

This section features original works on pathographies—that is, (auto) biographical accounts of disease, illness, and disability—that provide narrative inquiry relating to the personal, existential, psychological, social, cultural, spiritual, political, and moral meanings of individual experience. The editors of this section are Nathan Carlin and Therese Jones. For submissions, contact Nathan Carlin at Nathan.Carlin@uth.tmc.edu.

### *Thriving in Adversity*

#### *Psychotherapeutic Experiences in a Bone Marrow Transplant Unit*

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**Abstract:** This article is intended to highlight the unique vulnerability associated with a severe medical illness. It outlines important considerations that are relevant to patients but perhaps especially relevant to medical providers. There are many factors that contribute to recovery from a life-threatening illness. Essential, but underestimated, factors include (1) a vision for what the meaning of your life can be; (2) simple and unexpected acts of kindness that underscore the commitment of your providers to your well-being; and (3) the character of providers and the culture of the institution, which vary tremendously and are palpable to the patient.

**Keywords:** illness; vulnerability; adversity; meaning; kindness; character; culture

#### **The Story of My Illness**

I am a pediatric urologic surgeon who came to work one morning to perform a renal transplant only to realize that I was, myself, ill. It was a typical Tuesday morning, the day of the week I always reserved for urinary and pelvic reconstruction in children with renal insufficiency. On this day I was scheduled to perform a living related donor transplant in a child I had been following for years. Despite my commitment to this child and family, I arranged for another surgeon to take my place, as my fever and fatigue would prohibit me from operating safely.

I called my wife, Maureen, and together we went to see my primary physician. He ordered a chest X ray and blood work and indicated that he would call me with the results. We went home to await his call. That call was devastating. My hemoglobin level was half of what was normal, and my white blood cell count (neutrophil) was dangerously low. My wife called a dear friend, Cindy, who happened to be an oncology nurse. It was her day off, so she drove to our house to take us to the oncology unit where she worked. Before this day would end, I would receive a bone marrow biopsy and be given a

preliminary diagnosis of leukemia. I was reassured that I was most likely suffering from chronic myelogenous leukemia, a relatively indolent form of leukemia that can often be managed without a major disruption of one's life. I was given an appointment to return the next day to receive two units of blood and to confirm the biopsy result.

With a degree of cautious optimism, my wife and I returned home to gather our thoughts. When we returned for our appointment, I could sense an air of unease—that unease so often expressed by reluctance to fully engage the eyes upon greeting. As I was placed into an exam room, I was told that I would be seeing a different oncologist from the one that I had seen the day prior, the one who specialized in leukemia. "Not good," I thought. I was informed that I would receive a blood transfusion and be admitted for induction chemotherapy—my diagnosis was now acute myelogenous leukemia (AML). In just 24 hours, my life was forever altered. The prior week I was at the peak of my surgical career, with national prominence in my field of practice, but that day I was . . . "Who am I? Who am I now?" I wondered.

An intravenous line was placed, and a blood transfusion begun. My wife was escorted into the hallway as she collapsed in despair. I asked those who remained to allow me a few minutes alone. I watched as the blood progressed from the bag to the line and then entered my body—the body that had been, until now, so reliable, so seemingly indestructible. It seemed so invasive, so violating, so desecrating. I cried, almost uncontrollably. "When was the last time I cried?" I asked myself. I couldn't even remember. I was to be admitted upstairs to the oncology unit. So I had to gather my composure; I couldn't let my family see me like this. As I was wheeled to my room, we passed

other patients who were further along in their journey. Some were obviously weak, requiring assistance with ambulation. Others had those sparse, patchy remnants of hair. It occurred to me that they represented my future.

The first order of business was placement of a central line. No problem: I had placed hundreds of these myself and knew exactly what to expect. But then came the chemotherapy. I was mostly prepared for what was to come—the nausea and vomiting and the strict protective isolation with very restricted visitation: no flowers, no raw fruits, and no vegetables. Visitors would require a mask and gown. My wife was my lifeline. She brought in a mattress, moved the furniture in the room aside, and slept every night in my hospital room. She almost never left. Sometimes she would lie beside me in my hospital bed, and we would find comfort in each other's arms. I had so very much to live for.

As I was dealing with the side effects of chemotherapy, the genetic markers of my malignancy began to return from the laboratory; slowly, progressively, one or two each day. Each one would portend a worse prognosis than the last. My oncologist was the kindest and most gentle physician I had ever experienced. I remember him sitting with my wife and me, detailing the significance of my tests. I learned that if I were to have any chance of survival I would require a bone marrow transplant. Because of the poor prognosis, it would be a complicated transplant, and I could not be treated locally—meaning that I would have to leave my family. As it turned out, transferring to another facility would not be as smooth as I had anticipated. In the days preceding the transfer, I developed sepsis with high fever, accompanied by what by then was decidedly less tolerable: nausea and vomiting. My endurance was exhausted. I became unstable and required an air ambulance

transport to the chosen cancer center, an institution that was several states away.

As we left the hospital, one of my most vivid memories was being wheeled through the lobby of the hospital to the car that was to take me to the airport. A large crowd of friends and colleagues had assembled to send their love. As I passed through the crowd, these friends, surrounding me on each side, were wishing me their best and offering up their thoughts and prayers. By this time I was becoming disoriented, but I could recognize something, something in their eyes: "They don't think I'm coming back!" I thought.

Accompanied by my wife, children, and Cindy, we flew cross-country toward our destination. The flight seemed so long and so cold. Little did I know that I was to feel cold, literally, for the next two years, due to profound loss of weight. Once the plane landed, I was immediately transported to the emergency department. There were no beds available; the hospital was running at 110 percent capacity. The first night I would spend tucked away in a small alcove of the emergency department, with Maureen and Cindy sleeping on a couple of very small and very uncomfortable chairs.

Finally, a room became available, and I could hear my nurse calling in a report to the nurse who was going to receive me in the new unit. "He's a surgeon from Ohio," she said, and added, after a pregnant pause: "No, this one seems to be quite nice." I was sent to the X-ray suite, for a CT scan of the head and chest, on my way up to the room. In the confines of the scanner, I developed sudden and massive emesis. I struggled to get my mask off my face, but it was too late—I had aspirated. I was evacuated from the scanner, suctioned, and cleaned up. I seemed to be okay. Over the next several hours, however, my

condition worsened, and I was transferred to the intensive care unit.

I was by then very hypotensive and was placed on vasopressors. I was developing multisystem organ failure from sepsis. I was essentially unable to converse, but I could make out some of the conversations that were going on around me. They were explaining to my wife that they couldn't intubate me because patients with white counts as low as mine basically never survive on ventilation. Instead, they were able to support me with a BiPAP mask and 100 percent oxygen. The head of my bed was raised as high as it would go. "His chest X ray is a white out," I heard. "What?" I thought. I was now sufficiently aroused that I could ask to see my X ray. They pulled a computer screen to my bedside and pulled up my chest film. I couldn't see it; I needed my glasses. I remember trying to put them on my head, but there was no way that they would fit with the BiPAP mask in place. I folded my glasses so that I could hold one lens up to one eye in order to see the screen. Both of my lung fields were completely opacified, with the exception of a tiny crescent at the very top of each lung. "My God," I thought. "Is that me?" Over the next several hours I would fade in and out of consciousness. "My bed is moving," I thought. "I am being taken down endless corridors with strange lights and very odd, distorted walls. No, I'm hallucinating."

Surprisingly, over the next week, I slowly began to recover from my multi-system organ failure. More surprisingly, my neutrophil count began to gradually improve. I would ultimately be found to be in a short-lived remission. This would buy me sufficient time to gain enough strength to undergo a bone marrow transplant. I received a matched unrelated donor bone marrow transplant that would prove to be successful. The transplant process required greater

endurance than anything I had ever encountered. Once again I struggled with nausea and vomiting, much more intense than what I had experienced earlier. I also experienced intense and protracted pain, with the development of mucositis and viral cystitis. Unexpectedly, however, the greatest drain on my endurance was the emaciation associated with this entire process. I had severe anorexia and lost 40 pounds in weight. I was always cold, so cold that I would dread my daily shower, which was pure torture. Even walking would prove difficult, and for a time I required tremendous assistance with ambulation. I would be placed in a harness with handles in order to allow assistants to support my weight. The nights were long and lonely. There were screams from other patients who were in fear or in pain. The little sleep I was able to get was regularly interrupted by the piercing sound of alarms.

As I lay awake my thoughts would repeatedly—no, constantly—return to the same questions: Why? What about my family? Had I done enough to provide for them in my absence? Why me? Why now? How could this have happened at the very peak of my career? A few short weeks ago my career represented an important and unique contribution, both regionally and nationally. Would I ever contribute again? Would I ever be relevant again? Who am I? Who am I . . . now?

Edmund Pellegrino has so accurately described the fact of illness as severe vulnerability, a state of wounded humanity.<sup>1</sup> He defines humanity according to three concepts:

- 1) *Freedom of action*: Of course, the body is the means of this action, and mine just wasn't working.
- 2) *Freedom to make rational choices*: Even with a very substantial amount of background medical knowledge,

my illness involved concepts with which I was incompletely familiar. Further, my mind wasn't as clear as I was used to it being. I had to rely on others, much more than I could have anticipated, for the choices that I made.

- 3) *Freedom from the power of others*: I was, in all reality, completely at the mercy of the integrity, competence, and motivations of others.

As fate would have it, I survived. I returned home, and with great effort directed at exercise and attitude, I continued to progress until I had almost attained my baseline strength and stamina. Eight months after my release, a routine follow-up bone marrow biopsy revealed equivocal results. I would have to wait several days for the result of more sophisticated tests on the biopsy. When the call came, it was devastating—I had relapsed. I could barely remain standing. They offered me two choices: (1) a repeat bone marrow transplant or (2) forgoing treatment and letting the malignancy take its course. I was so conflicted. I wanted very much to live but could not imagine going through another transplant. I sought the advice of a close friend and colleague with whom I had worked essentially my entire career. The decision was impossible, even with all the help I could muster. Ultimately, I convened my entire family, and my wife and I presented the dilemma to our children. I indicated that, after a great deal of thought, I had decided to forgo a second transplant, as the first had been so disruptive to my family, and because the chance of survival was so low. Our children were outraged with this decision. My youngest son responded: "You won't know what I become." I was sufficiently moved that I immediately got up, packed my suitcase, and once again my wife and I made our way to the cancer center.

As it happened, a procedure that was in its infancy at the time of my first transplant had become more generally available. This was what was referred to as a haplotype-matched bone marrow transplant. This would originate from one of my children. They were all tested, and one, my youngest son, was found to have natural killer T cells that were mismatched for antigens on the cell surface of my malignant cells. Again, I received ablative chemotherapy. My son had his bone marrow harvested, and at the appropriate time his marrow was infused into my bloodstream. For a time, I received immunosuppression to prevent graft-versus-host disease. I was again cast into that intensive struggle of nausea, vomiting, pain, and emaciation. The graft took perfectly, and ultimately I recovered. I am now almost five years out from transplant with no evidence of disease. Although my strength and stamina have returned to near normal, I have been unable to return to my practice because of the risk of exposure to all of the viruses in the pediatric population that I had served. Further, I have painful peripheral neuropathy in my feet, eliminating my capacity to stand throughout the long surgeries that my practice entailed.

### **What I Have Learned**

What have I learned in this life-altering process? I have learned about meaning, kindness, and the vast differences (greater than I could ever have imagined) in quality among providers and hospitals.

### *Meaning*

I received a great deal of solace from Viktor Frankl's *The Will to Meaning*,<sup>2</sup> which I brought with me, and from the work of his student, Alex Pattakos, specifically, *Prisoners of Our Thoughts*,<sup>3</sup> which

I purchased during my illness. These works spoke so clearly to the sense of vulnerability that overwhelmed me. "How many opportunities," I wondered, "had I missed to help my patients and their families negotiate their crises?" Specifically, Frankl's concept regarding the critical importance of nurturing one's attitude during such times was instrumental. His concept is that between any situation and our response to that situation there is a gap. In this gap we have the unique capacity to make choices. Specifically, we find in this gap our *freedom to will* and our *will to meaning*. Frankl notes that "a man who becomes conscious of the responsibility he bears toward a human being who affectionately waits for him, or to an unfinished work, will never be able to throw away his life. He knows the 'why' for his existence, and he will be able to bear almost any 'how.'"<sup>4</sup> Pattakos presented seven exercises to help unlock a mind so encumbered by such vulnerability. I practiced each one, as I knew that my attitude would be pivotal as to whether I lived or died. He stated that "when we choose our attitude in light of what I would call true optimism, we actually make three choices: (1) We choose a positive attitude about the situation at hand. (2) We choose an attitude that supports a form of creative visualization about what's possible. (3) We choose an attitude that generates passion for the action that makes the possible become a reality."<sup>5</sup>

I focused on one of Frankl's gripping stories regarding his time as a prisoner of war in a Nazi concentration camp:

I repeatedly tried to distance myself from the misery that surrounded me by externalizing it. I remember marching one morning from the camp to the worksite, hardly able to bear the hunger, the cold, and the pain of my frozen and festering feet, so swollen from

hunger-edema and squeezed into my shoes. My situation seemed bleak, even hopeless. Then I imagined that I stood at the lectern in a large, beautiful, warm and bright hall. I was about to give a lecture to an interested audience on the "Psychotherapeutic Experiences in a Concentration Camp." In that imaginary lecture, I reported the things that I am now living through. Believe me, ladies and gentlemen, at that moment I could not dare to hope that someday it would be my good fortune to actually give such a lecture.<sup>6</sup>

"What power," I thought—turning adversity into contribution. Following his lead, the title of my lecture (which I have now given several times) was to be "Thriving in Adversity," and I subtitled it "Psychotherapeutic Experiences in a Bone Marrow Transplant Unit."

#### *Kindness*

The mind is indeed a very strange entity. As I now look back on my experience from a distance, my memories of the pain accompanying my mucositis and cystitis, the protracted nausea and vomiting, and even the oppressive weakness of emaciation are now surprisingly blurry. I have to concentrate in order to reexperience these sensations in my mind (which I very seldom do). What is surprising to me, however, is how several small acts of kindness remain in my memory with such force and vivacity that they dwarf even the worst of the pain and discomfort I encountered.

*The nurse.* Once I had recovered sufficiently from my bone marrow transplant, about 60 days from the time of the transplant, I was allowed to leave the hospital and set up residence in an apartment nearby. It was almost like being a real person. I would return, initially, every day and later three times a week for blood tests as well as blood

and platelet transfusion as needed. One day, I was walking in the hallway on my way to receive a blood transfusion. Suddenly, and with absolutely no warning, I developed severe emesis. "What a disgusting mess," I thought. A nurse, who had no previous knowledge of me, ran to my assistance. I was so embarrassed. With no remaining sense of pride that I could call on, I can remember apologizing repeatedly for the mess I had created. She recognized how dehumanizing this felt for me. She was so incredibly caring and supportive as she helped me to a chair and then proceeded to clean up both me and the hallway floor. Continuing with this overwhelming compassion, she assisted me to my appointment.

*The doctor.* When we returned for our office visits to see the physicians, we would be placed in an examination room. Whenever we were in the hospital, we were required to wear a mask continuously. The one exception was in the examination room. I remember sitting and talking to my doctor when my mask, which I had placed in my lap, fell to the floor. I reflexively reached to pick it up. "Don't touch that," he exclaimed, as he darted across the room to pick up and then discard my mask. He was concerned, of course, that I would get an infection. The expression on his face conveyed such genuine concern that it was obvious to me that he was completely invested in my recovery. I must, I thought, work as hard as I can to get through this not only for myself and my family but for him as well. I wondered, "Could this be part of the solution to the challenge of compliance?"

*The patient.* The waiting rooms for all of our visits were extremely crowded. There were long rows of chairs, often positioned back to back and separated by a partition of glass. One day, while

awaiting my appointment, I sensed that someone was looking at me from behind. I turned to see a young man looking at me. He looked a lot like I—and almost everyone else in the waiting room—did: bald, extremely thin, and bundled up in way more clothes than would normally be appropriate given the ambient temperature. As our eyes met, he placed his hand up to the glass. Reflexively I placed mine to exactly mirror the position of his. This incredible moment of solidarity haunts me to this day. God, I hope he made it.

### *Discrepancies*

My illness has placed me at the mercy of several hospitals and a multitude of providers. How, I wondered, could you explain the variation in quality to which I was exposed? The providers, for the most part, appeared to be similarly knowledgeable and skillful. Rather, I discovered, it was their character—the culmination of the virtues they had cultivated over the years—that seemed to make the difference. The discrepancies among hospitals were similarly troublesome—palpable, I believe, to any patient requiring protracted care. These hospitals had very similar facilities. Their vision and mission statements were nearly identical. And, yes, they all very proudly displayed posters declaring them to be among the top hospitals in the United States. “How,” I thought, “can they all be the best?” It was the institution’s culture, clearly, that made the difference. For both providers and hospitals, these differences were not dependent on some ephemeral, touchy-feely, feel-good sensation. It was much, much more than that. It was advocacy. It was ownership of the outcome of care. And, yes, it was the willingness of providers to efface their own goods in order to promote those of their patients.

### **What I Hope For**

Since my return, I have had the great opportunity to sit on the ethics committee as well as the physician practice evaluation committee of my institution. It is my distinct hope that I will learn enough in this process to understand how medicine might be changed for the good of the patient. Initially, I thought the answer was professionalism. Certainly, we all recognize that we are facing a crisis in professionalism on a national basis. Unfortunately, frustratingly, just as the policies and procedures we have established to eliminate medical error have been less productive than initially hoped, so have our efforts on professionalism. The fact is, with very rare exception, providers know how they should and should not behave. They know that their behavior can influence the outcome of care. They know that they should remain current from the perspective of knowledge and skill pertinent to their practice. They know that their inability to work respectfully and cooperatively with other providers is fundamental to the effacement of coordinated care and that this inability sets the stage for error. Further, they know that the manner in which they engage their patients is fundamental to the establishment of trust and hope so essential to a positive outcome.

How, then, can we possibly hope to change the character of providers and the culture of hospitals? I now believe that the answer will be more fundamental than an effort on professionalism alone. It will require revisiting the very philosophy of medicine: how we are to think about who we are and what we do. So much has changed since the wonderful work of Pellegrino and Thomasma, in which they described medicine as occurring precisely at the interface between the provider and the patient. The provider worked for

the patient. The professional would make a promise, a “profession,” to the patient as to his or her current competence as well as advocacy and ownership regarding the outcome of care. The medical action would be technically right and morally good. This implicit contract could only be based on the character and virtues of the provider—ultimately, there can be nothing else. The commodification of medicine has changed this dynamic, irreversibly. Physicians now, for the most part, work for hospitals. Documentation and billing activities erode the face time that providers should spend with their patients or in reflection as to whether or not the judgments they have made should be revisited. The moral angst is palpable. How do we change institutional culture and virtue in the face of all these adversities? It is to this end that I have now become a graduate student in philosophy. It is my hope that, somehow, I might turn my tragedy into a contribution.

**Notes**

1. Pellegrino ED, Thomasma DC. *A Philosophical Basis of Medical Practice*. New York: Oxford University Press; 1981, at 208. Pellegrino writes:

When a person becomes ill, he is therefore in an exceptionally vulnerable state, one which severely compromises his customary human freedoms to use his body for transbodily purposes, to make his own decisions, to act for himself, and to accept or reject the services

of another. The state of being ill is therefore one of wounded humanity, of a person compromised in his fundamental capacity to deal with his vulnerability.

2. Viktor Frankl was professor of neurology and psychiatry at the University of Vienna Medical School. He established a system of logotherapy/existential analysis founded on humanity’s freedom to will and humanity’s will to meaning. He attributed much of his understanding to observations made as a prisoner of war in a German concentration camp. Frankl VE. *The Will to Meaning*. New York: Washington Square Press; 1985.  
3. Pattakos A. *Prisoners of Our Thoughts*. San Francisco, CA: Berrett-Koehler; 2004, at 4:

This book explores seven Core Principles that I have derived from Frankl’s work: (1) we are free to choose our attitude toward everything that happens to us; (2) we can realize our will to meaning by making a conscious commitment to meaningful values and goals; (3) we can find meaning in all of life’s moments; (4) we can learn to see how we work against ourselves; (5) we can look at ourselves from a distance and gain insight and perspective as well as laugh at ourselves; (6) we can shift our focus of attention when coping with difficult situations; and (7) we can reach out beyond ourselves and make a difference in the world. These seven principles, which I believe form the foundation of Frankl’s work, are available to us anytime, all the time. They lead us to meaning, to freedom, and to deep connection to our own lives as well as to the lives of others in our local and global communities.

4. See note 2, Frankl 1985, at 101.  
5. See note 3, Pattakos 2004.  
6. Frankl VE. *Viktor Frankl Recollections: An Autobiography*. New York: Plenum Press; 1997, at 98.