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NEXT THEME: "BLACK & WHITE"

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Doctor Yenta

John Schumann, MD

As an internist, I'm trained to *do* things:

I *listen*. I *ask*.
I *examine*, *order*, and *test*.
And then I *assess*.

I certainly try to *treat*. All too often, this includes *prescribing*.

What frequently gets lost in this paradigm is that on many occasions, the listening part is often enough.

Take Gene, for instance. He's a retired biochemist. When I met him for the first time as a patient, I took a standard social history: I asked about employment, hobbies, and habits.

"I'm emeritus," he explained, sitting hunched forward in the chair, looking out from Harry Caray spectacles.

"What does that actually mean?" I pushed.

He told me about his walks, his weekly lunches, his mail, his invitations, his memoirs. "Do you still do experiments?" I asked.

"I dream about them every night," he replied.

Pause.

His wistful admission pierced me. I felt helpless; there was nothing I could *do* about his loss. I ruminated on it for some time. Then I had a dream. An epiphany of sorts. *Emeritus* came to me to mean *lonely*.

I knew another emeritus: my rabbi. He, too, struggled to find the right balance between activity and restfulness in retirement. Why not bring them together to see what could happen?

Gene: an octogenarian Jew-turned-atheist; a scientist, discoverer, and Renaissance man passionate about music and art.

A.J.: an octogenarian rabble-rousing rabbi; a social justice crusader, scholar, and "fiend for culture" (and his beloved White Sox!).

They were the same age. Of similar backgrounds. Neighbors for thirty years, though they'd never met.

I proposed a series of conversations. Interviews, really, in which I'd ask them about their lives. I wanted to understand their hopes, dreams, and experiences through the tumult of the twentieth century. Gene was worried the rabbi would try to bring him back into the fold. When I obtained assurances of no proselytizing, the dates were set.

We met every Thursday on a quiet corner of campus for a semester. I brought the questions and the tape recorder. *Thursdays with Gene & A.J.*, we jokingly called it.

I tried to hit the big themes: work, accomplishments, family, their philosophies, politics, faith, and philanthropy.

I'm not sure why I did it. I think I felt each man's loneliness, and I hoped to lessen it by providing them companionship—with each other, and with me.

I also think I felt my own need for role models of well-lived lives. I hoped to nurture my non-medical self by tapping into sprightly minds encased in enfeebled bodies and revealing their accrued wisdom.

It worked. A patient came to me with a problem and I *did* something: I helped him make a new friend.

John Henning Schumann is Assistant Professor of Medicine at the University of Chicago. He co-chairs the faculty advisory board of the university's Human Rights Program and is an affiliate of the MacLean Center for Clinical Medical Ethics. Dr. Schumann blogs at <http://glasshospital.com>. schumann@uchicago.edu



HAPPY

Snapshot

Confidentiality & Consent Disclosure: The author has deleted the last names of the individuals quoted, but no details of their story have been altered. The author received permission from his patient Gene to publish the information in this essay. The author did not attempt to obtain permission from his rabbi AJ because he is deceased.

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ABOUT THE COVER

“Happy” was a cranky old bastard of a dog. The dachshund’s name was an ironic joke, but it also could have been the literal truth—maybe every moment he was snarling and snapping at ankles, he was as happy inside as a dog can be.

I’ve met a few medical students like that—jubilantly cynical, they take great pleasure in the role of crank. I think many of them are trying on a professional persona that confuses cynicism with sophistication, dourness with intellectual rigor, and optimism with naiveté. It’s amusing to watch a twenty-two year old who’s never cared for a patient deliver a studied performance of “jadedness,” but the stakes are too high to enjoy it. That sour construction of the professional persona ranges from boring to toxic, and it’s up to medical student mentors to offer an alternative.

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Yet some of the contemporary interest in happiness can turn even the most upbeat among us tart. NU’s undergrad campus boasts a “Happiness Club,” a student group “committed to increasing the happiness of members of the

Northwestern community” through “sticker giveaways, chalking sidewalks, building sandboxes, free hugs and hot chocolate! ... There could not possibly be a happier group of people on campus!”

The alternative to misanthropy isn’t goony levels of forced cheer. That brand of screaming sunshine feels as dishonest as a cynical young student’s know-it-all/seen-it-all pretense, or the professorial variation that asserts “miserable and overwhelmed” as proxy for “dedicated and important.” They’re all grating despite their disparate affects because each feels rooted in an underlying falseness.

Wise medical mentors focus on engagement and authenticity more than “happiness.” In *Letters to a Young Artist* (Anchor 2006) actor/writer Anna Deavere Smith reflects on how Miles Davis epitomized cool, not just with his album “Birth of the Cool,” but also with his manner of speaking softly and saving all his emotion for his music. Deavere Smith is tired of that detachment. She argues for “the death of cool,” which “would probably bring more tones, more color, more emotion, more love, more raw spirit, more argument, more energy. More authenticity? More compassion? More laughter? More tears? More open hearts? Try it,” she writes. “Be uncool. As uncool as you can possibly be. ... Be hot.” (193) If mentors can rally students and practitioners to be “hot,” the rest will probably take care of itself.

Dogs don’t hang back and act cool. Raw spirit, argument, emotion—Happy was hot. The only one in the family who was really fond of Happy was Gramps, who was equally ornery. One day Gramps accidentally backed over him with the car, and Happy was buried in the backyard.

Ten years later, the family walked by their old property. They had moved, and new owners were demolishing their old house. A bulldozer excavating the backyard had knocked over a tree and they spotted Happy’s skeleton high in the roots—perfectly intact and still wrapped in a baby blanket. Happy was clearly meant to stay with them, they decided, so they took his skeleton home and put it in a closet. Then they met Chicago artist Jessica Joslin.

Joslin has built a whimsical menagerie of cyborg beasts out of animal bones, antique hardware, and fragments of flea market finds. Joslin grew up wanting to be a zoologist—as a child she was enchanted wandering among the animal skeleton displays at the Harvard University Natural History Museum, and her family kept a curiosity cabinet of natural objects they collected on hikes. “I didn’t have any sense that bones were considered macabre,” Joslin says. “I simply saw them as a beautiful clue to some mysterious animal that had once been there, the same as a seashell.” Now she combines her fine art training (Parsons School of Design and the School of the Art Institute of Chicago) with the technical skills she’s gained working as a commercial model maker building prototypes of toys. Many of her animals balance on balls or ride bikes and have fine mechanisms that allow movement, so her collection might strike some as an anti-vivisectionist’s Body Worlds. But Joslin has a strong affinity for animals. She says she obtains the bones from the same licensed distributors natural history museums use, and takes care to use only reputable companies whose specimens are legally and ethically obtained. “I don’t think of what I’m doing as dark, necessarily,” she says. “I see the work as part of the love for the living creature—and if they’re going to have a life after death, I want it to be fun.” Happy is the first of the beasts Joslin has made to commemorate a pet using its actual bones, and his family commissioned the work with only one instruction: “Make something wonderful.” The research that says pets make people happy probably didn’t have post-mortem applications in mind. But now Happy the dog has become a piece of art his family’s very happy with.

—Katie Watson, Editor

A wide range of Jessica Joslin’s work can be seen at jessicajoslin.com, and she can be contacted at jessica@jessicajoslin.com.



AP photo by Bill Sikes

Maternal Indications

Shelley Sella, MD

The seven years that I worked with Dr. George Tiller at Women’s Health Care Services (WHCS) in Wichita, Kansas providing first, second, and third trimester abortion care were the happiest professional years of my life to date. If not for Dr. Tiller’s assassination on May 31, 2009, I would still be working there.

Abortion clinics don’t conjure up the adjective “happy” for many people. Yet I was happy doing this work, sometimes ecstatically happy, because I was providing excellent medical care with a wonderful mentor and staff, and because every week I saw transformative joy in the women I cared for. Passing through the gauntlet of nasty protesters, many women walked into the clinic scared and desperate. Some walked out sad, some walked out relieved, and some walked out radiantly joyful.

WHCS specialized in third trimester abortion care. Numerically, the great majority of our patients were in their first trimester; our third trimester care was low volume and high intensity. Women came to WHCS for later term abortion services from all over the country because these services weren’t available where they lived. Some came for fetal indications, because there was something very wrong with their baby. Others came for maternal indications—some had medical conditions that became life threatening due to their pregnancy; others were severely depressed and

often suicidal due to the circumstances of their pregnancy. Those with psychological indications were often young and had hidden the pregnancy from themselves and others for as long as they could.

WHCS patients were seen in the clinic during the day and returned to hotels to sleep at night. The abortion process for third trimester patients takes place over several days because at that stage labor must be induced. The medical process begins with inducing fetal demise with a fetocidal agent and slowly preparing the cervix with sticks of seaweed called laminaria. Once the cervix is ready, labor is induced.

Dr. Tiller always said that the technical component of the practice, premature delivery of a stillborn, was the easy part. What was more difficult was addressing the emotional needs of our patients. To fill that need, we held “support and healing groups” where patients could finally tell their stories in an atmosphere of unconditional love and acceptance. Patients found this incredibly helpful. They often told me how much they appreciated not being judged.

I was drawn to the women who came to the clinic for maternal indications. They were a particularly isolated group. Some can easily understand the need for third trimester services for a lethal fetal anomaly; maybe even for a non-lethal anomaly that would lead to severe mental or physical disability. It’s the abortions on healthy babies in the third trimester that poses the most difficult ethical dilemma for some. Once I took care of a religious conservative 24-year-old

(continued on next page)

accompanied by her parents. She didn't drink or smoke, and she had pledged to God and family that she would be abstinent until marriage. So she was shocked to find herself pregnant at 27 weeks after the fruit punch she drank at a party was spiked with Rohypnol, the date rape drug. Unlike some anti-abortion patients who believe in abortion only in cases of rape, incest, and me, this young woman's experience opened her and her family's eyes to the plight of other women. One day as we talked, her mother said, "You don't know the story until you *are* the story."

For me, this seemingly simple sentence holds the key to why I provide abortion services to all women, from the first through the third trimester. Seeing the humanity of the woman in front of me and listening carefully to her story I can fully empathize with her, open my heart, and help her. I believe that gestational limits are artificial and arbitrary, and that frees me to help everyone with their multiplicity of experiences.

There is something tremendously liberating on focusing exclusively on the woman—treating the dead baby respectfully, but always being concerned solely with the woman's emotional and physical well-being. There is only one patient. This is a dramatic shift away from the paradigm of woman as a vessel, a carrier, a manufacturer of precious resources, and toward one that recognizes the full humanity of women.

Before working at WHCS I had performed only first and second trimester abortions. I believed, though, that abortion care shouldn't be limited to an arbitrary gestational age. This belief was confirmed in my first week working in Dr. Tiller's clinic when the third trimester patients I cared for included a 12-year-old, a mother of three who had been gang raped, and a woman who had recently had cancer surgery and was receiving both Coumadin and chemotherapy, both known teratogens. The 12-year-old was perplexed by her bodily changes and didn't realize she was pregnant until she was far along. The woman who had been gang raped was too traumatized to seek earlier care. And the woman with cancer (and her doctors) assumed her pregnancy symptoms were related to the surgery and chemotherapy until the 25th week of pregnancy.

The third trimester patients I saw at WHCS experienced incredible desperation, a desperation heightened by the ever-growing pregnancy. Some women tried to self-abort, then came to us after their attempts to do it themselves failed. One woman tried to end her own pregnancy by injecting herself with a hormone used to abort livestock, using a coat hanger, hitting herself in the abdomen multiple times, drinking alcohol to excess, and throwing herself upon saddles. Then she came to Wichita.

One woman said that if she couldn't have an abortion, she'd be looking for illegal ways to cause a miscarriage. "Any way to lose it. Even if that means losing my life, too. I sound like a friggin' psycho when I say that. It's not any place I thought I'd ever be." Another woman told me, "If I knew nine women out of ten would die, I would still have an abortion." I had been working at WHCS for almost seven years when I met this patient, yet



A protester at the Union Square vigil after Dr. Tiller's murder
Photo by Bud Korotzer, Next Left Notes

the extreme distress evident in her comment hit me like a blow to the gut. This woman was, to the outside world, doing just fine—educated, financially stable, supportive parents. Many might think, "What's the problem? Just have the baby," or "Just give up the baby for adoption." And another woman in the exact same circumstance might do that. However, the woman before me was absolutely desperate. I realized that it wasn't the objective reality, but rather this woman's perception of the reality that was important.

My ability to empathize with my patients' emotional reality was crucial to caring for them. I often found the emotional world they were living in heartbreaking. One woman said, "It is so hard to live right now. I don't hug anyone or stand in front of them too long for fear of somebody finding out. I just need help because I am afraid for my life. If this continues I will end my life. I'm just trying to hold on a little bit longer. I am trapped in this body. There is no way out."

A pregnant transgendered man said, "If I have to have this baby, I will kill myself."

A 16-year-old said, "The reason why I stopped eating is because my life has stopped."

And finally, one woman said, "The belief that I always had, that I could somehow handle everything that God faced me with, gave me a sense of strength. I don't see how I could go on living if I weren't able to have an abortion. I feel so worn down by the whole ordeal. I never understood how people could ever get to the point that they could just give up on their life. I understand how life can push a person to that point now. I used to love my life. It scares me so much that I could even consider giving up. I never thought I could feel so desperate. I want so badly to feel happy again."

Why Adoption Isn't the Answer

Some say the answer for women carrying healthy unwanted babies is adoption. Even in the pro-choice community some believe adoption is the answer at late gestational ages. In the case of the overtly suicidal patient, they might suggest admitting her to a psychiatric ward on a suicide watch for the duration of the pregnancy and then taking the baby away. For the tormented and distraught, the answer might be a "nice" home for unwed mothers and then relinquishment of the baby to a "nice" family. This might be an option for some, even a good option. But my patients have taught me that adoption isn't the right solution for everyone.

The adoption process can be both degrading and exploitive. An article in *The Nation* ("Shotgun Adoption" September 2009) focuses on the resurgence of mainly Christian homes for unwed mothers as an outgrowth of federally funded Crisis Pregnancy Centers. These centers "seek not only to induce women to 'choose life' but to choose adoption...." They seek to convince women that they are unfit to be mothers. One woman quoted in the article said, "They come on really pro-life: look at the baby, look at its heartbeat, don't kill it. Then, once you say you won't kill it, they ask, 'What can you give it? You have nothing to offer, but here's a family that goes on a cruise every year.'" This woman said she felt like a "walking uterus" for the Christian adoption agency.

In this model of motherhood, the woman who chooses an abortion is selfish because she is just thinking about herself and not, in the language of anti-abortion activists, the pre-born human being. At the same time, the young unmarried woman who carries her pregnancy to term and keeps the baby is selfish because she is only thinking of herself and she doesn't know what's best for her post-born human being. In this model, unwed pregnant women are treated like a Third World nation whose natural resources are available to be looted and plundered. But once the baby is born and exported to the good family, who cares about the devastating aftermath for the women?

The women who came to Wichita didn't feel like adoption was an option. Dr. Tiller's views on adoption resonated for many of them: "It's like cutting off an arm and being able to function afterwards, but always being aware that your arm is missing and wondering what happened to it." One teenager said, "I don't feel I can emotionally handle the pain of not knowing how safe it is, if it's in good hands with a different family or worrying or thinking about it for the rest of my life."

Other patients expressed concern for their potential children. A 17-year-old told me she didn't want to put her baby up for adoption "because I've heard stories about women giving up their babies and the children are mistreated, and I couldn't bear that. And, if I have an abortion—as cheesy as it sounds—it'll go to heaven." Another patient said, "I can not find comfort in the thought of abandoning a child and depriving them of their real blood family."

Parents of my young patients often told me their own stories, which revealed why they supported their daughters'

"You don't know the story until you are the story."

abortion decisions. Some had been adopted and/or had grown up in unhappy homes. One parent had a sister who had been forced to carry a pregnancy to term and give the baby up for adoption, and the sister had suffered deeply since. That couple was particularly adamant that even if they had to walk to Kansas, they would bring their daughter for the abortion she wanted. A 17-year-old patient's mother told me that some people in whom she had confided suggested adoption. She asked me in an anguished voice, "But what about *my* daughter?" To her, her moral duty and imperative was to take care of her daughter.

I believe that focusing on the women—their stories and their needs—is paramount. That's what makes it possible for me to provide abortion care in all trimesters without hesitation. From my first week at WHCS I admired the young women we cared for. I admired their bravery, their goals, and their dreams for the future. A teenager once said to me, "I see girls at my school being pregnant and they have a baby and quit school and they say they will be back, but they don't come back and they end up working at grocery stores and I don't want to be one of those girls." Should this teenager be condemned to the "dungeon of mandatory motherhood," to quote Dr. Tiller, because life circumstances brought her to our clinic at 26 weeks instead of 16? Do we deny her her life? Ultimately, we must decide: Who is the patient, the woman or the baby? If the answer is the woman, then the need for third trimester abortion is clear.

The women I've served inspire me to continue this work in the face of my mentor's murder. As one woman said at the end of her week at WHCS, "Oh my god. I look in the mirror and I see me again." And *that* is happiness.

Shelley Sella is an Obstetrician Gynecologist based in Oakland, California. From 2002 to May 31, 2009 she was mentored by, and practiced with, Dr. George Tiller. She is honored to be able to carry on his legacy in her current work with Dr. Curtis Boyd at Southwestern Women's Options in Albuquerque, New Mexico.

Confidentiality & Consent Disclosure: The author has deleted details that might make the patients quoted or described in this article recognizable to others, but no details have been altered. The author did not attempt to obtain permission from these former patients because she no longer recalls their identities, and therefore could not contact them. The author has chosen to publish de-identified information obtained in the context of the physician-patient relationship to increase understanding of all women who seek later term abortions, and the author believes that if she had been able to contact the former patients represented in this article, they would have given her permission to use their de-identified statements and stories for that purpose. The author wishes to thank both the women represented in this article, and the many other patients who have shared similar statements and stories with the author over the years.

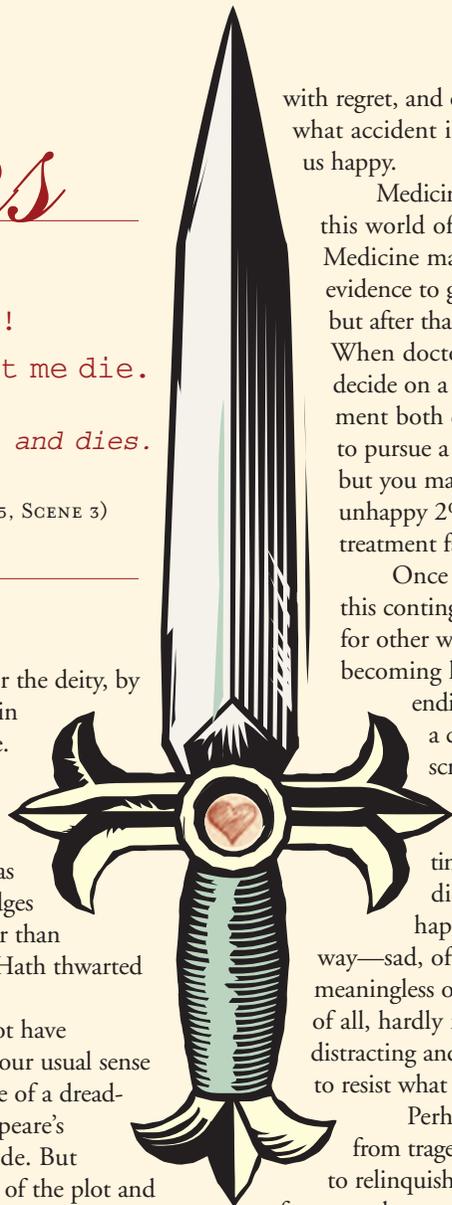
Perhaps

O, happy dagger!

This is thy sheath. There rust, and let me die.

Juliet takes Romeo's dagger, stabs herself, and dies.

—WILLIAM SHAKESPEARE,
ROMEO AND JULIET (ACT 5, SCENE 3)



Catherine Belling, PhD

Awakening from a medically induced coma, Shakespeare's Juliet finds that Romeo has poisoned himself and chooses to end her own life. Saying "O, happy dagger!" she stabs herself.

How can an object like a dagger be "happy"? The word's apparent incongruity may tempt us to pursue some kind of sexual-romantic personification of the dagger—mightn't it be delighted to be buried in Juliet's lovely flesh? This may be an available subtext, but we would be wrong to take it as the line's primary meaning. Juliet has just been chiding Romeo for drinking all the poison himself and leaving her none. She hears voices outside and knows she must hurry to die before she and the body are found—but how? Then she notices his dagger and exclaims in relief. The presence of the dagger is fortunate. She counts herself lucky to have found it. It will—happily—enable her to remain with her love, in the tomb and in death. The dagger is "happy" because it enables her to achieve the only ending that, under the circumstances, is right.

"Happy" is a narrative idea. It concerns how things happen and how we make sense of what happens. Both words—happy and happen—come from the same etymological root, from Old Norse via Early Middle English: *hap*. It means chance, or luck, whether good or bad. It means plot events that are controlled not by the characters

but by the author, or the deity, by blind fortune or plain random coincidence. When Friar Lawrence realizes his scheme to save Romeo and Juliet has failed, he acknowledges that a "greater power than we can contradict / Hath thwarted our intents."

Tragedies do not have "happy" endings in our usual sense of the word. Because of a dreadful mistake, Shakespeare's lovers commit suicide. But within the structure of the plot and the rules of tragic form, fortune leads necessarily, and significantly, this way. We may weep as Juliet dies, and as the Montagues and Capulets, sobered by their children's deaths, at last make peace. To be star-cross'd, as these lovers are, is to be ill fated, unlucky, doomed. Yet to be star-cross'd in the kind of story we call a tragedy is also for those stars, or fate, or the author, to give us a coherent and meaningful—and therefore *happy*—ending. The "happily ever after" of comedies and fairy tales, with their reunions and weddings, relies for its meaning on the silence that follows it. Happiness over an extended period is so elusive that there may be no storyteller who can describe it without exposing disillusionment. No real life can sustain continuous happiness. Most of us can recognize happiness only in retrospect, with nostalgia, sometimes

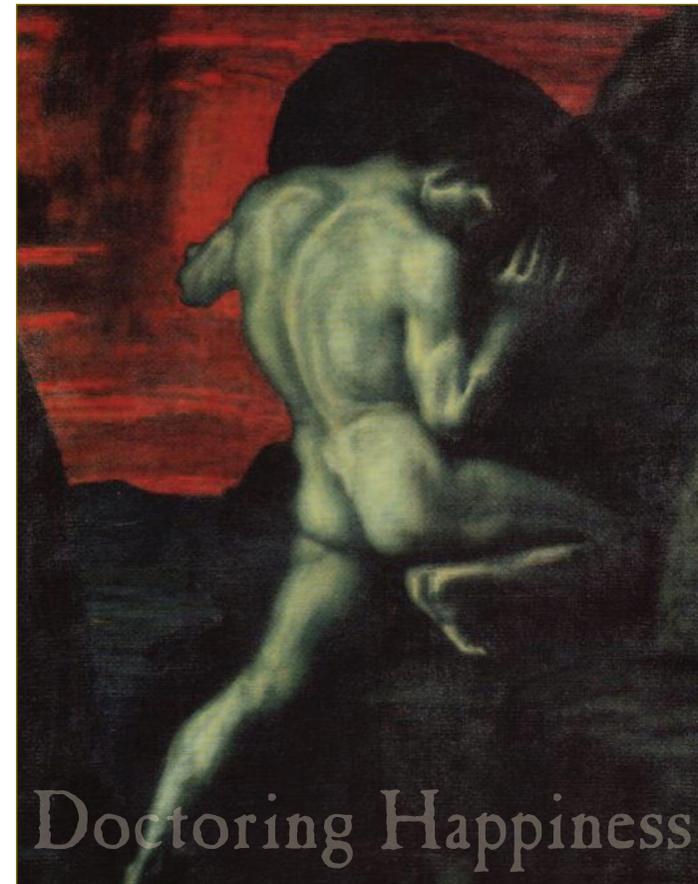
with regret, and often amazed by what accident it was that made us happy.

Medicine is practiced in this world of happenstance. Medicine may have enough evidence to give us the odds, but after that it's still a gamble. When doctor and patient decide on a course of treatment both do all they can to pursue a happy outcome, but you may still be in the unhappy 2% for whom the treatment fails.

Once we acknowledge this contingency, we can look for other ways to think about becoming happy. A happy ending may not mean a cure, or the indescribable perpetuity of "ever after." There will be times when the hero dies but it's still a happy ending in its way—sad, of course, but not meaningless or wasted or, worst of all, hardly noticed amidst a distracting and misguided fight to resist what must happen.

Perhaps we can learn, from tragedy and etymology, to relinquish some of our need for control over what happens and focus instead on working out what kind of story we can tell with it. For happiness is not something we can simply secure for ourselves. We can pursue it; we can do all in our power to put in place the conditions we imagine will make us feel happy. But whether or not we actually capture happiness (or realize that we have, if we do) depends on all the other variables. With luck we'll be happy. Perhaps.

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Steven H. Miles, MD

Advertisers, drug manufacturers, and sitcoms are largely to blame for the muddled state of happiness. It is hardly possible to talk about happiness today. A jumbly collage of images of partying college students, the quiet joy of hospice patients, the phony smiles of politicians—all these and more seem to obscure any single concept of happiness. As a therapeutic goal, such a mess seems to offer little guidance. It is possible, even necessary, for doctors to clear up this mess in order to be healers.

Happiness is not an emotion. Emotions are transitory responses to states of comfort, safety, or jocularity. They have a big facial signature, which is why advertisers use japing figures to sell lounge chairs, casinos, and bad food.

Happiness is not mood. Mood is a setting on a humoral thermostat that Renaissance medicine usually tied to organs thought to function as emotional furnaces. Dysthymia and euthymia refer to the thymus, an organ in the chest where intense emotions are felt. Biliary, choleric, and jaundiced temperaments rise from various colored biles of the liver; melancholy is named for the excess of black bile of the spleen. The light-hearted sanguine temperament is the signature of an excess of excited, pulsatile, aerated blood. Phlegm was thought to come from the brain, so viscous phlegmatic introverts could never jump for joy at a fast food hamburger no matter how much an advertiser paid them. The first sardonic types had ingested a plant from Sardinia which cause them to die gasping like laughing hyenas. Good riddance.

It is disheartening to think of happiness as a mere thermostat setting. Doctors of body and mind seem smitten

with such engineering metaphors and, by implication, with becoming janitors. We physicians use happiness scales, and drug companies happily vend pharmaceutical humor-modifiers to counterbalance excesses or deficits. Certainly, some people are glad to be raised from the depths of melancholy (whether its cause is black bile, a lack of serotonin, or an existential crisis), and some are relieved when a sanguine mania becomes less obnoxiously effervescent. But the patient soon learns that a more comfortable thermostat setting does not mean that they are "happy."

Happiness is not affect. Affect is the display of experienced mood and emotion. As such, it is socially conditioned behavior. Proper Minnesota Scandinavians do not wail their dead; they get dour—a mood in which their characteristic phlegmatism congeals to hardness (from Latin: *durus*).

And happiness is not a type of personality. It's moods that can become so entrenched they seem integral to personality. Can a dysthymic person be happy? Curmudgeonly myself, I say "yes." Can a bipolar person be happy? I am of two minds on this.

So what is happiness? I side with the Greeks, who did not see happiness as a noun. Plato nailed happiness as human flourishing. Aristotle expanded on this idea, arguing that happiness arises from living a virtuous life in pursuit of upholding something that was ultimately worthwhile. Inventor Bucky Fuller, author of *I Seem to be a Verb*, would surely agree. The idea that doctors should help patients articulate or seek a sense of purpose and meaning was favored in a recent, less threadbare sense of doctoring. Carl Jung argued that a relationship to spirituality and to the moral archetypes of human consciousness was the foundation of health. Victor Frankl, founder of logotherapy and author of the phenomenally successful books *The Doctor and The Soul* (1955) and *Man's Search for Meaning* (1946), held that helping patients find meaning in their lives was the ultimate definitive therapeutic act. Psychoanalyst Otto Rank and psychologist Rollo May brought such ideas to existentialism, and humanists responded: Camus appropriated the story of Sisyphus, a person who held himself to be a peer of the gods. As a punishment for his feckless lack of deference, Sisyphus was fated to roll a boulder up a steep hill. Every time he neared the summit, the boulder would slip and roll back to the bottom again, forcing him to start anew. Answering the question of how to live when life seems pointless is the task of happiness. Camus concludes his analysis of the fate of Sisyphus: "One must imagine Sisyphus happy."

Jocularity, mood, polite social behavior—these are too thin a gruel for rolling the daunting boulders of death and disability that patients face with their doctors. Some kind of positing of meaning, secular or religious, is the response that enables patients to flourish. Doctors must seek a more intimate encounter, not in order to proselytize, but to gently help patients find the rolling axis of their values and accomplishments to enable them to make their uphill journeys. As we do so, we may hope to find such skills for ourselves.

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“We Treat—Jesus Heals”

Revisiting the Mix of Religion and Work

J Kayle Lee, MD

I recently worked at a hospital in rural Kenya as a faculty volunteer for a general surgery residency program, and during my first surgical case I was interrupted to pray. As I listened to the team pray in the patient’s native language, I realized I was jealous: as an American Christian, I envy their ability to apply their faith at work.

Tenwek is not merely a hospital funded by faith-based organizations. At Tenwek Hospital, the practice of medicine is intentionally intertwined with the Christian faith. Tenwek started as a provisional clinic in 1935 and has grown into one of the largest mission hospitals in Africa with over 300 beds. The hospital’s motto is “We Treat—Jesus Heals,” and its employees strive daily to live out its mission statement: “To be a witness for and to glorify the Lord Jesus Christ by offering compassionate medical care to those who need health services.” Each ward’s morning report starts with sign-out and ends with a hymn and devotional. As I rounded with the surgery team, I would hear strains of different hymns as we walked from ward to ward. Personal and hospital prayer requests are shared with announcements after educational conferences. The surgery residency program integrates Bible study with medical training. There is a chapel in the center of the campus, and many of the employees attend the Tenwek Sunday church service. And—as I quickly learned after that first surgical case—every OR patient is prayed for before the case begins. Religion is a blatant, deliberate, and integral part of working at Tenwek.

But I was most struck by the humility, compassion, and joy of the employees of Tenwek Hospital. I had never experienced such a pervasive positive spirit in a hospital. Both missionary and local staff loved coming to work, working with others, and taking care of their patients. This general

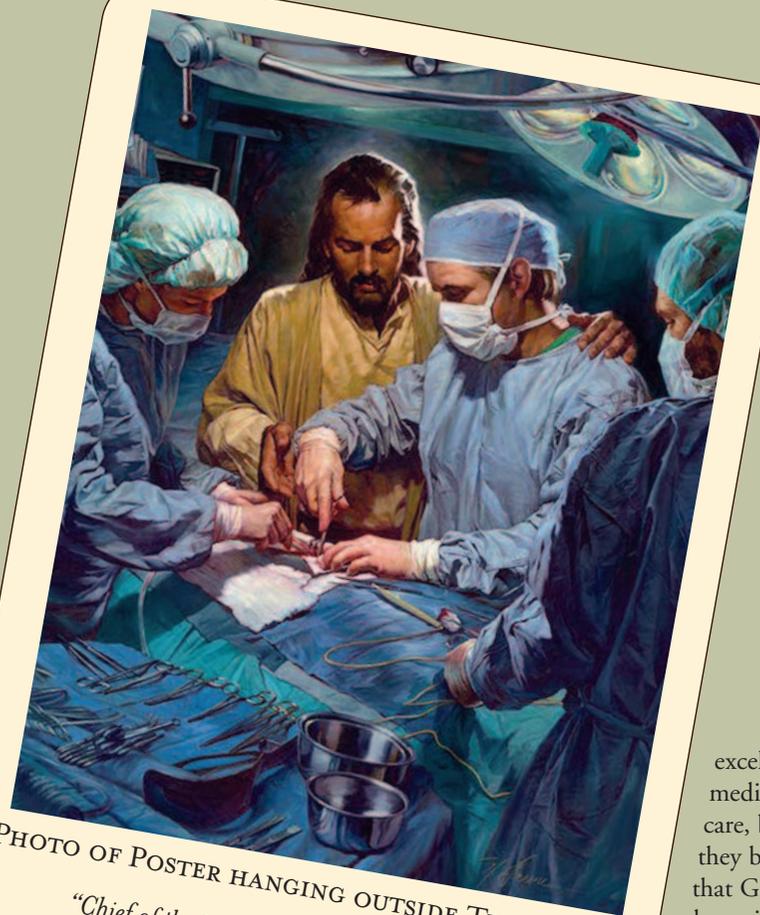


PHOTO OF POSTER HANGING OUTSIDE TENWEK OR
“Chief of the Medical Staff” by Nathan Greene

excellent medical care, but they believe that God determines the outcomes. This perspective helps them cope with much of the frustration

and disappointment that comes with working in healthcare. They also have a community of affirmation, support, love, and common beliefs, and an element of accountability to work with industry and integrity.

During my last week at Tenwek, two young men came into triage—brothers who had been in an altercation in the fields. One had struck the other with a hoe, cracking open his skull. Overwhelmed by remorse, he later stabbed himself in the neck. Family brought the pair to Tenwek, and the offender sat in a chair next to the stretcher where his brother lay dying. He had guilt and horror and hopelessness on his face. I operated on his brother, but the brain damage was

terminal. Then I operated on him and was able to repair his neck injuries. On my last day I found a nurse who could translate and asked him whether he had been told what had happened to his brother. He shook his head—he had not spoken since arriving at the hospital. I told him his brother had died the morning after surgery. He was not surprised, and he stared ahead, pained and hollow. I had treated his physical trauma, yet clearly he was still in need. I couldn’t do anything more for him as a physician, but I wanted him to know that God can heal completely. With a nurse translating for me, I prayed for him. Back in the U.S., if I had offered to pray, my prayer probably would have been just for his recovery. But at Tenwek I also prayed that he would know that he was still alive for a reason and that God had forgiven him and loved him. I then told him it was my last day of work. As I said goodbye he whispered the first words I’d heard him say: “Thank you.”

I don’t know what specifically he was thanking me for, but I felt profoundly happy at that moment. I was grateful to have surgical skills that could help him, but it was wonderful to have the opportunity to express my faith,

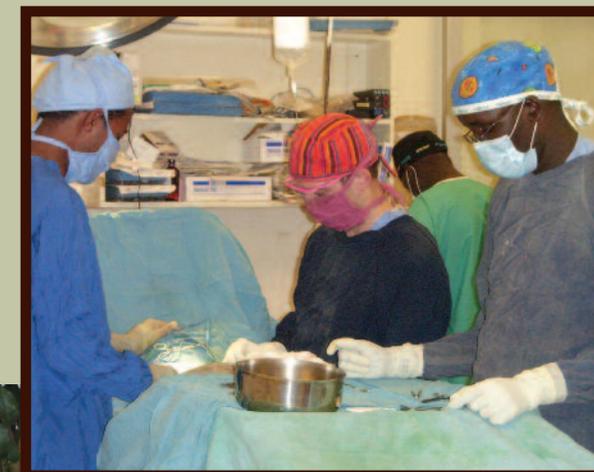
and to have my religion be a part of how I cared for him as a patient. I was fulfilled by having the freedom to follow through on a conviction, being able to help him more and in a deeper way, the fact that he finally talked, and that he felt he had received something to be thankful for. It was a sense of fulfillment that I seldom have at work in the U.S.

Tenwek was unlike any work environment I have experienced, and this encounter gave me a renewed outlook on what I do and don’t do at work. In America, the issue of religion in the workplace is often avoided or indiscriminately discouraged. Patients’ personal faiths are advocated with cultural sensitivity training, chaplain visits, and religious services at the hospital, but staff members have few ways to express or apply their religion. It’s as though work should be a time when people should not wholly be themselves, but be sterile and innocuous instead. Yet my time at Tenwek reminded me that work provides greater gratification when we can be true to our beliefs.

Mahatma Gandhi said, “Happiness is when what you think, what you say, and what you do are in harmony.” It’s challenging to consider how I can incorporate my faith into my work in the U.S., but my experience at Tenwek has inspired me to do so.

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Confidentiality & Consent Disclosure: No details about the patient quoted and described in this article have been altered. The author did not attempt to obtain permission from this former patient because the international context would have made reaching him unusually difficult, and because she believes anyone who could recognize him is unlikely to read this article. The author has chosen to publish de-identified information obtained in the context of the physician-patient relationship because this interaction was central to the author’s own story of her personal experience of religion in the workplace, and the author believes that if she had been able to contact the former patient represented in this article he would have given her permission to use his de-identified information for that purpose.



An attending, resident, scrub nurse, and anesthesiologist praying before a case begins.



Is Satisfaction Enough?

MK Czerwiec, RN, MA

A practitioner of sadomasochism changed my thinking about patient happiness. I was a new nurse about to stick Danny's right arm with a large needle for an IV site, and I said something about the pain I'd be causing. "Being a patient is a lot like practicing S&M," Danny replied. "You subject yourself to something unpleasant in the hopes of a greater pleasure."



But for Danny, practitioners of health care fell short when compared to practitioners of S&M. "In S&M, we make a contract about what will happen. We establish a safe word. If I say that safe word, I know the pain being inflicted on me will be stopped. The problem with being a patient is that we don't get a safe word, and you doctors and nurses are constantly breaking your contracts."

I asked Danny what he meant by that last part, the contract breaking in health care. "Doctors and nurses are constantly telling me an intervention won't hurt, but then it does hurt." To further his point, he described a situation where a nurse taking him to radiology for a chest x-ray told him he'd be back in his room in fifteen minutes or so. Instead, Danny spent three hours alone in the cold radiology department hallway with no blanket, no explanation, and no apology.

Danny wanted me to understand that he wasn't dissatisfied with the care he was receiving in the hospital—he assured me that he felt he was receiving high quality care, and that he was satisfied with that obviously crucial aspect of his hospitalization. His issues were with the way in which that satisfactory care was being delivered. Those issues kept him from being happy about his care and from feeling good about the intentions of the doctors and nurses, who were "constantly breaking [their] contracts" with him.

I began to wonder about the distinction Danny drew. He was "satisfied" but not "happy" with the care he received. The distinction makes sense to me, and Danny articulated it well. If a patient rates his or her care on a one to ten scale, I imagine "satisfied" falling as a midline measure, possibly a five, whereas "happy" would rate an eight or higher. A "happy" patient seems qualitatively better off than a "satisfied" one, which makes me think making patients happy is a worthy goal.

But Barbara Ehrenreich offers a cautionary note: as a former breast cancer patient, she might argue against striving for patient happiness. In *Bright-Sided: How the Relentless Promotion of Positive Thinking Has Undermined America* (Metropolitan Books, 2009), Ehrenreich decries the endless promotion of happiness she encountered when she had breast cancer. She witnessed what she describes as a feigned and encouraged attitude of happiness as an all-encompassing aspect of caregivers and the "pink ribbon culture" that, in her view, used an offensively heavy hand in encouraging her to embrace a happy outlook.

Ehrenreich defines happiness in *Bright Sided* as a forced positive attitude, an unnatural cheerfulness. In contrast, I define happiness here as something that's both more and better than satisfaction. I wonder, though, whether Ehrenreich's definition and mine might blur when caregivers consciously strive to have happy patients, creating a kind of "happy is as happy does" environment of false cheer—the kind of environment that produces the mammogram waiting room Ehrenreich describes, in which, "Almost all of the eye-level space had been filled with photocopied bits of cuteness and sentimentality" (16). The danger of adopting a "patient happiness" rubric is that it could be misapplied to require patient cheer. Instead, we should seek something more like patient contentment; patients who sense that individual concerns are being addressed in a compassionate manner. Truly "happy" patients and families would feel they are not being cheered up or simply cared for, but rather cared about.

There's a significant body of quality-analysis literature that reviews healthcare delivery outcomes from multiple perspectives (like safety or patient satisfaction) in multiple healthcare settings (like hospitals and clinics). But this literature frequently muddles the distinction between satisfied and happy patients. As Cynthia Barnard, Director of Quality Strategies for Northwestern Memorial Hospital, put it, "We do not measure 'happiness' but rather conceptualize our measurement of patient responses [to surveys] as their 'satisfaction' with care. There may be some interesting differences in these ideas."¹ Similarly, media reports on satisfaction studies typically have headlines describing happy or unhappy patients, yet the stories actually report on levels of patient satisfaction.

The criteria categories used to measure patient satisfaction in many institutions were established in *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care*.² Margaret Gerteis and her research team conducted lengthy health care quality studies, and her book describes their conclusions about the way quality in health care should be evaluated. "Quality in health and medical care has two dimensions: one is objective, technical; the other is subjective and qualitative. However dazzling the technological achievements of medical science over the last fifty years, the patient's experience of illness and medical care is at the heart of the first purpose of clinical medicine—to relieve human suffering" (22). In

defining this perspective, Gerteis goes on to describe seven measures of patient-centered care, including respect for patient's values and preferences, physical comfort, alleviation of anxiety, and involvement of friends and family. Gerteis's metrics quantify the distinction Danny drew for me: he was satisfied with the objective care he received from the doctors and nurses in the hospital, but he was not happy with the subjective aspects of his care. In the end, the hospital experience exacerbated rather than relieved Danny's suffering, and by that measure the hospital failed him as a patient and its mission as an institution.

Gerteis's distinction reminded me of a job I had in nursing school. As part of a pilot study, I conducted phone interviews with thirty next-of-kin to patients who died while hospitalized. I was continually amazed that family members not only remembered long-past seemingly small and ordinary considerations provided by caregivers, but that they also cited these considerations as responsible for their high level of satisfaction with the care given to them and the deceased patient. Some family members warmly recalled caregivers providing pillows, coffee, or a private space for family to gather outside of the patient's room. They also appreciated caregivers sitting with them, even (maybe especially) in silence. It was certainly not a happy time, but the family felt happy, in retrospect—somehow beyond satisfied—with the care they and their

loved one had received. In a keyword analysis of the interview content, one of the most commonly used words to describe positive attitudes toward care was "nice," as in, "they were nice to us." I don't think Ehrenreich would object to that; these families were describing genuine kindness, not empty cheerleading. Those phone calls made me believe that being nice makes patients and their families more than satisfied with their care. It makes them happy.

In Danny's situation, a nurse on his unit would be "nice" to call down to radiology to see why Danny had been gone so much longer than expected; it would have been "nice" of a radiology tech passing Danny in the hallway (for the eighth time) to ask Danny if there was a problem, taking the time necessary to ameliorate the situation. These are the kinds of things that elevate satisfied patients to happy ones.

It doesn't seem like a big deal, and yet patients don't always get this kind of attention. Why not? Maybe only happy caregivers have the emotional energy required to not just complete the technical aspects of their jobs, but also to be nice to their patients. According to a 2009

study in the *Journal of Healthcare Management*, the single most important factor in patient satisfaction appears to be hospital personnel morale.³ John Griffith, a professor at the University of Michigan School of Public Health, evaluated thirty-four community hospitals in nine states. Each hospital had received a Malcolm Baldrige Quality Award, a nationally recognized quality benchmark for various industries. These hospitals consistently had caregivers who reported feeling involved in the decision-making process of their work environment and who were rewarded for positive outcomes. Responsibility for happy patients then falls not only on the shoulders of front-line caregivers, but also on those responsible for creating and managing the

environments in which care is provided. (Interestingly, the word "happy" doesn't appear Griffith's published study—it says these hospitals "delight their patients and caregivers," but the measure it considered was patient and employee "satisfaction," as well as outcomes like an "enthusiastic workforce" and "strong worker loyalty." Yet in a press account, Griffith said the award-winning hospitals he studied had the "happiest" patients and caregivers.⁴)

Patients and their caregivers have a shared fate. As David Blatt, a physician at Advocate Illinois Masonic in Chicago, once told me, "We're all just people taking turns being sick. I may be the nurse today, but I could be the patient tomorrow." So making the case

for happy patients is in all of our interest. Satisfied is good, but happy is better.

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Confidentiality & Consent Disclosure: The author changed the name of the patient quoted in this article, but no details have been altered. The author could not obtain permission from this former patient because he is deceased. The author has chosen to publish de-identified information obtained in the context of the nurse-patient relationship to improve treatment of hospital patients generally, and the author believes that had she been able to contact this former patient, he would have given her permission to use his de-identified statements and story for that purpose.

- 1 Personal communication, February 27, 2010.
- 2 Margaret Gerteis, Susan Edgman-Levitan, Jennifer Daley, and Thomas Delbanco. *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care* (Jossey-Bass, 1993).
- 3 *Finding the frontier of hospital management*. Griffith JR, J Healthc Manag. 2009 Jan-Feb; 54(1):57-72.
- 4 "Happy hospitals make happy patients." *ScienceDaily*. Retrieved March 22, 2010, from <http://www.sciencedaily.com/releases/2009/02/090209152414.htm>



Chronic Illness and the Challenge of Triumph

Seema Shah, MD, MSPH

1998 New Year's Resolution: Take at least one great trip a year.

2007 New Year's Resolution: Go out once a month?

My chronic illness and disability mean life isn't what it used to be, or what I thought it would be. It can't be. Many of the things that made me "happy" are just not possible anymore. I can no longer practice medicine, or participate in many activities that brought me joy. These are major losses.

Chronic depression first took hold in 1998, followed by chronic fatigue syndrome (CFS) in 2002. I've been on disability and unable to work as a family doctor since 2004. Trying to navigate the world

and rebuild my life while living with disabling chronic illness has changed my vision of my own life and deepened my understanding of how physicians can be most helpful to patients in similar situations.

The Fighting Myth

Society as a whole (including health care professionals, friends, family, acquaintances, and even strangers) puts never-ending pressure on those living with chronic illness to "get better." There is the expectation that everyone should be able to overcome illness—if they fight hard enough—and return to a pre-illness state of health. The "fight" can take many forms, from trying every treatment possible to having the right attitude.¹

I inform my practice partner (and friend) of the CFS diagnosis I've just been given. I can tell she is underwhelmed by the diagnosis, dismissing its severity.

My history of depression doesn't help matters, already making me weak and suspect in her eyes. "You can choose to focus on the positive," she says.

Illness has put a strain on our working and personal relationship. I feel judged and resented for even having these illnesses, let alone needing to take time off.

Medical sociologist Arthur W. Frank observes that the expectation of triumph dominates in our culture to the point that "everyone around the ill person becomes committed to the idea that recovery is the only outcome worth thinking about."² As Kathlyn Conway, a psychotherapist who has been diagnosed with and treated for cancer three times, points out, the "triumph over adversity" ideal is a constant presence in the lives of those who are ill and/or disabled:

The triumph narrative holds enormous sway in our culture. It is not simply a narrative that one can take or leave, but one that the ill and disabled must contend with in the media, in personal interactions with doctors, in conversations with friends and family, and even in themselves.³

"So how is your health? Any better?" my mother expectantly asks. There is hope in her voice, even though nothing has changed for years.

"The same as the last time we talked," I respond, referring to our phone conversation a few weeks ago.

"So it's not getting any better?" Her hope has turned to disappointment.

Though I understand her desire for me to get well, having this conversation every few weeks can be frustrating.

No matter what I say and how many years pass, most friends and relatives are either still waiting for me to return to my "old self," or have grown tired of the wait.

Susan Wendell, a feminist philosopher living with CFS, notes that "people with disabilities or incurable illnesses often find that long after they have accepted the conditions of their bodies, their friends and acquaintances want them to continue looking for cures."⁴

Over the years, I've repeatedly been given unsolicited advice from family, friends, acquaintances, and even strangers about how to "get better." In addition to the ever-popular *get some exercise*, I've received (and tried) many specific suggestions—prescription medications, a rehabilitation program with a personal trainer, an elimination diet, intravenous nutrient infusions, vitamin complex injections, naturopathic supplements, and brainwave biofeedback, to name a few—with little effect.

"Did you see the article in last weekend's Globe and Mail about a new treatment for CFS?" my therapist asks.

I have, but only because my sister has already pointed it out to me, also excited about the soon-to-be-available "Lightning Process" that can reportedly cure CFS.

They don't understand why I won't pursue this therapy, leaving us all frustrated.

Oftentimes, the quest for a cure can become prolonged (or indefinite), because, as Wendell observes, "to turn down a suggestion is to risk judgment that you do not want to get well."⁵

It has taken some time, but my sister and therapist now understand my unwillingness to try yet another treatment. For some friends, however, my reluctance just reinforces the belief that those with depression and/or CFS could get better if they only they tried hard enough.

Fighting the Myth

March 4, 2007

Most importantly, I need to get well (depression and fatigue) —until I do that, nothing else really matters. I can't move forward until then.

Reading old journal entries reminds me how long I've been fighting. But after a while, it's hard not to get tired of fighting, tired from fighting.⁶ Trying every possible treatment recommendation can become a full-time job—a fruitless one at that. I grew tired of spending what little energy (and money) I had on yet another treatment that didn't help, not to mention the emotional cost of repeatedly getting my hopes up only to see them dashed.

In the case of chronic illness, psychiatrist and medical anthropologist Arthur Kleinman stresses that "the quest for cure is a dangerous myth that serves patients and practitioners poorly."⁷ Given that chronic illnesses are, by definition, incurable, complete recovery is an unrealistic expectation that leads to feelings of failure among both patients and health care providers. The endless and single-minded search for a cure can also keep those who are chronically ill in an indefinite state of limbo.

Instead, Kleinman proposes "a paradigm of care that substitutes a pragmatic notion of illness maintenance and disability reduction for the myth of cure."⁸ Frank highlights the importance for those living with chronic illness to determine "how to live a good life while being ill."⁹ He suggests that health care professionals can help in this process by "helping patients learn to think differently about their post-illness worlds and construct new relationships to those worlds."¹⁰

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I don't let my illness define me. When I say this, I mean I don't *let* it define me, it just does. It's not a matter of choice. That is not to say that's all there is to me, nor is it to say that it isn't possible for me to have a meaningful life. But everything in my life constantly lives in the shadow of chronic illness. It's there 24/7 and factors into every equation of my life.

As Wendell describes, trying to restructure one's life within a changed reality becomes even more difficult when others do not see this as a positive step:

Others resisted believing that I might never regain my previous health and ability, they tried hard to talk me out of attitudes and actions they saw as 'giving up hope' and that I saw as acceptance and rebuilding my life.¹¹

Changing Resolutions

1998 New Year's Resolution: Write... creatively, that is.

2007 New Year's Resolution: Continue with creative projects.

At some point, I came to realize that reaching a certain level of contentment in my life would involve restructuring my life and my life plan. A big part of this has been letting go of unattainable goals like returning to practice or traveling the world, and focusing on goals that are potentially attainable within my new reality. As so eloquently put by Floyd Skloot, a writer who also lives with CFS, this rebuilding has meant finding "the places within me that illness could not touch."¹²

Illness brought me back to creative writing, an interest that went by the wayside once I hit medical school. It was not a conscious return; I started writing about what I was experiencing as a way to help make sense of things. I also began reading narratives of illness written by other people, which I found incredibly valuable.

Over time, I discovered the various ways creative writing and literature could be beneficial for health professionals and for people living with illness and/or disability. When I had to leave general practice permanently, I saw the combination of literature and medicine as a way I could potentially contribute in a meaningful way and make valuable use of my background, experience, and interests within the constraints of my illness-related limitations.

During the past few years, I've explored the use of literature in health care through reading (and reading about) illness narratives, writing my own narratives of illness, and developing and facilitating literary workshops for health professional students and people living with chronic illness. The health professional workshops use a short story about a depressed woman to help students better understand the lived experience of chronic illness.¹³ The patient workshops use the reading and writing of illness narratives to help chronically ill individuals make sense of their experience and feel less alone.

As rewarding as these activities have been, they have been limited by both energy and opportunity, and I remain on disability. Life is far from perfect, but it is better than it was a few years ago. I attribute most of the improvement to changes I've made in my life, as opposed to changes in my condition. Limiting my activity level and pacing myself has been beneficial. It has also been helpful to surround myself with people

who can truly appreciate who I am *now*; I am very fortunate to have a few people in my life who do. However, finding something meaningful and enjoyable to focus on has been crucial. I have been able to begin to rebuild my life in the past few years only because I haven't put all my energy toward searching for a cure and, instead, put some toward searching for contentment.

March 4, 2007

*I think writing will be my salvation (if I'm ever salvaged)...
Not because I'm so good at it, but because I get lost in it,
I get a certain satisfaction from it, it gives me energy
(the kind I'm needing).*

My experience has led me to believe that health care providers should expand the ultimate goal of care from "restoring the integrity of a body and/or mind" to "repairing the integrity of a life." When chronic illness prevents a patient from engaging in previous identity-defining activities, health care providers can help patients identify and foster interests, skills, and strengths that are still possible within their illness-related limitations. This can help reshape identity and rebuild meaning. Helping patients identify societal barriers to participation and looking for ways to overcome them can also help accomplish this. As a health care provider, asking "What role can I play in helping this individual reach the best quality of life possible?" can open new possibilities in the provision of care.

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¹ Kathlyn Conway. *Illness and the Limits of Expression*. Ann Arbor, Michigan: University of Michigan Press, 2007, 17-24.

² Arthur W. Frank. *At the Will of the Body*. New York: First Mariner Books Edition 2002, 1991, 64.

³ Conway, 37-38.

⁴ Susan Wendell. *The Rejected Body: Feminist Philosophical Reflections on Disability*. New York: Routledge, 1996, 97.

⁵ *Ibid.*

⁶ Seema Shah. "The Music Stopped." *Blood and Thunder: Musings on the Art of Medicine* (Fall 2009).

⁷ Arthur Kleinman. *The Illness Narratives: Suffering, Healing, and the Human Condition*. Reading, MA: Perseus Books, 1988, 229.

⁸ Kleinman, 8.

⁹ Frank, Arthur W. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: The University of Chicago Press, 1995, 156.

¹⁰ Frank, *Wounded Storyteller*, 6.

¹¹ Wendell, 27.

¹² Floyd Skloot. *The Night-Side: Chronic Fatigue Syndrome and the Illness Experience*. Brownsville, Oregon: Story Line Press, 1996, 152.

¹³ Seema Shah. Writing Medicine: Narrative and literature helps community members express personal stories of chronic illness [Physicians Speak Out About Arts and Medicine]. *International Journal of the Creative Arts in Interdisciplinary Practice*, Issue #8. Retrieved from <http://www.ijcaip.com/archives/IJCAIP-8-Shah.html> (2009)

Jumping Into Our Field's Third Stream: Bioethics, Humanities, and the Creative Arts



Clod Ensemble Under Glass (2009) Photo by Manuel Vason

Martin Kohn, PhD

It was last fall's Year One orientation and I was about to be introduced as the newest member of the Cleveland Clinic Lerner College of Medicine staff. The faculty member preceding me handed out 3x5 index cards with the prescribed flow of the patient interview printed on them, and it came to me in a flash—I spotted an innocent-looking student and sketched out the arc of a scene in my head. I was introduced and I told the class that "although I've been doing this work for almost thirty years, I'm still nervous." I went over to the student I'd spotted and asked if he'd hold my hand while I presented. He did, and I spoke for a few more minutes. Then I asked the young man if it seemed awkward for an "elder" to be looking to him for support, and whether or not how to deal with the trust this stranger put in him was prescribed on the 3x5 card he'd just received. The student said "no," the answer wasn't on the card. I offered three more scenarios, and each time the students said they couldn't find the answer on the card. Then I laid the cards out on the floor in front of me and made a very narrow path with them. I began walking the narrow path of their curriculum (explaining that curriculum means "course"—a path to follow). I put a regular sized sheet of paper in an area off the path and stood on it. "This is where reflection happens," I explained. "It's where you can seek refuge from the 'doing' and reconnect with the 'being'—the values, beliefs, character you'd been developing and which you carried with you by the bushelful into this place—but which is sometimes lost in the fast pace of medical education, in the tsunami of information."

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The many artists I've worked with in my nearly thirty years in the medical humanities taught me much of what I know about the reflective space I illustrated that day. They've taught me new ways to access it, and even how elements of storytelling and performance can enhance my own teaching. The most memorable and enjoyable work of my career has come through organizing, witnessing, or participating in programs that included significant doses of the creative and performing arts.

I've recently realized that my experience reflects a trend. Bioethics and medical humanities is already a hybrid field, but a third stream of work grounded in the arts has been gathering steam—so much so that I believe this third stream of work should be considered an equal partner in the field. The arts play such an essential role in igniting the stories emanating from the medical humanities and issues grounded in bioethics that they have become a most useful (perhaps indispensable) means of carrying our work to our students and the communities they will be practicing in.

That's because the arts have the power to awaken us to our experience in the world; they enliven the narratives we write and the issues we argue about. The arts affect us through the realm of epiphanic knowing, described by literature professor Anne Hunsaker Hawkins as “abrupt and total, a kind of awareness that is experienced as a flash of insight or a sudden recognition.”¹ However, the arts need not stand alone: she also describes how epiphanic knowledge can be configured as nodes for narrative knowing to flow through. Epiphanies combine with narrative to form a linear mode of thinking that moves “toward and then away from moments of insight and recognition” (41). And regarding the moral dimension of care, Hawkins also praises epiphanic knowing as a vehicle for doctors to become “better able to recognize ethical issues in the day-to-day practice of medicine” because of its power to explore or reveal latent (hidden or sacred) meaning (42).

I am currently (and happily) redesigning a course for first and second year students at Lerner College of Medicine that I've titled *The Call of Medicine/Stories in Medicine—Our Patients' and Our Own*, in which I've combined the three ways of knowing, or “meaning-making,” described above (the epiphanic, temporal, and moral) with three other realms of knowing (generalizable, reflective, and synoptic).² Vitaly important, and illustrative of third stream (creative arts) presence in our field, is that the design includes student involvement in jointly constructing artwork that will be aimed at community wellbeing and shared with the community. This is intended to move the creative work of medical students away from more insular self-congratulatory modalities (in-house literary and art publications), and toward co-constructed creative work that aims to make communities less toxic places in which to live. More generally, our learning work will be driven by a syncretistic approach to teaching: immersing faculty and students in a creative, not-quite-containable aggregation of ways of knowing that reveals and revels in complexity. We will also envelop ourselves in a new aesthetic of humane medicine, which Alan Bleakley, Robert Marshall, and Rainer Brömer of Peninsula Medical School in the United Kingdom describe as a living aesthetic text—one that students enter and dwell in.³ Relying on both ardor and rigor—passionate determination—science-driven medical students will be asked to dwell in the humanities and arts as well, fully exploring the art of living, while discovering that both arts and sciences are based in wonder and discovery, in dogged investigation and creative application.

The success of a medical humanities program depends in part on the culture in which the program resides, and the Cleveland Clinic takes innovation seriously—it has an Arts and Medicine Institute, an Office of Patient Experience, and a vibrant Department of Bioethics. So nine months after I was introduced to the medical students, I wasn't surprised to find myself leading a group of staff (mostly physicians) in a half-day workshop called “Creativity and the Pulse of Humanistic Healing.” Poet-psychiatrist Richard Berlin was in town as a visiting faculty presenter for the workshop, and I tapped three of Cleveland's finest actors (one of whom is also a playwright) to transform Richard's poetry into performance—and (in vivo) to transform the creative writing of the workshop participants into dramatic presentation as well. The next week I happened to see two splendid productions outside my institution: the premiere of a one-act play of Richard Selzer's story *Diary of an Infidel* in New Haven, and a performance of nurse-poet Jeanne Bryner's story *Foxglove Canyon* at Akron City Hospital. Many hundreds attended each performance, and experiencing these three events in one week triggered my own epiphany: the culture of medical humanities and bioethics is changing. A Buffalo Springfield song began running through my head: “There's something happening here...”

Exploration of what's happening elsewhere confirms my belief that the creative arts stream is becoming a full partner in our field. In Denver, the Fulginiti Pavilion for Ethics and Humanities, slated to be a centrally located meeting space for campus and community, includes an exhibition gallery. This is an

important “in on the ground floor” statement; it is architecture that recognizes the deep contribution of the arts at the Health Sciences Center of the University of Colorado at Denver. This architectural statement is an echo of Penn State Hershey's proud placing (in 1967) of its Humanities Department on the first floor of its new medical school. (Penn State continues on its creative path through its “Graphic Storytelling Project” and the “Patients as Teachers, Medical Students as Filmmakers Video Project.”) In Maryland, Liz Lerman Dance Exchange has recently received a grant from Met Life to use tools they've developed in movement as a means of helping health care students explore their roles. In London, Ontario, *The International Journal of the Creative Arts in Interdisciplinary Practice* (arts, health, training, and education) was recently founded by Cheryl McLean, and its most recent issue is titled “Physicians Speak out about Arts and Medicine.” In England, a theatre and performance company called the Clod Ensemble is making big waves with *Performing Medicine*, a project that aims to “create dialogue across disciplines, between the arts, humanities and medicine; across departments in universities; across institutions; and between artists, scientists and the general public” which was created in association with the School of English and Drama, and Barts and The London School of Medicine and Dentistry at Queen Mary, University of London.⁴ Also in England, Alan Bleakley is working towards the radical synthesis of creative arts and sciences in the Peninsula Medical School curriculum. And in Australia, there has been a growing movement in community cultural development through the arts that sees programs in health as its natural partner because both are concerned with wellbeing and change.

“Arts foundries” are a potential next step toward the full integration of creative arts into our (formerly) hybrid field. Physician Jon Hallberg (who described his Mill City arts-based clinic project in the last issue of *ATRIUM*), physician-writer Jay Baruch of Brown University (who was recently awarded a fellowship to develop arts-based medical humanities work at Brown), and I are working on a plan to create a network of arts foundries. We envision them as places where health professions students, art students, visiting artists, and community members come together to create live performance works that could also potentially reach others as touring productions or via radio or web-based downloading. This network of foundries would provide arts-infused common ground for exploration of the nature and future of health at our health professions schools and in our communities. Our proposal may not be as transgressive as the work Augusto Boal advocates in *Theater of the Oppressed* (1974), but we still see this as redemptive work—creative and collaborative change based in art and community development, not service. We see our creative art-based efforts working in tandem with non-traditional frameworks for understanding medicine and health in order to further its impact. For example, we are inspired by Aaron Antonovsky's Salutogenic school of thought in public health, Dennis McCullough's call for Slow Medicine (an analog to slow food, slow cities), and Nicholas Christakis's research on the connection between social networks and health. Like these adventurous thinkers, we welcome all who are considering a foray into our field's third stream—c'mon in, the water's fine.

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¹ Anne Hunsaker Hawkins, “Epiphanic Knowledge and Medicine.” *Cambridge Quarterly of Healthcare Ethics* (2005) 14: 40-46 (41).

² I am indebted to Philip Phenix's work in curriculum philosophy, in particular his book *Realms of Meaning* (McGraw Hill 1964).

³ Alan Bleakley, Robert Marshall, and Rainer Brömer, “Toward an Aesthetic Medicine: Developing a Core Medical Humanities Undergraduate Curriculum.” *Journal of Medical Humanities* (2006) 27: 197-213.

⁴ <http://www.performingmedicine.com/about.htm>

The arts impact us through the realm of epiphanic knowing, described by literature professor Anne Hunsaker Hawkins as “abrupt and total, a kind of awareness that is experienced as a flash of insight or a sudden recognition.”

An Illuminating Shadow

Sabrina Derrington, MD

Leaving the hospital after a 30-hour shift, I squint in the bright sunlight as I walk past cafés full of people chatting and laughing. They look relaxed. I walk quickly, feeling indelibly marked, not only by my wrinkled scrubs and tired face, but also by the whirl of mortality, survival, triumph, and tragedy that I just left. It takes a while for that surreal sensation to wear off. When it finally does I feel so at home in the sunshiny world I almost forget the hospital. It feels good to ignore death for a while. I am reluctant to go back, thinking that if I just had more time I might find myself, achieve some sort of equilibrium. But once back in the pediatric intensive care unit, I have to question whether any sort of self I found outside would be the real me.

The twenty beds of our PICU are filled with a steady stream of children from one month to twenty years of age whose medical conditions put them at risk of dying. Our job, the charge from every parent who entrusts his or her child into our care, is to prevent that death from happening. Most of the time we succeed—children are incredibly resilient, and we have an armament of medical technology and a dedicated team of nurses and physicians. But when we fail, death wins—and a family leaves the hospital with an empty car seat. A monitor sits dark and silent. We fill out paperwork, we clean up the chaos of wires, tubes, syringes, and pumps. We wash and cover a small body for transfer to the morgue. We look each other in the eyes, saying everything and nothing. We share hugs, tears. Eventually somebody says something to make us laugh. And life moves on.

“How do you do what you do?” Like anyone who works in critical care, I’ve been asked that question a million times. I know it’s asked sincerely, often out of admiration, but the underlying implication of abnormality hits close to home. It is strange to work at this shifting interface of life and death. We bounce between extremes of joy and sorrow, sometimes changing our whole demeanor as we walk from one bedside to the next. We struggle over just how much emotion to display—and we worry more about the emotions we don’t feel than those we do. And that’s just inside the PICU. Attempting to integrate what we experience at work with the relief we feel while relaxing in sunny coffee shops or at home with family is difficult if not impossible. Do we care too much or too little? Are we heroic or hardened? Complex or compartmentalized? Is a happiness that coexists with such infinite sorrow a farce, an affront, or an epiphany?

Some thirty years ago, far from tertiary medical centers and modern bioethical dilemmas, Annie Dillard wrestled with similar incongruities in her Pulitzer Prize-winning book *Pilgrim at Tinker Creek* (Harper Collins 1974). When I first read this book in college I immediately connected with Dillard’s contemplative delight in nature, and I loved her honest, organic prose. What I couldn’t anticipate then was that her pilgrimage

“Terror and a beauty insoluble are a ribband of blue woven into the fringes of garments of things both great and small.”
Accepting the insolvability of the equation, the chaos of the situation, and our own confusion and discomfort is what allows us to truly feel alive.

would so closely echo my journey in medicine, or that I’d keep returning to her words to clarify emotions I could never adequately express. Dillard chronicles a year spent living by a creek in Virginia’s Blue Ridge mountains, where she explores her world with the curiosity of a child and the mindfulness of a monk. She delights in the abundance and intricacy of the life she finds there, but within a few pages horror intrudes. Down by the creek, Dillard watches a frog lose its vital spark and crumple in upon itself as a giant water bug literally sucks the life and substance from it. Throughout the book the dark thread of death repeatedly confronts her in the form of parasites and their improbable life cycles, the excesses of insect reproduction and the seeming expendability of those millions of young. She questions the deeper implications of “the very compromising terms that are the only ones that *being* offers: ...if you want to live, you have to die” (183). Life is a flimsy proposition, she discovers. Death is unavoidable, and we are left alone, it seems, to attempt to understand *why*.

She’s right: it’s the *why* that challenges me the most. One of my first mentors in critical care said that it wasn’t the sleepless nights or the long days that exhausted him, it was the meetings with families. It’s the impossibility of explaining to a parent why *their* child is going to die; it’s the questions in our own heads as we watch cancer or sepsis suck the life out of another child. Sharing our frustration, Dillard laments that “we don’t know what’s going on here ... our life is a faint tracing on the surface of mystery” (10, 11).

Dillard struggles against the meaninglessness of death, but even as she mourns she is struck by the irrepressible exuberance of life. “Cruelty is a mystery,” she writes, “and the waste of pain. But if we describe a world to compass these things, a world that is a long, brute game, then we bump against another mystery: the inrush of power and light ... there seems to be such a thing as beauty, a grace wholly gratuitous” (9). We have only to open our eyes to witness spectacular beauty and extravagant grace—in the sunlight sparkling on Tinker Creek, in the smile of a child made healthy again, in the perfect dive of a swallow, in the hope that parents carry like an Olympic torch. And while not one of us is secure from injury or disease—shadows will always challenge the light—I’ve realized, just as Dillard did, that it is this inextricable entwining of life and death, of beauty and horror, that defines reality: “[This] is the thorn in the flesh of the world, another sign, if any be needed, that the world is actual and fringed, pierced here and there, and through and through, with the toothed conditions of time and the mysterious, coiled spring of death” (237). That coiled spring pierces me through as I look at the photographs strung around many of the PICU beds. The child I’ve come to know is attached to machines and tubing, struggling to survive, and bears little resemblance to the grinning, playful toddler or beautiful teenager in the pictures, but as I stand there I feel the sacred presence of that life with shattering poignancy.

Lazlo Földényi, a Hungarian philosopher and art critic, asserts that true happiness cannot be separated from melancholy, which he associates with a deep insight into the fragility of our own existence. Dillard agrees: “Terror and a beauty insoluble are a ribband of blue woven into the fringes of garments of things both great and small” (27). Accepting the insolvability of the equation, the chaos of the situation, and our own confusion and discomfort is what allows us to truly feel alive. “The point is that not only does time fly and do we die, but that in these reckless conditions we live at all, and are vouchsafed, for the duration of certain inexplicable moments, to know it” (80). In the PICU, where only a few moments separate stability from crisis, the fragility, complexity, and splendor of life are unmistakable. What happens there is unquestionably real, a distillation of what it means to be human. Experiencing this reality requires that we open ourselves up to feel our patients’ pain, to know the love of their families, to cry and to laugh together, to experience with them great joy and great sorrow, and to bear witness to the horror that exists on the other side of beauty. Maintaining that sort of vulnerability takes a toll—but I would not choose the alternative. I’ve long felt that the unspoken doctrine in medical training of professional distance and emotional separation is toxic to us as caregivers and compromises our mission. Any wall we erect to try to protect ourselves from experiencing sorrow and death also prevents healing—for both us and our patients and families. But if instead we choose what is real, if we choose to see and feel, to be part of the dance of life and death that occurs in our PICU every day, we stand to gain more than we ever risked losing. I’ve accepted that I will never be able to answer *why*, I will never have the perfect words to tell a grieving family, I will go into every day feeling inadequate, and I will fight battles that I often lose. I will be stretched, peeled, and torn, and it will be entirely worthwhile. In her inimitable way, Annie Dillard taught me that. “I cannot ask for more than to be so wholly acted upon. [It] is a price I would willingly pay ... for being so in the clustering thick of things, rapt and enwrapped in the rising and falling real world” (224).

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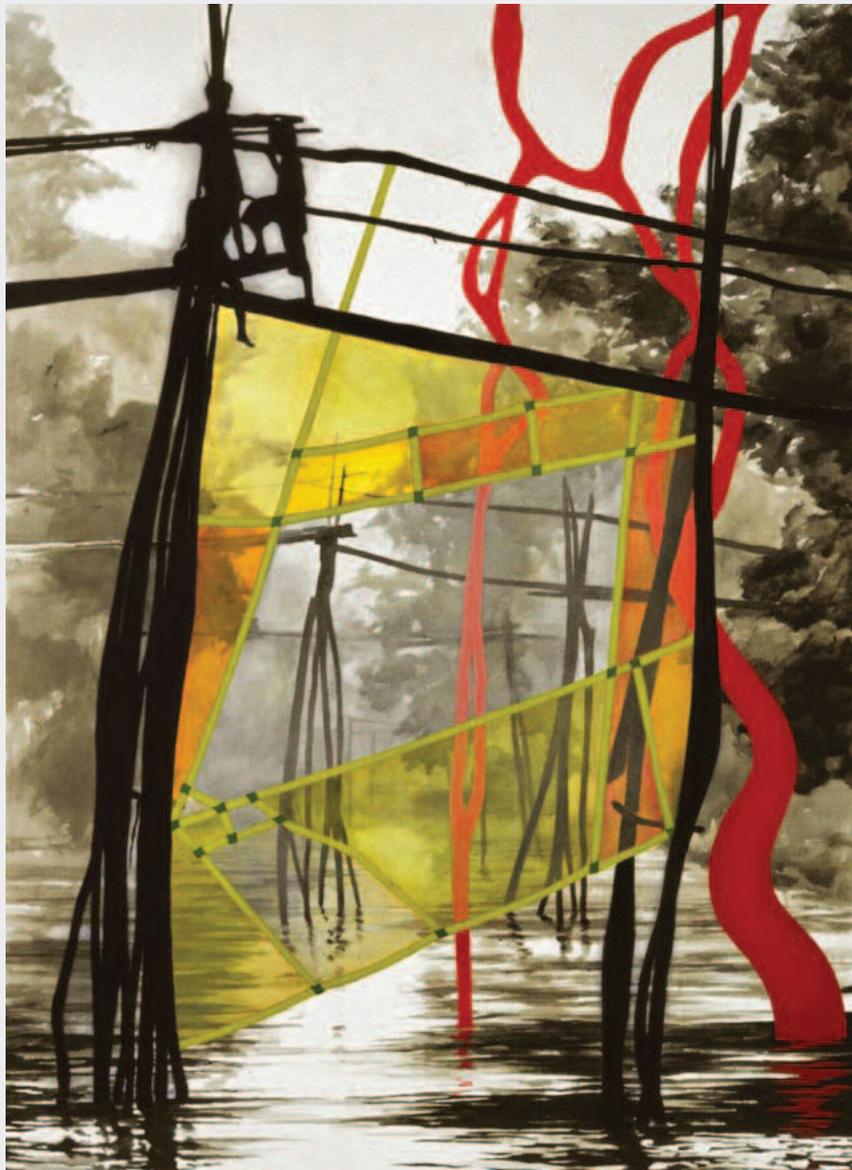
ARTISTS AMONG US:

Happiness as an element in health professionals' artist statements

Pamela Brett-MacLean, PhD,
Michelle Casavant BFA, and
Diana Young Kennedy, MSc

Aristotle believed that human beings are “made for happiness,” philosopher Jean Vanier argues.¹ Vanier describes Aristotle’s concept of *eudaimonia*, a complex notion of living well, fulfillment, and flourishing in relation to happiness. This suggests an energetic component to happiness: happiness experienced through and in relation to an array of positive actions. Learning what contributes to the happiness and wellbeing of health professionals is of increasing interest to individual practitioners, as well as their various professional associations and schools.² For example, in their essay on physician wellbeing, Shanafelt, Sloan and Habermann assert that “physicians must identify, nurture, and defend their personal interests and values if they desire personal and professional satisfaction in life.”³ In 2005 Tony Delamothe, the deputy editor of the *British Medical Journal*, wrote an editorial on happiness subtitled “*Get happy—it’s good for you*,” which included suggestions for enhancing happiness through activities pursued in one’s “spare time.”⁴

Artmaking is an avocational activity some health-care practitioners engage in, often in a serious, committed way. John Stone, an emergency physician and poet, outlined some of the historical connections between art and medicine, making reference to the special case of anatomical illustration and noted physician-artists.⁵ In a collection of essays compiled in *Doctors Afield*, twenty-seven physicians describe how endeavors such as writing, playing music, and artmaking have infused their lives with a creative energy that has enriched them personally and professionally,⁶ and other first-person accounts of being a physician and artist continue to appear.⁷ This article focuses on the work of everyday health professional-artists (“HP-artists”) by considering the “artist statements” they write to accompany their artwork.



Kate Collie, PhD, MFA, Tram Chim #3, oil and acrylic on canvas 1994, exhibited at “After Work”

In 2009, we organized a juried art exhibit called “After Work” which was hosted by the McMullen Gallery at the University of Alberta Hospital in Edmonton, Alberta, in collaboration with the Arts & Humanities in Health & Medicine Program at the University of Alberta. Over seventy healthcare staff, faculty, residents, and students responded to the call for submissions, fifty-one HP-artists were invited to participate in the show, and over sixty artworks were exhibited. We reviewed all of the HP-artist statements and identified a number of recurring themes. Two prominent themes were artmaking as a joyful, enlivening activity, and artmaking as a way of achieving balance.

ARTMAKING AS A JOYFUL, ENLIVENING ACTIVITY

Many HP-artists described the experience of creating art as a joyful, enlivening activity. They described the process of working with art materials or working toward a sense of

rightness with the emerging form as being an inherently rewarding activity. As three different HP-artists put it:

- *I paint because it is an enjoyable activity of its own. I enjoy all stages of the painting process. This involves the initial stage of coming up with an idea, the process of making it, dealing with the challenges that come up as I carry out the painting, and ultimately finishing the work for others to view. When I paint, I get into a mind state where I am totally absorbed in the activity, but at the same time enjoying the process.*
- *I am able to transform myself to another dimension where time stands still and my only focus is on the torch and the molten lump of glass in front of me. While working at the torch, one cannot dwell on the state of the world, and the hectic pace of life—and lab work is forgotten. For me it is a most amazing, almost magical transformation and it leaves me feeling refreshed and calm and also excited.*
- *I find I can lose myself in the creation of something and several hours could go by without my realizing it. I can become mesmerized by the plains and hollows of a person’s facial structure. The way shadows can cast a secretive and mysterious quality or the way light illuminates and enhances certain features. Sometimes I wonder at the drive I feel, and where it comes from.*

Psychologist Mihaly Csikszentmihalyi has used the term “flow” to describe the “state in which people are so involved in an activity that nothing else seems to matter; the experience itself is so enjoyable that people will do it even at great cost, for the sheer sake of doing it.”⁸ He associates flow with optimal experience, characterized by feelings of “joy, creativity, the process of total involvement with life.”⁹ Many of the HP-artist statements described a state of “flow” as awareness merged with the action of creating the artwork:

- *There is a focus when I paint that eliminates everything around me, except the work in front of me there is a peace which descends when I concentrate on line, form and colour.*
- *Creativity offers a unique portal to freedom, and answers a profound need to disappear into the process of making something that didn’t exist before, interpreting an image in a new way, or communicating an idea or experience. There is a calm bliss of losing myself in the materials at hand, and when I take the time to draw and paint I feel different —*

greater mental clarity, energy and curiosity, and a sensation of untroubled quiet. After painting I sometimes feel like I went away and came back from an inward holiday.

Many of the HP-artist statements conveyed the idea of artmaking as being a vital, rewarding activity that they found energizing.

ARTMAKING AS A WAY OF ACHIEVING BALANCE

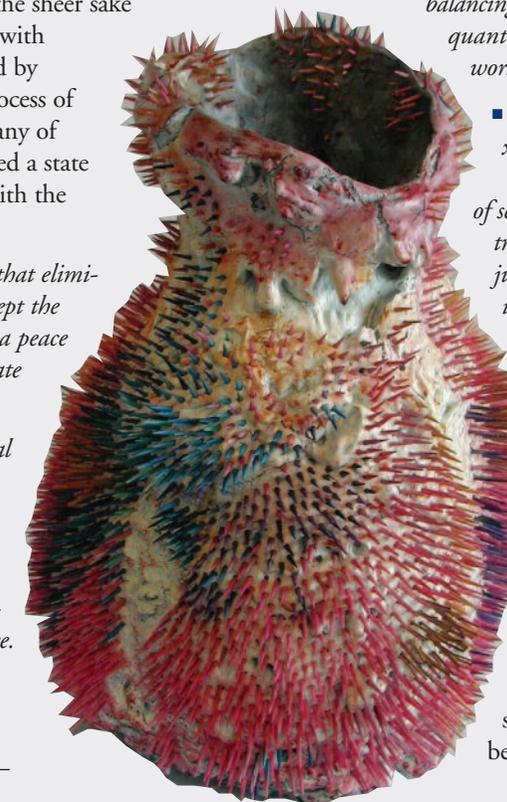
Work-life balance has been identified as an important strategy for promoting wellness among physicians and other health practitioners. Several HP-artists described how artmaking helped them to achieve an integrated balance in their personal and professional lives. As four different HP-artists put it:

- *My artwork provides a much welcome balance to all the other activities in my daily life. I have found that by creating art I have much more balance in life and that my well being is put into harmony quickly, reliably, and gently. Artistic creativity makes me feel more integrated in terms of body, mind, and spirit.*
- *As a medical laboratory technologist, my work day is very regimented, precise and highly interactive. There are pretty much rules for everything. Although some of this discipline does translate to art, there are basically no rules and painting is quite solitary and meditative. This makes it a pleasingly complementary activity to work. ... I think we need the balance.*
- *[Photography] allows me to enjoy and appreciate the complexity and variety of life’s experiences to be had, thus balancing the greater part of my life that is spent quantifying and categorizing the natural world with myopic focus.*

- *Sitting in a dark room and reading x-ray images with my gaze fixed firmly on my monitor, I try to make sense of seemingly meaningless interfaces, subtle transitions, and swirling masses of white juxtaposed upon black. ... After a long day in the dark, my senses are overwhelmed.*

The world is full of so many shades of color. Every glance outside my window yields endless possibility. ... My canvas sits in front of me. This time, I am the one producing something out of nothing, for someone else to interpret and put together. My art will take over now, allowing me to use colour to bridge the monochromatic pictures of my work ...

Some of the HP-artists described a strong and enduring interrelationship between their work in healthcare and



Kathleen Newman, MSc, Tangaroa’s Pitcher, mixed media sculpture 2007, exhibited at “After Work”

(continued on next page)

their commitment to artmaking. For example, as two HP-artists wrote:

- *There is a symbiotic relationship between my work life and the art that I create, not in my spare time, but in the balance of time that I am not providing respiratory care. Each feeds the other, pulls from the other, and informs the choices that I make.*
- *I began painting 15 years ago. ... I was looking for a focused outlet for my creativity as a balance to the stresses of work. ... Now I find that I need my work in healthcare to give me balance and grounding from my painting! The two complement each other perfectly. I have much enthusiasm for both my work in healthcare and my artistic work, as they both provide lifelong learning and improvement with experience.*

OTHER OBSERVATIONS

In addition to these thematic elements, HP-artist statements mentioned concepts such as enhanced perception, creative excitement, and feelings of intrinsic satisfaction. Many of the HP-artists described how artmaking offered a means of cultivating a frame of mind that fostered reflection, insight, and appreciation of what was meaningful to them in their professional and personal lives. Several also described how the inspiration and energy they experienced from being involved in artmaking helped them to cope with the daily challenges of their work. One HP-artist described her commitment to artmaking as personally enriching, but also viewed her artwork as a gift to others: “I hope that the peace that the work creates within me translates to those who come to view it.”

CONCLUSION

The artists among us often go about their healthcare work unrecognized. As amateur artists (for the most part, although notable exceptions exist), they are art lovers who attend to aesthetic aspects of the world around them. They devote time and energy to learning techniques and approaches that provide them with a level of mastery in rendering artistic visions inspired by both their personal and professional lives. Engagement in the arts can help bring an enriched presence of being, both personally and professionally, through cultivation of attention, awareness, and other reflective processes. Nurse and senior lecturer P. Anne Scott suggests that in relation to medicine, the “arts may stimulate: (a) insight into common patterns of response (common or shared human experience); (b) insight into individual difference or uniqueness; and/or (c) enrichment of language and thought.”¹⁰ These patterns of thoughtfulness may contribute to patient-centredness, and perhaps also to the experience of happiness and satisfaction in one’s professional and personal life. Future inquiry could productively explore the habits of mind HP-artists cultivate as they work to establish work-life balance and infuse their lives with joy and happiness. In contrast to the stereotype of the “tortured artist,” excerpts from HP-artist statements written for the “After Work” exhibit suggest that many of the health professionals who

participated in the exhibit view their arts-based involvement as rewarding and renewing; a marvelous, fulfilling activity. As Vanier wrote: “Aristotle is a wise man. He seeks to reinforce all the positive energies that might help the men of his time to become more human, more just, more open to others, and by virtue of this very fact, to be happier, or to rediscover the fact that they were made for happiness.”¹¹ It is not by *having*, but by *doing* what is positive and meaningful to us that we find happiness.

Sample of Online Exhibits of Art by Health Professionals

<http://physiciansart.com>
<http://creative.md/>
www.artbynurses.com
www.woundedinactionart.org
www.healthcarefineart.com

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Confidentiality & Consent Disclosure: The authors did not request IRB approval before analyzing the text of HP-artist statements because they were not embarking on a systematic review intended to produce generalizable knowledge. The authors did not seek affirmative permission from the HP-artists because these HP-artists originally wrote and posted their narratives as authored texts intended for public consumption. However, the authors chose to email the quoted HP-artists and give them an opportunity to opt out of having anonymous excerpts of their artist statements published. None opted out, and almost all responded with affirmative consents.

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- 2 M Bazargan, M Makar, S Bazargan-Hejazi, C Ani, & KE Wolf. (2009). Preventive, lifestyle, and personal health behaviors among physicians. *Academic Psychiatry*, 33, 289-295. S Taub, K Morin, MS Goldrich, P Ray & R Benjamin. (2006). Physician health and wellness. *Occupational Medicine*, 56, 77-82. V Yiu. (2005). Supporting the well-being of medical students. *Canadian Medical Association Journal*, 172, 889-890. J Wallace, J Lemaire, & W Ghali. (2009). Physician wellness: A missing quality indicator. *The Lancet*, 374 (9702), 1714-1721.
- 3 TD Shanafelt, JA Sloan, & TM Habermann. (2003). The well-being of physicians. *American Journal of Medicine*, 114, 517.
- 4 T Delamothe (2005). Happiness: Get happy-it’s good for you. *British Medical Journal*, 331, 1489-1490.
- 5 J Stone. (1985). Medicine and the arts. *Theoretical Medicine*, 6, 309-325.
- 6 MGM Curnen, H Spiro, & D St. James. (1999). *Doctors Afield*. New Haven, CT: Yale University Press.
- 7 SKH Aung. (2007). Integration of arts and medicine: Enrichment and enhancement in healing. *University of Alberta Health Sciences Journal*, 4 (1), 21-23. S Byth. (2004). The doctor is an artist. *The Medical Journal of Australia*, 181 (11/12), 626-627.
- 8 M Csikszentmihalyi. (1990). *Flow: The psychology of optimal experience*. New York: Harper and Row (p. 4). See also M Csikszentmihalyi. (1996). *Creativity: Flow and the psychology of discovery and invention*. New York: Harper Perennial.
- 9 Csikszentmihalyi. (1990), p. xi.
- 10 PA Scott. (2000). The relationship between the arts and medicine. *Medical Humanities*, 26, 5.
- 11 Vanier, 198.

A New Normal

Kristi Kirschner, MD with Ginger Lane

Twenty years ago, my new friend Ginger looked up at me from her wheelchair and offhandedly said, “You know, my life is happier now than it was before.” I was stunned. What did she mean? HAPPIER? How was that possible?

Ginger had acquired quadriplegia from a skiing injury about 5 years prior to that comment. She and I had become friends and colleagues in the early 1990s when we worked together with other women to set up the Health Resource Center for Women with Disabilities at the Rehabilitation Institute of Chicago. I had come to know her as a disability rights activist, a peer support coordinator, a grandmother, and a pioneer in disability dance. I also knew about a few more personal details of her life, including her divorce, her recurrent bladder infections, and her occasional problems with transportation and personal assistance. I understood that she had adapted, and perhaps was even thriving—but the idea she could see herself as *happier* than she was before she became a wheelchair user was incomprehensible to me.

I was fresh out of my residency then, working with patients with acute spinal cord injury. As a young physician I was very much in tune with the devastation some of my patients felt after the onset of their disability—and with how odd I felt when they didn’t seem devastated. Should I be concerned about a 23-year-old patient who always seemed upbeat? She was newly paraplegic from a horseback riding accident, and as far as I knew she never even cried or expressed sadness. It just seemed weird to me. Was she in denial? Or my patient who immediately expressed gratitude—for being alive, for second chances, for an opportunity to take his life in a new direction. Where was the sadness, the anger, the depression I had been conditioned to expect? I recently asked Ginger to reflect with me on the responses that bewildered me twenty years ago.



Ginger Lane and Anita Fillmore performing “Prayer.” Photo by Lisa Green

Ginger: Ever since I became disabled 25 years ago I've been intrigued by the attitude of most non-disabled people that disability is a fate worse than death. Or at the very least, that quality of life will inevitably be poor. I've found quite the reverse to be true for myself and for many of my friends. I want to see my children and grandchildren grow and learn and thrive, and I still want to experience new things. What made me happier after my accident is basically three things: developing new and meaningful friendships through lived experience; finding a new purpose, which is working to improve the lives of others; and discovering a different way of pursuing my first love, dance. But people assume the worst, and I do wonder why that is. Maybe because it's unfamiliar? Envisioning a life beyond one's own experience is difficult, it requires imagination and a willingness to move outside your comfort zone. Perhaps it also needs a risk-taking personality and a leap of faith.

Kristi: Over the last 22 years, I've come to know many patients like you. Not every patient shares your view, but a significant number do. I now realize that this response to disability shouldn't be so striking. What's striking is the astonishment we in the Western world (like me twenty years ago!) feel when we observe this possibility.

Ginger: I'm often struck by the reactions of those who see me on the street. Children are open and curious—"Wow, can I try your chair?" they'll ask. Adults are guarded and fearful. They say, or I get the feeling they're thinking, "Oh, I'm sorry. Is it permanent? Life must be so hard for you." Why are people so afraid of something different? Perhaps they fear losing their autonomy, even their identity. But we disabled are not childlike or dependent. We are teachers, doctors, artists, parents—we're productive members of society if we're not constrained by prejudice or barriers. We Americans put great emphasis on being fully independent, but that's a myth. We rely on each other for many things. What IS important for

people with disabilities is to be able to choose from a variety of options so we can determine and direct the care we may need. We want, in other words, to be in control of our lives.

It's not just Western culture that views life with a disability as "less than equal." I've met people around the world who are startled to see me out in public. (And by myself, without a health attendant!) Medical professionals in other countries have told me their disabled populations were mostly hidden away at home, cared for by family but out of sight. Their cultures had taught them that disability equals shame and failure.



Ginger Lane and Anita Fillmore performing "Prayer." Photo by Lisa Green

Kristi: So how did you find your path to wellbeing after your injury? And how long did it take?

Ginger: Finding peace and happiness took its own path, of course, and took a long time. When I broke the 6th and 7th vertebrae of my spine I became paralyzed from the chest down, with limited hand function. I was stunned to discover a profoundly altered body after my skiing accident. I asked myself, "What now? Am I still me? I can see my body, but I can't

really feel it. What does this mean? How will I live, care for myself, my family?" I was married with three children, and I was a dancer, teacher, and choreographer. Movement was essential to my life and I couldn't imagine living without full function. I asked my doctors if I would spend the rest of my life in bed. I was relieved to learn otherwise but still didn't know what to expect and I was very concerned about my family. Things like cooking, laundry, homework, and time together worried me a lot. Could I still be a good mother, a good wife? So Kristi, while you had some expectations of what life with a disability might be

like for your patients, I had absolutely none. I felt like an infant, needing to rely on others to blow my nose, turn in bed, or wipe a tear from my eye. I was tremendously sad and grieved my loss. I felt overwhelmed and strange. I wasn't really angry, but confused and scared.

Kristi: I've seen this too—that absolute fear, the sense of impotence when one is newly disabled. So what then? What helped you move on from that point?

Ginger: Well, I stopped thinking of my injury as an assault on my body, but perhaps an opportunity to find another "new normal"—me as a person with a disability. I learned what my body could do, what I could still feel. Occupational and physical therapy helped me get stronger, taught me to sit up by myself, roll over—things a baby could do so easily. Dressing was slow at first but got easier with practice. Still, working on these things was better than lying in bed feeling sorry for myself. This was my attitude—a pragmatic way to deal with the existing situation, and it worked for me. Some sessions with the staff psychologist were also helpful.

I also took comfort in seeing I was not alone. Everyone on my rehab floor had spinal cord injury and was dealing with the same physical and emotional issues. All in the same boat, we commiserated, struggled, and cheered our successes. When we ventured out as a group we laughed and stared back at passersby who stared at us! These outings helped restore our self-confidence.

Then I got home and had to figure out how to get milk from the fridge, scramble eggs, and get a sweater from the top shelf without the support of rehab staff. Yes, I had to make adjustments, and they weren't just the physical ones of squeezing through tight doorways, looking for ramps, or handling dressing. I needed to plan how I could participate in family activities—like on bike trips, I decided that I'd drive the van and set up hotel and dinner arrangements. That way we could still have fun together.

Kristi: Some of what you describe seems intrinsic to **you**—to your character and personality. Researchers who study resilience and positive psychology talk about an emotional "set point." For instance, if we are asked to rate the satisfaction we feel with life over the last month on a scale of 1-10, with 1 being a state worse than death and 10 being ecstatic, most of us would be about a 7. In other words, we tend to be pretty satisfied with our lives. Though life events can cause momentary perturbations one way or the other, over time the majority of us

tend to drift back to our life satisfaction "set point." That's whether we win the lottery, whether we are born into poverty in Calcutta, or whether we have a spinal cord injury. Do you think this is true? And if so, why?

Ginger: Yes, I think that's very true. In the article "The Victorious Personality" (NYT magazine, May 20, 1986) writer/lecturer Gail Sheehy explored the concept of resilience. Through numerous interviews she found that those who had lived through a traumatic experience early in life either were naturally resilient or had developed particularly good coping skills that would help them through later difficulties.

Like the survivors Sheehy studied, I had some trauma in early childhood. I was born in Berlin at the beginning of World War II. After my mother was killed in Auschwitz my siblings and I survived the Holocaust by living in hiding. After the war we stayed in three different refugee camps before coming to America where I was adopted by an American couple after first living in several foster homes. I learned a new language, got used to a new name (my old one sounded too German), adapted to new customs, new schools. With this new identity I established my first "new normal" and was very happy. Perhaps this early experience enabled me to deal successfully with my later accident. I had returned to what I call my "core personality." This would correspond to your "set point."

Kristi: Wow—that's intense! So you came to your injury having not just survived but thrived after earlier life trauma. How did you get from learning how to live with your spinal cord injury to becoming the engaged community member and activist you are?

Ginger: I visited a disability rights organization where I felt the comradeship of people viewing the world through the same lens: the disability lens. Folks were engaged in peer-to-peer exchanges; activists worked for equal rights. An acceptance of self does not mean an acceptance of a given circumstance, and I learned I wasn't the only one who needed

to adjust, society had a responsibility to promote and protect our rights too. I started working to improve access to health care and housing, remove barriers that create isolation, and provide support. Choosing to working on disability issues gives me a sense of purpose and enhances my self-esteem. And the added bonus? I met friends like Judy, Rene, and Riva because of my spinal cord injury, and they exposed me to a world I would never have known. That's why I say my life is happier than before. Before it was full, now it's fuller. It's richer.

Kristi: I assume that doesn't mean that there aren't difficulties. My patients tell me that there are still many daily frustrations of living with disabilities. Personal assistants or transportation services may not show up, the wheelchair can break down, the catheter can leak, a restaurant or store entrance may be inaccessible. But such frustrations don't capture the totality of their life experiences.

Ginger: I don't think adapting to new circumstances is sufficient for wellbeing. Happiness can only occur if one has an inner sense of self and is able to say, "I am what I am" without apology. Sometimes a life-altering event is an opportunity for self-discovery, for examining values and re-evaluating priorities. It also means acknowledging random moods of discontent. I've learned to accept mine and know they are temporary.

In psychiatrist Viktor Frankl's seminal work *Man's Search for Meaning* (1946), he writes that life never ceases to have meaning. Frankl spent four years in a Nazi concentration camp, lost his wife and entire family, and was stripped of his profession and writings. Still he chose to continue his life's work in his mind. This enabled him to not only survive but to find meaning through his suffering. Though man may not always be in control of his life, he can choose his attitude towards a given circumstance. He always has a choice.

(continued on next page)

Kristi: The importance of meaning seems central to your life and sense of wellbeing. You described earlier how working on disability civil rights issues was critical to you; it also strikes me that your work in creating new art forms in dance is another source of deep meaning. In a *Chicago Tribune* article about your performance of a piece called *Prayer* in Momenta's recent dance concert you said, "It is not about overcoming my disability, it is about contributing to dance and pushing the boundaries and expectations of movement.... It is like getting older, we all have limitations. We can't do the same things we did when we were 18, so we have to learn to adapt our thinking, or in this case, choreography, to fit the current situation."* How did you learn this? It's amazing to think about how you went from learning to sit up again to exploring the possibility of wheelchair dance—that's a real leap!

Ginger: My rehab friends taught me to wheel backwards, pop wheelies, and spin like a top. That wasn't work, it was fun. So I started experimenting with different arm movements and speeds and I began to feel like my old self—a dancer again. A lot was trial and error but I kept at it, knowing it was also a good way to exercise. Somewhere along the line I met Alana, also a dancer. I joined her young company and then added choreography to performing. Dance gives added meaning to my life.

Kristi: I'm amazed (and a bit chagrined) at how off-base my biases and assumptions were as a young physician, but we really weren't taught much about disability in medical school. Most of what I've learned has been from my patients over the years, and what you describe resonates so well

with these experiences. Though the loss of physical function with disability is often devastating initially and results in a plummeting sense of wellbeing, I've seen over and over that people feel very differently two years later. You talk about the importance of relationships in your "new normal"—to love and be loved, as well as the need to have a sense of purpose or

The dance "Prayer" is the story of a mother and daughter set to the music of Franz Schubert. Ginger also interprets it as a personification of the pre- and post-disabled self, and what it means to let go of one dream and give flight to another.

To see a video of Ginger Lane performing Prayer, see <http://vimeo.com/9591596>



meaning in one's life. Being "free from want" is another recurring theme in the lives of my patients. People need basics like accessible safe housing, durable medical equipment, transportation, and personal assistance services, and that goes back to the importance of your work in disability rights. But I want to return to question of happiness. Twenty years ago you told me you weren't just "as happy," you were "happier" after your accident.

What do you make of that now? And is it really happiness, or is that word a surrogate we use to describe something else—like contentment, wisdom, joy, or inner peace?

Ginger: *I think happiness is all the things you mention: wisdom, inner peace, feeling comfortable in your own skin, forming relationships, engaging with the world, and feeling successful at something, whether it's running a marathon or baking a cake or closing a business deal. It doesn't really matter what we call it; if we feel good about ourselves that's happiness, isn't it? There's a great feeling of freedom when you don't have to explain yourself or make excuses for who you are. Maybe that's a benefit of getting older. And Kristi, I don't think you should be chagrined at your early assumptions, they were natural. So much depended on your exposure and early experiences. But think how far you've come!*

* Elizabeth Vassolo, "Disabled dancer reaches for dreams in 'Prayer,'" *Triblocal*, 03/01/10. Viewed June 13, 2010 at http://www.triblocal.com/Glen_Ellyn/detail/148593.html

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THE PLEASURE OF BIOETHICS

Tod Chambers, PhD

Why do people "do" bioethics? If we assume the majority in bioethics are involved of their own volition—that is, few of us have family being held captive by radical bioethics terrorists who are forcing us to do this activity, and even fewer are in it for the money—then what's the motivation for being in the discipline? What does it mean when health care professionals say that they have an "interest" in bioethics as if it were a hobby? Anthropologist Mary Douglas once noted that a good beginning question to ask of any social activity is, "What do these people get out of doing this?" So what do people get out of being bioethicists?

I suspect that one of the primal pleasures is the intellectual puzzles that are raised in bioethics. In *The Pleasure of the Text* (Hill and Wang 1975), literary critic Roland Barthes distinguishes between two types of pleasures that one receives in reading a text. The first is simply the normal pleasure of experiencing a text that in essence confirms our cultural assumptions: this would be the kind of enjoyment one would experience in reading an Agatha Christie mystery. The second type of pleasure is bliss, which is experienced when the text "discomforts ... unsettles the reader's historical, cultural, psychological assumptions,

the consistency of his tastes, values, memories, brings to a crisis his relation with language" (p. 14): this is the kind of enjoyment one receives from reading, for example, a postmodern mystery by Jorge Luis Borges.

Bioethics also has these two forms of pleasure: the normal pleasure of ethics cases where one comes to confirm the basic moral principles of medical ethics, and the bliss of cases where there is a profound unsettling of philosophical assumptions. The kind of enjoyment we receive from being in the field, I believe, has profound implications for the kind of issues the discipline decides warrant investigation and those that are thought uninteresting. When we speak of "great cases" we're usually speaking of blissful ones; cases that don't merely require resolution, but rather require us to rethink central convictions. Yet these blissful cases are, like the "interesting" cases of clinicians, usually the result of horrible, tragic events in other people's lives. Like the goddess Aphrodite who took the war god Ares as her lover, the deepest pleasures for bioethicists may come not from decreasing conflict, but from discovering new conflict.

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Havidol: "When more is not enough"

Artist Justine Cooper parodies direct-to-consumer pharmaceutical marketing for lifestyle-enhancing drugs through the savvy, multi-faceted campaign she's created for her fictional drug Havidol ("have-it-all"). At <http://havidol.com> consumers can learn about the discovery of "Dysphoric Social Attention Consumption Deficit Anxiety Disorder," complete a self-assessment checklist to print and bring to their doctor, and watch testimonials of happy patients cured by Havidol. In galleries, Cooper has exhibited the Havidol print ads she has designed to look at home in different magazines, like the one below. (People magazine, Havidol Print Ad, 2007.) In 2008-09 Cooper was Artist-in-Residence at the Center for Medical Simulation in Cambridge, Massachusetts, and that led to her most recent project: "Living in Sim" uses medical mannequins to explore the complexities in the current online media and healthcare environments. *More information on Cooper's work can be found at <http://justinecooper.com>, and she can be contacted at mail@justinecooper.com.*



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See important additional patient information on the next page.

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