

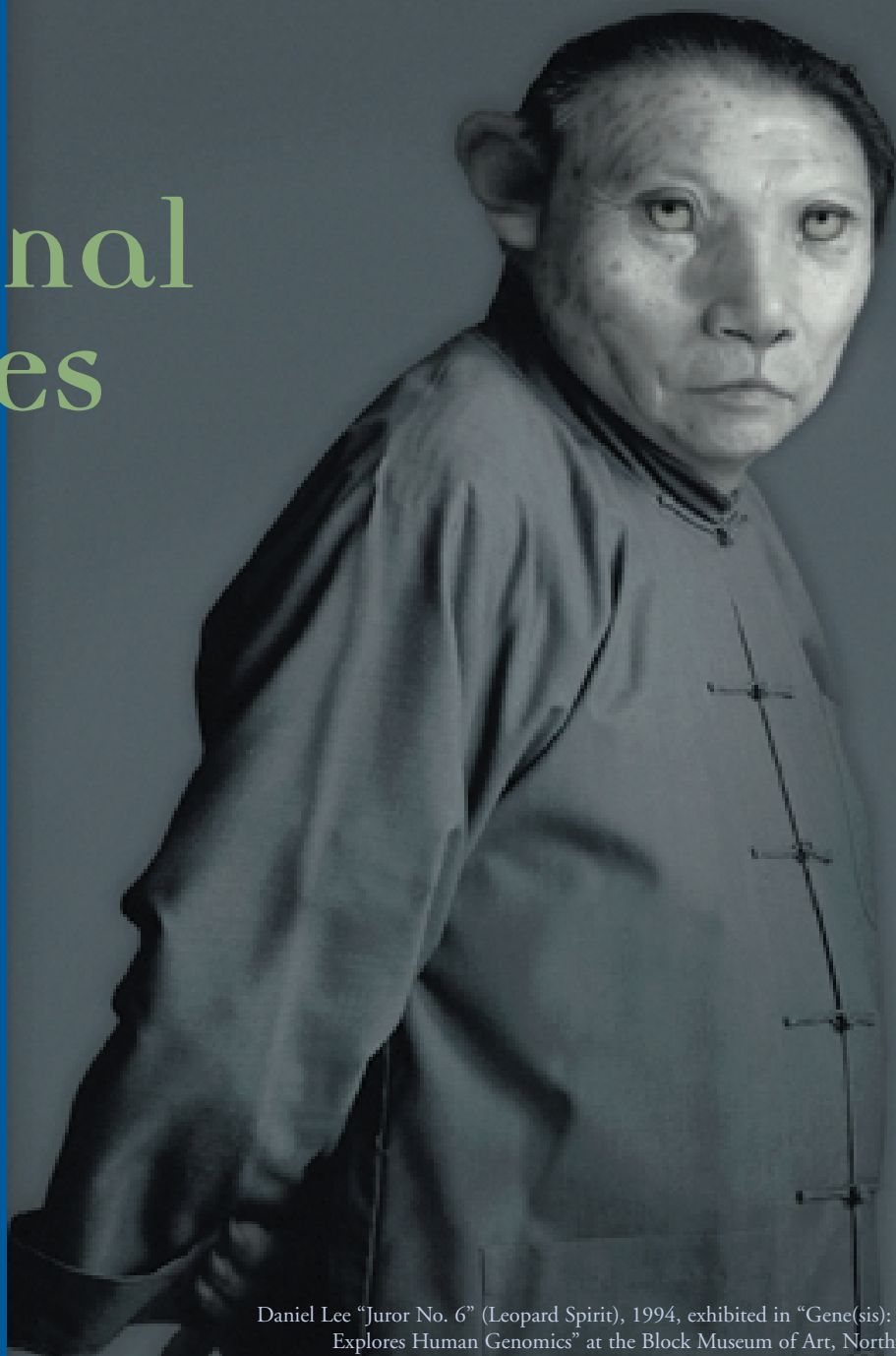
Issue **2**

# ATRIUM

Winter 2006

The Report of the Northwestern Medical Humanities and Bioethics Program

liminal  
states



Daniel Lee "Juror No. 6" (Leopard Spirit), 1994, exhibited in "Gene(sis): Contemporary Art Explores Human Genomics" at the Block Museum of Art, Northwestern University.

## about the cover

*Judgment: Juror No. 6 (Leopard Spirit)* 1994 by Daniel Lee was exhibited at Northwestern University's Block Museum of Art as part of *Gene(sis)*, a traveling exhibit of contemporary art created in direct response to recent developments in human genomics. *Gene(sis)* seeks to bridge art and science by elucidating technical advances for a lay audience, examining ethical issues raised by genomic research, and encouraging public discourse about its potential impact. Lee's *Judgment* was featured in the exhibit's "Boundary" segment, in which artists investigated the now permeable boundaries between species.

Myths of hybridity haunt our most ancient cultural imaginings. In Greek and Roman mythology, both the chimera and the centaur are half-human, half-animal, and human-animal hybrids are also prevalent in Hindu, Buddhist and Native American mythology. Lee's initial inspiration for his transgenic art was the Chinese Zodiac: what if people born the year of the ox actually resembled an ox? *Judgment* is a series depicting the mythological Buddhist court that determines a dead soul's destiny in the afterlife, and its judge and jurors are inspired by the 108 creatures (one of which is a human being) in the Chinese Circle of Reincarnation. The jurors in Lee's court are "suspended characters and spirits," Lee says. "But they are not only jurors. They are the witnesses and they are ourselves."

Like the liminal creatures he depicts, Lee's medium is a hybrid made possible by new technology—since 1993, computers have allowed him to combine his drawing, photographic and fine art skills into one medium—and his images lie between traditional categories of art. "They aren't drawings, they aren't paintings and they aren't photographs; they are something entirely different created on the computer." Lee doesn't just combine photographs of animals and humans, he manipulates animal features onto the human face using Photoshop tools on his desktop Macintosh.

In *Judgment* Lee responds to anxiety that blurred boundaries between humans and animals will move from fables to the front page. Lee has also used his unique style to explore subjects like Darwin's theory of evolution (*Origin* 1999), and a variation on xeno-transplantation (*Harvest* 2004) in which he imagines a future when livestock is genetically engineered to supply human organs, and the animal organ hosts begin to evolve with distinctly human traits.

Daniel Lee (known as Lee Xiaogin in Chinese) was born in China in 1945. After receiving his BFA in painting at College of Chinese Culture he moved to the U.S., receiving his MA in photography and film from Philadelphia College of Art. Lee's work has been shown internationally in solo exhibitions, and it is included in public and private collections around the world.

The MH&B Program is grateful to Mr. Lee for his generosity in sharing his work and ideas with ATRIUM. For more information about the artist or the *Gene(sis)* exhibit of which Mr. Lee's work is a part, visit [www.daniellee.com](http://www.daniellee.com) or [www.gene-sis.net](http://www.gene-sis.net).



Daniel Lee "Juror No. 10" (Cat Spirit), 1994, exhibited in "Gene(sis): Contemporary Art Explores Human Genomics"

## The Medical Humanities and Bioethics Program

### Faculty

Kathryn Montgomery, PhD—Professor of MH&B and of Medicine; Director

Peter Angelos, MD, PhD—Associate Professor of Surgery and of MH&B

Tod Chambers, PhD—Associate Professor of MH&B and of Medicine

Alice Dreger, PhD—Visiting Associate Professor of MH&B

Joel Frader, MD—Professor of Pediatrics and of MH&B

Kristi L. Kirschner, MD—Associate Professor of Physical Medicine and Director, Rehabilitation Institute of Chicago Donnelley Family Disability Ethics Program

Scott Moses, MD—Assistant Professor of Obstetrics and Gynecology and of MH&B; Director of Ethics Education, Department of Obstetrics and Gynecology

Douglas Reifler, MD—Associate Professor of Medicine and of MH&B

Mark Sheldon, PhD—Senior Lecturer in Philosophy and in MH&B

Katie Watson, JD—Lecturer in MH&B

Mark Waymack, PhD—Adjunct Associate Professor of MH&B

Laurie Zoloth, PhD—Professor of MH&B and of Religion; Director of Ethics, Center for Genetic Medicine; Director, Center for Bioethics, Science and Society

### Fellows

Aviva Goldberg, MD—MH&B and Pediatrics

### Staff

Brock Daniels, MPH—Student Editorial Assistant

Pelmyria Knox, BA—Program Assistant

Ellen LeVee, PhD—Program Assistant

# liminal states: The challenge of new-onset disability

Kristi Kirschner, MD

Seventeen year old Jeffrey Galli is playing with family and friends poolside on a hot summer day. He dives, hits the bottom with his head, and his spine cracks. He's not breathing.

The Fourth of July, 1998, is transformed from idyllic laziness to nightmarish panic in the blink of an eye. His father starts mouth-to-mouth resuscitation. The ambulance arrives and Jeffrey's life is turned over to the well-oiled machine of critical care services. Within hours he is stabilized in the ICU on a ventilator, his spine immobilized by bolts screwed into his skull. Jeffrey has suffered a hangman's fracture, with breaks in the first and second vertebrae, just below the skull.

In *Rescuing Jeffrey*, Richard Galli chronicles the first 10 days of his family's experiences with his son's injury and the difficult medical decisions they faced. As a rehabilitation physician, I've cared for hundreds of patients with devastating new-onset disabilities caused by events like a sudden spinal cord injury, a stroke, or a brain injury, and although each patient's journey is unique, Jeffrey's story feels representative.

When we see patients like Jeff in the acute care setting, they are living in a liminal state—betwixt and between, existing moment to moment in a gray zone. The past is irrevocably gone, the future hard to imagine. “Old normal” can't be regained, “new normal” hasn't yet arrived.

## Monday July 6

*Almost every time Jeffrey woke up, he had to learn about his accident as if for the first time. He would rouse out of his medicated sleep, disoriented. He would ask what happened. He would be eased into understanding. He would eventually remember the accident, at least part of it. And then he would be reminded—but to him it was news each time—that he was paralyzed. Each time he would cry. (p. 44)*

Jeff's life is changed forever. His spinal cord injury is as severe as it gets, and his chances for substantial neurological recovery are miniscule. Jeffrey is completely paralyzed from his neck down. He will require a ventilator to breathe for him.

In the ICU, Jeff is just beginning to process this information, and will continue to do so for a very long time. His healthcare providers will struggle with how much to tell him, and over what time frame. Gradually, though, the implications and enormity of the injury will sink in.

*“Jeffrey,” I said, “you are not your legs. Jeffrey is not in your legs. Jeffrey is up here.” I tapped his head. “Jeffrey is up here, and that means you are still here, all of you.” (p. 44)*

Who is Jeffrey right now? We know his body has changed, but what about his identity or his personhood? Is Jeffrey somehow a fundamentally different person now?

Jeff's father's belief, that disability resides in the body and personhood in the brain, is shared by many. Christopher Reeve recounted that when his wife said, “You're still you and I love you” after his injury that it “saved his life.” But are Jeffrey's dad and Dana Reeve right? Might a professional dancer and a mathematician locate personhood (or big pieces of it) in different places? Is “you're all in your mind” just a happy fiction we tell paralyzed patients? And what are the implications of that construct for those with brain injuries that result in substantial alterations in personality, comportment, ability

to recall their history and process new information? Patients in situations like Jeffrey's are often engaged in a life-or-death struggle with the kind of existential questions that have occupied philosophers, theologians, psychologists and neuroscientists for centuries with no clear consensus, and it's our job to help them. Perhaps the best way to understand questions of personhood and identity is by studying the lived experiences of those who have been through such transformative events.

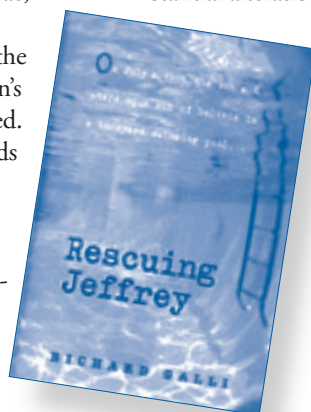
Two days after his injury, Jeffrey spelled out on his letter board that he wanted to die. Later, his father asked him:

*“When you go to sleep, do you want to stay asleep and never wake up, or do you want to wake up again?” His eyes widened. “Wake up,” he said.*

*Wanting to live, wanting to die... To the extent that he wanted the nothingness of death, it was certainly only a reaction to the fact that at present he couldn't get anything else he wanted. (p. 52)*

In my experience, Jeffrey's response is the norm. As unimaginable as one's current circumstances may be, overwhelmingly people with new-onset disabilities of both body and brain look for ways to reconstitute their fragmented sense of self and go on.

But what about the rare person whose desire to die is fixed, repeated and persistent? In those cases the phenomena of shifting identities leads to some of the thorniest ethical dilemmas in rehabilitative medicine. It's as if “old normal” is at one end of a tightrope, and “new normal” lies at the other end. Injury has shoved patients off the platform and onto the wire, but not everyone is willing to inch across. Occasionally a person says they'd rather end it now and jump.





Traditional notions of autonomy in Western clinical medical ethics support a competent adult's right to refuse medical treatment even if it will result in their death. The dilemma is the relationship between an identity in flux and decision-making capacity. People in

liminal states have lost their bearings, their sense of self

may be fragmented by the loss of their identity-defining roles and characteristics. The person might be legally competent, but I've come to believe notions of autonomy that aren't sensitive to the terror and panic inspired by waking up in a liminal state are incomplete, because this is not a position of strength from which to exercise "autonomy." Assessing a desire to die after a new life-altering disability is tricky business, because most wishes are like Jeffrey's: born of anguish and momentary despair, counterbalanced with questions about the future, expressed hopes, and emerging moments of pleasure again.

And even when the desire to die is consistent, what if we have reason to believe that the "future" person would make different choices than the pre-accident person? The available empiric data would favor that perspective—more often than not, people do change their minds about what is acceptable to them once they have lived with disability. Life and death decision-making is even more precarious when a surrogate decision-maker is involved, as was the case with 17 year old Jeffrey. Surrogates try to "make decisions as they believe the person would if they could." But what if that person is somehow fundamentally altered by their disability? What if the person might regain the capacity to speak on his or her own behalf if we just wait long enough?

It's hard to say exactly at what point after an injury like Jeffrey's a person has enough understanding of their circumstances and the full range of options (including what life with disability is really like) that providers can feel confident their refusal of life-sustaining treatment is "informed." Probably not in the Emergency Room, or the first few days of care in the ICU, but beyond that decision making capacity must be assessed on a case-by-case basis with respect for the fact it's not a simple, binary, all-or-none question; it's a matter of degree. One thing that is clear to me though—the sooner the person can regain control over as many variables of their lives as possible, the faster this capacity will return. That means providing an accessible call light and answering it promptly, restoring communication, using assistive technology to allow the person the ability to control lights, radio, TV channels and access to phone or computer systems, providing foods and clothing that the person requests, and on and on.

July 11

*Over the days, however few, I had come to understand that a new Jeffrey was being born. I had become the father of two Jeffs. Both births had been violent.*

*On November 26, 1980, Jeff had come to us by cesarean section... The second birth involved less blood but a longer labor. The water had broken a week ago. Now he lay in his electrified, telemetric bed—his high-tech womb- surrounded by machines, plastic snakes, odd noises. Without moving an inch, Jeffrey was being reconstituted into a new being, one who might or might not be able to thrive in his new environment...*

*That isn't Jeffrey in there. That is a chrysalis. (pp. 148-9)*

The transition between identity as an able-bodied person and an identity that incorporates radical body change does not happen overnight, nor easily. Patients like Jeffrey have to go through a reorientation process to ground their new sense of self, and that process is different for each person. Nonetheless, there are some common experiences.

Psychologist Nancy Kerr has described a five stage model of adjustment to disability: First there is shock and lack of comprehension, then expectancy of recovery to "the way I was before," and then a period of acute distress, or a readiness to "give up" (which can include thoughts of suicide) as the patient mourns. Stage four is defense, when the person develops interest in learning about new life possibilities and barriers are acknowledged, circumvented or conquered, and stage five is adjustment—when the person has incorporated disability into identity, and no longer considers it as a barrier to be fought.

As with Elizabeth Kubler-Ross's stage theory for dying and grieving, these stages aren't discrete and finite, but on a continuum and variably experienced. Such theories can't capture the reality of the experience for all people, but they do provide some normative guidance and perspective.

While patients like Jeffrey discover that some possibilities are closed to them, they also find that many others are not, and some may be possible in an altered way. Jeffrey will still be able to communicate, read, learn, love, express and experience a full range of emotions, enjoy the sun and cool breeze on his face, control where he goes and what he chooses to invest his energies in. He'll be able to enjoy the taste of food, music and art, live on his own with assistance, work, marry and possibly someday even be a parent.

There are other experiences that will be available to Jeffrey because of his injury. Though not of his choosing, he will live life at a slower pace, learn to plan ahead, and be more attuned to his relationships with others. He will learn about interdependency and the very clear communication required to get his care needs met. He will likely develop a heightened sensitivity and empathy for others who are disabled, stigmatized, disenfranchised and discounted by others. He may become an advocate for social justice. These are skills and values that many of my patients with disabilities tell me give their lives great meaning, and they would not want to lose—even if they could be cured of their disabilities.



*Between Jeff the baby and Jeff the quadriplegic, it was the quad who exhibited the greater capacity for self-determination.*  
(p. 149)

It takes a long time to develop a solid new sense of self; some data suggests it can take up to two to five years after an extensive disability such as a spinal cord injury.

As Jeffrey moves through each stage of the continuum of care—acute care, inpatient rehabilitation, outpatient rehabilitation, and finally to his new “stable state”—he will become a little less liminal. He will begin to know his altered body, his boundaries, his possibilities. He will begin to make plans that focus not just on “getting by” but on the meat of life: his social roles, his relationships, his dreams.

This evolution does not happen in a vacuum. While his personality and coping style will play an important role, so will the environment. The reaction of his family and friends will be critical. Will they embrace him? Avoid him? Pity him? Subtly express concerns about his “being a burden?” The support of the acute care team and a skilled rehabilitation team will also be invaluable, though it pales in comparison to his social networks. In recent years the lengths of stay for patients in inpatient rehabilitation units have become very constrained. While the “medical needs” can often be managed in the space of a few weeks to a month or two, patients like Jeffrey are losing the benefit of the therapeutic milieu—an environment that is set up to

*“[W]hat if we have reason to believe that the ‘future’ person would make different choices than the pre-accident person? The available empiric data would favor that perspective—more often than not, people do change their minds about what is acceptable to them once they have lived with disability.”*

meet his needs, staff who understand disability and a community of patients who are having comparable experiences. Meeting others who have lived with similar disabilities for much longer can also be very helpful for some.

The broader community’s response is another layer that can help or hinder the transformation process. While the disability civil rights movement has resulted in substantial changes in both the built environment and social attitudes, we are still far from a world where people with disabilities are seamlessly incorporated into the fabric of society. Barriers and prejudice can chip away at a fragile fledgling identity, and result in internalization of despair and feelings of devaluation.

One way we can help empower patients to regain their self-efficacy or locus of control is recommended by psychiatrist Jodi Halpern. Therapeutic empathy is the ability to engage with the patient in a partnership and resonate with

his/her experience while also maintaining a sense of one’s emotions as distinct from those of the patient’s. One of the most important functions of health care providers may be to engender curiosity and help patients imagine different possibilities. Negotiating time-limited trials of treatment, with frequent nodal points for re-evaluation and re-negotiation, may be one way of helping a newly disabled person regain the ability to be self-determining.

It is only through the multiple acts of expressing will, desires, likes and dislikes, needs and priorities that one’s identity becomes reconstituted. My sense is that the liminal state diminishes when patients are no longer passive, or the subjects of someone else’s story, but have regained authorship of their own life’s narrative.

#### AFTERMATH: JEFFREY RESCUES HIMSELF

Today Jeff is most certainly the author of his own life. Out of respect for that authorship, I called Jeffrey to ask him about life in the seven years since his accident, and I invited him to read and comment on a draft of this article. Jeff had some very strong reactions and disagreed with me in several places, which I find enormously valuable. His corrections have been incorporated into the text, and in order to preserve his “voice” I include many of his comments (noted in parentheses and/or italics) below. Some of the following information is also from his father’s website, “Paralysis Sucks: Spinal Cord Injury and how to live with it” ([www.gallilaw.com/jeffhome.htm](http://www.gallilaw.com/jeffhome.htm)).

After his acute care hospitalization, Jeff spent three months at two different inpatient rehab units, then returned to the family home with some home modifications. Eighteen months after his injury he returned to high school, where he became a member of National Honor Society (*yeah, but not for academic reasons. My grades sucked*), and hammered his SATs with scores of 1520, graduating in June 2000 (*yeah, but it’s a BS test. I don’t think highly of it*).

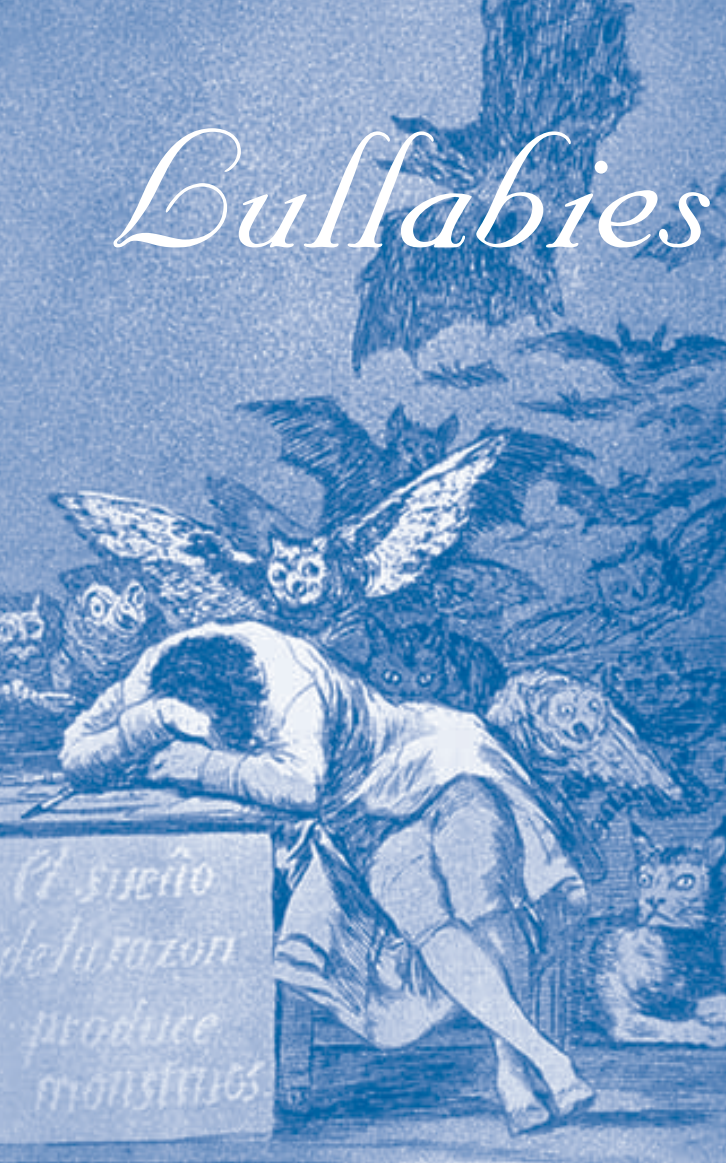
In the fall of 2000, he started college at the University of Rhode Island. He elected to continue living at home due to the complexities of coordinating his care needs. (He has a nurse with him about 18 hours a day.) Though not all the buildings at the university are fully accessible, the school has been very accommodating and ensures that Jeffrey can take the classes he desires. He now has a phrenic nerve pacer which means that he is off the ventilator during the day, and on it only at night. It takes him about three hours to get ready for school; thus he is taking only two classes a semester and hasn’t yet decided on a major (*It’s mostly because I’m not a very dedicated student*). 3

With a wireless microphone and voice recognition software (*more so the Quadjoy mouse*) he is able to surf the Net, listen to music, do homework, email and operate his television.

When asked about what might have been helpful in the first few weeks after his injury, number one on his list was better quality sleep. He remembers going days without sleeping and feeling pure emotional exhaustion—although not physical exhaustion, which worried him a little at first.

*(“The challenge of new-onset disability” continued on page 6)*

# Lullabies



"The Sleep of Reason Produces Monsters," from *Caprichos* (1799) by Francisco Goya.

Aviva Goldberg, MD

Walk through a children's hospital late at night and you will see three types of people sleeping. The first are the patients, sick children attached to monitors and oxygen resting in beds and cribs. Next you'll see the residents, so-called because they actually seem to live in the hospital. In sparsely furnished call rooms, they catch power naps on sagging twin beds between the inevitable shrieks of the beeper.

Then there are the parents, trying to fit themselves into the awkward space between the sleeping doctors and small patients. They twist their bodies on recliners beside their children's beds, toss on couches in the intensive care waiting room, sometimes even sleep in cafeteria chairs, heads slouched over tabletops. Some of the new ones can't sleep at all; every beep of a monitor rouses them like a modern-day water torture. The veterans sleep a little more soundly. Vital sign checks every four hours do not wake them, nor are they disturbed by the hum of a floor buffer.

They have trained themselves to sleep through almost anything—but they always, always wake to their own child's cry.

Parents with a sick child are in a nebulous emotional space as well. They doggedly remove themselves from their homes, jobs and often other children to set up camp in the hospital, but on arrival many feel helpless and useless. "Am I needed here?" they wonder, as basic childcare tasks seem irrelevant compared to the massive technology being directed at their children. They can't play doctor,

*"No matter how child- or family-friendly hospitals become, or how long a child stays, the hospital is never home."*

they aren't the patient, and it's hard to see how to parent in this place, so they struggle to find their role. "Even if I'm not needed, how can I be anywhere else?"

Parents of hospitalized children can't take away their child's illness. What they can do, and what we must help them do, is remain a center of calm and familiarity for their child, even as their own worlds are spinning out of control. Negotiating that role in the hospital can be difficult, and I am always humbled by parents who rise to the occasion. During my residency, I met the parents of a girl with liver cancer who held a vigil at their daughter's bedside for 4 months, neither of them missing more than a few days of work the entire time. They re-arranged work shifts, spelled each other off at the bedside, and made sure that their daughter was never alone. Their hurried exchanges twice a day reminded me of nurses at change-over: a brief summary of the day's events, a hug and a promise to see each other at the next shift change. Despite what must have been overwhelming stress and fatigue, they always had a smile and a kind word for the medical staff, and they always had enough energy to sing with their daughter, her favorite activity.

Many hospitals have responded to the need for family involvement by allowing parents to stay with their children 24/7, encouraging them to take over "normal" care like bathing and diapering, and allowing young siblings to visit. But no matter how child- or family-friendly hospitals become, or how long a child stays, the hospital is never home. Parents are the bridge between the world of the hospital and the home their child longs to return to, and the job of kissing boo-boos and singing lullabies has heightened significance when it's in response to IV pokes and the need to drown out beeping monitors. Parents' role in the lives of their children changes in the hospital, but we must constantly remind them, and ourselves, that there is always a place for them here.

# Healing as Transgression of Liminal Space:

## *The Country of the Well and the Country of the Ill*

Laurie Zoloth, PhD

I watch all movies (annoyingly enough, will add my family) as a bioethicist on the hunt for meaning. I watched *The Motorcycle Diaries* in just this way, attentive to the way the film pivots around the moment of transgression at its core, when the pampered medical students make a journey into the marginal lives of impoverished lepers. As student doctors they are white coated, with work to do. Yet their experience as travelers dislocated from home and social class has already taught them about the value of solidarity. They watch the river flow between the camp of the doctors and the camp of the ill and ask: *what is the difference between us?*

Precisely. For at its best, to give care is to immerse oneself in the river that borders the terrain of illness. It is, of course, the possibility of death, that cold river that no one has ever crossed, and the film climaxes when the student who will later become Che Guevara enacts a remarkable deepening of his praxis of transgressive treatment. He swims the unswimmable river between the two camps, nearly drowning (for he is an asthmatic, always frail), drawing a line across the river's margin with the facticity of his own wounded body. And I turn to my family and say, "This is what healing is supposed to risk—this is the work of the real doctor and nurse, to swim right over there."

To work as a nurse or doctor is to see the candescence of the ill and to understand that they are neighbors. Health care providers are persons with papers allowing them to pass from the country of the well to the country of the ill. Like all sojourners, one learns the language, and

for the length of the journey one is a participant in the poverty, indignity and courage of the ill. It is a curious thing, this liminality of caregivers: one is both an advocate and a refugee. Crossing the river in one direction, one brings news of the world of the well, the frame of reference, the small solid houses of ordinal life. Crossing the river the other way, one brings news of the ill, saying, "Listen to the narrative of the one you cannot hear, allow this story to change your theoretical claim." While one is not really a citizen of the country of the ill, one is not fully at home in the country of the well either.

I began to write this small story for ATRIUM to say merely that the desperate passion (meaning love, meaning sincerity, meaning intensity) of medicine and nursing is like that swim across the river and back, day after day. The river is truly chancy, both in the real, contagion sense and in the existential sense. I wanted only to use this narrative, a good cross-over in humanities and bioethics, to illustrate, well, how to cross over with grace and courage, and how one could think of the broaching of the river by health care providers as the core ethical task of our work.

Then came the Hurricane Katrina, and talk of water and the ill became more than a metaphor; we needed to wade across quite literal floods of water and equally real floods of despair in the suddenly revealed country of need. In response, this winter colleague Joshua Hauser and I will offer a seminar called "Katrina and its Complexities" as one of the MH&B Program's Humanities seminars, as a way to think about all of the ways that we live in the two countries, and the rivers between.







Jeffrey Galli with his sister Sarah

*("The challenge of new-onset disability" continued from page 4)*

He also remembers very long stretches of boredom. During the first week after his injury Jeffrey says he remembers spending a large percentage of his time ruminating about his injury, but after that week the balance began to shift fairly quickly in the direction of greater time focused on more mundane things. In responding to the analogy of the "old normal" at one end of a tightrope, and "new normal" at the other end, Jeff said: *Actually, it's more like, even psychologically, the person suddenly finds themselves on the new platform, and the cable has been cut. The choice is about whether or not it matters overwhelmingly.*

In talking about the transition process, Jeffrey described two types of adaptations, the emotional and the practical. For him, the emotional was "huge" and most intense in the first two weeks after his injury, but it dropped off rather quickly—he says it fluctuated for a little while after that, but wasn't really "huge" again. He says it continued for years after that, but after some point in the first year, the continuation was of very minor adjustments, eventually only really noticed on reflection.

Jeffrey says the practical adaptations never end but now he is more comfortable asking for simple things that he can't do for himself and sees it as the reality of his life. He also feels a strong sense of self-determination—when it comes to his life, he is the "final authority."

Jeffrey told me his father's book has been incredibly helpful to him and provides a "structure for his memories" which were quite distorted, particularly for that first week. Though he is glad to be alive, he also expressed pride that his parents took the decisions regarding his medical care as seriously as they did and considered the full range of possibilities.

Jeff had this to say about the questions raised in my manuscript about the locus of identity: *"My opinion is that a large part of someone's personality, or 'personhood', or identity, is shaped by their physical abilities and how they apply them. It's not all in the mind and expressed verbally or absent action; so if someone's lost the action, they've lost some part of their identity."*

He was critical of my comment that shortened inpatient stays in acute care deprive patients of the hospital's "therapeutic milieu"—*"Sorry, overrated. The milieu*

*experience does not reveal much more after a month or two of rehab, on top of acute care."*—and unimpressed with the concept of "therapeutic empathy," the ability to resonate with the patient's experience while also maintaining a sense of one's emotions as distinct—*"As long as it's only one way. It doesn't really work for everyone."*

Finally, I close with Jeffrey's response to my passage on what disability brings (as opposed to what it takes away). My perspective is based on the reactions of many patients, but this is a welcome reminder that we can never presume to know how any particular individual will experience life.

There are other experiences that will be available to Jeffrey because of his injury. He will live life at a slower pace [1], learn to plan ahead [2], and be more attuned to his relationships with others [3]. He will learn about interdependency [4] and how one must be very clear in communicating to get his care needs met [5]. He will likely develop a heightened sensitivity and empathy for others who are also disabled, stigmatized, disenfranchised and discounted by others. He may become an advocate for social justice [6]. These are skills and values that many of my patients with disabilities tell me give their lives great meaning, and they would not want to lose—even if they could be cured of their disabilities.

1. *This was forced on me, it did not become "available". I am unable to refuse it.*
2. *...about completely distracting matters, like breathing, which must now be planned, and restricts the scope of any larger plans. I guess I'm planning more, but why's that good when I'm planning about less?*
3. *and forced into relationships that are dysfunctional and best avoided (like with racists who can't be told to shut the fuck up because the relationship must not be allowed to end), or are frustratingly over-dependent (ask my parents).*
4. *Not learn about, but, again, forced to be dependent. And it's not very "inter-".*
5. *One must rely on communicating one's medical needs, like breathing, when one can't take care of them oneself. Why is that better?*
6. *As long as I don't have to leave the house much, because I kinda, sorta, can't.*

*Sorry if all that was harsh, but, well...sorry.*

<sup>1</sup> Galli R. *Rescuing Jeffrey*. Chapel Hill, North Carolina: Algonquin Books, 2000. Also see <http://www.gallilaw.com/jefflife.htm>

<sup>2</sup> Gill, CJ. Divided Understandings: The Social Experience of Disability, Chapter 13 in *Handbook of Disability Studies*, Albrecht GL, Seelman KD, Bury M (eds); Thousand Oaks, California: Sage Publications, 2001.

<sup>3</sup> Patterson DR, Miller-Perrin D, McCormick TR, Hudson LD. "When Life Support is Questioned Early in the Care of Patients with Cervical-Level Quadriplegia." *NEJM* 1993; 328 (7): 506-9.

*Acknowledgment: Thanks to Katie Watson for her writing and editorial skills, her active engagement and her generosity of spirit.*





# Real Toads in Imaginary Gardens

Kathryn Montgomery, PhD

Fiction seems to be the antithesis of what medical education is about: hard facts. Short stories and novels may be concerned with real toads (as Marianne Moore once claimed about poetry), or at least toads very like ones we're familiar with, but the events described never happened, the characters are imaginary, and the places where these lies unfold often do not exist. Even William Carlos Williams, a general practitioner specializing in pediatrics during the Depression whose story of a pediatric house call is often read as reportage, may have invented every word of it. Yet readers who know that "The Use of Force" is a short story are expected to accept as true the doctor-narrator's rather defensive account of a child's violent resistance to diagnosis and his overpowering response. The truth of fiction is not undercut by its factitiousness.

Fiction creates a liminal realm that is true but not factual. Fabricated, contingent, phantasmagoric but undeniably real, the liminality of fiction is both the source of its power and the reason it is disregarded. A story's paradoxically unreal reality is exactly where its value lies, especially for medical education. Human experience and the representation of meaning are essential equipment for a physician, yet there are few patients in medical textbooks. Crammed with anatomical structures, organ systems, symptoms, syndromes, diseases, and therapies, the astronomically expensive tomes that dominate the pre-clinical years lack representations of the very people practicing physicians must deal with: whole people whose lives are interrupted and sometimes entirely altered by illness. Short stories, poems, and drama fill that void.

Readers who deeply value the solidity of science and its invariant account of the world can find the idea of truth in fiction disconcerting, but invented stories invite our imaginative participation and, as Wayne Booth's *The Company We Keep* taught us, compel our ethical judgment. We emerge from fiction's made-up reality slightly different, more widely experienced people who have responded to and learned from imagined events and people.

Sometimes fiction is itself about liminality, which in its broad betwixt-and-between sense is a part of the human predicament. Even though literary realism is the mode most widely used in medical education, I've often assigned Franz Kafka's *The Metamorphosis* in required ethics courses. Its main character, Gregor Samsa, wakes



one morning feeling not quite himself and discovers that he has acquired the little legs and the exoskeleton of a cockroach. No physician will ever confront these symptoms, yet Gregor's gradual acquisition of roachly attributes—the joy of his discovery that the old lump of cheese he would have rejected before is now gloriously delicious, the horror and loathing his appearance provokes in his mother and father—all resemble the transformation that, at worst, is experienced by newly disabled people and the dying. Even his devoted sister comes to regard him as an object and begins to neglect him. When eventually she declares he is no longer the person who was her brother, his death is immanent. Gregor's story isn't factual, you can't look up his malady in a pathophysiology text—yet it conveys an essential truth that many factual accounts of illness and decline cannot.

Good stories lack the replicability of fact. Because they can mean different things to different readers and reveal new facets each time they are read, the fiction-averse find them even more suspect. *The Metamorphosis* is a good example: a psychological account of a family drama, it has also been read as an allegory of Jewish life in Prague a century ago, or the story of alienation inherent in modern capitalist or urban life. But such multiplicity, as historiographers have recognized, is the truth of human experience: multiply meaningful, hard to pin down in a phrase, most nearly captured in narrative, and resistant to factual or statistical summary.

Despite its factitiousness, then, fiction is truth—or, what comes to the same thing, it represents it. It is true to human experience both in its details and in its multiplicative representation of meaning. Science, meanwhile, with all its considerable strength, has not a thing to say about either.

Williams, who besides being a small-town physician at the beginning of medical specialization arguably was the most influential twentieth-century American poet, captured this most powerfully near the end of Book I of *Asphodel*.

*It is difficult  
to get the news from poems  
yet men die miserably every day  
for lack  
of what is found there.*

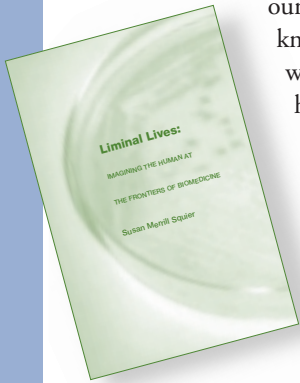
You could look it up. It's a poem.

## A Conversation with Susan Squier

Tod Chambers, PhD

**Tod Chambers:** In your book *Liminal Lives*, you draw on the notion of liminality anthropologist Victor Turner popularized in the sixties, but you find some essential features of his notion wanting in relation to our contemporary lives. Could you explain why you found it necessary to rethink Turner's original formulation?

**Susan Squier:** When I was rereading Turner, I had just participated in a workshop on what Robert Proctor calls "agnatology"—the construction of ignorance, or the way our conceptual frames limit what we can know. And with that concept in mind I was struck by the limits Turner set on his concept of liminality. He defined it as a set of fluid cultural negotiations that enable people to manage what are essentially species typical, ineluctable, biological experiences of transition: as he put it, "the movement of a man through his lifetime, from a fixed placental placement within his mother's womb to his death and ultimate fixed point of his tombstone and final containment in his grave as a dead organism". Turner emphasizes the unchanging nature of human biology with his spatial metaphor, moving us from a fixed point in the womb to a fixed grave. It's a rhetorically and conceptually powerful metaphor. But time has moved on since Turner's use of it. Now, in the time of in vitro fertilization, organ transplantation, inter-species cell and tissue transplantation, stem cell research, 'embryo adoption,' and surrogacy, it didn't seem to reflect the actual biology of human life. Even that initial 'placental placement' is subject to negotiations that aren't only cultural: we might call them biocultural. So I started thinking about how that notion of liminality—of being on a threshold between one state and another—might be helpful as a way of thinking about our biomedical practices as well. And the ways that we are reshaping our very biology, medically and culturally, just jumped out at me. Of course my extension of liminality is not a critique of Turner, so much as an extension of his productive term, a pushing on its boundaries in the name of understanding that our biology, too, is increasingly a cultural production. The extension of Turner's formulation seemed to capture something essential about our current focus on reconceptualizing, re-engineering if you will, nearly every aspect of the human lifespan, so that we have changed the way we conceive and give birth, as well as the way we age and die. The recent case of Terry Schiavo, which came after the book was published, seems to me to provide another example of the way we are bioculturally responding to what used to be a fixed fact: that we all must die.



**TC:** Do you think that scholars of bioethics were unable to attend to the larger cultural features of the Schiavo case? That they were unable to see that this was a type of "moral panic" in response to a reshaping of our biology?

**SS:** Your comment captures something that has frustrated me for a while about bioethics: its narrow (or shall we say disciplinarily technical) focus. Paul Lauritzen recently published a fascinating essay in the Hastings Center Report that spoke to this question (and that drew on work that I did with Cathy Waldby on stem cell research). Lauritzen made the case for a broadening of bioethics to include art and literature, which I agree with, but to my way of thinking Lauritzen himself doesn't go far enough in his argument. His definition of bioethics is constrained by a focus on species-typical human behavior, neither accepting the possibility that human morality could be improved by widening its commitments beyond the human species, nor accepting the possibility that the notion of a 'normal' human morphology and lifespan could itself be too limiting. My work in disability studies, and my current project in animal husbandry and human-animal relations really makes me push Lauritzen's notion (which he borrows from Martha Nussbaum) that ethics is necessarily centered in "the notion of natural human capacities that give rise to basic human rights." I believe a time will come when bioethicists look back on this as a very narrow, blinkered notion, both in its construction of the field as dealing only with "natural human capacities" and in the notion that bioethics deals with exclusively human rights. But this is probably farther than many bioethicists are willing to go today, particularly with the cautionary case of Peter Singer confounding our responses to animal rights, disability rights, and the scope of bioethics.

**TC:** This reminds me that the only satisfying definition I have thought of for a human being is "The animal that refuses to be an animal." Your book explores the fear that humans have of liminal beings that seem to challenge the human/animal divide. I was particularly intrigued by the connection that you found between hybridity and race. How did you come upon this?

**SS:** Well, first of all the whole range of imaginative literature (children's and adult; canonized and popular culture) raises this question powerfully: from Charles Kingsley's tale of the blackened chimney sweep who becomes an elf in *The Water Babies* through H.G. Wells' *The Island of Doctor Moreau*, with its tropical island of engineered "beast people," to Maureen Duffy's novel of the same name about a human-gorilla hybrid named Gor who leads an uprising. Each of those works of fiction uses racialized terms to address issues of hybridity in terms that are redolent of anxiety as well as powerful social critique. In addition, I'd read nearly the entire run of *Amazing Stories*, the

science-fiction magazine founded by Hugo von Gernsback in the '20s, and the theme of ominous, racially-charged hybrid creatures figures there as well. So when I started reading the Warnock Report, and then went from there to the "Muller Report" (the Final Report of the Human Embryo Research Panel), the racialized, emotionally-charged, anxiety-laden language just jumped out at me. It was a real shift from "bureaucratese," suggestive of some excessive psychic investment in the issue.

*TC: My final question is about method. I think your new book is important not only for the subject matter but also because you try to delineate a particular method for literature and science. How has your own approach to this discipline changed?*

**SS:** At the beginning, I was very influenced by the important work done in science studies by historians and philosophers of science, as well as anthropologists and sociologists who have worked on the cultures of science. Over time, however, I realized that none of them took literature seriously as an object of investigation, though many of them had annexed the tools of literary scholars such as attention

to metaphor, image, and tone. As I thought about this, I realized that it reflected a resistance to acknowledging the importance of literature: to exploring the cultural work that literature does, and how it shapes as well as reflects the course of scientific practice. I wondered what interests were served by this resistance to considering the force of literature, and I began to consider it an occasion of agnology—the production of ignorance—that literature was kept outside the focus of the discussion in science studies. Once I began investigating the literary context of scientific practices—doing a literary ethnography of the context of science if you will—I found in literary texts far more latitude to debate, explore and address the anxieties and desires raised by scientific practices than appeared in either scientific or policy discussions. Exploration of the literary precedents and contemporary context for scientific innovations revealed a much more messy, contested, ambiguous picture than was available to scholars focusing only on the philosophical, historical and sociological aspects of science. It also challenged the hierarchy (unspoken, but powerfully in force) that put fact above fiction, rather than realizing that the two are intertwined in our cultural imaginary and in the practices that follow from it.

## PASCAL'S WAGER 2.0

Katie Watson, JD

Some of the most vexing issues in medical ethics are fueled by liminality—women's bellies swelling beyond neat categories of "person" or "tissue," adolescents dancing on the threshold between childhood and adulthood, unconscious people who seem neither fully alive nor fully dead—and our approach typically involves reducing liminal distress by creating new categories: pre- and post-viability fetuses, pediatric assent, PVS.

Cryonics runs counter to the impulse to escape the discomfort of liminality. Instead, it works to replace a rather fixed category, death, with a new liminal state called "suspension." The Cryonics Institute (CI) is one of two facilities in the country where people submerge their corpses in liquid nitrogen in hopes of being "reanimated" in the future. Located outside of Detroit, CI maintains 69 bodies in encased in sleeping bags frozen in what sci-fi author and CI member James Halperin calls "the hopeful ice."

"Suspension" at CI's glitzy rival Alcor in Scottsdale, Arizona costs \$120,000, almost four times more than CI's \$28,000 price tag, making CI feel classically Midwestern—it's the working man's cryonics. Unlike Alcor, CI doesn't have regularly scheduled tours, but my curiosity about why people would do such a thing compelled me to ask CI permission to visit.

For purposes of this meeting I set aside the scientific question of whether "cryonic suspension" could work. The

"If you wait long enough, cryonic suspension may be offered by HMOs and may even be covered by Medicare. We hope that you and everyone in your family live that long. But that may not be the case... Don't risk your life— or theirs. Make a choice. The only reasonable choice: for life. Don't throw away your future. Sign up with a cryonics organization." [www.cryonics.org](http://www.cryonics.org)

fact that the bylaws of the Society for Cryobiology (a professional group for scientists studying biological systems in low temperatures) forbids membership to anyone who believes in, advocates or practices cryonics is enough for my operating assumption to be "no." To me, the more interesting question is whether post-mortem gambles require any proof of efficacy at all. As 17th-century mathematician and scientist Blaise Pascal wrote, a person who can't prove God exists has two choices: if you believe in God and you're wrong, you rot like you thought you might, but if you don't believe and you're wrong, you lose eternal life. Therefore, he argued, the rational thing to do is bet on the existence of God.

Perhaps people who buy suspension contracts are just upping the ante on Pascal's wager. CI has over 500 members who know there's no guarantee that nanotechnology will advance to the point where it can repair cellular freezing damage, or that future medicine will be able to reverse the effect of whatever killed them.



# Cryonic considerations

But given a state of uncertainty, cryonicists believe the best bet is freezing oneself just in case. Perhaps it's just a sign of the times that the wager is on science, not God.

So five hours after leaving Northwestern, I followed my instructions to turn at the now ominous-sounding "Still Meadows Condominiums" into a dull industrial office park that's home to CI's tidy building. I was greeted by CI President Ben Best, a former taxi driver and computer programmer, who had agreed to give me an hour of his time. An awkward, pale man in his 50s wearing large square glasses, a flannel shirt and key rings clipped to his jeans, he struck me as a landlord single women would instinctively avoid.

"Future medicine should be able to stop, reverse and rejuvenate all aging processes. Future medicine should be able to keep everyone perpetually young and healthy." [www.benbest.com](http://www.benbest.com)

Mr. Best was alone in the small facility. He led me through CI's "no frills" environment (beige industrial carpet, cheap paneling and a joke poster of serious-looking cryonicists holding lab equipment titled "American Gothic of Medicine") to its conference room, which features happy photos of the frozen in warmer times. In his Internet writings Mr. Best comes across as confident and articulate; his personal website is full of bluster and intellectual gamesmanship. So I was surprised that in person he seemed vulnerable, fidgety and hesitant. I expected a salesman, but he gave short, guarded answers without hubris.

In an era of medical ethicists' insistence that "good death" isn't an oxymoron, Mr. Best says old age is a disease and accepting a "natural" lifespan is suicidal. CI's website says dying is selfish (society would rather have Shakespeare than an empty parking spot), and that the currently living have as much of a "right to life" as the unborn. ("Make your choice—for life.") We just have to freeze ourselves until science catches up with this philosophy, which Mr. Best believes will occur in less than fifty years.

Mr. Best wears tags around his neck and wrist indicating he is a whole body donor under the Uniform Anatomical Gift Act because the UAGA provides a vehicle for cryonics facilities to "own" the body of a member when the organization has been named the recipient of a whole body donation. Cryonicists have also formed a 501(c)(3) religion called "The Society for Venturism," the main tenet of which is avoidance of autopsy. CI's savvy website encourages members to tell their doctors and future funeral homes of their wishes, offers templates for adding cryonics instructions to Durable Powers of Attorney, suggests terminally ill members transfer to a "cooperating hospice" CI has found in Michigan, and offers strategies for disclosing one's status as a cryonicist to friends and family that reads like a helpful "coming out" guide. Instead of the "good death," the goal of this work is a "good suspension."

Mr. Best explained that CI froze its first body in 1967, but it flew under the regulatory radar until 2003 because its activities didn't fit any established legal category—it wasn't a cemetery, mortuary, or medical research facility. (The law doesn't know how to react to liminal activities either.) "Before we were free people doing business in a free country," Mr. Best said, explaining that there wasn't any local reaction to CI's presence until Alcor made headlines by freezing the severed head of baseball legend Ted Williams. That affair prompted Michigan authorities to issue a cease-and-desist order, threatening to close CI.

That's the other big difference between the two facilities—most of Alcor's "patients" are "neurosuspended" (head-only freezing) whereas all of CI's "patients" are intact. CI thinks neurosuspension is bad public relations ("Tissue viability isn't the issue here—social viability is.") but it has no scientific or philosophical objection to the process, because "by the time freezing damage becomes reversible it should be feasible to regenerate a new body for the head, or else transplant the brain to a cloned, brainless genetic twin," the CI website says.

When Mr. Best showed me around the storage room where the bodies are kept, I confess the clean concrete floor and giant white tanks reminded me of a microbrewery. As we walked, he told me that after about six months of negotiation, Michigan authorities rescinded the cease-and-desist order and licensed CI as a cemetery. It doesn't really function as one, though. No one leaves flowers, no plaque memorializes who is frozen in which "cryostat," and although the website says relatives are welcome to visit, Mr. Best seemed surprised when I asked whether anyone did. (No.) What impact does this have on the grieving process of the deceased's family?

I was also upset to learn some were frozen without their explicit consent. This fact affects the gender skew—according to Mr. Best, although CI membership is approximately 75% male, members' choices to freeze their predeceased wives and mothers means about 50% of the

"Many people have migrated from virtual stone-age conditions to modern industrialized countries and have thrived. Cryonicists could be like a third-world immigrant community in the world of the future." [www.benbest.com](http://www.benbest.com)

frozen are women. However, this is consistent with the tradition of next-of-kin choosing how to handle remains when the deceased left no instructions.

The language cryonicists use is rich and troubling. They refer to the dead as "patients" who "deanimated." So, for example, the CI website says its oldest "patient" has "survived" since 1967, "and that's a lot more than a lot of his contemporaries can say." Of course by "survived" they mean he died, then was "suspended." Cryonicists reject stop/start terminology, because they're creating a linguistic

liminal state too. "Let's not be confused by language... The dictionary definition of 'death' is permanent cessation of vital functions. Therefore, if someone is recovered, that means he wasn't 'really' dead in the first place, and we think that's the best way to look at it." The CI website explains that cryonics doesn't violate religious codes because they don't plan to "raise the dead," just heal the sick from their "cryo-coma." CI's website is incredibly sophisticated, thorough and well-written, but it can't dodge the word entirely: it also says the oldest "patient" was 100 and youngest was mid-20s "at time of death."

Before we left the storage room, Mr. Best gave me permission to photograph the cryonic vats. When I stepped next them for scale I reflexively smiled like a tourist in front of a ball of string, then laughed in embarrassment when I realized my mistake.

"I'm sorry! I just... don't know how to look next to a tank of bodies."

Mr. Best called out "Hold on!" and sprang out of the room. He returned with a copy of CI's newsletter "The Immortalist" and pointed to its cover photo of CI founder Robert Ettinger grinning in front of the tanks.

"See! It's okay to smile!"

And that's when it clicked: On his website Mr. Best writes, "Enthusiasm for living is the driving force behind the desire to live," but this was the first time in our meeting he seemed at all animated or spontaneous. He didn't seem passionate about living right now, much less for another thousand years. On his website he describes a difficult childhood that bred a sense of distrust, alienation and indignation that "has made love and intimacy difficult." "Ultimately I have always been preoccupied with survival. Despite my intense desires for an intimate relationship I was always terrified that such a relationship (and sex) would destroy any possibility I might have for the survival of my mind." A female friend posted this description of Mr. Best on his website: "His idea of intimacy sometimes scares away the very people he is attracted to. ...One thing he is making sure of is that he lives long enough to heal himself fully to appreciate the multidimensional aspects of living an authentic life." As Mr. Best writes, aging and death "mean the futile loss of my life's lessons." So perhaps the desire for life extension isn't necessarily borne from a lust for life; for some it's grounded in a feeling they need extra time to master life's intricacies.

The question is whether time will resolve these issues, or whether we'd all still be our fundamental selves in the future, resurrected only to have similar problems in different clothes. I felt tremendous relief the day I realized I could create a space between the pressure of the "to do" list and the finality of the trash can by labeling one of my hanging files "Good Intentions." I wonder if cryonics is just a more dramatic version of my folder, a place holder for all the things we think we'd do if we just had more time. That file contains my fantasy self, a woman who can swing dance, only shops at organic farmers' markets and has a clear understanding of how planes stay in the sky, but I know it's unlikely this fabulous lady will ever materialize,

largely because I don't want to do those things enough to, say, actually do them. Perhaps it's fair to assume that if I'm not running a soup kitchen, writing the great American novel and flossing by age eighty, it wasn't just time that stood in the way.

As Mr. Best walked me to the door I asked if he'd been interviewed by other ethicists.

"Yes. But most ethicists don't like life extension. Especially the advisor to the president."

"Leon Kass?"

"Yeah, him."

We stood in the July sunshine on CI's disturbingly lush lawn as I responded maybe that's because what CI is doing contradicts current trends in the bioethics community like recognizing the limits of technology, or accepting inevitable deaths. I said I worried cryonics both reflects and expands upon the unrealistic expectations medicine already endures.

"But you're not like scientists who test a hypothesis. Why do you say 'community'? Are you saying ethics is a field?"

Surprised at the turn in our conversation I said yes, even if we rarely achieve unanimity we have a professional organization and annual conferences. Mr. Best seemed perplexed.

"You mean you all just have different opinions? You don't all agree with Kass?" It hadn't occurred to me to ask how cryonicists view bioethics, though a moment before I'd felt free to lecture on bioethicists' view of cryonics. Who's the narcissist now?

On the drive home I pondered why the life-extension fantasy thrills some and repels others. My grandmother would have found it ridiculous—a month before my visit to CI she died at home, and after 94 years of generally good health her primary feeling seemed to be "enough already." There's also a sense in which we already have "extended life." Pascal did pretty well with the 39 years he lived, but in 1900 when the average life span was 48, I imagine 40 year olds dreamed of reaching 60, and now that it's 78 in the U.S., most 70 year olds dream of making it to 90. What does it mean that some of us want even more? That ours is a species of insatiable procrastinators? Or that life is good?

My concern that cryonics is just a financial scam is why I have such a negative reaction to Alcor's high prices and the marble-and-chrome facility depicted in their web photographs; it all feels very slick and "Vanilla Sky." But Mr. Best seemed more like a weary Trekkie than a snake oil salesman, CI felt like a small quirky subculture of dreamers looking for community, and ultimately, the amount purchasers of CI contracts spend (\$1,250 lifetime membership plus something like \$150 a year for a \$28,000 life insurance policy) might not be that different from what some active church-goers and synagogue members contribute to their institutions. So if cryonicists' investment brings them a sense of community and hope for life after death, who am I (or Pascal) to judge.



# Becoming an Ethical Physician

Joel Frader, MD

The transition from layperson to physician tests one's moral mettle, requiring the acquisition of massive amounts of information, the development of new patterns of sleep (or lack thereof) and ways of interacting with strangers (e.g., poking and prodding them). In the process of becoming a health care professional, one starts thinking about his or her role with others rather differently. To accomplish these changes successfully, one needs to learn new rules of behavior. That used to occur implicitly, by what medical sociologists and psychologists have called prolonged adult socialization. However, since the 1970s, most North American medical students have had some version of medical ethics taught to them, providing explicit notions of behavioral norms for the profession of medicine.

Medical school faculties have thus put in place a staged curriculum in modern medical morality, trying to connect philosophical theory to everyday medical etiquette. In the preclinical years, idealistic students hear about and discuss contemporary theories of medical ethics. Of course, all this happens in the abstract—just like anatomy or organ system physiology—without much opportunity to appreciate its application to actual patients, families, doctors or nurses.

Unfortunately, the ethics curriculum takes something of a back seat to the “hard science” as the content appears less “objective” and clear-cut than the material that ends up on nationally administered multiple choice tests. Thus the “hidden curriculum” telegraphs the “real” message to students: the value of an ethics curriculum pales in relation to boards-oriented accumulation of “facts,” you do not have to reflect seriously on your values or even change your behavior, you only have to sit through this material. That most clinicians neither remember nor use the details of neuroanatomy or biochemistry, but do conduct ethically sensitive interactions with patients and other members of the health care team, is somehow unpersuasive.

The undermining of the importance of ethics in professional life gets reinforced “on the wards” in the third and fourth years. When Northwestern students meet with ethics faculty to discuss the application of ethical principles to clinical realities, as they do on most of their major clinical rotations, many have forgotten the content or language of their ethics course. More importantly, they have seen that residents, attending physicians, and other clinicians (nurses, social workers, psychologists, etc.) often do not abide by the “moral rules.” The keystone of patient autonomy, informed consent, seems breached more often than not. Life on the wards teaches students that consent documents are bureaucratic forms the patients (or surrogates) need to sign so that work can get done, not guides to careful discussions with patients about alternatives and the patient's values or preferences. Students observe patient good subordinated to physician choice or convenience, rather than a carefully weighed consideration of the patient's best interests. Patients from different socioeconomic groups get different, not similar, care, a fact that raises questions for the attentive student about the meaning of social justice.

Over the course of medical school, students stop identifying with patients and begin identifying with and as doctors. The lay idealism most students bring to their new profession shifts toward what students and their mentors perceive as practical necessity. The work-a-day world of hospital and out-patient care wears away at students' personal morality and the message of the preclinical ethics courses. Students becoming doctors do not just forget the professional ethics taught in years one and two; in my experience, many come to view medical ethics with skepticism and contempt.

What goes wrong? Why the disconnection between ethics theory and practice in teaching hospitals? Why does idealism fade among medical recruits? I speculate that despite the maintenance of relatively high economic compensation, medical “professionals” see themselves less and less as members of a “true” profession and more as part of the class of highly skilled workers. Sociologically speaking, professionals claim and have a societal warrant for self-regulation of their occupational behavior. Many modern doctors, especially but by no means limited to trainees, feel they have become mere employees, subject to rules and whims of outsiders such as administrators, insurers, testing and licensing bodies. This loss of professional autonomy translates into a lack of meaningful control over patient care. Without the perception of professional autonomy, pride in profession becomes difficult, if not impossible, to sustain.

This interpretation suggests why the renewed “professionalism” movement within medicine will not succeed. The attempt to resurrect the ideals and ideology of medicine will fail unless it addresses what Marx called the relationship of the workers to the means of production. We should not expect medical students to adopt our ethics theory without a practical reality that allows medical workers to feel they actually have deep, connected, responsible roles in the lives of their patients. The modern hospital, if not entire medical care system, does not foster such feelings or connections. The real challenge for most of those transitioning from layperson to medical professional lies in finding ways to achieve meaningful connections with patients. Medical schools and teaching hospitals that hope to graduate ethically competent physicians must facilitate those relationships, not undermine them as they do now. While the economics of health care and the interests of medical faculties are not likely to facilitate the necessary wholesale change, I believe that patients and professionals alike would find the necessary investment worthwhile in the long run.

\* Many have looked at this issue over several decades. Some of the more recent relevant articles include: Caldicott CV, Faber-Langendoen, K. Deception, Discrimination, and Fear of Reprisal: Lessons in Ethics from Third-Year Medical Students. *Acad Med*; 2005; 80(9):866-873; Griffith CH, Wilson JF. The loss of student idealism in the third year clinical clerkships. *Eval Health Prof* 2001;24:61-71; Feudtner C, Christakis DA, Christakis NA. Do clinical clerks suffer ethical erosion? Student perceptions of their ethical environment and personal development. *Acad Med*;1994;69(8):670-679; Hafferty FW, Franks R. The hidden curriculum, ethics teaching, and the structure of medical education. *Acad Med* 1994;69(11):861-871; and Woloschuk W, Harasym PH, Temple W. Attitude change during medical school: a cohort study. *Med Ed* 2004;38:522-534.

*Acknowledgment: Thanks to Charles Bosk, PhD, a medical sociologist at the University of Pennsylvania, and Katie Watson JD of the Medical Humanities and Bioethics Program, Feinberg School of Medicine, for assistance with this piece.*





*Ranjan, 2005*

Touch therapies reach the heart of suffering through our common possession, the body. In *Strong Touch* (2005), photographer Suzette Bross explores complementary and alternative therapies on the margin of medicine, capturing the experience of clients and practitioners of Reiki, acupuncture, moxabustion, Thai massage, energy work, chiropractic and more. Bross's powerful photographs were exhibited last fall in the reading room of Northwestern's Galter Health Sciences Library, and can be seen at [www.suzettebross.com](http://www.suzettebross.com).

## Instincts and the Evitable

I agree with Dr. Frader that hidden and informal curriculum messages are always the most powerful, and that ultimately the best way to cultivate ethical and humane physicians is to create a health care system that fully embodies the values we want to convey. However, I still believe that students can temper their developing professional values through reflection, underscoring positive interactions and distancing themselves from the negative examples they might otherwise unconsciously absorb. To this end we have extended our learning community structure, with its routine reflective writing assignments and small-group discussions, throughout the four years of medical school. We aspire to nurture the students' better instincts, as demonstrated by the following essay Amit Patel wrote as an M3.

—Douglas Reifler, MD

## *Behind Open Doors*

*Reflective Essay for Patient, Physician & Society III,  
Amit Patel, Class of 2003*

I never thought that we would talk about the patients right outside of their rooms. When we did discuss the bleak future of my patient, I thought that we would at least close the door. However no attempt was made to close the thick wooden door, and no attempt was made to lower our voices to prevent Mrs. S from hearing us discuss her dismal prognosis. She had occluded her middle cerebral artery and would have considerable right-sided weakness for the rest of her life. The attending broke the news to her eloquently, but Mrs. S already knew because she had overheard our conversation outside of her room.

I wanted to close the door and I know that the other two students also wanted to close the door. None of us did because we were unsure if that was right. Situations that seem obviously wrong tend to get lost

in the realm of accepted behaviors of residents and attendings. The behaviors may not be morally right, but they are ok for practice. Because the doctors govern hospital morals, the patients are expected to accept these subtle lapses of conscience.

The art of treating patients is just that. It cannot be learned from a book, and it cannot be taught in a lecture. This knowledge is acquired through practice and by observing experienced clinicians. Like eager apprentices learning a sacred trade, medical students and residents search for more than correct analytic processing methodology. They want to be good doctors, not just adept at diagnosing. Treatment is more than making a diagnosis. Whether they realize it or not, the superiors teach through their actions. Taking the time to smile at the patient or even simply closing the door are acts of humanity that will be reproduced in the generation of physicians to come.

# Thoughts on Hanging with the Liminal

Alice Dreger PhD

Ask a certain kind of pediatric surgeon about the outcomes for his surgically “normalized” patients—the conjoined twins separated, the intersex kids made to look more like typical girls, the children with full smiles healed of cleft lips—and he’ll tell you how many weddings he’s been invited to.

Sex (masquerading as marriage) weaves in and out of surgical normalizing stories. The liminal newborn finds herself surrounded by adults buzzing with two inextricably intertwined fears: one, that the child will grow up never to have sex; the other, that she will grow up to have sex. The liminal newborn is a social emergency, and the impulse to cut her into a more comfortable category runs strong, because both these fates feel intolerable.

Seeing this, I find myself remembering the reaction to my brown-skinned-blue-eyed-nappy-haired brother in our otherwise white town. “We like Paul, but he’s not for our Gina.” Paul was five at the time. Why was Mrs. Pagnota thinking about my brother’s sex life?

Sex happens just past the edges, and perhaps that’s why anything else also stuck just past the edges gets lumped with sex. Like death (see Michele Foucault, or

Woody Allen). And oysters (a liminal thing to ingest if ever there was one). When Ellen Weissbrod was making a film about Lori and Reba Schappell, who are conjoined at a part of their faces, she showed some footage from the film to people on the street in New York. One woman’s reaction was simply this: “I mean... sex...”

Yes, sex, but why that? Why not, “I mean... showering”? Or, “I mean... sleep.”

Maybe it is that evolutionary history in each of our cells that makes the liminal about sex, such that the reaction to the liminal is really about survival. The non-liminal bits of us face the liminal bits of the other wondering whether this variation means heightened or reduced chances for continuation of the species/self. That tension between the sure thing and the bet that might be better.

“Liminal,” from “limen,” meaning “the threshold of a physiological or psychological response.” And this is how you know you’ve found someone in a liminal state: you feel in yourself that physiological and psychological response. The heightened visual sense, the whirring gears in your head, the lava flow in your gut. You know they are on the limit because you are suddenly there with them. All a-twitter.

Katie Watson, Editor. To respond publicly to anything in ATRIUM, email your comments to [k-watson@northwestern.edu](mailto:k-watson@northwestern.edu) for posting in the virtual discussion at [www.medschool.northwestern.edu/mhb/atrium/comments.html](http://www.medschool.northwestern.edu/mhb/atrium/comments.html).



Medical Humanities and Bioethics Program  
Northwestern University  
Feinberg School of Medicine  
750 North Lake Shore Drive, 6<sup>th</sup> Floor  
Chicago, Illinois 60611  
[www.medschool.northwestern.edu/mhb](http://www.medschool.northwestern.edu/mhb)

Nonprofit Organization  
U.S. Postage  
PAID  
Northwestern University