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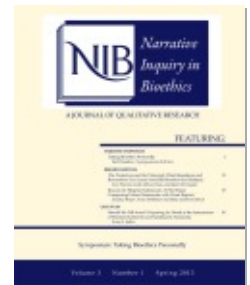
## No Surprises, Please!

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## Taking Bioethics Personally

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**Abstract.** This narrative symposium examines the relationship of bioethics practice to personal experiences of illness. A call for stories was developed by Tod Chambers, the symposium editor, and editorial staff and was sent to several commonly used bioethics listservs and posted on the Narrative Inquiry in Bioethics website. The call asked authors to relate a personal story of being ill or caring for a person who is ill, and to describe how this affected how they think about bioethical questions and the practice of medicine. Eighteen individuals were invited to submit full stories based on review of their proposals. Twelve stories are published in this symposium, and six supplemental stories are published online only through Project MUSE. Authors explore themes of vulnerability, suffering, communication, voluntariness, cultural barriers, and flaws in local healthcare systems through stories about their own illnesses or about caring for children, partners, parents and grandparents. Commentary articles by Arthur Frank, Bradley Lewis, and Carol Taylor follow the collection of personal narratives.

**Key Words.** Illness narratives, bioethics, clinical consultation, narrative symposium

### Introduction

A few years ago at a national conference I got into a conversation with a prominent bioethicist. She recalled that in the early years of the development of bioethics, she had been a part of a working group that focused on, what was commonly referred to as, euthanasia. On the first day, they spent the morning carefully prying apart the various forms of passive and active euthanasia, the definition of natural death, and the importance of refining what was considered a “good” death. When they took a break for lunch, they discovered during the casual conversation that all of the members of this working group had been involved in the care of a dying

family member, an experience that had profoundly affected how they thought about the very issues that they had been brought together to discuss. After lunch, they returned to the conference room and resumed their philosophical discussion, yet the personal revelations and insights of the prior hour were never mentioned as they continued their analysis of the proper care of dying.

I find these type of narratives in bioethics particularly fascinating. For an intellectual discipline that attends to morbid matters that we must all face (disease, death, tenure decisions), it is striking that there has been so little attention to the embodied world of the bioethicist. In my home discipline of comparative religion, the scholar Wilfred Cantwell

Smith characterized academics studying religion as akin to “flies crawling on the outside of a goldfish bowl, making accurate and complete observations on the fish inside, measuring their scales meticulously . . . but never asking themselves, and never finding out, how it feels to be a goldfish” (1991, p.12). Bioethicists have tried with various degrees of success to understand how it feels to be a sick goldfish but they seem to believe that they, themselves, are flies outside the fish bowl while in reality they are goldfish as well, waiting their turn to join the ranks of those they are observing. Susan Sontag begins her anti-metaphor book, *Illness as Metaphor*, with a striking metaphor; she notes that we are all born holding “dual citizenship, in the kingdom of the well and in the kingdom of the sick” (1990, p. 3). Even the most blessed of us will at some time be “obliged, at least for a spell, to identify ourselves as citizens of that other place.” This issue of *Narrative Inquiry in Bioethics* has as its focus the manner in which that journey, either by oneself or as a travel companion with an other, alters how we think about the moral issues involving the citizens of that other kingdom which we considered as we lived in the kingdom of the well.

We asked the contributors to this narrative symposium to relate personal stories about the experience of being ill or caring for a person who is ill. We were particularly interested in those stories that changed how they thought about a moral problem in medicine. We wanted to know what insights into bioethics they had after an illness experience, insights that could not have been gained save for such an experience. In what manner do the moral social scripts that they carefully constructed for the physician–patient relationship suddenly need to be radically altered when they became a part of such a relationship? If they had such an experience before entering the field, would it have altered the way in which they thought about bioethics? And, finally, did this illness experience change how they think about the field of bioethics, itself. Do we need to rethink bioethics as a practice?

We sent this call to a few of the most used listservs in bioethics, and we received a remarkable

number of responses from those in the bioethics community. On reflection this seems to have been both surprising and not surprising at all. It is of course unsurprising that we have all been touched in some manner by illness and death. But the number of stories from the various people who contributed to this project were also surprising in that these stories of sickness which had so powerful a resonance with their understanding of bioethics had simply not been a part of their writing until now—the one notable exception being Rebecca Dresser (2011). The relationship between the intellectual autobiography and the biological autobiography can present itself in a number of complex ways. We may have illness experiences that so profoundly affect how we see a subject but they exist as a secret subtext under the scholarly text. I believe it was the rhetorician Kenneth Burke who asserted that we more often reach a conclusion then move backwards to create an argument for it and thus in a manner always presenting our arguments backward to the way we came to understand ourselves. Or to put it simply, as the Queen pronounces to Alice, “Sentence first—verdict afterwards.” As I write this introduction, the conservative senator Rob Portman publicly revealed that he has reversed his stance against gay marriage. This reversal did not come about because he had a radical shift in his political ideals, for he has unambiguously asserted that it was brought about by his son’s disclosure that he was gay. Portman’s earlier position, he stated, had been rooted in his own experience within a faith tradition that “marriage is a sacred bond between a man and a woman.” Some commentators on this story have presented Portman’s decision as indicating that he will change his political positions in relation to what makes his life easier, yet others have seen Portman as someone who has the courage to change his positions in relation to his life (Gabriel, 2013).

The essays that I find the most interesting are those, like Portman’s story, that reveal how our personal experiences alter our various philosophical positions. I do not wish to suggest that I believe—or in any manner advocate—that personal experience should “triumph” over philosophical reflection in

the field of bioethics. I do believe that these essays do bring forth questions that need to be addressed in bioethics, but in the face of the various epiphanies in these essays I have become most curious of the manner in which bioethics has been thought through the perspective of a “healthy” persona. My interest in this feature of bioethics has been profoundly influenced by Arthur Frank, who has graciously agreed to be one of the commentators for this issue of the journal. Frank has been one of the most powerful critics of bioethics for the manner in which it has emphasized the clinical perspective over that of the patient’s, abstract analytical papers over illness narratives (1997). For Frank, the essays provide a rich exploration of the “microethical.” The second commentator, Bradley Lewis, has also brought a unique perspective to the field of bioethics. Lewis a psychiatrist as well as a cultural studies scholar, brings to bioethics a concern for issues of power, representation, and the construction of dominant medical narratives (2006). His commentary provides a close reading of how the cultural construction of normality is expressed in these personal narratives. Finally Carol Taylor, trained in both nursing and ethics, attends to Donald Schön’s notion of “reflective practice,” and she observes a striking feature of these personal stories, the narrators rethought how they approached medical ethics education. Schön’s notion of the reflective practitioner, which he thought of as a key feature to advanced education, should make us wonder if bioethics as a practice needs to explicitly reflect on the relationship between our biological biography and our intellectual biography.

## References

- Dresser, R. (2011). Bioethics and cancer: When the professional becomes personal., 41 (6), 14–18.
- Frank, A. W. (1997). *The wounded storyteller*: Chicago: University Of Chicago Press.
- Gabriel, T. (2013, 4 April). Doubts and Downloads in Ohio After Portman’s Shift on Gay Marriage. *New York Times*. Retrieved from <http://www.nytimes.com/2013/04/05/us/politics/senator-portman-ohio-fallout-shift-same-sex-marriage.html>
- Lewis, B. (2006). *Moving beyond prozac, Dsm, and the new psychiatry: The birth of postpsychiatry*. Ann Arbor: University of Michigan Press.
- Smith, W. C. (1991). *The meaning and end of religion*. Minneapolis: Fortress Press.
- Sontag, S. (1990). *Illness as metaphor ; and, AIDS and its metaphors*. New York: Doubleday.

## Personal Narratives

### Nourishing my Grandmother’s Soul

Ayesha Ahmad

‘*Bismillah*’ . . . ‘*Bismillah*’ . . .

These were sounds of a whisper, worshipping ‘*In the name of God; Most Gracious, Most Merciful,*’ but they strung through the air, holding onto moments that lost their meaning of time.

My grandmother’s voice resonated infinitely.

I heard her. I heard her many silences; her heart fell quieter, falling from life. Her prayers found a union elsewhere, closer to somewhere that was not here. Her stories stole the space of the sky, leaving her narrative floating, softly ebbing away.

I heard her hunger—a crying connection to the rhythm of her life—the dawns and the dusks and the gatherings of a day’s blood, nourishing a continuation of tomorrow.

Grains of her origin rained over us. From a village, hiding beneath mountains and the crescent of a particular moon, my grandmother was born, cradled and nurtured by a creation of eras old.

Through passages of time, my grandmother had travelled, treading upon different lands, but her hands, her hands always held the soil that held her soul.

Then, today; today she lay, shrouded by whiteness and invaded by an artificial life; tubes taking her breath, a machine counting the heartbeats that we once danced to, and chemicals replacing the purity and simplicity of a life as clear as water.

My grandmother transcended life—yet, she was still dying.

In Islam to be nourished is to fulfill life and to fulfill death. To die a ‘good’ death is to die nourished.

Between my grandmother and the doctors, and us, stood a bold question—on her dying day, should we invade her body further and insert the means for artificial nutrition?

Islam prohibits the withdrawal of hydration and nutrition at the end stages of life. However, these requirements to maintain nourishment may be fulfilled by means such as oral swabs to keep the mouth moistened or interventions such as a nasal–gastric feeding–tube. The underlying tenet is be preparing for the next life; to be nourished physically, as well as spiritually.

During a Muslim’s life, fasting (saum) during the period of Ramadan is one of five pillars of worship, faith, and religious practice. Fasting is not obligatory among the ill or affirmed. A purpose of fasting is to achieve a purification of the soul through engaging in spiritual reflection and reducing our attention to our physical needs. Although during dying fasting is not practiced as nourishment is vital to prepare for the next life, the significance of Ramadan emphasizes the realms of our existence—we are not constrained by our bodies. In an Intensive Care Unit (ICU), being unable to converse in a shared language, and entangled with technological apparatus add to the feeling of a loss of agency due to the body’s condition. Being spiritually free is a graceful recognition of our dignity.

## Entering Death

Our suffering is a relief. Through our suffering we can obtain a purification of our sins. Our hardships, illness, and tragedies are moments ascribed for the story of our life. Our story is never our own narrative. The owner must only be Allah, solely. Our story is very important because it was created before we were born. Our births and our deaths were written before we could see—and yet, we never fully see. Our physicality is a limitation; we are formed through our extension in time and space, but this encloses us to perceptions akin to the surroundings

we live in, defined by our experiences and the lands we seek close by.

Dying is a release from our earthly boundaries. Our restraints begin to ebb away. We find a new way of being. This is why the journey of our death needs to be carefully prepared for.

*“We have removed your veil (of worldly perception) so your power of sight is now really sharp” (Holy Quran, 50:22).*

Preparing for death requires a great magnitude of insight and sometimes requires an ability to separate from our emotive instincts. Caring for a relative, and juxtaposed with expertise in ethics, and medicine, we can hold different loyalties—how may a perceived sacredness of medicine interact with the absolute sacredness of the body? Here, there are different invocations of sacredness; medicine primes its sacredness through knowledge—our medical practices are inherently focused on innovating the body’s functional integrity in order to annihilate disease. A spiritual sacredness, rather, reminds us of the temporality of our body.

From here, we find the sacredness of our body—the body is the “origin and destiny” of God (Sachedina, 2005)—the body is the seat for our spiritual existence. In this sense our teleology—our final cause—for how we act towards the body is to meet the ideals of purification through prayer, rather than trying to return the body towards the life we knew away from the divine time when we are to embrace our death. Whilst we are dying, we will turn so that we are facing Mecca, facing the next life.

## Purifying the soul

The preparation for our death is a form of purification. Our body becomes the means for mediating our continued spiritual existence and our transition for the next life; for determining the place where our souls are to remain until the Day of Judgment—God’s final word on humanity. Some souls remain in their grave, whilst others will stay above the skies, or be at the highest point.

A decision to provide nourishment for a dying Muslim who is unable to undertake the tenets of good health—feed and hydrate oneself—is subject

to the tenet of purification. We are merely keepers of our body—our body ultimately belongs to God, thus we must care for our bodies and we must not hasten death. Nutrition and hydration thus represent a respect for the perseverance of life as well as a preparation for death. Only God knows our time of death; we can make our assessment of our human condition but only God may take us to return to him. We must make our decisions accordingly—not to hasten death, and also to respect that for a Muslim a death is a blessing—we continue into the next life, we remain somewhere.

Creation is ultimate and absolute. Our lives and our deaths are not distinct—supplying nutrition allows us to respect the sacredness of both and at times such as these moments with my grandmother, I discovered that our modern medicine structures life and death as conflicting dichotomies. We cannot sustain one without exhausting the other. To make a claim that a decision to ensure my grandmother is nourished so her death is prepared for and for a good afterlife is nonsensical to a system that grounds its view of who we are based on empirical observations of what is life and what is death. Nourishment in this context only serves to issue sustenance to the physical body, and the physical body is only held in living.

To treat death as having matter is not translatable to a discourse where only the tangible is permitted and prioritized; and nourishing with the purpose to embrace both life and death conditions, representing the physical and spiritual, is a relationship that challenges ethical reasoning in our clinical contexts. Persons are recognized in medicine of course, especially their narratives, but personhood is premised on the existence of the body—a debate we encounter most vividly at the beginning of life. A body that serves as a ‘temple’ (Sachedina, 2005) for this life is a different ontology for being a person.

## Concluding

The body, until death, is part of a constellation of relations. We may delve into decisions about the treatment of another individuals’ body because we are sharing the phenomenon as a created being by God. We may be guided by the referential we use

within our methods of worship; through scriptures, community, prayer, and faith. Yet, our gaze forms also from our hearts, and only God knows our written story. Somewhere, though, within ourselves we also know because our Creator gave us a gift to be our own narrator. In the uncertainty, therefore, of a hospital whereby the lights illuminate the body’s pattern of death, we have our narrative to find. Through prayer, there is clarity. Nourishment at the end-of-life may also ensure a person’s consciousness remains alert enough for prayer; prayers for finding one’s narrative, and finding one’s own mortality, seeking forgiveness, and remaining close to God during the passage between lives.

The French philosopher, Jean-Luc Nancy (1993), writes existence is a cradle for our birth and death, both of which are only ever known by others. I wrote earlier about the land—the soil that held my grandmother’s birth. Now her imparting death was becoming and the grave very different from where she was born. But our origins and ending are always with God; we return to the same place. From here, I could navigate the contrast of the spirit of my grandmother’s, now ancient, land, with where she lay now, receiving oxygen not from the wild winds within the mountain’s enclaves, but travelling through the plasticity of containers and tubes into a heart that remained hers only.

Nourishment, as I have described, symbolizes our greatest appreciation for our created lives—and deaths. Yet, a nasal-gastric tube is an alien object; it appears in a context claimed to be value-free, neutral, rootless in culture or morality. Our metaphysics for using the nasal-gastric tube as a tool needed to be reconciled with our own telos. The decision to insert, almost invade, the body is hard to illustrate in my mind’s imagery, where I see all the histories of my grandmother’s narrative colliding with the strangeness of medicine, where medicine is the Other; yet I am used to the patient as the ‘Other’. This discrepancy was a challenge.

Similar to the relationships and narratives discussed so far, the final decision to insert a nasal-gastric tube was also a conglomeration of voices from the body, the soul, Medicine, and prayer.

Whilst in prayer (Salah) in my grandmother’s hospital room, a few hours before the procedure



was due to take place, the praying became her final time and held her death.

## References

- Nancy, J. (1993). *The birth to presence*. (B. Holmes, Trans.). Stanford, CA: Stanford University Press.
- Sachedina, A. (2005). End-of-life: The Islamic view. *Lancet*, 366 (9487), 774–9. doi:10.1016/S0140-6736(05)67183-8



## The Foretelling

Sheila Crow

In the dream it was my mother who was dying. *I was sitting on one end of a sofa in a vaguely familiar living room with my mother, lying supine, her head cradled in the palms of my hands. Tufts of wiry grey hair scorched by years of cheap home permanents stuck out from the sides of her head like puffs of torn cotton. I caressed the rubbery, soft skin of her hands and watched as her chest rose then fell hard with each breath—a tubular and hollow sound that whooshed in and out through parched lips across an otherwise soundless room. From behind us, rays of sunlight streamed through the large curtainless window and hung in the air like warm amber on a cool, fall morning. I placed my mouth next to her ear and whispered it was okay to die.*

Then the scene abruptly ended and the next one began.

*I was standing in a doorway watching my mother walk with purpose down a vacant hospital corridor. The walls and floors were blindingly white and bare. The only darkness was that which emanated from the shadows of the other doorways and I watched, as she moved deliberately from one room to the next. When she finally reached me, her mouth relaxed, her brow unfurled. She smiled in the way only a mother can smile when she sees her beloved child. Her eyes softened with relief. I took her hand in mine and we began a slow, deliberate walk down the hallway, toward the door with the red EXIT sign.*

Waking from the dream, I was shaken by its intensity, but believed it was nothing more than my

subconscious reminding me my mother was nearly 80 and I should pay more attention to her health and at the very least, give her a call. Two weeks later I became acutely aware the dream was not about my mother, but rather, a foretelling, about me.

In late October 2006 I had made the annual trudge to my gynecologist—a quirky woman about my age, with thick, wild straw-blond hair. I was 45 years old. My body and mind were physically and intellectually fit. My graduate work was nearly complete and I was looking forward to a long and productive career working with medical students. A week later the nurse called to tell me the Pap results were inconclusive and a colposcopy was needed. Over the course of 25 years, I'd had two abnormal exams and on both occasions the re-test results returned normal. While not particularly anxious, I felt a nagging sense this could be more serious than what I was allowing myself to believe. I promptly stuffed the voice a little deeper and scheduled a follow-up visit and colposcopy the week before Thanksgiving.

It was nearly five o'clock on a Friday afternoon, and I was the only patient remaining in the clinic. Stripped from the waist down and covered with a thin, white cotton sheet, I lay back on the exam table and focused my eyes on the brightly colored mural splashed across the ceiling. To ease our discomfort, the doctor and I talked about the weather and our plans for the holiday season. When she finished the exam, she said she was not too alarmed, but had noticed some abnormal tissue and suggested I return for a biopsy. I sheepishly asked if the biopsy could wait until after the New Year. I was expected to graduate in December and the holidays were busy. Surely a month would not matter, and in any case, I felt terrific. She hesitated. I asked what she would do if she were me. We agreed I would call the office the following week and schedule the biopsy for January. Christmas was a wonderful, hectic holiday, but by January, I still hadn't made an appointment.

The first week of February my body started changing rapidly. Intermittent, sharp pains in my abdomen suddenly started causing me to double-over. My stomach felt full and bloated after just a

few morsels of food. My first reaction was to dismiss the pain and medicate my symptoms. I was working out and running 25 miles a week. Active people just didn't get sick. I convinced myself the problem was indigestion and tried several over-the-counter products, none of which helped. Finally, I went to a walk-in clinic managed by a physician-friend and was referred for tests. The blood work, chest X-rays and a gallbladder ultrasound were normal—another indication that nothing serious was wrong. Yet, with each breath I took, and with each mile I forced myself to run, I continued to feel worse. My husband and I flew to Las Vegas for the weekend to celebrate a friend's birthday. Most of the weekend was spent in the hotel bed, drifting in and out of sleep sustained by pain pills. Monday morning I called my primary care physician to request an emergency appointment.

The following day an MRI picked up an abdominal mass that was not seen by the earlier gallbladder ultrasound. It wasn't until the radiologist asked me if I was aware I had an abdominal mass (and then proceeded to demonstrate with his hands just how big it was) that I began to consider that something might be seriously wrong. I went home and called the only oncologist I was willing to consider—a woman known by colleagues for physically carrying her patients to the car when they were too weak to walk. The next morning she took my medical history and conducted an in-office ultrasound. My turning point—Aristotle's *peripetia*—occurred the following day when she called to inform me that I had cervical cancer. I remember the sweatpants and t-shirt I was wearing, the black swivel stool I was sitting on, how the morning sunlight played across the wall, and how her words of cancer left me feeling naked and cold.

When we believe we are dying, everything superfluous falls away, leaving only what is truly important. My prognosis was so poor that colleagues encouraged me to leave behind a set of lessons they could share with future medical students. Each time I visited the oncologist's office, she encouraged me to not postpone anything I deemed important. For two years, she never failed to ask me if I was living life as I wanted to live it. One day,

when I queried her about this, she said she was concerned that the chemotherapy and radiation treatments had only postponed the inevitable. To which she meant, my death.

During the next many months, I was forced, much like Leo Tolstoy's protagonist, Ivan Ilych, to examine the moral and ethical dimensions of my own life. As a result, I also began to reflect on my experience of teaching medical students the tenets of the ethical practice of medicine. With little formal training in bioethics, I was adept enough at facilitating conversations and helping students focus on what some might call 'neon' ethics—those dramatic ethical dilemmas dealing with matters of Life and Death. We debated the pros and cons of physician-assisted suicide, respecting a patient's decision to forgo life-sustaining treatment, the headline-grabbing controversies of Karen Ann Quinlan and Terri Schiavo, and the opt-in or opt-out approaches to organ donation. Teaching second year medical students how to respond to the dilemmas they might face as future physicians involved applying certain analytic principles to manufactured (although perhaps realistic) ethical situations. These formal sessions usually occurred with a group of 10 students and one or two facilitators for one hour per week for eight weeks, a curriculum not unlike what many medical schools around the U.S. use to discuss ethics. To illustrate how unmemorable these sessions were, I had, as part of research project before my cancer, conducted a series of one on one interviews with fourth year medical students and found that most had only a vague recollection of participating in an ethics course in their second year and couldn't remember what ethical issues were discussed. In my mind, this signaled a problem with what and how we were teaching ethics to second year medical students. However, it wasn't until my own life-threatening illness, that I began to fully appreciate that medical ethics can't be taught like a biochemistry course and that teaching principle-based ethics will not counteract the values, beliefs, and attitudes that students experience as part of the hidden curriculum.

As a result of my illness experience, combined with my prior work in the humanities, especially



literature and medicine and the use of narrative methods, I realized that I had been teaching students that ethical principles were like a handy tool, something they could use, or not, as the clinical situation required, rather than focusing my attention on enhancing the moral character and professional identity of the individual student, or what I have since come to call, the *everyday* ethical practice of medicine. Like Anatole Broyard, Howard Brody, Oliver Sacks, Arthur Kleinman and others, I wanted my physician to listen to my story of suffering, to recognize my plight and to engage with me on a deep emotional level. If I had to stand on the precipice of death, then I wanted a physician who had the courage, and as Albert Camus might say, the “common decency”, to stand there with me. This kind of care was what mattered most to me. My oncologist, much like Ilych’s Gerasim, did not trivialize or dismiss my narrative of suffering. Instead, her actions represented the antidote to the mechanical and often uninvolved attitude prevalent in medical practice today. Each time she entered my hospital room she made choices, conscious or not, about how to act and communicate with me, which in turn positively or negatively affected my care.

From my perspective as a patient and as a teacher of medical ethics, I came to understand that my “reversal of fortune” was something principles could not attend to in any meaningful way. Principles could not help me make the decision of whether or not to accept the standard practice of care or to gamble with a new treatment protocol. Principles could not get me off the bathroom floor the Sunday afternoon I was certain there was no fight left in me, but my oncologist could. Her voice on the other end of the telephone line reassured me that I was strong and that no matter the final outcome, she would be there with me. I needed a physician who was compassionate, discerning, and trustworthy, in addition to being highly skilled and knowledgeable in the area of cervical cancer. It is this weaving of ethics into the fabric of every encounter with a patient that matters most. This lesson, I thought, is what medical students need to learn.

As it turned out, the oncologist was wrong about my two-year and five-year prognosis—a fortuitous miscalculation, which I am grateful to look past.



## No Surprises, Please!

Dena S. Davis

Ten years ago, I decided that I needed a built-in CD player for my old Toyota. A careful consumer, I consulted on-line sites and magazine reviews, and finally took myself to the local retailer, where I was confronted by a stunning array of options. I listened to a bunch, compared prices, talked with the salesperson, and eventually made my choice, paying for the device and the installation. I picked up my car two days later, eager to punch the buttons that would surround me with sparkling sound. A block later I pulled to the side, utterly dismayed. To my astonishment, my dashboard now sported a light show, with colored bars that shimmered and grew with the pitch and decibel of the music. I was appalled.

I did a U-turn back to the dealer, loudly complaining that I hated this device and would never have knowingly bought such a thing. Why hadn’t he told me, I demanded. He was taken aback. I had never asked, he said. Of course, the monster device had been installed and could not be removed without a great deal of expense. I finally put masking tape over the disco show and learned to live with it.

Three years later, a thief broke into the car and stole the CD player. Hallelujah! A second chance! I took myself to a different retailer and chose another player, obsessively asking about light shows and other forms of visual ambush. Two days later I drove smugly home, my dashboard no longer channeling *Saturday Night Fever*. All was well. Until, that is, I turned off the car and prepared to exit. Beep! Beep! The new device was emitting an irritating, high-pitched electronic tone, that ceased only when I slammed the door shut. U-turn. Back to the dealer.

What the hell was this, I demanded (my distaste for light shows exceeded only by my hatred of electronic beeps). Oh, the clerk reassured me, that's your anti-theft device. It will go off every time you exit the car, unless you remove part of the CD player and take it with you. No, it is not possible to disable it. Why didn't I warn you? Well, you didn't ask.

I am now the happy owner of a Mini-Cooper, with a built-in CD player that blessedly does its job and nothing else. But I often think of this experience when I think about informed consent. And I especially think of it when recalling my own fairly recent experience with consent for elective surgery.

A few years ago, I made up my mind to have my breasts reduced, something I had been thinking about for decades. Although my breasts were disproportionate enough that insurance covered the procedure, in fact I was never physically uncomfortable; I disliked the way I looked and was fed up with the difficulty of finding clothes that fit. I scheduled an appointment with the head of the relevant department at my local hospital. I had a long talk with this lovely man, took an information sheet, went home and thought about it some more. A friend had undergone the procedure; she told me it hurt like hell for the first 24 hours, which turned out to be about right. I also worried about the anesthesia; this would be my first experience of being "out." I pondered for a few weeks and finally made an appointment for surgery a few months hence. Before the actual surgery, I had a number of minor appointments to check my general health, take pictures for the insurance company, and one final chat to make sure I understood what the procedure entailed and my likely breast size afterward. In fact, when the day finally came, the last thing I remember before I "went under" was the surgeon checking with me one last time about my future cup size.

So . . . 24 hours of pain, two days of *West Wing* reruns, weeks of careful showers, a return visit to make sure everything was healing nicely, and eventually I could give up the soft post-surgery bras for a trip to the mall for *the real thing*. For the first time since early adolescence, I could buy lacy bras at reasonable prices in the same stores as my friends. Well, not exactly.

Turns out, after surgery my nipples are permanently erect, and show through most bras and even opaque turtlenecks. Every time I get dressed I have to check the result and weigh the advisability of inserting nipple shields. Otherwise I will be walking around campus looking like a coed in a wet t-shirt contest. I have traded one self-conscious hassle for another. Would I have done it anyway? Probably, but that's not the point. The point is that I wasn't warned about a result that, now that I've traded stories with lots of women, turns out to be quite common, common enough that I should have been told.

Two years later, I had another surprise. A "lump" I discovered on my breast was diagnosed as a cyst and I was told that cysts on the scar lines were fairly common after surgery. Having that information probably would not have deterred me from the operation, but it certainly would have saved me 48 very anxious hours.

Bioethics literature is full of writing about the difficulties patients encounter when trying to assimilate complex medical information while they are ill, tired, and scared. Often, the patient's psychological challenges become the platform for a subtle attack on the value of autonomy or a belittling of the value of informed consent. My story is interesting precisely because those barriers were largely absent. I was not anxious or ill, was encouraged to ask questions, and had all the time in the world. Nor can I accuse the physician of paternalism; I think he was truly neutral about whether or not I should have the surgery. Nonetheless I was blindsided by things that I could not have asked about because they would never have occurred to me.

Heather Gert (2002) has pointed out that placing information in the context of informed *consent* has the unfortunate effect of encouraging physicians and ethicists alike to talk "as if physicians are required to provide all *and only* information necessary for securing informed consent" (p. 23). Informed consent focuses on information a reasonable person needs to make a decision, but there is much more information that most prospective patients need and want. As Gert explains, there are few facts that would deter most people from

deciding to have a broken leg set, but there is much more that the patient needs and wants to know. How long will she be in a cast? When can she drive? Can she get the cast wet?

Part of the problem, as I have written elsewhere (2010) is that the concept of informed consent arose out of litigation. Since the patient can only win a suit if the missing information would have caused her to make a different decision, it is that information that tends to take precedence. In our society, law and ethics tend to merge in people's minds, and legal standards are often taken to be ethical standards as well. But law is just one important (and minimalist) expression of what constitutes good physician–patient communication. “If we say, time and again, that physicians must provide information *for the purpose of gaining informed consent*, and don't say anything more, it may be too easy to slip into thinking that a certain bit of information can be passed over because—as anyone really would agree—there is no chance that information about *this fact* will alter the patient's decision” (Gert, p. 24). A better standard is the one suggested by Gert: reasonable patients want whatever information will keep them from being surprised. And if, in the end, the patient *is* surprised, that should only occur if the physician is surprised as well. “In other words, the physician should ensure that the patient undergoes no unsurprising surprises” (Gert, p. 24).

Would my physician be surprised to hear of my experiences with the sequelae of breast-reduction surgery? I suspect not, but I don't really know. The carefully orchestrated set of encounters between me and the medical staff did not include an opportunity for the patient to report back. Perhaps I'll send them this essay.

## References

- Davis, D.S. (2010). The ambiguous effects of tort law on bioethics: The case of doctor–patient communication. *Journal of Clinical Ethics*, 21, 264–271.
- Gert, Heather J. (2002) Avoiding surprises: A model for informing patients. *Hastings Center Report*, 32, 23–32.

## A Terrifying Truth

Rebecca Dresser

My father died of cancer when he was 39 and I was twelve. No one told me or my two younger brothers that he was dying. He went to the hospital in October and died in December. We saw him just twice during that time, for this was an era in which visiting children were unwelcome in hospitals.

Although no one explained what was wrong with my father, we knew it was something bad. My mother was never home and we spent many hours in the care of aunts and other relatives. Every so often, one of us would work up the courage to ask when our Dad was coming home. The vague replies we received were meant to reassure us, but had no such effect.

I'll never forget this unsettling time. The old world I could count on had disappeared. The adults around me acted as though everything was fine, but why was my mother crying in the middle of the night and why were we eating casseroles prepared by our neighbors for dinner? The evening we learned that my father had died was horrible, but it was a relief to know the truth. I remember thinking, *Oh, so that's why everyone's been acting so strangely.*

This is the way I learned that people should tell the truth about serious illness. This is the way I learned that “shielding” people from bad news does them no service. And this is the way I became interested in medical ethics.

Cancer was my introduction to truth-telling in medicine, burdensome treatments, and end-of-life care. My childhood nightmare began a life-long fascination with topics like these. Years later, just before I started law school, the Karen Quinlan case was in the headlines. I followed the case closely, and enrolled in every course I could that addressed legal and ethical issues in medicine. I knew there weren't many law jobs in this area, but vowed to look for any opportunities that might be out there.

Through a combination of persistence and good luck, I found a position in a medical school's ethics center. I began teaching and writing about things

like advance directives, surrogate decision-making, and clinical trials. Although I always remembered the time of my father's illness, cancer became primarily a professional rather than a personal matter.

Then, 42 years after my father's death, cancer became personal again. After months of disturbing symptoms and doctor visits, I received my own cancer diagnosis. Like anyone else, I was stunned to learn that I had cancer. Yet I didn't completely lose my professional outlook. When I heard my diagnosis, I thought, *this doctor is breaking bad news*. I had studied and taught medical students about this physician responsibility, and now I was seeing it in action.

The rest of cancer was like this, too. I struggled through harsh chemotherapy and radiation treatment the same way that other patients do. But when I was able to step back from the demands of treatment, I marveled at how much I was learning about my professional field. Cancer was giving me a new understanding of patient autonomy, treatment decision-making, relationships between patients and clinicians, and many of the other subjects that were the focus of my academic work.

Although my second cancer experience produced many of the same feelings I had had during the first one—disorientation, fear, and isolation—it was also very different. I knew much more about the world of illness and medical care than I did at that earlier time. Yet having cancer myself made me realize how much was missing from my professional understanding of that world.

I vowed to make use of my new knowledge, but didn't think I could do it alone. So when I went back to work, I got in touch with some medical ethics colleagues who had been through their own cancer ordeals. We met to talk about our personal experiences and eventually produced a book called *Malignant: Medical Ethicists Confront Cancer*. But the book couldn't cover everything we learned, and one thing it omits is what cancer taught me about truth-telling and serious illness. As a 12-year-old, I learned how frightening it is when people don't tell you the truth; as a patient, I learned how frightening it is when they do.

Knowing about a life-threatening diagnosis may be better than not knowing, but it is terrible knowledge. With it come impossible treatment choices—for me, the choice between surgery (possibly more effective, but more likely to leave me unable to speak and swallow) and chemotherapy (possibly less effective, but more likely to preserve speech and swallowing). I had no idea how to reconcile my desires to live and to protect what seemed to me essential physical functions. I needed my doctors' guidance to respond to the truth of my situation.

And once I made the decision to have chemotherapy, I evaded the truth. The truth was that treatment might be ineffective, but I didn't want doctors, nurses, or anyone else reminding me of that. I don't think I could have endured the pain, nausea, vomiting, and other side effects without some protection from reality at that time. Even now, as I approach my annual follow-up examination, I don't want to face the truth that my cancer could return. Indeed, since my diagnosis, I have never asked doctors to give me a specific estimate of my survival odds.

Truth-telling in medicine is necessary, but coping with the truth is more difficult than I ever imagined. I can see why my mother didn't want to tell her young children that their father was dying. Her effort to protect us was unsuccessful, but I now understand the heavy burdens that truth imposes. Before having cancer, I didn't realize how much help patients and families need as they deal with the truth. My mother needed clinicians who could talk with her about breaking the bad news to her children. I needed clinicians who could help me choose a treatment and then let me put aside the truth so that I could concentrate on getting through the months of debilitating chemotherapy and radiation.

Truth-telling is the least-worst action when serious illness occurs. But truth-telling is destructive, too. It inflicts a new and terrifying reality on patients and the people who love them. Besides telling patients the truth, doctors and nurses must act to diminish truth's destructive effects. Sometimes this means talking with patients about how they will convey the truth to their families and friends. Sometimes this means recommending a treatment

to a patient overwhelmed by the truth. Sometimes this means downplaying the truth that a burdensome treatment could fail. Personal experience taught me how complex and delicate truth-telling in medicine can be.

For me, cancer began as a personal crisis. Then cancer became a professional interest. And then, once again, cancer became personal. Now, with my colleagues, I am trying to bring the personal and professional together. I do this with some trepidation—I'm not sure how to bridge the gap between the two kinds of understanding. But I am sure of one thing. The voices of the cancer patient's young daughter, and the cancer patient she later became, belong in the medical ethics conversation.

## References

Dresser, R. (Ed.). (2012). *Malignant: Medical ethicists confront cancer*. New York, NY: Oxford University Press.



## What my Children Taught Me about Information Sharing in Medicine

Thomas D. Harter

Six years ago my daughter was born four weeks premature and spent five days in the neonatal intensive care unit (NICU). Four years ago my son was also born four weeks premature and had a two-week stay in the same NICU. Both hospitalizations occurred while I was earning my doctorate in Philosophy. While at the time I had not yet settled on a career path, I anticipated performing clinical ethics consultation in some capacity once I completed my training. These two experiences have significantly influenced my understanding of the information sharing process between care providers, patients, and patient's family members, and have helped shape how I perform clinical ethics consultations.

During a routine prenatal visit two days after starting my winter break, my wife and I were informed that her amniotic fluid was dangerously low and that labor should be induced to avoid

a potential still-birth. Fourteen hours later, at 36 weeks gestation, our daughter was safely delivered at 1:13 a.m. She was mostly healthy except that she had trouble nursing and breathing at the same time, an indication that her lungs were not fully mature. While I slept, a neonatologist informed my wife that our daughter was being taken to the NICU for further monitoring and medical management.

Our daughter was oxygenating in the low-to-mid 80s. Her oxygenation would need to be in the 90s before she could be weaned from her continuous positive airway pressure (CPAP). A small, blue mask covered her nose. Multiple wires adhered to her body to monitor her biorhythms. Her nurse said she was in a fragile but stable state. When we spoke with the neonatologist about an hour later, she said our daughter looked "pretty good," and that she did not think she would be in the NICU very long. The vague and meaningless timeframe of "not very long" stuck in my mind; focusing on those words was easier than just looking at my tiny baby who did not look "pretty good" to me.

We visited the NICU two to three times daily over the next four days. I always entered the NICU with baited breath because we never knew what to expect. On some visits the nurse's report was good—medically our daughter had improved since the last visit. On other visits the report included a unique setback, such as a failed attempt to decrease her oxygen support. What annoyed me about how this information was communicated was not the information itself, but that we never received any information about our daughter's care until we arrived at the NICU, and that we were never asked after she was admitted when or how much information we would like to know about her care. Having never experienced a hospitalization like this before, neither my wife nor I knew what questions to ask about the kinds of information we should and should not expect to receive. Not wanting to be labeled disruptive or unappreciative, I passively accepted the status quo of this information sharing process—trusting that we would immediately be informed if something really serious occurred with our daughter's health.

Although we identified and treated what we believed caused our daughter's premature birth,



we found ourselves facing the same circumstances two years later with the birth of our son. On a chilly Monday morning in early March, my wife's obstetrician again informed us that at 36 weeks gestation our baby's amniotic fluid was too low and that he would urgently need to be delivered to avoid a potential still-birth. The induction occurred the next morning. That evening, at 6:53 p.m., our son was safely delivered. This time, though, the obstetrician had arranged for a neonatologist to be present at the birth. Unbeknownst to us prior to the delivery, *their* plan was for our son to automatically be admitted to the NICU for monitoring.

Within thirty minutes of our son being whisked away, we went to see him in the NICU. Some of the same care providers who cared for our daughter recognized us. Like his sister, our son had trouble oxygenating and was receiving CPAP. One of his care providers informed us that a person's lungs are one of the final organs to mature prior to birth and that the lungs of boys tend to mature more slowly than girls. I believed this was a roundabout way of preparing us for a potentially longer NICU stay without explicitly being told to expect it.

Again my wife and I visited the NICU two to three times daily. However this time we had family visiting from out of town—mostly to help watch our daughter, while we attended to our son. It was also the middle of the semester and I was in the midst of grading mid-term exams, and preparing for my prospectus defense. The extra pressures of school and visiting family exacerbated my frustrations as we experienced the same kind of information sharing we experienced during our daughter's hospitalization. Again, mentally exhausted and not wanting to appear disruptive or unappreciative, I passively accepted that we would only hear information when we came to visit our son, but still trusted that we would be contacted sooner if something regarding our son's care needed our input or consent.

Unfortunately my trust of our son's care providers was violated and nearly broken because of a particular incident during his hospitalization. One evening within the first five days of his admission, a neonatologist told us our son might need an umbilical venous catheterization to ease

the administration of fluids and blood-draws for tests. Given that this information was presented as a descriptive fact about our son's situation, I did not take it as a request to place the catheter or as an explanation of a forthcoming procedure that would be performed as a standard of care without also seeking consent. When we arrived the next afternoon, our son's nurse informed us that the doctors placed the catheter that morning. The line was needed, but not emergently. Neither my wife nor I recall being consented before the procedure. I have since rationalized, however, that my perception of the conversation the night before the catheter was placed simply may have been different than the neonatologist's perception. Still, the shock of seeing a wiry line emerging from my son's navel and finding out about the procedure hours afterward is a bitter memory.

There can be many different rationales to explain my frustrations regarding our communications with care providers across both of my children's hospitalizations. For example, some of our children's care providers knew that I was a graduate student in philosophy and medical ethics. They may have assumed I was more familiar than I really was with hospitalizations and that my wife and I would be able—and know how—to be our own advocates regarding our concerns. Conversely, I assumed that our children's care providers who knew my academic background naturally would want to ensure they worked toward meeting our information sharing preferences. It is also possible that our children's care providers paternalistically decided not to burden us with trying to comprehend complex medical information or consent to otherwise common medical procedures. I already noted my belief that I was too passive regarding my concerns out of an irrational fear that voicing them would result either in negative consequences to my children's care, or me being labeled a troublemaker.

There are two ways in which these two hospitalizations have changed my perceptions of information sharing between healthcare providers, patients, and patient families. First, I now perceive the concept of information sharing as having a second vital component beyond just the message care providers attempt to communicate. Prior to these



two hospitalizations I was aware and appreciative of how care providers use verbal cues such as tone, inflection, as well as specific physical movements as tools to help communicate particular messages. What I did not really understand or appreciate until these two hospitalizations is the need to think about how the message being communicated will be, or could be, perceived—or misperceived—by the individual(s) receiving the message. Information sharing in medicine needs a contextual frame set by care providers to help patients and families calibrate their understanding of a message to the care provider's intent. I have no doubt that when I was told my daughter looked "pretty good" on her first day in the NICU that the message was intended to be positive. My understanding of "pretty good," though, was orientated to when she might be discharged. As I soon realized, the neonatologist likely meant she looked good relative to some other comparative measure but not that she was close to being discharged.

Second, I now fully appreciate the importance of consistency with respect to both the content and ways in which care providers inform patients or their families. It is frustrating for patients or their family members to hear one message from care providers and then hear what could be perceived as an opposite message from another provider—even when, in reality, the messages may not oppose each other. For example, during our first visit to the NICU with our son, the neonatologist told us that he "didn't look too bad." When he was discharged, however, a nurse congratulated us on our son leaving so quickly because "he was really struggling when he came in here [sic]." The messages from the neonatologist and this nurse do not contradict one another. Yet to my wife and me they conveyed two different meanings about his admission: the first painted his health in a semi-positive light, while the second painted his health in a negative light.

My two NICU experiences have also shaped how I perform clinical ethics consultations. Whenever I meet with a patient or the patient's surrogate for the first time, I try to avoid making any assumptions about the information sharing process, or about how much or how little information the patient

or surrogate has or wants regarding the patient's health status. To make such assumptions is tantamount to paternalism. It should not be up to me or any other healthcare provider to decide for a patient or the patient's representatives when they receive information or the depth of information provided to them. When consulted and speaking with a patient or the patient's surrogate for the first time, I ask how much information they know about the situation, how much information they would like to know moving forward, and if there is a preference about how often or when updates are provided. To assist with my point about consistency in the message, I also attempt to make sure that when I speak with patients or their surrogates that one of the patient's physicians is present during the conversation. The practice of asking patients or their representatives to identify their preferences about informative communication between them and care providers is also something I incorporate into my teaching of medical students, residents, fellows, and staff.

There are other important ways my two NICU experiences have influenced my thinking about bioethics and how I perform clinical ethics consultations. However, the lessons I learned relating to the concept of information sharing are the most prevalent and common. My hope is that I continue to find new ways to use these two experiences as examples of the importance information sharing in medicine, and that these two experiences continue to help my development as a clinical ethicist and father.



### **Fractured Humerous/ Fractured Humor—What a Broken Arm Taught Me About Racial and Cultural Privilege in Hospital Care**

Sara R. Jordan

**S**ome months after the incident, my husband would yell, in a fit of exasperated rage, "I'm leaving and you look less worried about

my leaving than you looked when he broke his goddamned arm." My husband always hated my relationship with my training partner as he saw it for what it is—an intimate relationship with another man. The night Henry had his arm broken, as I tore out of my house, to which I had just returned, away from my husband to the side of my training partner, I realized just how much I had come to be torn between the two intimacies. Throughout the rest of the broken arm episode, I came to learn much more about the content of the corollary to intimacy—publicity, particularly of the universalist stripe.

It's been 20 months since Henry suffered a spiral fracture of the humerus, and while the arm is healed and no long lasting effects are visible except for a lengthy two-centimeter wide scar on his left arm, my perceptions of myself as a culturally sensitive ethicist are scarred as well.

### Training Partners as Intimate Partners

Raymond Geuss says that an intimate relationship is one where we do things around that person that would provoke shame in us or reasonable disgust in others that were less intimate (2001, pp. 12–33). An athletic training partner is an intimate partner in ways that a sexual partner cannot be—the intimacy of training partners is acted out almost exclusively in a public space (e.g., gyms and race courses). Part of a long-term, committed, physically, psychologically, emotionally, financially, and publicly intimate relationship, training partners are those people who see our souls bare even if they never see us naked.

Henry was then, and is now again, my training partner *par excellence*. We run, lift weights, and paddle outrigger canoes together. We support each other often in the midst of competing mercilessly against one another. To me, he is sanctuary away from a difficult marriage and difficult job where I am a minority female working in a culture that I can never be part of, and a reminder that things can be fun, close and intimate in the middle of otherness. Against this background it is easy for even a casual observer to understand why, when a mutual friend called to say "I think Brad broke Henry's arm," I was terrified. Looking back, I was not terrified for

him—how could this person who is seemingly built of calm and steady nerves be "broken"—but for me. "Oh my God, who am I going to train with?!"

Brad (100+kg) and Henry (75kg) decided to arm wrestle drunk, which all orthopaedic surgeons know is an unfortunate choice of activities as the force of contrary motion often results in a spiral fracture to the humerus. I returned to the bar where I had left them in a drunken, post-race melee, to find Henry a focused lump of clammy, grey skin. I cannot remember what we said to one another, if anything, people were shouting at me that an ambulance had been called, but I remember looking at his eyes, trying to get him to focus on me as he went into shock, and, to my own surprise, I still recall vividly drawing his head to my chest and kissing him on the forehead like I would with a wounded child. The feeling was maternal—as he wavered in consciousness waiting for the ambulance men to arrive—I would have done anything to trade places or to take the pain from him. An integral part of me was hurt and, hearkening to Gadamer's (1996) description of the intersubjective challenge presented by the indescribability of pain, I pained to know what he felt so that I could know how to alleviate it. Pushing each other, feeling the other's pain, and pushing one another through it is what training partners do for one another and at that moment, I wanted to perform my usual role.

The contrast between realizing that I am closer to my training partner than I originally supposed stood in juxtaposition against the realization that, while Henry was in the same teaching hospital in which I teach Responsible Conduct of Research, serve as a member of the institutional review board (IRB), and work closely with colleagues in the Medical Ethics unit, I am further away from my colleagues than I supposed.

### Cross-cultural Complexities

Theorists of globalization like Thomas Friedman suppose that we are closer together due to global connections (2000). Others, like Pankaj Ghemawat suppose that closeness is all "globaloney" (2007). Throughout the three days of brief interactions

with the hospital staff (e.g., nurses, physicians) during Henry's surgery and convalescence, I moved distinctly away from the idea of positive, shared ethics as Seyla Benhabib (2002) proposes, or the inclusiveness that Iris Marion Young supposes is the product of close, focused, communication (2000). Instead, I moved towards a Diogenean theory of cosmopolitical bioethics—if we care for people in the specific, or we take as important the cultural specificity of other persons, we come to resent their difference and seek to find sources of evidence that they should be shamed. To be truly universal, we must not care at all—we must be shameless (Geuss 2001, p. 27).

This story, told from the standpoint of almost anywhere else, would not have the cultural implications it does. What complicates this narrative is that it occurred in the complicated location of Hong Kong. Hong Kong, famed as a gateway to China for the West, is a place beset by continuously evolving, chaotic, fractal, narratives. Culturally, Hong Kong is always, at once, many competing things—sea and hills, farms and International Finance/ Commerce Centers. We, as part of a large expatriate community, live in two worlds populated by intense narrative complexity—the English and Chinese speaking, but western focused worlds of our careers, and the Chinese speaking, multi-cultural pastiche that is our athletic world. The Chinese speaking world was what arrived on the ambulance and pervaded the healthcare sphere. It was the appearance of these cultural others to help my friend that started me down the path of realization that provokes the major point of this article—cross cultural niceties and universal inclusion evaporate, even for those of us with the knowledge to know and do better, when an intimate partner's health and well-being are at risk.

Iris Young describes the idea of Inclusiveness—generation of shared commitments through mutual struggle—as something that is generated through communication (2000, pp. 52–80). When we cannot communicate sufficiently with one another—perhaps we don't speak the language enough to get beyond greeting—there is no open space for including one another. And, where there is no inclusion

of others into our “moral community”, there can be no trust (Uslaner 2002, p. 2). Instead, the product of stifled communication is mutual hesitation, frustration, and recrimination. If it is the case that one side obtains special privileges because of insufficient ability to co-communicate the other side will invariably feel negated, put upon, and taken advantage of. I am sure the ward staff felt taken advantage of, because we could not communicate well. I was able to repeatedly violate visiting hours rules and access multiple locations that I should not have been able to, inevitably due to my English speaking whiteness.

In my pre-event mind, taking advantage of cultural competencies or tendencies would have been wrong. To railroad “others” with whiteness or cultural privilege or occupational status would have been a repugnant act deserving of moral re-education. How could someone not see the demands of universal respect at play? My pre-theorization of this event would have insisted upon notes and tones of gratitude, of a commitment to cross-cultural cosmopolitical communicative action that traded experiences, expertise, and offers of professional assistance in a mutually comprehensible language. But, the experience of the event was all otherwise.

My universalist moral commitments were dashed by the lack of a universal language. That the ambulance men (and they are all men here) did not check blood pressure and oxygen saturation on a patient that was clearly in shock, but still took time for one to check his phone, rattled my professional courtesy. That the radiology technician did not speak sufficient English to explain the x-ray procedure to my friend irked me. That the Accident and Emergency ward nurses were more concerned his fee was paid before putting him in a more sufficient sling suggested a lack of genuine professional commitment to me. That, once Henry was admitted, the ward nurses allowed me in to the unit—a large, open plan, shared unit—very late in the evening struck me as immediately a violation of rules. That they did not explain to him or to me the visitation rules, because they could not, provoked a sense of moral outrage—what was the content of this assumption that expatriates did not come to

teaching hospitals? I felt a tone of righteous anger when I overheard the nurses chatter to one another (in Cantonese) to ask who I was and whether his condition could be discussed with me. When they failed to grasp the concept “friend,” they listed me as girlfriend and attempted to change the next of kin status on his chart. I found the ward nurses’ heteronormative assumption of male + female = sexual union to be evidence of low-learning. And, if they did not realize that heterosexuality is non-compulsory and that Eleatic love is a genuine possibility, could they possibly know how to properly change a dressing, or could they begin to know how to properly insert the proposed rods and screws that would paste Henry’s arm back together? By the conclusion of the first evening, I was convinced that the hospital staff was incompetent. I had no clinical evidence of this—I never would have evidence of this, as they were fully competent and indeed excellent—but the lack of shared communicative capacity led me to this specious conclusion.

When Henry emerged from the hospital after three days, I was left with a lingering scar as well—could I consider myself to be an educated, culturally sensitive ethicist any longer, given that I had imagined incompetence of the “others” based upon the interactive effect of non-shared language and, by proxy, race?

### Post-Event Theorizing of the Role of Bioethicists in Cross-cultural Injury and Illness Management

My experience with the injury of my training partner taught me that a love of cosmopolitan theories of ethics and bioethics do not equate to a cosmopolitan love applied equally to all. Under times of stress, like most humans, I sought the comforts of the familiar and resented the discomfort of the strange and the incomprehensible. I learned that my pretense towards enlightened theory ruptured under contrary torsional forces, like those experienced by arm wrestlers, and the resulting spiral fracture of my own academic self-image is still held together by screws and bars that I am thankful cannot be seen without x-ray vision.

In the months following this event, as Henry convalesced and rehabilitated in his physical way, I turned to the problem of theorizing my experience. I had found that shared communicative capacity mattered more than I could have imagined for my ability to trust professionals of a different linguistic group and race. Contrary to Anderson’s theory of “imagined communities” of shared professional norms and language, I found that ordinary questions—where are blankets?—mattered more than professional communicative capacity—what type of post-surgical pain management do you propose? As I pondered at greater length my feelings of distrust followed by shame for that distrust, I stopped to consider whether there is a role for clinical bioethicists as cross-cultural navigators.

The bioethicists’ role, which I envision as distilling powerful emotive and analytic arguments for good and evil and placing those like salve onto complex medical situations, maps easily onto the role of a cross-cultural navigator. A navigator, or an individual trained to cross murky, rough, waters by reading the epiphenomenal signs of weather, constellations, and winds are those individuals that shepherd individuals across in times of distress. Without pausing to evoke the many images of the powerful navigators between the realms of life and death, I contend that future bioethics training ought to have components in cross-cultural navigation and communication. Instead of further programmatic learning in statistical or survey methodologies, students should be encouraged to seek culturally immersive internships that teach language and culture. Such experiences could allow students to come away from their training with a deeper cultural understanding as an aspect of academic training, which allows them to assist family members in cross-cultural negotiation situations to know how to apply the reasoning, language, and other epiphenomenon of one culture to another. Dangerously, though, reflecting on the Diogenean spirit of cosmopolitics described above, the consequence of navigating a family through the cross-cultural waters might be to bring them to the side where they do not care for the differences of the staff but care only for their loved one’s co-struggle

with difference and illness. By being cosmopolitical, we may encourage others to be shamelessly particularistic.

## References

- Benhabib, S. 2002. *The claims of culture: Equality and diversity in the global era*. Princeton, NJ: Princeton University Press.
- Friedman, T. 2000. *The Lexus and the olive tree: Understanding globalization*. New York, NY: Farrar, Straus and Giroux.
- Gadamer, H-G. 1996. *The enigma of health: The art of healing in a scientific age*. Stanford, CA: Stanford University Press.
- Geuss, R. 2001. *Public goods, private goods*. Princeton, NJ: Princeton University Press.
- Ghemawat, P. 2007. *Refining global strategy: Crossing borders in a world where differences still matter*. Boston, MA: Harvard Business School Publishing Corporation.
- Uslaner, E. M. 2002. *The Moral Foundations of Trust*. Cambridge, MA: Cambridge University Press.
- Young, I. M. 2000. *Inclusion and democracy*. New York, NY: Oxford University Press.



## A Personal Experience of Prenatal Testing for Down Syndrome\*

By Chris Kaposy

This is the story of the prenatal diagnosis of my son, Aaron, who has Down syndrome. The events in this story happened during an important period in my education and development as a bioethicist. The decisions that my wife Jan and I made through the different stages of prenatal testing were influenced by what I had learned about disability as a bioethicist in training, and these experiences have shaped me as a practicing clinical ethicist.

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\* I owe thanks to my wife Jan for helping me remember the details of her pregnancy.

In 2006 I had completed my Ph.D. in philosophy with a dissertation on infanticide. This odd topic was hard to explain to non-philosophers, who were usually relieved to hear that I was opposed to killing babies. Much of my intellectual activity while writing this dissertation was devoted to coming up with arguments opposing Peter Singer's gratuitous use of disabilities like Down syndrome in illustrating that it is acceptable to kill infants. I had read quite a bit of literature on the quality of life of people living with disabilities, and the family lives of people who have children with disabilities. The evidence in both areas was quite different and more positive than the doom and gloom about disabilities that you find in Singer's books.

At the end of my Ph.D. in 2006 Jan gave birth to our daughter Elizabeth. Early on in the pregnancy, we had declined the offer of prenatal testing. Jan and I both thought that we could welcome a child with disabilities into our lives, so prenatal diagnosis would not change anything for us. Though both of us were (and are) prochoice, we would not have chosen to abort a fetus that tested positive for a disability. My feelings were greatly influenced by my doctoral research and what I had learned about cognitive disabilities while studying with my dissertation advisor Eva Feder Kittay, whose daughter Sesha has profound disabilities, and who has written eloquently about her family life with Sesha.

In 2008 Jan was pregnant again. It was a planned pregnancy. As we had done the first time around, Jan declined the offer of maternal serum screening in our early prenatal visits to the midwife. We were planning a home birth. Midwifery care was more readily available in other places in Canada, but in our province, midwives were just on the cusp of being granted hospital privileges.

Around the 19<sup>th</sup> week of her pregnancy, Jan went for a routine ultrasound. I came along. The ultrasound was a step we took voluntarily, since we wanted to know about any major abnormalities that the ultrasound could reveal, and we wanted to have a look at the fetus and see the beating heart. Toward the end of the procedure, the technician excused herself and went to speak briefly with the radiologist. She did not explain why. Soon afterward we



learned the reason. The ultrasound had turned up two echogenic foci on the fetus's heart. Our province did not allow midwives referring privileges, so the referral for an ultrasound came from our family doctor. The doctor explained that an echogenic focus is a bright spot on an ultrasound that does not indicate a physical abnormality, but is associated with a higher risk for a chromosomal abnormality. After reading the radiologist's report to us over the phone verbatim, our doctor emphasized that if we wanted more information, Jan should get a maternal serum screen blood test—the prenatal test we had initially declined.

Our overall feeling after hearing from the doctor was one of panic and dread. The ultrasound had given us just enough information to believe that something could be wrong with the fetus, but not enough information to tell us for sure, to tell us what the problem could be, or the chance that nothing was wrong. We knew that some chromosomal abnormalities are fatal prenatally or, even worse, soon after birth. We also knew that the most common chromosomal condition is Trisomy 21, or Down syndrome. My thoughts returned to what I had learned about Down syndrome during my doctoral studies. We had the option of dropping the issue and refusing any further tests. But the offer of more information was irresistible. The day after hearing the results of the ultrasound, Jan went to have blood drawn for the maternal serum screen. We were craving reassurance that nothing was wrong, and hoping that the test would yield only a small or negligible risk of problems with the fetus. During the blood draw our family doctor put Jan's mind at ease by explaining that the majority of echogenic foci are found with normal pregnancies.

But the results of the maternal serum screen test did not give us the reassurance that we wanted. According to the test, there was a 1 in 6 chance that the fetus had a congenital condition of some kind—a Trisomy or perhaps spina bifida. This risk factor was absolutely shocking to us. We knew from previous conversations with midwives and doctors that a chance of 1 in 250 was considered "screen positive". We had heard stories of women

who had received results of 1 in 100 or 1 in 50, and these numbers had shaken them. For these women, amniocentesis revealed no abnormalities. But 1 in 6 was unprecedented for us. It seemed almost certain that the fetus would have a disability of some kind. And to my mind, if it was almost certain, then it seemed ridiculous that the testing result could leave the impression that there was a 5 in 6 chance that the fetus would be unaffected. I resented the way that the 1 in 6 risk factor played cruel unresolvable games with my mind. One in 6 sounds like bad odds, until you give yourself the hope that 5 in 6 represents. But if 5 in 6 are good odds, then why do people have their lives upended when the result dips below 1 in 250? This was the lowest point for me.

Of course, we were offered further testing. Our midwife was still in the picture, helping us cope with all of this information and these decisions. Any follow up tests would have to be pursued in the maternal–fetal high risk unit at our local hospital specializing in maternal and child health. The next step was a detailed ultrasound performed by a highly skilled specialist physician. We also spoke with a genetic counselor. The physician told us that if the ultrasound showed the fetus's nasal bone and femur to be large and well-developed, then there was a chance the fetus was unaffected. The genetic counselor said that Jan could have an amniocentesis. If the amnio diagnosed an abnormality, all options were open, including ending the pregnancy. We agreed to the detailed ultrasound as a first step, and were drawn even deeper into the scenario of a medicalized pregnancy that we had sought to avoid with midwifery care, a planned home birth, and our initial refusal of prenatal testing.

From the time that we received the maternal serum screening results, Jan and I were involved in deep discussion. We discussed the meaning of the 1 in 6 risk factor, and our willingness to have further testing. We talked about what kind of parents we wanted to be, what kind of family we wanted to have, how a child with a disability would affect Elizabeth's childhood, and what we would do if the fetus had a disability. Jan decided



that she could have an amnio if we still felt we needed more information. We both arrived at the conclusion that if the fetus was diagnosed with Down syndrome, we would bring the baby into our family rather than terminating the pregnancy. This decision was in keeping with our previous plans, and with our ideals of what it means to be parents. Still we hoped that there would be no such diagnosis.

During the detailed ultrasound, our physician frowned as he measured the fetus's nose. He said that he didn't like what he saw. The bone was on the small side. Interestingly, during this ultrasound he asked us whether we wanted to know the sex of the "baby". We did want to know, and found out that Jan was carrying a boy. At the end of the ultrasound, while we discussed the findings and the next options, the doctor left an image of the fetus on a large screen on the wall in front of the bed where Jan had been lying. The doctor did not know our plans to continue the pregnancy. I have always wondered since then about the directive influence of presenting a large image of the fetus to prospective parents undergoing this process, calling the fetus a "baby", or the temptation of personalizing the fetus through offering information about the sex. Prospective parents who are leaning towards the option of termination might find these actions unwelcome.

The detailed ultrasound did not give us reassurance, so the last option was amniocentesis. The same specialist performed the amnio. I could not watch as he inserted the huge needle into Jan's belly. The extracted fluid was sent for rapid analysis. A few days later the genetic counselor called with the results. The result was positive for Down syndrome. Jan sobbed with uncontrollable grief. I held it together and tried to comfort her. She had retained hope that the baby was unaffected. I guess I had already accepted that the baby, our son, would have Down syndrome.

I am not sure how and when the grief passed, but it passed fairly quickly. There were more appointments, and ultrasounds every week to track the baby's growth. Fed up with all of the surveillance, Jan skipped one of her ultrasounds and had a sunny

picnic on our back deck with Elizabeth, who was then almost three years old.

The birth of our son Aaron on May 17, 2009—delivered by midwives in hospital—was a joyful occasion. He arrived with no immediate health problems, and he brings happiness to our family to this day. Aaron is now an incorrigible three-year-old boy who loves his sister, enjoys singing and dancing, eating French fries and playing with his trucks. He has some cognitive and physical delays, but his friendliness, his happiness and his sociability overshadow these delays when you meet him. We cannot imagine our family without him.

When I think about what I have learned as a bioethicist through this experience, many things come to mind, but I will focus on two. The first has to do with autonomy and informed choice. On the face of it, the decisions we made through the prenatal testing process all met the standards of informed consent. Ideally, health care workers and the health care system foster and facilitate autonomous informed choice. But rather than feeling as though our autonomous choices were encouraged by the system, I felt as though autonomous choice is something that has to be won, and fought for, in spite of it all. Some philosophers define autonomy as the ability to make decisions in keeping with your deepest values—the values that provide you with an identity. The choices we made during the process of prenatal testing challenged our values, buffeted our emotions, and we felt influenced on many sides. The main difficulties were not with inadequate disclosure of information—a major focus of discussion and litigation around informed consent. Instead, the main challenges we faced were with the influence of technology. Each successive testing option acted like a teaser, providing slightly more information than the previous one, with the promise of even more information during the next step with a more invasive test. Once we were into the cascade of prenatal tests, we were carried all the way to an amniocentesis. It would have been very difficult to step out of the flow of testing.

The second lesson I have learned is to avoid being judgmental as much as possible. There was

a time when I believed that Jan and I would never agree to prenatal testing. From the outside, a person's actions may seem wrong, confused, or out of character. But from the inside, in the midst of an all-consuming traumatic experience, there are usually good reasons for the choices people make. I am now a clinical ethicist. Health care personnel often come to our ethics service seeking direction and guidance on their moral duties. The need to reserve judgment is an ideal I try to live by (though I don't always succeed). I find it important to keep an open mind and to listen to all sides of a story when dealing with conflict. Being nonjudgmental is also the first step toward empathy. As a clinical ethicist I have often needed to be an advocate for patients. I can understand and identify with some of the troubles patients find themselves in, in part, because of the experiences I went through with Jan prior to the birth of our son.



## When Worlds Collide

By Monique Lanoix

Soon after I defended the proposal for my doctoral dissertation in philosophy, a close family member and I were involved in a serious head-on car accident. Paul (not his real name) suffered a closed head injury that resulted in important cognitive and motor deficits. He now resides in a long-term care nursing facility.

As a result of this experience, I came to be well acquainted with the acute, rehabilitative and extended care services offered to individuals with severe head traumas in the Canadian healthcare system. This sudden immersion into the world of cognitive impairment, to the manner in which healthcare professionals deal with cognitively impaired individuals and to the ways in which significant others must navigate their way through the maze of medical care has had a profound effect on me. In fact, it transformed my research.

From the acute care setting to rehabilitation and long-term care, there are many encounters and incidents that have left their mark on me and, most significantly, made it clear that the way in which individuals with severe impairments are treated should be scrutinized. In particular, there are two incidents that I want to share, as they were instrumental in motivating and informing my research agenda and the way I perceive on-going healthcare services.

The first of these significant encounters was with a physician who specialized in pain management and rehabilitation. About six months after the accident, Paul was transferred to a rehabilitation unit. During his stay there, the rehabilitation team thought it would be beneficial if he received an injection of botox in order to help him regain some mobility in his right hand. Now that I reflect on that recommendation, I realize how ill-conceived this was but at the time, I had no idea. I was still in shock, months after the accident. It is hard to explain how fog can hang around for so long but it does. The injection did not really help; actually, Paul had not recovered enough cognitive function yet to make this worthwhile, but the accepted dogma concerning the window of opportunity for significant brain recovery made it imperative that any rehabilitative procedure should be attempted as soon as possible. For this reason, the physiotherapist and occupational therapist had recommended this as an avenue worth pursuing. However, what happened during the appointment has had a far greater bearing on me than on the actual outcome for my relative. If it was a routine encounter for the physician, it was extremely revelatory for me.

The physician came in and examined Paul and asked if she could bring students to observe him. These were neurology residents and she wanted to demonstrate some of the clinical signs of frontal lobe damage. Although he has significant cognitive deficits, Paul can engage with others; however, at that time, he was much less responsive than he is now. In addition, he was in a new environment and, as is typical of frontal lobe injury, this had a negative impact on his capacity to react appropriately. The physician was giving my relative a chance to receive

a treatment that was quite expensive, and although it was covered under the Canadian healthcare plan, I had been told of the cost. Because of this expense and the fact that, at that time, this procedure was still fairly new, and finally because I believe that learning is important, I said yes to her request. She brought in the students; they stood in silence. She asked Paul to follow her finger and they watched as she explained he had had a frontal lobe injury and how his behavior was demonstrating typical sequelae. Everyone was polite; however, I felt Paul was being used—very odd that feeling. After that I promised him and myself that I would never let him be treated in that manner: as an object.

In bioethics, questions pertaining to the ethical treatment of research subjects are central. Concerns such as that of informed consent, of inclusion in trials, and of the freedom of subjects to stop participating in trials have been examined extensively in the literature. The protection of subjects who cannot consent is also a topic that has been the subject of strict policies and guidelines. Although this particular consultation did not engage any of the traditional concerns of research subjects, and it was conducted well, it still left me ill at ease. The encounter with the physician and her students was raising a different issue for me. Everyone was very polite and respectful; it was a learning opportunity for those residents. What happened that made it so awful? I cannot point my finger directly at what caused me such discomfort except to say that in the moment in which the physician was asking my relative to follow her finger, I saw him as they did: an object displaying particular features worthy of study. He was a curiosity and the living example of an unfortunate accident to a brain. It made me aware that the manner in which we encounter individuals who are cognitively impaired, and by extension the manner in which we care for them, is a question that needs to be examined closely as it has enduring and wide-ranging ethical implications.

The second occurrence was in the nursing home where Paul now resides. A nurse who was leaving the facility wrote a card, which was posted in the common room, to say that she had enjoyed her time there. However, she also added something to the

effect that she understood that the residents living in the nursing home were now shadows of their former selves. That seemed rather insulting but, in fact, it is often what people think even if they do not articulate it as openly. It is true that my relative does not have the full range of capacities that he used to have. Why then must he be portrayed merely as a lesser stand-in for the person he used to be? It made me reflect that the capacities that remain must be perceived in a manner that is not always comparative to the ones Paul used to possess. This is of course true of most of us as we age: as we move through the corridor of life, we change and become different variations of ourselves. Undoubtedly a severe traumatic brain injury is a disruption that is profound. But I refuse to concede that it entails the loss of some status and I have grappled with this question at length. I have asked myself whether I defend Paul's right to be treated as a full member of society because I have a personal bond with him and I am able to make an easy link with his past self. If I cringe when people encounter him, and if I am afraid of the manner in which they will respond to him, is it because I have known him for a long time? Of course the answer is in part yes, but I also want to hold on to the intuition that a lack of agency should not automatically cancel a person's membership in the moral community. It is an opportunity to understand more fully how we should encounter people with profound cognitive impairment.

Crucially, these events made it clear to me that theoretical concerns cannot be separated easily from practical ones. Conceptual debates over the status of moral personhood may be elegant theoretical pieces; however, such arguments have very real implications for someone such as my relative and for the caregivers and relatives of such individuals. Bioethics cannot afford to be an abstract undertaking devoid of context or of social responsibility.

I had already understood philosophy to be a social project, and these experiences drove me to reflect on the experiences and environments I was now encountering in a more systematic manner. My reflections can be grouped under three general areas of inquiry and concern. First, the way in which society and medicine portray persons who have become

impaired. This is relevant for persons who suffer a traumatic brain event such as an accident or a stroke and also for persons who have dementia. What happened in that first meeting is that I witnessed how Paul became primarily a body for those residents and, that furthermore, his body was solely the site of impairment. In that short time span, all the attending residents could perceive was the consequence of a brain injury. Because the encounter was short, the residents had not had any opportunity to engage extensively with Paul. Nevertheless, the objectification that took place was very tangible to me. The result is that I have tried to make it so that this situation does not occur in Paul's daily life. I strive to create a situation where he is perceived as a whole person, which he still is. When caregivers encounter him, I hope that he is treated with respect and that he is not simply an object of care. One of my research questions pertains to the treatment of persons with cognitive impairments and, related to this, the manner in which society provides care for them, which is my second area of inquiry.

Nursing homes are shocking places for those who first encounter them. It seems to me that if we, as a society, understand those who require substantial amounts of care as persons with full moral status, we might make the institutions where they live better places. This requires analyzing what it means to take care of another person: what are the intricacies of this work, what do workers do when they care and what helps them perform their care activities well? If good care is lacking, then it would be beneficial to try to identify the obstacles to good care. I spent a lot of time at the nursing home in the initial years after Paul moved there. I was able to see how the activities of care are accomplished and the problems the attendants are facing. The work these individuals are performing is not valued by society. I saw some very good attendants who cared and were deeply committed and I saw other ones who were just doing their job because it provided a paycheck. Although it is difficult to force someone to care, this type of work requires special skills and training can help. However, the institutions that are charged with providing care do not always recognize this.

Finally my experience of being at my relative's side led me to think more deeply about the role of families. This is certainly not unique to me: I was initially a surrogate and most of the time an advocate for Paul's care. In the early stages, very often, I was therapist doing games with him and stimulating him. All these roles are essential and healthcare professionals will reinforce the need for family involvement, especially in the early aftermath of brain injury. However, at some point, the family member, a welcomed caregiver, becomes less central to rehabilitation once the person with a brain injury has been institutionalized. At that point, the family caregiver is portrayed as an unwanted intruder or is charged of not wanting to let go, and consequently of being too demanding. Therefore, the role of families, of the caregiving they perform needs to be understood within the context of a complex and evolving system of care delivery.

This is the manner in which I became involved in brain injury and long-term care. In the initial acute stages of Paul's treatment, I was often told how expensive it was to provide healthcare to someone so profoundly disabled. But what was the alternative? Those who do not fully recover are perceived as failures, broken and beyond repair. However, there are not always happy, glorious stories of full recovery. Stories such as mine are essential as they push us to comprehend more fully the meaning of providing good and adequate care.



## The Education of Josephine's Mom

By K. Jane Lee

*"Is there still a heartbeat?"* Overhead lights flash by as the words croak out of my throat, tight with pain and fear. "Yes" comes the response, although there is really no way for anyone to know. The fetal monitor was left behind as they rush me to the operating room. Moving now, finally, after too much time in the delivery room indecisively

watching the ominously low heart rate; too much flailing, misdirected activity; too much time wasted while my baby's brain starves for oxygen. I feel one last feeble kick in my side and then no more. My baby is dying inside of me.

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"You have a girl. They took her to the NICU. Your husband went with her." The words float to me through the waning haze of anesthesia. My heavy eyelids crack open to see a nurse wearing scrubs at my bedside.

*"What were the APGARs?"*

*"Three, three, and three."*

*Hmm, not good. My eyes slip closed.*

Some time later there is a different voice at my bedside. It is my colleague, a neonatologist, speaking to me as a fellow physician.

"We brought your daughter to the NICU. She had an irregular breathing pattern so we intubated her."

*"Okay." Good, good—a little support for her breathing is good.*

"Her crit was quite low, so we're giving her some blood."

*"Okay." Sure—blood is good.*

"She's been having some tremors—some jerking of her arms and legs. I don't *think* they're seizures, but I'm giving her a small dose of phenobarb to calm things down just in case."

*"Okay." Don't be ridiculous, of course they're not seizures—my daughter doesn't have seizures—she's got no reason to have seizures. But if it makes you feel better to give her a little dose of phenobarbital it's not worth arguing about.*

*"Do you have any questions for me?"*

*"No. Thanks."*

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Readers who are health care providers may ask, "What is she thinking? Doesn't she realize that her daughter just suffered a brain injury? That she has every reason to be having seizures?" And they would be correct. To be sure, the neonatologist communicated with me in a way she thought was very clear, building on what she believed I already knew with significant, additional information about my daughter's condition. However, I wasn't able to process the information properly.

For years before Josephine's birth, I was a pediatric critical care physician and a bioethicist. Further, I was already a mother to a child who, while extraordinary in my eyes, was a typical child. These roles had taught me that people sometimes don't "hear" the message that physicians intend to send. I knew that stressful circumstances made processing information difficult, and that repetition and varied approaches may be necessary for there to be true patient or parent understanding. I knew this. But until that conversation, when my educated mind inexplicably shifted to an alternate reality, I didn't *really know*. Despite years of formal education, that conversation—and my retrospective realization of what happened in my head, was the beginning of my real education and learning about medicine and bioethics, communication and perception.

Today, Josephine is six years old. While these years of being her mom have taught me innumerable things, there are two lessons that I've found particularly relevant to my work. The first lesson is about communication, and has two parts. The first part, just illustrated, is that even if we as professionals try to communicate clearly and thoughtfully, there is a good chance the patient or family will interpret the message differently than we intended. The second part is that specific words can be tremendously powerful.

When I first returned to work after Josephine's birth, I would take every free moment to hide in my darkened office, lit only by a small desk lamp and the soft glow from my computer screen. In my quest for answers, I would pore over every available piece of information about Josephine's life, tears silently streaming down my face. *What does this all really mean? Just how bad is it? Will she get better? What can I expect for Josephine's future? My future? My family's future?* My mind jumped from my memories of Josephine's birth, to a few scattered pages of her medical records (I hadn't yet thought of requesting the complete set), to research articles—around and around—with no answers forthcoming.

Then one day a copy of a clinic note was forwarded to me (out of courtesy or error), documenting Josephine's follow up visit with the neurologist. I eagerly devoured it, hoping for some subtle



confirmation of my most profound wish—that Josephine’s brain wasn’t *so* bad, that it would get better, that one day I would look back and wonder why I was ever worried. Instead, what I found took my breath away—left me feeling physically ill, hollow and hopeless. There, in harsh black and white was the word—“encephalopathy.” In layman’s terms, it means a brain that doesn’t work right. No qualifier like “mild,” “transient,” “possible”—just “encephalopathy”—a permanent, immutable condition.

Now, this should not have surprised me. I saw the evidence of this in my daughter every day—unable to suck or swallow, unable to lift her head, eyes that didn’t fix on objects or track (*could she even see?*), hands that didn’t grasp or reach. But it didn’t seem real, certain, irreversible, until I saw the word—until it was an actual diagnosis. Had anyone ever mentioned the word? I am sure that they didn’t. Was it assumed that I had figured it out? Perhaps, but I hadn’t. And that one little word knocked me off my feet. So, lesson one, communication, was revealed in sudden spurts, appreciated in retrospect, and is now applied to my work.

The second lesson has been about perception; specifically, differences in how people with neurodevelopmental disabilities are perceived. This lesson crept up on me slowly, as I made the gradual transition from seeing Josephine with a physician’s eyes to also seeing her through a mother’s eyes.

When I used to look at children with neurodevelopmental disabilities, I saw only the disabilities. My colleagues and I shared skepticism of “those” parents who voiced things about their child that we could not see, such as their child’s thoughts, feelings, and abilities. I recall one patient who was frequently admitted to the pediatric ICU. From my view, the child was completely non-responsive; her mother, however, would consistently offer a running verbal interpretation of her daughter whenever I was in the room. Comments ranged from, “She likes you, I just saw a little smile,” to “She’s not feeling well today, something is making her uncomfortable,” to “Oh, she’s about to have a seizure. There! She just had one—did you see it?” Whether the comment was referring to a smile

or a seizure, the child looked exactly the same to me. I saw nothing but blank eyes, a slack face, an immobile body. And frankly, I thought perhaps the mother’s grasp on reality was slipping a bit.

During Josephine’s first few weeks of life I saw her through physician’s eyes. Fearful of her disabilities (whatever they would be) I was certain that her life would be horrible, certain that our entire family had just been doomed to a lifetime of misery and fruitless struggle caring for a child who would never be interactive, never really be a person. My dread of this was so great that when another parent I met briefly in the NICU shared with me that he didn’t expect his child to make it home, I secretly wished to change places with him. But Josephine did come home. And the way I saw her began to shift. Several months later, beginning to see with mother’s eyes, I somewhat nervously confided to one of my colleagues, “I think Jo responds to me sometimes,” continuing on in a rush, “I don’t want to turn into one of *those* moms—you know the type . . . but I think maybe she does.” Slowly, my perception was changing.

A couple of years later, I was receiving report about a patient in the ICU. “She’s a 13 year old girl with cerebral palsy, post-op day one, from a spinal fusion for neuromuscular scoliosis. Pain control has been adequate. By the way, mom is *convinced* that she is cognitively intact.” I could practically hear the physician’s eyes roll, her voice thick with doubt that the spastic, non-verbal child in the bed could *possibly* be able to think, understand, communicate. I opened my mouth to protest, but then closed it just as quickly. Although I was well on my way to seeing the hidden potential, I wanted to be viewed as an objective, rational professional. I didn’t want to be perceived as an irrational parent who thinks that her child and others with profound disabilities had all the potential in the world. I was still afraid to be seen as one of *those* moms.

If you catch a glimpse of my daughter the way most health care professionals see her, perhaps around the hospital or at a clinic appointment, you’ll see a girl in a wheelchair, head lolling to one side, eyes not aligned, saliva dribbling from her open mouth into her bandana. You might call her name in greeting but there is a good chance



she won't look at you or even indicate that she has heard. She may not respond to me, either, and perhaps you'll think I am deluded in my expectation that she will. I know this is what people see—I see it too. This is how she typically behaves when we are in clinic or in the hospital; she's usually tired, cranky, withdrawn, and sometimes not feeling well. You might conclude based on these observations that she has very little cognitive function, very little personality, very little potential.

Now, I have become one of those moms. I see the potential. I believe in my child. Here is Josephine through a mother's eyes: I see a social girl who freely gives wide, toothy smiles by way of greeting to those she knows and likes (especially her big sister); a focused girl who can hold her head up straight and fix her eyes with incredible intensity on her favorite television program; a stubborn girl who will throw an all-out, screaming, arching, thrashing, hair-pulling tantrum when she doesn't get to watch the aforementioned favorite television show; a mischief-maker who will intentionally pee on any unsuspecting novice who changes her diaper, and then dissolve in fits of belly-shaking laughter; an expressive girl who is non-verbal but uses an iPad and an eye-gaze controlled voice-output computer to communicate; a first grader who knows her numbers, letters, shapes, and colors, and is learning to add, subtract, and read; a child who has reasonable cognitive function, a multifaceted personality, and marvelous potential.

Two very different views of the same child, and they are both right.

So much of what I do as a bioethicist involves this conflict. Issues such as: quality of life and potential of a child to experience, enjoy, interact—all leading to some form of the question, "Why are we doing this procedure/surgery/treatment?" Parents and health professionals asking the other—spoken and unspoken, "Why can't you see what is really going on?" The truth is, they are both seeing. They see different things. And what each sees is valid—a part of the larger truth.

I carry this lesson into my work as well. I speak out now; I try to see both sides, and help each side

see the other perspective. It doesn't always work, of course. But I try. I know there are more lessons ahead of me; my education is not yet complete. In the meantime I try to take this wonderful education and use it to improve my work. I hope that you, too, will embrace these lessons without ever being in a position to *really know*.



## Body Alienation and the Moral Sense of Self

By Jackie Leach Scully

### Once Upon a Time . . .

Once upon a time, a woman who had always been physically robust and healthy began to lose weight. Attributing it to exercise (good) or work stress (not so good), she did not at first connect it with the intermittent abdominal pains she'd also been having. But then both weight loss and pain rapidly became uncontrollable and she was diagnosed first with an ovarian cyst, then appendicitis. The appendectomy was a keyhole procedure that, we were told, would mean she went in on Thursday and would be taking a rehearsal again on Monday. But other things happened: the operation resulted in postoperative abscesses, and further surgery to deal with them revealed a tumour and perforated gut that required the removal of two sections of intestine and left a 30 cm long incision. And that became infected, which eventually required the insertion of a vacuum drain and seven further procedures to re-open and clean the wound, one of which (for reasons I won't go into here) had to be performed without anesthesia. It would be a two month stay in hospital and a total of 16 weeks before the wound completely closed.

This is a tale of my partner's illness and the consequences of surgical intervention, and there are lots of different narratives that could be told: a story of physicians' inability to admit to error, of avoidable difficulties in doctor-patient communication, about

how easy it is not to notice that you are getting horribly sick, or even about how the level of care a patient is getting magically improves when her partner is driven to reveal she's a medical ethicist. The story I want to tell this time, though, is how what happened made me think harder about the connection between the body and the self, and the moral force of embodiment. As an observer, the most striking and yet unanticipated aspects of this experience were the distress, suffering, and sheer physical and cognitive labor that my partner required simply to deal with what was happening to her body, not straightforwardly because of the illness itself—although that came into it too—but equally because of the surgeries and their consequences. Thinking as a bioethicist, it seems to me that my partner's sense of herself as a person—as a moral agent—was profoundly unsettled during that period by her loss of her sense that *her body was herself*.

### Moral Agency and the Body

Let me give some (real) examples. We all recognize at an intellectual level that having to converse with your surgeon while she is upright and clothed and you are in bed in a backless nightgown can harm your capacity to speak with her on level terms as a self-determining agent: as a concept, it's not hard to grasp that it feels undignified, especially for those like my partner who are used to being in leadership positions. But more than a question of dignity, the weirdness of holding reasoned conversations with almost complete strangers while experiencing such an unfamiliar comportment of the body causes disruption to the sense of self. In Bourdieu's terms, the patient's normal *habitus* (Bourdieu, 1990, p. 53) has been removed, and with it her ease with the rules of the game, some of her sense of continuity with who she is, and the kinds of choices she would normally wish to make.

Even a 'minor appendectomy' is still an utterly unnatural thing for an organism to undergo. For much of human history, having your abdomen sliced open has simply meant you are going to die,

and there's not much to be done about it except lie down and wait for the lights to go out. As a species we are unused to an embodied reality in which this is done deliberately and is survivable. On waking up and realizing that she had a 30 cm wound down her front, my partner experienced a not very well concealed horror, a feeling which was intensified when the incision became infected. Not only did this mean more surgery; the incision had to be opened and then left open to heal slowly. For several weeks, she had an unfamiliar view of the pink and meaty inside of her body. Worse was the smell of infection within the wound and struggling not to assume this meant her body was rotting from the inside out. The revulsion was profound and atavistic, and led to an equally instinctive reaction to distance herself from this. *That* is not my body; *this* is not me.

During the period when the infection was being drained by vacuum, she was tethered by tubing that ran from her abdomen to an external pump the size of a couple of large bricks and which sucked and wheezed noisily. The pump was a constant, noisy, painful (the suction pulled at the incision), unwanted presence; an exogenous, inanimate artifact that at the same time was more intimately part of her body, and the survival of her self, than any human being around her. *That* is even less my body: my body is even less *me*.

I've said that I felt my partner's moral agency was unsettled by her alienation from her body. By having an unsettled sense of moral agency, I don't for a moment mean that she lacked the capacity to make decisions about her treatment or care. To someone who had known her for more than a quarter of a century, however, it was clear that for at least a time her self-concept lurched and shifted along with the shifts in how her body was and had to be treated. She still had the capacities of an autonomous and self-determining agent, but the transient yet radical instability of her body made problematic the self she was determining through her choices and expressed wishes. As her partner, on the occasions when I had to make choices for her, I found it harder to be fully confident about my knowledge of what she would want, as she

continued to express her own insecurity about who she now was.

### Repairing Alienation

I've come to understand that we have to acknowledge illness and even 'routine' surgery as entailing some degree of alienation from the body as one's *self*, and that this is likely to compromise a person's ability to think and act in ways that are consistent with the way they were "before." Through this personal experience, what has become clearer to me is not just the importance of taking the subjectivity of the body more seriously in the medical experience, but that this commitment translates into apparently banal things to do with touch, movement, posture and so on. These are the ways in which morally important features like respect, care and autonomy are mediated, and the continuity of personhood preserved as much as possible.

One implication is that it is important to think about minimizing those experiences that are bound to alienate from the body, or that exacerbate the inevitable degree of self-disruption that comes from illness or trauma. Sometimes, experiences like these are genuinely inevitable, as part of the package of medical care. Still, a little imagination could be brought in; restoring some equality of bodily comportment in doctor-patient conversations, for example. For a patient to be lying down might be unavoidable; but surgeons can sit so that they are on eye level, and they can shake hands as equals, and that can make a significant difference. It may be impossible to eliminate entirely the shock of seeing an incision or dealing with the machinery, like a vacuum pump, that turns your body into alien terrain. But I wonder if what we need to do here is stand back from and reconsider the routinization of surgery, a process that now seems to me more than a little problematic. Both surgeons and the public now take for granted interventions into the body and its integrity without marking them as more than minor interruptions into everyday life. But they aren't, and medical interventions that disrupt bodily integrity, temporarily or permanently, need to be treated with respect for their impact on

personal identity as well as other more tangible potential consequences. Surgeons themselves are particularly prone to a banalization of the literally unnatural interventions they make every day, and might need reminding from time to time that they should not expect their patients—or the bodies of their patients—to respond to these disruptions of their embodied selfhood with quite the same equanimity.

### The End

Stories should have an end, and this one doesn't. My partner recovered, and has progressed a long way towards the recuperation of her body, in its novel form and markings, as her self. We continue to talk about what the experience meant for her, and what I can (and by habit, have to) make of it as a bioethicist. As I write this, two years after the events that began this story, the abdominal pain has returned and she is preparing for surgery once again. At least this time we'll be better prepared; and this time, I'll be on the lookout for the points where biomedicine turns body and self into strangers, and continue to search for ways to repair the join.

### References

- Bourdieu, P. (1990). *The logic of practice*. Palo Alto, CA: Stanford University Press.



### Two Journeys

By Katherine A. Taylor

I have wrestled with whether to tell my cancer story for over a decade now. Haphazard notes, essays begun then abandoned, are scattered through my untidy subject files. When *Narrative Inquiry in Bioethics* called for story proposals, I took the bait.

## A Cancer Journey

The doctor's call came on a winter day in 1999. Actually, it was Thursday, February 11, at about 5:30 p.m.—the scene is seared in my mind like a movie I can replay at will. I had just buckled my two-year-old daughter into her booster seat to feed her dinner. The doctor was calling about the results of a biopsy performed the previous day of an enlarged lymph node in my neck, a node that had been followed for a year with antibiotic treatments and an earlier negative biopsy, a node he had assured me “did not look like cancer” after he removed it. Given that assurance, I had almost forgotten about the biopsy, and was going on with the mundane and joyful business of living, raising a young daughter and writing my dissertation for my PhD at Georgetown.

“You have cancer,” the doctor told me, as my daughter gazed at me calmly, her thumb in her mouth. I struggled to just as calmly take in this shocking news as she began pleading “hungry, Mommy!” The mundane was shattered. As many cancer narratives attest, getting the “bad news” divides your life into “before and after” cancer diagnosis, a time of blissful ignorance, and then of fear and vigilance.

It is that fear that I most remember about the next few days and months, fear and a deadening sense of numbness. My doctor told me that the node was positive for thyroid cancer, but that it was a treatable cancer that “no one ever dies from.” I felt as if he were congratulating me on getting a “good cancer.” And while I did feel fortunate over time, at that moment I could not process those assurances because the fear was overwhelming. I called my neighbor to please come collect my daughter, along with the valentine cards that still had to be prepared for her preschool classmates the next day. I then waited with dread for my husband to get home from work—I had not told him the news over the phone when he called to say he was on his way. So began our journey into “cancer land.”

Over the next day or two, my husband researched treatment for papillary thyroid cancer on his computer while I lay on the couch, unable

or unwilling to process any medical information. I simply shut down. The sense of vulnerability and dread at having to face this diagnosis at age 39, and with a young child, was surprisingly disabling. I brought my husband with me to every doctor's appointment because I could not trust myself to ask the right questions or remember the information given. I had always prided myself on having extensive medical knowledge; after all, I was a former medical malpractice defense lawyer, and now a bioethicist. But that confidence and competence failed me as a cancer patient. I desperately needed a physician I could trust, and who spoke to me frankly but with care and compassion. My professional experiences, however, made it hard for me to fully trust any physician—that is probably the curse of most patients who have more than passing knowledge of medicine and the medical system.

Thankfully, there was no need to make any difficult medical decisions because the treatment plan for papillary thyroid cancer was well established. After my cancerous thyroid gland was removed, I would receive a scan to determine how much radioactive iodine was needed for an “ablation” of any remaining thyroid cancer cells in my body. (Since only thyroid cells take up iodine, the cancer cells can be targeted by radioactive iodine, making papillary thyroid cancer one of the “gold standards” of cancer treatment.) But in order for the cells to be prepared to take up iodine for the scan and subsequent ablation, I would need to become progressively hypothyroid over the next few weeks by forgoing any thyroid supplementation. (There is now medication that makes it unnecessary to “go hypo” before the scan and ablation, but at the time its efficacy was less established.)

Becoming hypothyroid was a tough road: it made me increasingly lethargic, depressed, and somewhat loopy, all the while caring for a young child. (In order to be diagnosed as being hypothyroid, one's level of thyroid-stimulating hormone (TSH) needs to be over five; my level was 152 by the time I got my scan). I was walking and talking and thinking in slow motion. I no longer trusted my driving, and needed my mother to come and help care for my daughter.

I did find the caring and trustworthy doctor that I sought, in my endocrinologist. Not so in my surgeon, or the nuclear endocrinologist who oversaw my ablation. Both were at times patronizing and dismissive of my concerns. As I tried to tell my surgeon that I could no longer sing (probably due to a vocal cord damaged during surgery), he interrupted me with the cheery declaration that I was “well on [my] way to a full recovery.” I felt a profound loss at no longer being able to sing to my young daughter, and in fact I did not recover my singing voice for years. I also encountered dismissive treatment by some hospital medical staff. One intern suggested that my cold hands (a symptom of hypothyroidism) were caused by the fact that it was snowing outside. He also discounted my report of facial numbness (a symptom of low calcium levels caused by damage to the parathyroid during surgery), only to have to keep me an extra day in the hospital to administer supplemental calcium.

It is impossible to tease out whether some of this behavior was because I was a (relatively young) woman, or whether these doctors treated all their patients this way. I suspect it was a little of both. I felt at times that I was seen as one of those female patients who “worry too much.” One wonders if I would have encountered this attitude if I had been a 60-year-old white male. Perhaps I didn’t act with enough authority, with the expectation that I would be listened to rather than with entreaties to be heard. But it shouldn’t be the patient’s responsibility to earn respect.

My hospitalizations in a major teaching hospital, for my thyroid surgery in March and then for radioactive iodine ablation in May, were mixed experiences at best. I learned that being hospitalized renders one helpless and sleepless. For my ablation, I was put in a seclusion room with plastic covering everything, even the phone. My radiation levels were measured by a Geiger counter after I was given the pill of radioactive iodine, which was carted into my room in a lead container and then offered me in a paper cup. I literally had no provider in my room for two days, until my radioactivity had decreased. My food trays were left for me outside the door, on the floor in the hall, sometimes with

no one even telling me the tray was there. I was told to throw all my leftover food into a trash bag in the bathroom, which began to smell because no one came to collect it.

I understand the real concerns of health care providers over exposure to radiation, but nowadays most ablation therapy is given outpatient. This raises concerns about exposure to household members. When I took my first scan dose of radioactive iodine, the technician failed to tell me that I should not have close physical contact with my daughter for a day or two, a fact I learned later. Unknowingly, that very evening I held her in my lap and read to her for at least 30 minutes.

I recovered from my cancer treatment, moved to Princeton, New Jersey a few months later with my family, and the waiting and worrying began. Interminable waits in doctors’ offices for appointments, waiting for blood tests and results, waiting for thyroid scan results, waiting through the weekend for CT scan results that might have foretold a recurrence. Being a cancer “patient” requires lots of patience, as the “waiting room” joke goes. There is simply no excuse for the waiting required of vulnerable and anxious patients, and surely no patient should have to wait over the weekend for critical test results.

Three years later, in 2002, I was diagnosed with a melanoma in situ, an early stage melanoma, on my foot. The years of riding horses bareback and barefoot in the El Paso desert had caught up with me. The melanoma was excised by a plastic surgeon, and I went on my way, with instructions to get a body exam every six months. That experience left me tired of being a cancer patient, and depressed. For some reason, we tend to feel that one bad experience with illness should inoculate us against a second (or third). No hospitalization was required, only hobbling around on crutches for a week or two.

I have been cancer free since my melanoma removal in 2002. I live with more vigilance and medical appointments than the ordinary person, I suspect, but I am thankful every day for my full life, including the gift of twin daughters after repeated radiation exposures had required me to delay having more children.



### A Professional Journey

My professional interests have evolved as a result of my illness. I was a philosophically trained lawyer-ethicist who tended to deal in theory and policy. After I was diagnosed, I began to read (voraciously) first-person illness narratives and other accounts about cancer patients. Initially I did this because the readings helped me feel less alone—as a relatively young cancer patient (age 39), I had no personal experiences or friends with the disease. But as time went by, I began to appreciate how reading these accounts could provide invaluable lessons to ethicists and health care providers, and the importance of the study of “narrative medicine” as urged by Rita Charon and others.

I have grown more interested in clinical ethics, and better recognize the value of nurses, and their empowerment, as members of the health care team. I certainly encountered caring and compassionate providers during my illness, but in all honesty most of them were nurses. I would argue that a study of the nursing code of ethics would be as valuable for physicians as it is for nurses. Relatedly, the principle of “respect for patient autonomy” should be expanded to that of “respect for persons,” which requires respectful attention to patients.

Being ill with cancer deeply affected my view of what is important, and often lacking, in morally-centered clinical practice. My greatest lesson was that patient vulnerability is a much larger factor in the physician-patient relationship than I had realized. While this point was brought home to me repeatedly in my clinical practicum long ago, I did not truly understand *what* that vulnerability meant until I became ill: how it *feels* to be debilitated and passive, how it affects the ability of patients to *take in* information, to ask questions, to make informed decisions. When that vulnerability is not recognized, when physicians treat patients as simply consumers of a service rather than as persons in need of a trusting and caring relationship, then physicians are excused from making a real effort to inform and care for their patients.

My experiences with dismissive physicians taught me the real value, and necessity, of respectful, compassionate communication with patients

and their families. I suspect the members of the hospital ethics committee on which I serve would accuse me of being a “Johnny one-note,” because I usually view the primary root of many difficult ethics cases as being the lack of good communication with the patient. Gifted communication, including the skill of really *listening*, is hard to find in health care, and should be better cultivated.

My illness affected my professional interests as much as it did my personal values and goals. Over time, I was happy to finally wake up without worrying about cancer, to live again my “mundane” family life, though I will never again take it for granted. I adjusted my professional ambitions in order to more fully enjoy my life. And I adjusted my view of what is important in my ethics work, with more theoretical pursuits giving way to include an involvement in clinical and narrative ethics that is deeply satisfying. I cringe when I hear others talk of cancer as being a “gift” (one I wish I had not twice received), but it has enabled my personal and professional growth in directions I had not anticipated.



### Teaching the Tyranny of the Form: Informed Consent in Person and on Paper

By Katie Watson

My colleagues and I in Northwestern’s Medical Humanities and Bioethics Program teach medical students a textbook vision of informed consent. We know physicians don’t always do it that way in practice, but we figure teaching how it *ought* to be done gives our students a fighting chance to decrease inevitable gaps between the ideal and the real.

In 2012 my father was diagnosed with terminal esophageal cancer, my partner and I both had minor surgeries, and a routine colonoscopy tore my mother’s spleen all in the course of six months. My “Year of Medical Management” made me realize my teaching about informed consent wasn’t just



intentionally ignoring a theory–practice gap—it was ignorant of how the modern medical workplace separates consent conversation from consent documentation, and how the “Tyranny of the Form” can undermine the decision-making process in surprising ways.

My father was a healthy 75-year-old who played his 36<sup>th</sup> season of softball in the summer of 2011, but in the fall he developed a persistent irritating cough, and in mid-January testing revealed an enormous tumor. He was quickly admitted to the hospital to figure out what to do with his tumor’s unusual fistula—a dye test showed that everything he swallowed went in (and mostly out of) a small gap in his tumor, creating an infectious pocket that would be fatal if it burst—and the high-stakes question was what to do about it. Multiple teams cycled through his room reporting their test results and differing assessments of risks and benefits for the various approaches they advocated. Every option included life-threatening risks in uncertain quantities, and there was no clear answer. The morning before the endoscopic procedure, my dad and his oncologist reviewed the possibilities and collaboratively decided to act conservatively, deferring the possibility of an esophageal stent or a drain through his back for later, and going with radiology’s recommendation of an exploratory scope of his esophagus to determine the origin of his tumor and inserting a feeding tube in his stomach in preparation for a low-dose palliative round of radiation and chemotherapy. It was a textbook-perfect example of option review and collaborative decision-making among physician, patient, and family—score one for informed consent!

That afternoon a surgery resident came in to “consent” my father for the next day’s endoscopy, and as he scanned the form he rattled off that they were going to place a stent. “No, they decided not to do that,” my dad says. “That’s okay,” the resident says, “go ahead and sign it and they’ll work it out tomorrow.” My dad looks to me from his bed, and I back him up. “There was a lot of discussion back and forth and it sounds like maybe surgery didn’t hear the final decision. Why don’t you check with Dr. D [Dad’s surgeon] to make sure everyone’s on

the same page and the form lists the right procedures?” The resident waves the consent form in the air. “This isn’t a legal document.” I don’t correct him: I am off the lawyer–ethicist–professor–clock, today I am a daughter in jeans curled in an uncomfortable chair who can still barely believe her hearty daddy has been bedded in a hospital gown. “It’s not a contract,” he says dismissively. “Just because you sign it doesn’t mean we *have* to do what’s on here—if it’s wrong we won’t do it. And,” he says hopefully, “you might want a stent later.” I smile. “Well then you’d want to talk to him about that then. Signing something we already know is wrong seems bad for safety, you know? With all these different teams . . . double-check with Dr. D, okay?” The resident leaves.

An hour later Dad’s oncologist calls my cell phone sounding confused: “I hear your dad refused the endoscopy?” I explain. She chuckles. “I’ll speak to the young resident.” Two hours later I walk into Dad’s room and the resident is back, this time with a radically different demeanor. He’d *never* want us to sign something that wasn’t right, he was just trying to figure out what was accurate so he could make a *corrected* form, does *this* look okay to Dad and me? *Wonderful*.

In *The Healer’s Power* (1992), physician-philosopher Howard Brody analyzed the power of the workplace, because he thinks discussing ethical problems in terms of the tension between care and work brings to light ethically relevant features that aren’t raised by more traditional ethics language or concepts.

In this situation, the workplace division of labor had one person get the actual informed consent (Dad’s oncologist) and another get documentation of that consent (the surgery resident). When these roles are separated, the person sent to document consent invariably lacks full knowledge of the actual consent conversation. But what accounts for the resident’s resistance to changing the form when the patient informed him of its error?

From a workflow perspective the resident was under asymmetric pressure: if he’d gotten a signature he probably wouldn’t catch trouble for adding an inaccurate consent form to the chart unless it

resulted in a surgical error. And of course revising the form lengthens his to-do list. But if it doesn't matter what the form says, why are we signing it at all? During my father's hospitalizations I came to think of the hospital as a "health factory" with a gravitational pull toward efficiency that can disempower both physicians and patients. As Brody observes, "[t]here is a direct conflict between the routine and power of the workplace and the goal of patient autonomy" (p. 68).

Brody invites ethicists to use the language of power, but he doesn't analyze the power of language. Consider the expectation embedded in the directive "go consent her"—converting consent to a verb establishes "yes" as the goal and constructs patient refusal as a failure of the person sent to get "consent." The emphasis on outcome in "go consent her" also suggests the physician has a stake in the patient agreeing with the recommendation, one strand of which could be beneficence ("I think this is best for you and am invested in your wellbeing"), another could be personal power ("rejecting my recommendation is an affront to me and/or my expertise"), and Brody's focus on workplace power suggests a third strand—the patient who says no disrupts the momentum of a very expensive assembly line. (Twenty years later, Sharon Kaufman's ethnographic research, *And a Time to Die: How American Hospitals Shape the End of Life* (2005), confirmed Brody's insight about the pressure to keep things moving in the hospital).

I used to chafe at this language (Aren't they sent to get the patient's decision? Would the response to refusal change if the shorthand were "go decision her" or "go risk-and-benefit her"?). This experience made me rethink my objection: when a higher-up has already had the conversation and the "yes" is a done-deal, "go consent her" is an accurate affirmation of the separation of conversation and documentation. In that situation, the person who leaves the room without a signature has failed a clerical task. Sadly for this resident, a glitch in the assembly line put a faulty form in his hand. From a safety perspective he should have been rewarded for catching an error, but his behavior on both occasions suggests he could have

been responding to punishment (feared or actual) for disrupting workflow.

In other instances, the two acts of American medical decision-making—discussing the procedure with someone who knows about it and documenting your decision—are combined. That was the case two months later when I needed surgery to remove uterine fibroids. Five days before surgery I had an appointment with my doctor's Fellow to review the procedure. The Fellow did an exemplary job of explaining risks, benefits, and alternatives in plain language and answering my questions. I caught the professorial part of my brain thinking, "Now *this* is informed consent" as the Fellow spoke—I was genuinely impressed with her.

Then she handed me the consent form, which said: "If any presently unknown conditions are revealed in the course of the procedures named above which call for different or further procedures, I hereby consent to and authorize the performance of such procedures as well." I reflexively cross this out as I read it, and the Fellow looks startled. I explain that I always cross out blanket consent sentences because I'm not agreeing to any and all procedures, only the one we discussed. She responds in what I register as a patronizing tone: "What if you were dying? Wouldn't you want us to save your life?" I wince at the hint of antagonism, sitting up straight. "Yes. I would. And you'd be authorized to do that by emergency exceptions to consent. But if you found a non-emergent condition you recommended other procedures for, I'd want you to discuss it with my surrogate." She says nothing. Fine. I read on, reaching the parts that say I consent to assistance or observation by medical students. During our conversation I told the Fellow that my doctor was fine with my request to exclude students, and the Fellow agreed that made perfect sense given my teaching role. Now I'm more anxious, but with suspended pen I say, "So I should cross out the consent to students too . . ." and she flinches. "No, no. You can't cross anything else out." "Why not?" "I'd just hate for it to hold up your surgery. People see something scratched out, then people have to talk about it . . ." "But couldn't you just tell them it's alright? I just want the form

to match what we said." "We can't *guarantee* no students will come in." "Then we should talk about that more!" "It's not that, they won't . . . I'd just hate for your surgery to get held up to the point you had to come back another day." It's silent for a moment as I process my options. Then she adds, "At some point you just have to trust us, right?"

She's right: I shouldn't agree to have my naked body jacked open while I'm unconscious unless I trust the people doing so to take care of me. And medically, I do. But I was asking them to care for me personally when I asked them to keep my students from seeing me like that, and "at some point you just have to trust us" felt like a threat, the elbow that says I'd be safer if I traded formal protection (the form) for personal protection (her word, which she has just indicated can't be "guaranteed"), which frightens me because now I realize I need her to *want* to protect me. "Trust us" frames my desire to alter the form as an offensive expression of mistrust, and suddenly the negotiation is personal: when I'm unconscious, is she more likely to bar students because the form says so, or because I deferred to her need to avoid responsibility for a form kerfuffle in the workplace? As Brody observes, "In the hospital, it may, ironically, be the interns who are guilty of using what little power they possess against the patients instead of for them. . . . [P]atients who do anything untoward or unexpected present a threat to the intern's all-too-limited power to control his environment" (p. 68). I'm the epitome of the empowered patient (a lawyer on the hospital ethics committee being treated at her own institution!), yet I felt bullied into signing a form that didn't reflect our verbal agreement in the hopes my deference to her paperwork inspires her to protect my dignity when I'm helpless. Brody is correct: "Patients quickly pick up the usually unspoken message that they will get the best 'care' precisely to the extent that they facilitate and do not impede the flow of the workplace" (p. 68).

My "Year of Medical Management" offered many events that deepened my understanding of the practice of informed decision-making, but these two examples translate most clearly to the classroom. In this small anecdotal sample there

was no theory–practice gap—I was delighted these informed decision-making conversations actually met the textbook ideal I teach. It was the documentation of that consent that turned junior physicians into flummoxed functionaries. Our teaching isn't incorrect; it's incomplete. The textbook we use only remarks that asking house officers to obtain consent signatures "might be problematic" if the patient has questions the inexperienced physician can't answer (Lo, 2009).

But now I believe there are other ways in which house officer administration of forms can undermine consent. Dad's surgical resident was right that the form is not a binding contract, and wrong that it's not a legal document—consent forms are specifically created as evidence that will be admitted in court if memories of that conversation diverge. I never want one of my students to pressure a patient to sign an inaccurate form, and I want them to understand that saying "it doesn't matter what the form says" is disingenuous—if Dad underwent an incorrect surgical procedure he signed off on, the burden of proof would be on him to establish the conversation was different. In my case, perhaps the Fellow's understanding that what the form says *does* matter is part of why she didn't want to promise on paper what she had promised verbally. I want my students to keep the spoken and printed word in synch, never expediently agreeing to something they can't really commit to. And on an institutional level, I need to contemplate whether I should be teaching about workplace pressure on young doctors as an issue of organizational ethics.

## References

- Brody, H. (1992). *The healer's power*. New Haven, CT: Yale University Press.
- Kaufman, S. (2005). *And a time to die: How american hospitals shape the end of life*. New York City, NY: Scribner.
- Lo, B. (2009). *Resolving ethical dilemmas: A guide for clinicians* (4<sup>th</sup> ed.). Baltimore, MD: Lippincott Williams & Wilkins.