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.

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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 A.J. because he is deceased.
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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 experi- ence 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 tell 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 respect- fully, 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 vehicle—her 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 should be an arbitrary gestation- al 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 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 that 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 overly suicidal patient, they might suggest not “aborting” the baby but putting it up for adoption. “Thirty Clues” (”Shogun Adoption” September 2009) focuses on the resurgence of mainly Christian homes for unwanted 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 can give it to a family that already has one 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 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 about herself and that she doesn’t know what’s best for her post-birth human being. In this model, unwanted preg- nant 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 woman? 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 women.”

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 mistrat- ed, 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’ 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 gro- cery stores and I don’t want to be one of those girls.”

This teenager was condemned to the “dungeon of mandatory motherhood,” to quote Dr. Tiller, because life circumstances brought her to our clinic. “I went to the clinic and we deny 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 opposition. 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 July 2009 she was mentored by, and practiced with, Dr. George Tiller. She is honored to be able to contact the former patients represented in this article, they would have given her per- mission to use that de-identified information, 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 stories and voices with the author over the years.

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

O, happy dagger!
This is thy sheath. There rust, and let me die.

—William Shakespeare, Romeo and Juliet (Act 5, Scene 3)

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

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, love, in the tomb and in death. The line's primary meaning. Juliet has 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.

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

A tragic flaw 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 at Juliet's death, 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, unluckily, 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 "happy ever after" of comedies and fairy tales, with their reunions and weddings, relies for its meaning on the silence that follows it. Happiness in an extended period is so elusive that there may be no story-teller who can describe it without exquisitely diluting it. 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.

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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 a fact. Afflect is the display of experienced mood and emotion. As such, it is socially conditioned behavior. Proper Minnesotan Scandinavians do not wail their dead; they get dour—a mood in which their characteristic philosophization 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 person could spend a full lifetime boating, and still not achieve a feeling of human consciousness was the foundation of health. Victor Frankl, founder of logotherapy and author of the phenomenologically 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 slide 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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Steven H. Miles, MD

Advertisers, drug manufacturers, and strooms are largely to blame for the muddled state of happiness. It is hardly possible to talk about happiness today. A jumble 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 peculiarity. 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. Bilious, 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 function as emotional furnaces. Dysthymia and phlegmatism congeals to hardness (from Latin: durus).

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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 at 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 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 felt filled 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 what when 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 teaching him personally difficult, and became the absolute person who could recognize him is unlikely to read this article. The author has chosen to publish de-identified information so that the content of the physician-patient relationship might reach the intended audience. 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.
Is Satisfaction Enough?

A practitioner of sado-masochism changed my thinking about patient happiness. I was a new nurse 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 your contract.”

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 he was being prepared for a mammogram. He had been told 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 satisfied with the care he was receiving in the hospital—“there’s more and more of it than anyone can handle, whether Ehrenreich’s definition and mine might blur when caregivers consciously strive to have happy patients, creating a kind of ‘happy as is happy’ 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 missapplied to require patient cheer. Instead, we should see some kind of 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 made happy for their own sake.”

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 conceptionalize our measurement of patient responses (to surveys) as their ‘satisfaction’ with care. There’s not some interesting differences in these ideas.” 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. 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, evidence 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.” 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 makes 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; he 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 were happy, as well as those who were “constantly breaking [their] contracts” with him. “Doctors and nurses are responsible for their high level of satisfaction with the care given to them and the deceased patient. Some families had recalled caregivers providing pillows, coffee, or a private space for family to gather outside of the patient’s room. They also cited these considerations with the deceased patient, 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 me.” 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—somehow beyond satisfied to happy ones—with the 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, but 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.1 John Griffith, a professor at the University of Michigan School of Public Health, evaluated the difference between the University of Michigan and Atrium Health, which 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 more ready 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 delivered. Interestingly, the term “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 ways in which hospitals he studied had the “happiest” patients and caregivers.

Patients and their caregivers have a shared fare. As David Blart, 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.
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.” The “fight” can take many forms, from coming 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 felt judged and resentful 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.”5 As Kathryn 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.6

“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.”10

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.

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.”

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 tried hard enough.

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.”

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. 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.”9 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.”9 Frank highlights the importance for those living with chronic illness to determine “how to live a good life while being ill.”11 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.”11

(continued on next page)
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.10

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."11

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 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.
The many arties 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 realms 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.” 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 (hidded 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, narrative, and moral) with three other realms of knowing, or “ways of knowing.”

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, we will be looking to our learning work will be driven by a synesthetic 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 Blakely, Robert Marshall, and Rainer Brunner of Peninsula Medical School in the United Kingdom describe as a living aesthetic text—“a creative, not-quite-containable aggregation of ways of knowing that reveals and revels in complexity.”

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.”

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Leaving the hospital after a 30-hour shift, I squint in the bright sunlight as I walk past cafes 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 at home in the sun

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.

And life moves on.

“What is your favorite memory?” “What’s the worst?” “How do you do what you do?” These and similar questions come at you over and over, sometimes with sincere curiosity, sometimes with a sort of reverence, as if to touch the mystery of what we do directly. We are not that sure what to say, not that our memories are remarkable—no, it is the places in between, the times we don’t remember that are the ones we would like to keep. It is the sense of something beyond words that is shared, or something that is beyond us that we share.

Lazar Lazlo, 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: “And life moves on. " ‘Terror and a beauty insoluble are a riband of blue woven into the fringes of garments of things both great and small.” Accepting the insolubility of the equation, the chaos of the situation, and our own confusion and discomfort is what allows us to truly feel alive.

Tinker Creek, Virginia Blue Ridge Mountains. Photo by Tonya Green Breese.

Sabrina Derrington, MD

An Illuminating Shadow

In the 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 inexplicability 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 irresistible 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 irrevocable condition of things. ‘There is no light in the world, no sign, 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 tubes, 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 that life work, the work of the world, is still going on.

Lazlo Foldényi, 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: “And life moves on. ‘ ‘Terror and a beauty insoluble are a riband of blue woven into the fringes of garments of things both great and small’” (27). Accepting the insolubility 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 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 all be worth it. 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 enraptured in the rising and falling real world” (224).

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Tinker Creek, Virginia Blue Ridge Mountains. Photo by Tonya Green Breese.
ARTISTS AMONG US: Happiness as an element in health professionals’ artist statements

Pamela Brett-MacLean, PhD, Michelle Gevaart BFA, and Diana Young Kennedy, MS

Aristotle believed that human beings are “made for happiness,” philosopher Jean Vanier argues. 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. 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.” 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.

Artmaking is an avocational activity some healthcare practitioners engage in, often in a serious, committed way. John Stone, an emergency physician and poet, included suggestions for enhancing happiness through activities pursued in one’s spare time.

In 2009, we organized a juried art exhibit called “After Work” which was hosted by the McNally 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 work 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 must 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 me 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.” He associates flow with optimal experience, characterized by feelings of “joy, creativity, the process of total involvement with life.” 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 person’s need to disengage 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 —

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 experiences to be had, thus balancing the greater part of my life that is spent quantifying and categorizing the natural world with a mystic 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 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.

(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 other reflective processes. Nurse and senior lecturer P. Anne Scott describes her relationship 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.” These patterns of thoughtfulness may contribute to patient-centeredness, 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 and artistic work that HP-artists cultivate to 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 reinvigorating, a marvelous, fulfilling activity. As Vanier wrote: “Artsotle 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.” It is not by hating, 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 enacting on a research study with a identifiable 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 strand 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.


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 her 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 first struck by her tendency 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 their injuries. I feared their anxiety and with how odd I felt when they didn’t seem devastated. You should be concerned about a 23-year-old patient who always seemed upbeat? She was not really typical from a traumatic 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 the injury, 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 tree. I just casually asked Ginger to reflect with me on the responses that bewildered me twenty years ago.
Ginger: Ever since I became disabled 25 years ago, I’ve been intrigued by the attitude of many 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 opposite to be true for many of my friends. I want to see my children and grandchildren grow and thrive, and I still want to experience new things. What made me happy after my accident was 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 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 astonishing way in which we in the Western world (like me too) saw in the 1970s and 1980s how people with disabilities are 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 their disabled populations more hidden away at home, cared for by family but out of sight. Their cultures had taught them that disability equals shame and failure.

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? Can I 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, I had none.

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 collaborated, struggled, and cheered our successes. When we ventured out as a group we laughed and stared back at passersby who were, well, passed over! Those 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 new, but “impossible” to get onto your body, 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 a plan how I could participate in family activities—like on bike trips. I needed a plan how I could participate in family activities—like on bike trips. I needed to plan how I could participate in family activities—like on bike trips.

Kristi: Some of what you describe seems intrinsic to you—to your character and personality. Researchers who study the concept of positive psychology talk about an emotional “set point.” For instance, if we are asked to rate the satisfaction we feel with life the last month on a scale of 1-10, with 10 being ecstatic, most of us would be about a 7. In other words, we tend to be satisfied with our lives. Though life events can cause momentary setbacks or 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 you do this 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 and 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.

Kristi: What made me happy after my accident was 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.

Ginger: 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, still move—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 living 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.

Kristi: I started working to improve access to health care and housing, remove barriers that create isolation, and provide support. Choosing to work on disability issues gave me a sense of purpose and enhanced 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 full. It’s richer.

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

Ginger: So Kristi, while you had some expectations of what life with a disability might be, I had none.

Kristi: Interesting! So you came to your injury having not just survived but thrived after earlier life trauma. How do you get from learning how to live with your spinal cord injury and being the engaged community member and advocate you are?

Ginger: I visited a disability rights organization where I felt the camaraderie 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 what’s 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 work on disability issues gave me a sense of purpose and enhanced 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 full. It’s richer.

Kristi: I assumed 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 told me their disabled populations were more hidden away at home, cared for by family but out of sight. Their cultures had taught them that disability equals shame and failure.

Kristi: What made me happy after my accident was 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.
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 was critical to you; it also strikes me well being. You described earlier how seems central to your life and sense of meaning to my life.

What do you make of that now? And is it really happiness, or is that word a surrogate for 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 embarrassed at your early assumptions; they were natural. So much depended on your exposure and early experiences. But think how far you’ve come!


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Ginger Lane has been a dancer, teacher, and choreographer for over 40 years. She has been employed at Access Living for 21 years as Coordinator of Peer Counseling Services for the Rehabilitation Institute of Chicago, Schwab Rehabilitation Hospital, and other hospital settings. She is currently Arts & Culture Coordinator at Access Living, and she is a member of MOMENTA Dance Company. glane@accessliving.org

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

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 territory 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.

Tad Chambers, PhD

The THE PLEASURE OF THE BIOETHICS

Artur 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,” 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 in different magazines, like the ones below (People magazine, Havidol Full Page Ad, 2008). 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://arturjustinecooper.com, and you can be contacted at Artur@arturjustinecooper.com.