OR CONDITION DIRECTLY LEADING TO DEATH* (a) Coronary Thrombosis				INTERVAL BETWEEN ONSET AND DEATH sudden			
*This does not mean the mode of death, such as heart failure, stroke, etc. It means the disease, injury, or complication which caused death.				20. ANTECEDENT CAUSES (b) Idiot.				All His life.			
21. DATE OF OPERATION none				22. MAJOR FINDINGS OF OPERATION none				23. AUTOPSY YES <input type="checkbox"/> NO <input checked="" type="checkbox"/>			
24. ACCIDENT SUICIDE HOMICIDE				25. PLACE OF INJURY (a) Home, farm, factory, street, office, etc.				26. (CITY, TOWN OR TOWNSHIP) (COUNTY) (STATE)			
27. TIME OF INJURY				28. INJURY OCCURRED WHILE AT WORK <input type="checkbox"/> NOT WHILE AT WORK <input type="checkbox"/>				29. HOW DID INJURY OCCUR?			

scious, fears that permeated my family’s life. In turn, I absorbed these lessons of disability-as-tragedy to assimilate, ponder, and eventually question.

As Bobby’s shadow was illuminated, I realized the tragedy wasn’t so much Bobby’s disability, but the harshness of the times and the social response to a child and family in need. Through no fault of his own, my uncle was disabled. Through no fault of their own, his family was unable to provide for his needs. Bobby was born in an era that was still caught up in the allure of eugenics, even sporting “fittest family” contests at State Fairs. I now wonder if the narrative of disability-as-tragedy could have been written differently.

What if, rather than stigmatized and removed from society, Bobby had been embraced as a valued member? What if his family had been supported in providing care for him in the community? What if his siblings’ needs weren’t pitted against Bobby’s needs for care?

Questions like these flow freely through my mind as I ponder the pressing needs of my patients and their families. Disabilities and human differences don’t have to result in tragedy. I can’t rewrite the ending of

Bobby’s life story, but I can round out the picture, fill in the details, and embrace him as a valued uncle I wish I could’ve known. In addition, by recognizing the psychological “shadow” role he played in my family, I find that a much richer, integrated, and complex story of humanity emerges. And for now, that’s the best answer I have for why I’m a rehab doc.

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The most powerful narrative, the first-person illness narrative, is produced when artists themselves suffer and create self-portraits.

Fig. 1

Illness Narratives in Art

Paul M. Wangenheim, MD

Illness narratives are created when patients tell their stories to the world, and the private experience of suffering is brought out in the open. Only patients can tell their true stories before they are taken over and transformed into medical histories. Narrative competence is the ability to hear and understand these stories and it can bridge the gap between the sick and those who care for them.¹

Literature provides us with the largest source of narrative material, but narratives aren't limited to the written word. They can also be found in the close reading of paintings. Painters have used their artwork to tell stories from as long ago as cave paintings, hieroglyphs, and Grecian urns. Writers use plot, context, voice, and metaphor to weave stories. Artists use line, color, forms, and allegory to create the narratives we see on the canvas. Each one has a story to tell for those who are willing and able listen. There are parallels in the connection that is forged between reader and writer, and viewer and painter, and narrative competence can be acquired from both sources.

Many illness narratives in art are found in the genre of portraiture. Narratives are portrayed in realistic, figurative pieces. The portrait artist sets context by choosing a locale. Plot is represented by the arrangement and interaction of the figures in the painting. The inclusion of objects in the painting adds elements of detail to the story. Voice is established by gestures and facial expressions, and on occasion, by looking the viewer directly in the eye. Allegorical symbols in paintings can replicate the power of the written metaphor.

Although there are similarities between the lessons learned from writers and painters, art is not processed and understood in the same way as prose. Reaction to art is driven by a visual and often instantaneous impression; it is a personal experience and highly interpretive. The artist's creativity and the viewer's interpretation combine to create meaning. A painting is limited to one moment of time, captured in a single scene. The painter must work with these temporal limits, but at the same time, she or he is armed with the power of visual representation to create words in the viewer's mind. Paintings must be read again and again. As with prose, close reading reveals the work's subtle meanings and messages.

Medical narratives are found in portraits of the sick, in scenes of illness and suffering, and in depictions of the relationship between doctor and patient. The most powerful narrative, the first-person illness narrative, is produced when artists themselves suffer and create self-portraits. An example of this kind of

first-person narrative can be found in the works of Francisco Goya y Lucientes, one of Spain's greatest artists. He was at the pinnacle of his career when illness struck. Goya was flourishing as the beneficiary of royal patronage. He painted the wealthy, the famous, and the carefree, idyllic lives they lived. In 1792, while commissioned to paint a series of scenic tapestries depicting aristocratic Spanish life, he fell ill. He suffered high fevers, followed by paralysis, partial blindness, severe vertigo, and roaring tinnitus. He barely survived and was left permanently deaf.² At only forty-six, Goya was visited by the specter of death. It would haunt him for the rest of his life.

Goya's illness found a voice in his art: a narrative of his affliction, his fear of death, his realization of the dark side of life, and the story of his suffering. In the years following his illness, Goya produced a series of numbered prints entitled *Los Caprichos* ("Whims"). They marked his departure from colorful, stylized portraits to portrayals of the dark and macabre side of life. In No. 43, *El sueño de la razón produce monstruos* ("The sleep of reason produces monsters"), 1796-1797, we see a man draped over his desk, sleeping in an uncomfortable position. A flock of malevolent owls and bats with their wings ominously spread circle over his head, haunting his dreams. A lynx, the symbol of the afterlife, watches the macabre scene.

Los Caprichos also reflects Goya's tormented soul. No. 40, *¿De que mal morirá?* ("Of what illness will he die?"), 1796-1797, portrays a doctor—patient relationship. (Fig.1) A moribund patient lies on a bed. A witless physician, portrayed as a donkey resplendent in a suit, examines the pulse. In the background hooded figures wait, just beyond the bedside scene. Death looms while the patient lies helplessly between the incompetent physician and the fearsome unknown.

Goya survived his illness, and he lived with and painted his dark visions for nearly forty more years, including a period of troubling works referred to as the "Black Paintings." At the age of eighty-two, after a relapse, he painted another doctor-patient portrait with an entirely different story. In *Goya curado por el doctor Arrietta*, (familiarly known as "Self-portrait with Dr. Arrietta"), 1820, the artist speaks to us in the first person. (Fig.2) He looks directly at the viewer. His body is the narrative. His age, weakness, and hemiparesis are all evident. His doctor is beside him offering him an allegorical cup of human kindness; his strong horizontal arm braces the patient. The shadowy figures are ever present, but this time the physician stands between the patient and his fears. Goya included a handwritten testimony of gratitude below the work in the style of a religious votive, crediting his doctor with curing him. The painting is reminiscent of Arthur Frank's "communicative body," with Goya's own body telling the story. As Frank explains, "Human communication with the world, and the communion this communication rests on, begins in the body."³

Illness forever changed the nature of Goya's paintings. Reading Goya's paintings, we learn the story of a devastating illness, the resulting fear of death, and the physical ravages of a chronic illness. The initial narrative of anger and fear is replaced with one of resignation and gratitude. As Arthur Kleinman writes: "The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering."⁴

Illness narratives can be found in paintings as well as text. Goya tells us his story with powerful images. He was haunted by his brush with death, and his art reflected the profound change illness had on his life. Art is an immense resource of narrative material, and narrative competence can be gained by close reading of the powerful stories paintings can tell.

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¹ Rita Charon. Narrative Medicine, A Model for Empathy, Reflection, Profession, and Trust. *JAMA*. 2001; 286:1897-1902.

² Robert Hughes. *Goya*. New York: Knopf, 2003, pp.127-130.

³ Arthur Frank. *The Wounded Storyteller*. Chicago: University of Chicago Press, 1995, pp 27-53.

⁴ Arthur Kleinman. *The Illness Narratives: Suffering, Healing, and the Human Condition*. Reading, MA: Perseus Books, 1988, pp.49-50.



Fig. 2

Sleeping with ghosts: Cognition, emotion, and scholarship

Debjani Mukherjee, PhD

I'm lying in a bunk bed in a building where Nazis murdered people with disabilities, and the shadows are ominous. What was that noise? Who was tortured here? And what am I learning by sleeping in a former killing center in Hesse, Germany? I toss and turn, trapped in an academic nightmare.

This isn't what I bargained for when I joined a summer institute on "Disability Studies and the Legacies of Euthanasia in Germany."¹



I expected my brain would be crammed full of new facts about state-sponsored torture and extermination, disability-stigma, bureaucracy, pseudoscience, and propaganda. I didn't expect the details would swirl around my head while I lie on this bunk in the darkness, or that my heart would be full of unbearable

sadness, overwhelming heaviness, and despair. I shut my eyes hard and plug my ears—maybe ghosts can't scare you if you can't see or hear them. Still, I swear I can feel them.

I experienced a dichotomy between what I knew and what I felt on this research trip, but a growing body of research questions this split between the rational and the emotional, or as psychologists parse it, cognition and emotion. The neurologist Antonio Damasio, in his classic book, *Descartes' Error: Emotion, Reason and the Human Brain*, writes, "[R]eason may not be as pure as most of us think it is or wish it were ... emotions and feelings may not be intruders in the bastion of reason at all: they may be enmeshed in its networks, for worse and for better."²

A recent issue of the journal *Cognition and Emotion* was devoted to the relationship and interdependence of the two concepts.³ Research from the affective neurosciences also "supports the conceptualization of emotion and cognition as separate but interacting mental functions mediated by separate but interacting brain systems."⁴ And there are various pathways for producing and experiencing emotion. The same stimulus might be processed by different parts of your brain depending on whether you sense danger instinctively or you're having a highly elaborated cognition about the stimulus.

When I sit down to write a lecture or an academic piece on what I learned in Germany, all those feelings come back to me. The way I process and remember the information is linked to the experience itself. As psychotherapy expert Leslie Greenberg notes, "Memories are thus marked to set off the emotional responses that were set off by the original event. The next time something is recalled, the person will feel the same way unless the emotion-schematic memory and associations linked to it are revised."⁵ It's hard for me to disentangle the disturbing facts and thoughts from the visceral chill and sadness. Sitting at my desk in Chicago, I feel the disabled ghosts at the Hadamar Memorial in Hesse; my chest tightens the way it did when I could barely breathe in the basement of a psychiatric institution. I feel sorrow, anger, and despair. Does the inseparability of my cognition and my emotion on this research trip mean I can't take a scholarly approach to the topic? Or is it false to assume that scholarly work isn't informed and shaped by emotion, in the seamless (and sometimes less-than-seamless) way our brains process complex information?

This experience also sensitized me to the contrast between studying killing centers through text and classroom work, and the experience of visiting the killing centers. As I read articles to prepare for the summer institute I could choose to put them down; I could control the amount of time that I immersed myself in the topic. When I discussed it in classroom-style settings I found the topic depressing, but in an abstract way. During our summer institute in Potsdam, I read and discussed the following passage from an academic text:

In the Fall of 1940, Kaufmann visited Bernberg, confiscated a portion of the institution for T4 ["T4" refers to Tiergartenstrasse Number 4, the address where the plans for this phase of euthanasia were created], supervised remodeling, and arranged the transfer of staff from Brandenburg. ... [U]nlike most other killing centers, the old Bernberg [psychiatric] institution continued its operations, sharing property and buildings with the killing center....⁶

When we visited the Bernberg Memorial I'd read about, part of a still-functioning psychiatric institution which has been continuously operating since the early 1900s, I could feel the disabled ghosts. I imagined them watching us go down to the gas chambers in the basement, down wheelchair-inaccessible stairs, where some of my colleagues with physical disabilities had to literally be carried down the stairs by hospital staff wearing white coats! I went to Germany knowing key facts and analyses, but I was completely unprepared for the physical, emotional, and cognitive experience of visiting institutions where disabled people were killed en masse.

The experience of the site-visits was intensified by our group process. We all chose to spend a summer month delving into legacies of euthanasia; we had written about and studied injustice and discrimination. We shared a basic

understanding of disability as a social category, and together we rediscovered and claimed the history. Day after day we researched the topic with a persistence that is typically desirable in an academic endeavor. However, this collegiality had its emotional toll as well. Alone, I would not have spent free-time watching Nazi propaganda or listening to true-life disability horror stories, linking them to current-day practices and perseverating on how crappy and unfair the world can be. At Bernberg the emotional expressions of my new colleagues—blank stares, welling tears, fearful faces—added to my own horror. The sight of people in white coats carrying group members down the stairs to the site of the gas chambers and the fact that the institution still operated as a mental hospital reinforced the medical model of disability. As a non-disabled psychologist who works at a rehabilitation hospital, I felt implicated by association.

I was ready to leave the Bernberg Memorial after about two hours, but we stayed for a full day of data gathering and inquiry. From my perspective, we were on an unrelenting search for data in the face of the horror (and for some, the terror) we were feeling. After the tour of the gas chambers, around hour five, I had to leave the building and get some air. I sat on a bench and wrote in my journal. I didn't want academic language to describe what I'd seen, and I couldn't believe that others were asking about the specific techniques used or the statistics of the killings. I had few words to describe what I felt and I definitely didn't want to listen, analyze, or discuss the topic as a scholarly pursuit. I needed to be alone and process, to find some respite. When I rejoined the group, we learned more disturbing facts and lingered in the rooms adjacent to the gas chambers. Later we returned to the basement and spontaneously had a memorial service for the victims. Some sang, others danced, I chanted a Hindu prayer. Using a different part of my brain, I conjured positive energies and tried to find comfort in sharing the sorrow. For a few brief moments, it felt okay.

Obviously this particular summer institute is an extreme example, but we often underestimate the emotional nature and content of academic work in the medical humanities and bioethics in general. We've learned from people with brain damage that an inability to process emotional information affects decision-making, social judgment, and interpersonal relationships. Yet a part of me would rather avoid these memories and I'm not sure I have fully processed the emotional information—four years after the fact the memories are still raw and my brain jumps to the painful feelings. So I work to turn off some of that emotion when I have to lecture or write on the topic, or even on issues closely related to it. Academics are quick to push emotion aside and go for the cognitive analysis, but all of our work is driven to some extent by what we're feeling, especially in ethics, where ideas of right and wrong can be deeply held and visceral. I wish I didn't continue to feel haunted by this project, yet it taught me unanticipated lessons about the false dichotomy between cognition and emotion, and the role of both in the practice of medical humanities and bioethics. And those lessons are welcome to linger.

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¹ See uic.edu/depts/idhd/DSGermany/. Accessed September 30, 2008.

² Antonio R. Damasio. 1994. *Descartes' Error: Emotion, Reason and the Human Brain*. New York: Avon Books, p. xii.

³ *Cognition and Emotion*, 2007, 21 (6).

⁴ Leslie S. Greenberg. 2008. Emotion and cognition psychotherapy: The Transforming power of affect. *Canadian Psychology*, 49 (1), 50.

⁵ *Ibid.*, p. 50.

⁶ Henry Friedlander. 1995. *The Origins of Nazi Genocide: From Euthanasia to the Final Solution*. Chapel Hill: University of North Carolina, p. 92.

observation that patient maltreatment has traditionally been “invisible” and “subject to denials” within the hospital setting. As Judith Richardson explains, haunting has great value as an egalitarian historical record. Ghosts, she writes, “are produced by the cultural and social life of the communities in which they appear” and thus “operate as a particular, and peculiar, kind of social memory, an alternate form of history-making in which things usually forgotten, discarded, or repressed become foregrounded . . . as items of fear, regret, explanation, or desire.” For Richardson, hauntings represent a means by which contemporary people recall and reckon with persons or events once rendered “marginal and invisible.” Thus,

HAUNTED HOSPITAL STORIES AT THE HEART OF THESE DEPICTIONS OFTEN ENCAPSULATE NOT ONLY GENUINE HISTORY, BUT ALSO A RECORD OF PUBLIC REFERENDA ON VARIOUS ASPECTS OF 19TH- AND 20TH-CENTURY HOSPITALS—FROM THEIR ARCHITECTURE AND APPEARANCE, TO THE NEW TECHNOLOGIES AND TREATMENTS EMPLOYED WITHIN THEM.

through haunted hospital myths that focus upon ethical transgressions against patients, the public has not only memorialized those patient populations whom historical instances of purported abuse, neglect, and maltreatment once marginalized, but has also given those patients voice, agency, and, by extension, a measure of justice. For these reasons, medical ethicists and medical historians would do well to examine the haunted hospital folklore that has so captivated the purveyors of U.S. popular culture.¹⁰

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¹ Dayle B. DeLancey, “Ethics, Historical Memory, and Medicine: The Haunted Hospital” (unpublished manuscript) and “Ethics, Cultural Memory, and Public Perceptions of Medicine: The Myth of the Haunted Hospital” (paper presented at the *Varieties of Cultural History* Conference, University of Aberdeen, Scotland, July 2007).

² Diane E. Goldstein, Sylvia Ann Grider, and Jeannie Banks Thomas, *Haunting Experiences: Ghosts in Contemporary Folklore* (Logan, UT: Utah State University Press, 2007), 7-9. Recent academic meetings provide good examples of emerging scholarship on haunting outside of the field of Folklore. These include the *Space, Haunting, Discourse* conference, Karlstad University, Sweden, June 15-19, 2006; the “Ghosts, Gender, and History I and II” panels of the *American Comparative Literature Association Annual 2006 Meeting: The Human and Its Others*, Princeton University, March 23-26, 2006; and the *Enchantment and Haunting: Creating Landscape through Performance* seminar, Royal Holloway, University of London, June 20, 2005. Significantly, much of this new scholarship comes from literature, a field traditionally receptive to haunting tales.



Avalon at Danvers, located in Danvers, MA. (Previously the Kirkbride Building of Danvers State Hospital.) © AvalonBay Communities, Inc.

³ For recent presentations of haunted hospital legends in popular culture, see “Trans-Allegheny Lunatic Asylum, Weston, West Virginia,” *Ghost Hunters*, Sci-Fi Channel, April 30, 2008; *Haunted Asylum (Dixmont State Hospital)*, VHS, directed by Marty Patterson (Pittsburgh, PA: PPS Productions, 2002), and Mark Meriman, “When Darkness Falls at Central State (*Haunted Indiana Part 3* Book Excerpt),” *Ghosts of the Prairie* Website, prairieghosts.com/central_state.html (accessed August 30, 2008).

⁴ DeLancey, “Ethics, Cultural Memory, and Public Perceptions of Medicine.”

⁵ *Ibid.*

⁶ Matthew K. Roy, “From State Hospital to Stately Homes,” *Salem News*, September 29, 2007; “Study—Structural Condition Assessment: Kirkbride Building, Danvers State Hospital, Danvers, MA,” July 16, 2002 (Peabody Institute Library of Danvers), 1-3; *Annual Report of the Trustees of the State Lunatic Asylum at Danvers* for the years 1878, 1880, and 1890 (Danvers Archival Center), 1-9, 27, and 1-3; Earl Bond, Dr. Kirkbride and His Mental Hospital (Philadelphia: J. B. Lippincott, 1947), 65 and 121; Michael Ramseur, *The Haunted Palace: Danvers Asylum as Art and History* and *The Eye of Danvers: A History of Danvers State Hospital* (Unpaginated draft manuscripts at Danvers Archival Center).

⁷ H. P. Lovecraft, “Pickman’s Model,” *Weird Tales*, 10.4(1927), 509; “The Shadow over Innsmouth” (1936) and “The Thing on the Doorstep” (1937) in *The Best of H.P. Lovecraft: Bloodcurdling Tales of Horror and the Macabre* (New York: Ballantine Books, 1982), 250, 225 and 241. (In some instances, Lovecraft called the institution “Danvers” or “the Danvers asylum.” At other times, he referred to the hospital as the “Arkham Sanitarium.”) For overcrowding and the patient abuse allegations of the 1920s and 1930s, see: Bond, 65 and 121; *Annual Report of the Trustees of Danvers State Hospital* for the years 1922, 1930, and 1937 (Danvers Archival Center), 3, 7, 19.

⁸ Marcia M. Cini, “The Hospital Palace at Danvers: Its History and Architecture” (Master’s Thesis, Boston University, 1991), 8-9; Marie Balter and Richard Katz, *Nobody’s Child* (1987; Reading, MA: Perseus Books, 1999), 31-41, 52-60, 66-76, and 89-136; and Ramseur, *Haunted Palace* and *Eye of Danvers*.

⁹ Jenna Russell, “All Souls That Haunt This Site Can Expect Arrest,” *Boston Globe*, September 6, 2005; Michael Puffer, “The Lore and Lure of Danvers State Hospital,” *Danvers Herald*, October 29, 2003; *Session 9* and *The Haunted Palace: The Making of “Session 9,”* DVD, directed by Brad Anderson (2001; Universal City, CA: Universal, 2002).

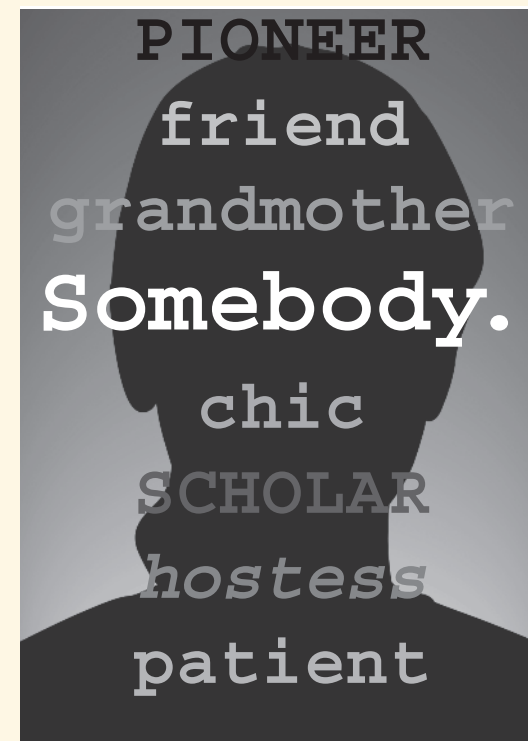
¹⁰ Gerald N. Grob, “Abuse in American Mental Hospitals in Historical Perspective: Myth and Reality,” *International Journal of Law and Psychiatry* 3.3(1980): 298; Charles I. Stannard, “Old Folks and Dirty Work: The Social Conditions for Patient Abuse in a Nursing Home,” *Social Problems* 20.3(1973): 329 and 340; Judith Richardson, *Possessions: The History and Uses of Haunting in the Hudson Valley* (Cambridge, MA: Harvard University Press, 2003), 3; and DeLancey, “Ethics, Historical Memory, and Medicine.”

Finishing the story: On reading obituaries

Nancy Berlinger, PhD

For as long as I’ve read newspapers, I’ve read the obituaries. It started when I was around eight years old. I’d scour the obits and death notices in the *Bergen Record* looking in particular for stories of people born in other countries. I was drawn to immigrants’ obituaries because I was fascinated by history, genealogy, and lives that, unlike my own, had started someplace that sounded more exotic than northern New Jersey.

I worked in an AIDS service organization at the height of the epidemic in the United States in the late 1980s and early 1990s, and this work was difficult to describe to my family and friends: “Isn’t it . . . sad?” For my colleagues and me, part of being “in AIDS” was reading about the work we couldn’t easily talk about.



My obituary-reading habit meant that I was reading about AIDS in the *New York Times* every day, bearing witness to those lives and reinforcing my commitment to my work. Living in New York City after 9/11 reminded me of those days—once again obituaries were “news,” dispatches from the front. Like everyone else, I read the special “Portraits of Grief” section of the *Times* every day, bearing witness to those lives and reinforcing my commitment to my city. When I travel I always read the

local paper, and I read the obits for a perspective on how lives were lived, how they ended, and how they were remembered in Salt Lake City, or New Orleans, or the Hebrides, or other places with distinctive regional and religious cultures. (I secretly aspire to a British-style obituary for myself, but suspect I’m not generating sufficiently eccentric material in this life.) In short, reading the obits is one of the few things I can think of that I’ve always done, as long as a newspaper is on hand.

Last winter I was catching up on the *New York Times* obits during a layover in Atlanta when I spotted a death notice for a woman I’d met at the hospital in New York City where I’m a volunteer on the chaplaincy service. Professional chaplains, and volunteers like me, work at the bedside . . . and in the hallway, the visitors’ lounge, and the kitchenette. Although this volunteer work doesn’t involve “doing” health care ethics, spending regular time among patients, families, and staff immerses me in the situations I think and talk and write about in my day job. I see patients right after they get the news: “We couldn’t get it all.” I see adult siblings trying to work together to make decisions on Mom’s behalf, sometimes suspicious of each other and of staff who are trying to help—or perhaps hurry—them. I see spouses who struggle to support a patient’s decision with which they may not agree: “It’s his life,” “It’s her body.”

What I do, mostly, is listen to stories about the people patients are, were, or may become. An elderly artist tells me, with modest satisfaction, “I was *Somebody*.” Another patient tells me how, when she visits her lake-side cabin in another state, she can live as if she doesn’t have metastatic cancer: “Nobody there knows, and it’s just never come up.” Another patient, nearly ninety, tells me story after story, evoking six generations of a family: “Are you sure you have time to hear all these old stories?” Yes. Please. Even when these stories are about family members long dead, the characters in them are living in the present tense. No one in my family seemed to have hung onto the stories of our own immigrant ancestors, so I notice those stories, the details that are remembered and told in other families—and also, sometimes, to chaplains, or to obituary writers.

Sitting on that plane, I read the story of this patient’s life and death in shock and sudden sorrow. This wasn’t the first time I’d spotted an obituary of someone I’d known but whose death I hadn’t yet heard about—working in AIDS, this happened sometimes. But in the early days of AIDS, we were always prepared for the

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likelihood of death. This time, I wasn't. The patient—the *person*—whose obituary I read in the airport was someone I'd gotten to know over several months, including an unexpectedly long hospitalization, followed by several shorter stays. I don't remember why I thought she was a scholar. Perhaps it came up during a chat, perhaps she was, to me, a familiar type with familiar accessories: newspapers, books, laptop. She was chic; she always wore her own pajamas, favoring bold stripes and prints. She had lots of visitors, and she introduced me to them by name—me, a mere volunteer! Perhaps she had the academic's knack of having to learn new names every semester; perhaps she was a gracious hostess at all times. During that first long stay, we mostly talked about current affairs. She was smart, sharp-witted, confident. Eventually she was discharged—back into the game, I imagined.

Some weeks later, I spotted her in the hallway. She'd been admitted with a complication, and was waiting to go downstairs for a test. She was weaker, and seemed apprehensive, although, gracious as always, she introduced me to her companion. They smiled at one another as they told me they'd been friends for decades. Later that winter, I saw her name on the patient census, and stopped in to see her. She was in bed, bald now from chemo. A friend was with her. We talked a bit. She was tired and short of breath, and I left quickly.

And that was that, until I read her obituary, a few weeks after that last encounter. I heard later that this was

a “hard death” for the staff, and I wasn't surprised. In health care ethics, we talk about the “informed” patient who is an “effective advocate,” one with a “strong sense of entitlement” to getting good care. This woman was a fine example of all of these attributes, but they don't explain why her death was “hard” for the staff. I suspect that she was also kind to them. And they probably liked her style, those fabulous pajamas.

What I read in the paper matched some of what I'd imagined of this patient's back story. She was, indeed, an academic, a “pioneer” in her field. She was also a grandmother, a legendary hostess, and a once-in-a-lifetime friend. Even in this idealized version of a life, the version memorialized by family and friends, it was safe to conclude that she was *Somebody*, that she was missed.

Because of the occasional, non-professional nature of my clinical work, I rarely find out what happens to “my” patients. When I started as a volunteer, my supervisor told me something rather important: if I saw a patient one week but not the next week, the patient had probably gone home, not died. So I tend to think of all the patients I've met as living, even though I know this isn't possible. But through the telling of their stories, in my memories they are still so alive.

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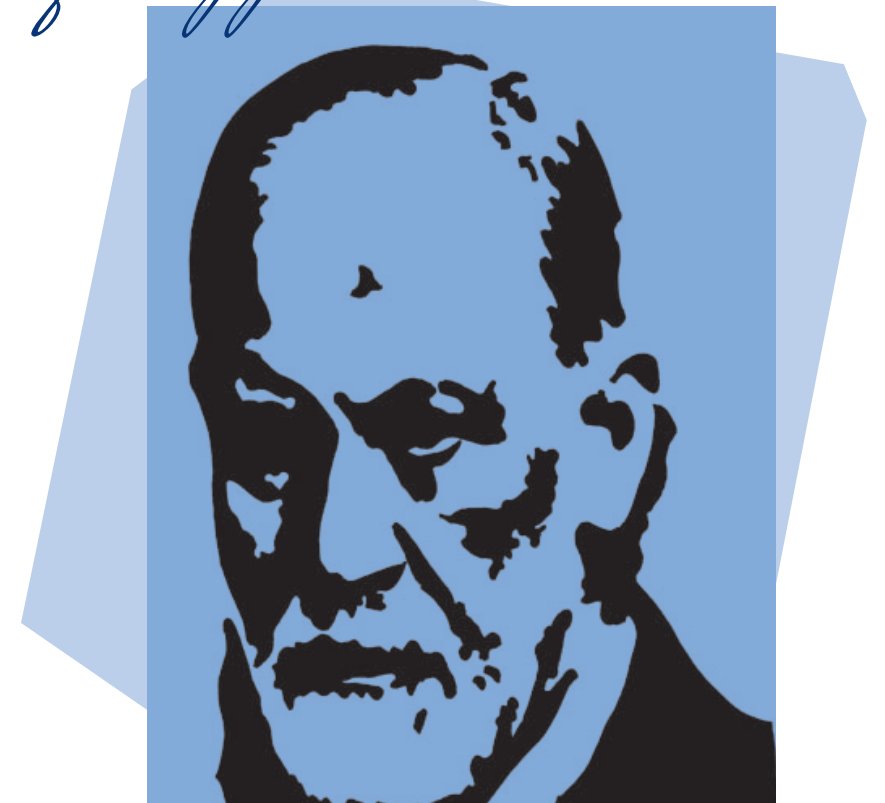
The Uncanny Approach

Jon Masin-Peters

The *Penguin Freud Reader*, a central volume in Penguin's new series of translations of Sigmund Freud's writing, abounds with references to the spectral nature of the famous doctor and his work. In the introduction, general editor Adam Phillips states that he has assembled the various pieces in order to allow “the curious, who are by definition not the converted, to discover what, if anything, is so haunting about Freud's writing.” That “haunting” concept is reinforced by the paperback's front cover, where a large white photograph of half of Freud's disembodied head sits against a black backdrop. On the back cover, a smaller image of Freud's head floats under a publisher's blurb describing Freud as “one of the most haunting writers of the modern age.”

But raising the question of what is haunting about Freud seems to lead to a re-tread of old debates about Freud the personality. A more interesting question is how the concept of haunting itself functions in Freud's writing. This inquiry leads to an important distinction Freud made between the word “haunt” and the related notion of “the uncanny,” a difference which holds significant implications for thinking about the psychoanalytic approach as well as current models of psychiatry.

In 1919 Freud wrote what is considered today one of the century's most influential pieces of literary theory. Titled “The Uncanny,” the essay investigates the peculiar affect that arises when something that was once familiar, cozy, and “homely” becomes strange and frightening—a doll or mannequin becomes animate; a person glimpses their own double; someone fleetingly wishes death upon another and it quickly comes to pass. Freud distinguishes the uncanny from the usual understanding of “haunted” which, he writes, is both a common mistranslation of uncanny (*unheimlich*



in German) and too bound up—for his purposes—with images of the ghoulish, the spooky, and the strange.

However, it is not completely clear why Freud finds it necessary to study the uncanny in the first place, and why this infrequent phenomenon makes him (temporarily) set aside his clinical investigations for aesthetic ones. He does make some suggestive comments in the essay's opening pages, where he states that the uncanny has its own “specific affective nucleus” which should allow him to locate it “within the field of the frightening.”¹ But this still leaves open the question as to why this “nucleus” needs to be distinguished in the first place.

Even though Freud doesn't say so explicitly, his conception of the uncanny is more than a tool of literary analysis. It can also be seen as central to an understanding of some foundational psychoanalytic ideas. Further, Freud's juxtaposition of the uncanny and the haunted could help to illuminate two competing contemporary psychiatric approaches to a condition which abounds in his work more than any

other: obsessional neurosis, or as it is known today, obsessive compulsive disorder (OCD).

As noted above, Freud's aim in the essay is to show that far from being induced merely by new, strange, and unfamiliar elements, the uncanny is aroused by those things that are or have been familiar to us. There are essentially two ways in which this occurs. First, when an incident occurs in which “primitive” ideas, long thought to have been surmounted (such as a belief in people with magic powers, a belief in the reality of ghosts), are suddenly perceived as if they are again possible, blurring the line between “psychical reality” and “material reality.”

The second way in which the uncanny arises is when a repressed childhood memory returns in the form of a neurotic symptom.

While differing in scope, the common thread in both of these instances of the uncanny is the central role played by a once-known past, which suddenly returns. Freud writes that the uncanny “is actually nothing new or strange, but something that was

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long familiar to the psyche and was estranged from it only through being repressed.² This is the exact approach of psychoanalysis, which, as Freud repeatedly points out in his clinical works, is to make the neurotic patient conscious that their present actions are not “new” but are in fact an “acting out” of childhood experiences.³ As he states in his later work: “The analyst’s task is always to turn the patient away from the threatening illusion; to show him again and again that what he takes to be a new, real life is actually a reflection of the past.”⁴ The analyst does this by drawing out these repressed memories of the past, in order to make him or her “do battle” and essentially work through these symptoms. This is made possible because symptoms are no longer seen as strange and intrusive, but once-familiar and therefore part of one’s own history. They are no longer to be excised, but tangled with; psychoanalysis then, helps the patient view symptoms as uncanny rather than haunting.

But as this “psychodynamic model” has largely been supplanted by the “medical model” of mental illness in the last 25 years,⁵ a “haunting” view of symptoms has become predominant. Haunting in this sense is different from the uncanny in that it does not include the “familiar” (*heimlich*) element which is so central for Freud. This means that neurotic symptoms are not seen as part of a coherent past, but rather as intrusive, alien, and in need of excision. Recent behavioral therapeutic mantras such as “It’s not me it’s my OCD” illustrate this conceptual separation. As one ethnographer recently noted, the consequence of this approach can be that the patient begins to feel as if their thoughts are not part of their “self” and that therefore he or she is in some sense trapped in a strange body.⁶ In excising these repetitive thoughts for their strangeness, the current medical model risks creating a new set of haunting effects (a strange self) even as it seeks to eliminate others (neurotic symptoms).

Does the potential for “haunting” in the medical model mean there should be a return of psychoanalysis as a clinical treatment? There are signs that this is beginning to happen,⁷ although critics of the psychoanalytic approach are right to challenge the sometimes absurd conclusions Freud reached. But an appreciation of Freud’s approach doesn’t necessarily discount the role that pharmaceutical and behavioral approaches can contribute. Instead it might augment them by helping patients see their obsessional symptoms not as foreign and strange (although perhaps frightening), but as part of a coherent self; uncanny rather than haunting, and therefore easier to confront.

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¹ Sigmund Freud. “The Uncanny,” in *The Uncanny*, ed. Adam Phillips, trans. David McLintock. London: Penguin Classics, 2006.

² “The Uncanny,” p.148.

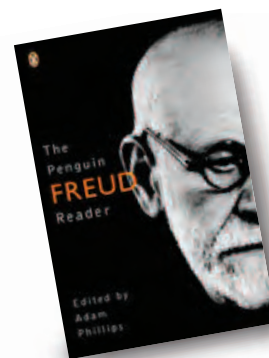
³ Sigmund Freud. “Remembering, Repeating, Working Through” in *The Penguin Freud Reader*, ed. Adam Phillips. London: Penguin Classics, 2006, pp. 391-401.

⁴ Sigmund Freud. “An Outline of Psychoanalysis” in *The Penguin Freud Reader*, pp. 1-63.

⁵ The notion of a split between the “psychodynamic model” and the “medical model” comes from Jennifer Fleissner. “Obsessional Modernity: The ‘Institutionalization of Doubt,’” *Critical Inquiry* 34 (2007) 106-134.

⁶ Anthropologist Tanya Luhrmann recently noted the case of a schizophrenic patient “who is ‘adamantly opposed to the medical model because to him it makes his thoughts, his goals, and his desires seem as if they are not really his own but due to something separate from himself.’” Quoted in Fleissner, p. 128.

⁷ Benedict Carey. “Psychoanalytic Therapy Wins Backing,” *New York Times* (Oct. 1 2008) A18.



Freud’s essay “The Uncanny” investigates the peculiar affect that arises when something that was once familiar, cozy, and “homely” becomes strange and frightening.

Payment in Kind



Larry Zaroff, MD, PhD

I’m not sure why a Jew would become the cardiac surgeon of preference for the Mafia, but I cured one and they kept coming like I was the new messiah. My Mafia patients were a joy. How scrupulously they followed orders: breathe and cough though your chest feels like it had been buzz sawed—it had, they did. Walk around the first day after heart surgery: walk they did. Bills? Not necessary. “How much, Doc?” Money on the barrelhead. No Blue Shield, no Medicaid, no Medicare, no co-anything. Cash. And perks. Steaks, flowers delivered to the door. Parking or speeding tickets? Not a problem. My friends had sticky tentacles, they were well connected with the ticket givers as well as the purveyors of the best groceries in town. Meat was a major interest to them.

I had known the man I’ll call John for ten years. Like any leader, John was by the bedside when his soldiers were wounded. Status and respect were evident when he walked into the room. He was of medium height, a bit paunchy, and he had an oversize head with black, black hair—midnight fur. He moved unlike anyone I’d ever seen: quickly, then pause, quickly, then pause, as if he were running from foxhole to foxhole. He was always looking, observing, noting, never—as I was to discover—forgetting. His clothes fit his furtiveness: sleek grey slippery suits, a perfectly-fitted white shirt with spread collar lit by a blood-red tie, always

red. I’ll admit he scared me though he was always polite: “So how’s the family surgeon?” I didn’t want to be part of his household, but I was drawn into the circle just by doing my job. Soon we were to become even more tightly glued, a nucleus, opposite charges drawn together, only separable by death.

I’d been having a nice day. The morning operation, an aortic valve replacement, had gone well, the afternoon paperwork was less than usual, and the patients returning for follow-up had no major problems. The quiet ended at 4:15, an unforgettable ninety-degree afternoon in July, when Dr. Kumar called me. “I’ve got a guy in the ED who had a big-time heart attack complicated by cardiogenic shock. We’ve started medical therapy, but he might need bypass surgery to survive. I know you’re not on call, but as awful as this guy looks, he insists he won’t see anyone but you.”

“What’s his name?” I said, already guessing he was one of my special patients. My anticipation at a challenging case was tempered by my knowledge of how powerful these men were. Every time I took care of one, I was concerned: What would happen if things went badly? Yet I too felt powerful, singled out to care for these violent men.

“I don’t know, he just said tell Dr. Zaroff that a member of his family is here.” I had to smile when Kumar said, “Larry, he sure doesn’t look Jewish.”

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“OK, Kumar, I’ll be right down. I have a large extended family.”

John’s blood pressure was seventy over thirty, his pulse barely palpable. Even in shock he frightened me. A fleeting thought: this guy could rip my heart out and insert it into his own chest. A fantasy, really, because John looked as if his next stop was the morgue. I had little hope for him. He was tough though. Dying easy wasn’t his style. He had resources. And he was surrounded by his army, who in this time before metal detectors carried their own emergency equipment. Louis, his main lieutenant, had bazookas for eyes and they gathered me in after I examined John.

“How long will he be in the hospital, Doc?”

I shrugged. “He’s very sick.”

An unacceptable answer. Louis moved his 290 pounds close to my chest, compressing my stethoscope. “What do you mean?” I knew what Louis meant: Don’t let him die, you fucker.

John was too sick for immediate heart surgery, but I calculated that there was another option, one chance to survive. A possibility. In the operating room under local anesthesia I threaded a “balloon” through the major vessel supplying blood to the leg. This heart-assist device was connected to an external pump that filled and collapsed the “balloon” in response to the heart cycle, raising the blood pressure and decreasing the work of the heart.

I didn’t want to be part of his household, but I was drawn into the circle just by doing my job.

Louis never left John, kept out of the sterile area only by an equally tough operating room supervisor. She too had her hard rules, her closed family of operating room nurses and surgeons. John improved quickly; the damage to his heart appeared to be minimized. He stabilized and three days later I removed the balloon, repairing his femoral artery with a portion of his leg vein. Through each of these uncomfortable procedures John never flinched. He watched, recorded, counted. Later he would repeat every detail—“Doc do you recall...?”

As I closed the leg incision, I thought, “Done, John will go home in a few days.” I was relieved as I explained his remarkable improvement to Louis, who almost smiled. Surgery for John would have been in the highest risk category—perhaps a death in the OR, the worst outcome for a surgeon. A hospital death, even an ICU death, isn’t as devastating for a surgeon. In the operating room, the surgeon is singular, in charge.

Everything falls on him. These deaths suggest failure of not just of intellect but also of hand, bad technique.

But I had miscalculated. My comfort faded. No easy way out. Within twenty-four hours John slipped back into shock, forcing us to insert a balloon into the other leg, after which he was transported directly to the cardiac catheterization laboratory, where angiography revealed severe blocks and a heart muscle that contracted feebly, a dying bird. The odds were terrible for John. Few survive open-heart surgery in cardiogenic shock.

“What are his chances?” Louis asked. I moved away quickly, barely nodding. “We’ll see.”

Not an easy decision—the consequences of failure loomed. Suppose I did the surgery and John died? Would the family spill their anger over me? Would Louis seek revenge? Or I could decide not to operate and walk away without criticism, an uncomplicated and effortless exit. Without surgery John would surely die, and a new leader would emerge. Perhaps the new boss would find another surgeon. The pressure to perform would be off. But training won. Cardiac surgeons are in the rescue business. Any chance of saving a life, no matter how slim, we try. I rode the elevator to the operating room standing beside John and he gave me a look, an “I-see-who-you-are-don’t-screw-up” look. A sign of who was still in charge. Even after the anesthesiologist put John to sleep that power lingered. Such a presence changes the odds.

I exposed and divided the breast bone using an electric saw. The heart lay hidden in the pericardium, its protective sac, a sick organ barely contracting in its nest. As I exposed the heart, now free but encumbered by its lack of blood, I saw its weakness. Despite the drastic limitation of its blood supply, it still strove to move, but the movement had no force.

John was alive because of the heart assist device. Yet I found no major scars, which suggested that his heart muscle had potential. It might yet recover. I attached John to the heart-lung machine: a tube draining blood from the right side of his heart and a second cannula returning blood to his body through the aorta. A heat exchanger lowered his body temperature. I packed ice slush around the heart. His organs would be protected by the reduced temperature. John’s heart stilled, stopped, stunned by the cold. I performed three coronary artery bypass grafts finding targets, areas of normal vessels beyond the blocks. These vein grafts carried oxygenated blood from the aorta through the distal open arteries to the dysfunctional muscle.

Would John’s heart beat again? The major question after any heart operation. I watched as the temperature rose. The heart quivered, as if trying to shrug off its bonds. No beat. But a more rapid trembling, a terrible movement. I applied the electric paddles, one on each side of the heart. An electric shock followed by nothing, no beat. Then a contraction. Another, finally many, like an early morning arousal, gaining speed. The heart



enjoying the ride, a return to life. I felt the same way. For a moment I held the heart in my hands and realized again that it is life itself. No matter how many heart operations I did, I always had this same feeling. A remarkable itinerary. Every moment the heart forces the blood to travel through the body. No other organ asserts itself so powerfully, not even the brain. The ventricles discard my hands, the muscles forcing my fingers loose. The heart is an amazing device: frozen to stone, warmed, it beats again. It’s the concierge of the body, caring, feeding every tissue, responding to unreasonable demands, with us faithfully from the moment we become.

Louis never left the ICU area. He was as attached to John as the catheter carrying fluids into John’s arm. I told Louis that John had a good heart now. He should do well. Louis made a fist, touched his chest and then touched mine. On the third post-operative day John had his fifth and last operation to remove the second balloon and repair the femoral artery with a vein graft.

Cardiac surgery is the sort of work that promotes feelings of invincibility for short periods of time, especially in surgeons just starting their own practice. (Until then it’s easy to blame your chief for disasters.) With experience, heart surgeons learn that success in desperate situations, like restoring life, is sometimes a matter of luck and the patient’s biological response to his injury as much as the skill of the operator. When doctors come to that realization, they, like the “Velveteen Rabbit,” are older, grayer, and human. As I was that day.

Yet the morning John was to leave the hospital I felt like Zeus. Cardiogenic shock. Five operations. Home in ten days. Standing outside John’s room, I anticipated applause, bravos from the large audience crammed beside his bed. Not a chance. As I entered, the visitors exited quickly and quietly, except for Louis. The motivation for this exodus was a flick of John’s head. I waited for an offer: college educations for my children, a new car, a case of 1961 Lafite? No sound from my resurrected patient, only another nod ordering my approach.

I came to the side of his bed. The bed rails were down. John lay under the sheets, silent. For a few seconds I wondered if a stroke had left John speechless. Then his arms, big and still muscular, reached out, captured my head, twisted down, and curled my ear to his mute mouth. I imagined the headline: Deranged Patient Kills Surgeon By Strangulation.

Then like an avalanche, the words, mouth to ear, slid naturally, unrestrained and continuous, a whisper. “If you want someone killed, I’ll do it and no one will ever know.” Louis, for the first time since I’d known him, smiled widely. He understood. He knew the words without hearing. John waited silently for a name.

To openly refuse John’s offer would be to insult him, something I never wanted to do. So I remained thoughtful. An anesthesiologist who blocked the development of cardiac surgery. A contractor whose roof repair leaked. My second inclination was to ask for a rain check. Who knows? My third and last inclination, the only correct one, was protracted silence. How could I explain the irony, a life for a life. John, I deemed, took the death of my larynx as an indication that I accepted his offer as it was intended, a supreme symbol of his gratitude. One I could take advantage of whenever I was in need.

I don’t believe one should take offense at John’s method of bartering. After all, the ways patients thank their doctors are varied. Some folks have good insurance; some families bring Chinese or pickles to the office. Some cry when they thank you or kiss your hands. It may come down to what’s most easily available.

I saw John frequently after he left the hospital. Always with Louis, who now smiled at me as if I were his favorite grandson. John seemed unchanged; harder perhaps, a bit gray, eyes darker. I saw him at checkups, at the best restaurants, visiting his friends in the hospital. He said little, but always an embrace, kisses, and a look that flooded me. His eyes said, “Well, who? How long can I hold this debt?”

When I retired and left the state, I heard from John every Christmas. A careful, non-sectarian card wishing me well. Always the “well.” A decade after I left, John died, then almost immediately Louis, the part dying with the whole. The yearly card from John’s brother said stroke, but that wasn’t the end. The holiday cards continued from the brother, then from John’s son. After ten more years, I moved again and the cards stopped.

Every winter I wonder if this is the year they’ll find me again.

Larry Zaroff focused on cardiac surgery for 29 years, then spent the next 10 years concentrating on mountain climbing. In 2000 he received a PhD from Stanford, where he currently teaches medical humanities. He also writes for the New York Times science section, works one day a week as a volunteer family doctor, and in 2006 was honored as Stanford’s Teacher of the Year. larryz.zaroff@gmail.com

We see dead people:

A failure of science and faith



Craig M. Klugman, PhD

Rational, scientific culture places an impermeable boundary between the living and the dead. In the United States, discussing someone who has died is socially acceptable for approximately six months after the death. Once that grieving period has elapsed, most Americans expect mourners to refrain from discussing the deceased. It is also considered aberrant for mourners to speak about feeling a presence, seeing a figure, or hearing foot-steps. Socially, the time for such “mind tricks” has ended, and mourners are expected to accept that the deceased is no longer a part of the reality of everyday life.¹ For “normal” people, the dead don’t talk to or with the living, the dead don’t intimately touch the living, and the dead certainly don’t hang around and warn the living of imminent danger. Science tells us that people who claim such experiences are delusional or experiencing abnormal grieving. Religion might tell us they’re being visited by demons.

Despite Americans’ strong denial of the possibility of interacting with the deceased, when Americans are surveyed by researchers, they report contact at surprising rates. Andrew Greeley found that 42% (619 of 1,473) of Americans in a national survey reported experiencing a post-death contact.² In a 2006 random telephone survey, 97% (196 of 202) of Nevadans the researchers spoke to had experienced two or more post-death contacts such as sensing the presence of the deceased, feeling the touch of the deceased, or hearing the deceased. However, when asked whether they have a connection with someone who has died, only 62.6% (127 of 202) said yes.³ Thus, in the Nevada study there was incongruence between *having* a haunting experience and *naming* it a

haunting experience. The problem with research on rates of contact with the dead is that the people who are willing to talk about the topic are that minority which already has an interest. In the Nevada survey, 75% of people contacted refused to participate (609 out of 811 subjects). Whether they were uninterested, uncomfortable, or busy we will never know.

Despite Americans’ strong denial of the possibility of interacting with the deceased, when Americans are surveyed by researchers, they report contact at surprising rates.

The types of contact with the deceased reported by studies like these vary widely, from images, to touch, to signs and symbols. In my own research, cited above, the most common contact (reported by 87 percent of subjects) is a dream about the deceased which feels like a true visit. In 2001, I completed a qualitative study of 15 death-history interviews of subjects in the Houston-Galveston area. The experiences those interviewees reported were similar to those later found in the Nevada telephone survey. James had dreams about his deceased partner in which his husband explained his life in purgatory, and how later he moved on to heaven.⁵ Carol talked about feeling her grandmother as a protecting presence, keeping Carol safe from harm and from traffic accidents.⁶ Dena talked about her dead husband physically touching her ankle, a unique form of intimacy. Although she believes the experience is real, it has created a quandary for her because her religion states that the dead go to heaven, not her bed. Other subjects talked about windows opening or closing, televisions and radios mysteriously turning on and off, or even a certain song playing over and over on the radio or iPod. They know that these happenings are caused by the dead trying to communicate.⁷

As a result of my research interests, I’m often asked to speak with people who have had post-death contacts, or to help people explore their desires for post-death contact, outside of the research context. One time I was invited to join Mary and her friend, a self-proclaimed psychic, to talk about Mary’s recently deceased father. Mary’s friend suddenly stopped the conversation and stated, “Stop looking. There is nothing under the floor.” Mary admitted that her father had always told her that he hid money under the floor and so when he died, she went into his apartment and started tearing up the carpets. One Halloween, Vanessa invited me to use a Ouija board to contact her recently deceased father. During our session, the Ouija board spelled out “Little Yellow Bird.” I looked at her and said that these things never work or make sense. Vanessa started crying because “Little Yellow Bird” was the name of a song her recently deceased father used to sing when she was a little girl. Another time, I comforted Trudy who was lamenting the loss of her husband on the nine month anniversary of his death. An observer to this conversation suddenly said “Sweet Muffin” and apologized because he had no idea where those words came from. Trudy stopped and smiled, later explaining that the phrase was a secret pet name she and her husband had for their dog.

Americans aren’t alone: hauntings by the deceased are a fairly common occurrence around the world. The Chinese have a particularly vicious form of contact with the dead, where a person who has been greedy in life becomes a “hungry ghost,” an apparition that can never be fulfilled and haunts his or her family and friends for ever more food, hell money, or attention. In the United Kingdom, Bennet and Bennet found that many widows believe that their deceased husbands come to them through words or as a presence.⁸ Studies in the Netherlands, Iceland, and Japan have shown rates of post-death contact ranging from 31 percent to 90 percent of subjects.⁹ The studies reporting rates of 42 and 97 percent in the U.S. put us in the middle to the high end of this range.

Americans’ public and private relationships with the dead weren’t always so conflicted. In the 19th century, holding séances and employing mediums was considered a normal part of American society. Many social societies were founded to explore matters of connections with the dead, and some included many leading scientists as members. The mid-1800s also saw an explosion in the writing and reading of consolation literature —religious treatises on how to have a good death and what to expect in the afterlife.¹⁰

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In this era, Americans were more open about spiritual matters relating to death and had a broader view about what constituted an appropriate topic of scientific research.

At the same time that most modern Americans discourage conversation about the dead and stigmatize individual reports of contact with the dead, collectively we're also fascinated by them. Books written by mediums (John Edwards, Allison DuBois, James Van Praagh, Sylvia Brown) are best-sellers, and television shows featuring mediums (*John Edwards' Crossing Over*, *Medium*, *Ghost Whisperer*) and movies about interactions with the deceased (*The Others*, *The Sixth Sense*, *Ghost*) are popular.

Contemporary U.S. culture simultaneously rejects, and is fascinated by, the possibility of ongoing relationships with the dead. The U.S. is both more scientific and more religious than in our past or than many other cultures.¹¹ "Hauntings" are a lived experience that neither science nor religion fully explains. Science discovers facts through a process of observing and experimenting. However, the soul, ghosts, and the afterlife have resisted attempts at scientific explanation. On the other hand, faith is belief in something absent empirical evidence. For many, faith explains how the world was created and why certain things are right and other things are wrong. Many of the dominant U.S. religious faiths describe what does and doesn't happen after death, but few teach the idea of contemporary living people interacting with the dead. In fact, if the dead are hanging around, then for people like Dena—the research subject mentioned earlier—it violates notions of heaven, hell, and reincarnation.¹²

Neither science nor faith—the backbone of how Americans order and explain the world—explains post-death contact. When faced with such cognitive and spiritual dissonance, modern Americans have chosen to publicly deny their post-death contact. But behind closed doors, our connections to the dead are as real and vibrant as ever.

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- 1 Elisabeth Kubler-Ross. 1973. *On death & dying*. New York: Macmillan; and Craig M. Klugman. 2001. Exploring experiences of dying: An analysis of death memoirs. Doctoral dissertation, University of Texas Medical Branch.
- 2 Andrew M. Greeley. 1987. The impossible is happening. *Noetic Sciences Review* 1, no. 2: 7-9.
- 3 Craig M. Klugman. 2006. Dead men talking: Evidence of post death contact and continuing bonds. *OMEGA* 53, no. 3: 249-262.
- 4 The 1987 Greeley article (note 2) is a summary of two studies Greeley conducted in 1970 (1,467 respondents) and 1984 (1,473 respondents); he does not report his response rate. Greeley's national telephone surveys asked about Americans' beliefs about life after death, religion, and paranormal phenomena. He concludes that the studies show an increase in belief in paranormal activity. My 2006 "Dead men talking" article (note 3) reports on a random telephone survey conducted in Nevada. The questions for this survey derived from Klugman 2001 (note 1) as well as from two focus groups held with spiritual leaders in Reno. The results from these two sources of qualitative data were then adapted into a quantitative survey. In this survey, there was a response rate of 21.8 percent which translates to 202 completed quantitative surveys.
- 5 Klugman, Exploring experiences.
- 6 *Ibid.* and Craig M. Klugman. 2007. Narrative phenomenology: Exploring stories of grief and dying. In *Meaning in suffering: Caring practices in the health professions*, ed. Nancy Johnston and Alwilda Scholler-Jaquis. Madison, WI: University of Wisconsin Press, 144-185.
- 7 Klugman, Dead men talking.
- 8 Gillian Bennett and Kate Mary Bennett. 2000. The presence of the dead: An empirical study. *Mortality* 5, no. 2: 139-157.
- 9 Marc P.H.D. Cleiren. 1992. Bereavement and adaptation: A comparative study of the aftermath of death. London: Taylor and Francis; Erlendur Haraldsson. 1988. Survey of claimed encounters with the dead. *OMEGA* 19, no. 2: 103-113; and J. Yamamoto, K. Okonogi, T. Iwasaki, and S. Yoshimura. 1969 Mourning in Japan. *Am J Psychiatry* 125, no. 12: 1660-5.
- 10 Ann Douglas. 1975. Heaven our home: Consolation literature in the northern United States, 1830-1880. In *Death in America*, ed. David E. Stannard. Philadelphia: University of Pennsylvania Press, 144-185.
- 11 In the Gallup Religiosity Index, which measures whether people of a country believe that religion is important in their everyday lives, the United States ranks 25th (with a score of 61) of 64 nations in religiosity. See Pelham, B & Nyiri Z. 2008. In More Religious Countries, Lower Suicide Rates. *Gallup News* (July 3). Accessed Nov. 10, 2008 via gallup.com.
- 12 Contemporary interactions with the deceased are played down by the mainstream religions. Often the founding mythologies of religions involve the deceased revisiting the earth such as the story of the Resurrection, the return of Elijah at Passover, visions of Mary, or the Eastern European Jewish folklore of the dybbuk, a possessing malevolent spirit. However, the teachings of most mainstream U.S. religions do not emphasize these beliefs today.



DEBORAH COSTANDINE, *My Boys* (2006)

Gretchen Case, PhD

Deborah Costandine was 21 years old when she delivered stillborn conjoined twins. Her pregnancy was proceeding normally, until the day in the eighth month that it wasn't. In 1977, ultrasound technology couldn't provide a refined image for Costandine's doctors, and they told her only that the fetus had died in utero and that she would need to deliver it. Costandine plunged into a deep depression and delayed delivery for a dangerously long time. On December 2, four weeks after that ultrasound, she finally checked into a Saint Paul, Minnesota hospital for induction of labor. The scene she remembers is terrifying: dark amniotic fluid spilling out onto the sheets, her rising sense of panic and isolation, and her own mother's screams when she was told that her daughter had delivered "a monstrosity." Costandine was given tranquilizers and moved immediately to a private room. The bodies she had delivered were spirited away before Costandine or any of her family saw them. She and the babies' father had the remains buried under a headstone inscribed "Michael David" because they weren't sure whether they had lost one son or two.

For decades, especially each December, the absent images of these dead children teased at Costandine's mind. Were they blond, brunet, or red-haired; blue or brown eyes? If they had survived, would they have grown tall, would they have had the capacity to wonder at the world around them? As the 30th anniversary of her twins' birth approached, Costandine felt a need to discover as much as she could about her sons. One part of this discovery process was to recover, with the help of MH&B Professor Alice Dreger, the medical records of her delivery. At last she had words to describe their rare physiology: cephalothoracopagus twins. This medical terminology led her to find images of other twins, not quite like hers, but similar enough that she began to visualize Michael and David's intertwined bodies. The boys had separate lower limbs and torsos, but they were joined at the chest with one skull contained in the other, so they appeared to have one head. In 2006 Costandine took this image into the ceramics studio. There she entered the second part of her discovery of her lost babies as she began to sculpt several representations of her children.

Her first sculpture, *My Boys* (above), is now in the collection of the Medical Humanities and Bioethics Program. MH&B purchased it after organizing an exhibit of Costandine's work at the medical school in December 2007. At the opening symposium, Costandine spoke about her art to a group of physicians, medical students, and community members. Costandine's conjoined-twin inspired art, which includes ceramic sculptures and acrylic paintings, provided entry to a profound conversation about physicians' admirable urge to protect patients from traumatic experiences, as well as the importance of attending to patients' needs in difficult moments of pain and loss. Just as any parent might pass a new baby around a room full of admirers, Costandine invited the symposium audience to touch and hold her sculptures. This sculpture, *My Boys*, fits sweetly into the crooks of both arms as you lift it, with the heft of one—or perhaps two—tiny boys.

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