

Editorial

I slew the beast!

James B. Mansfield

Department of Medical Ethics, Sherman Hospital, Elgin, Illinois, USA

E-mail: *James B. Mansfield - jbm5@comcast.net

*Corresponding author

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I slew the fire breathing, hideous, CA headed dragon a quarter-century ago in a no holds barred contest to the death. Yes, this is a bit of hyperbole, conceit, and narcissism as well as a good measure of tongue-in-cheek humor to describe the worst period of my life. And, note the use of the malignant metaphor setting up a battle of will between the afflicted and the affliction.^[7] I am going to describe my illness and analyze it using narrative ethics.

I was a 44-year-old practicing neurosurgeon in good health; in fact, in my obsessive fashion, I had just set a personal record of jogging on 42 consecutive days. A nagging cough came on for which my internist prescribed an antibiotic over the phone with temporary success. My wife (Karen) was and is my “right hand man,” so when my cough recurred and she heard me hacking away in our medical office she “demanded” that I request my internist to order a chest X-ray. I dutifully complied and went over to the immediately adjacent hospital to get it done. This was in 1990 in the era before digital radiology, so I was at the developer when the old-fashioned X-ray film came out. I looked at it on the viewbox and saw a softball sized tumor just to the left of my heart. After my stomach exited downwards through my anus and bounced back up to its usual location, the lines of battle were drawn.

Since I did not want to tell Karen the shocking news over the phone, I told her all was well and did not reveal the serpent’s presence until I arrived home. It was with great difficulty that I maintained the demeanor of the invincible warrior surgeon. Multiple needle biopsies of the tumor were inconclusive, as the reptile’s armor was too thick. So, I had open surgery to remove the beast and make a conclusive diagnosis. My first night in the ICU after my “sternum splitting” was the most painful of my life. The epidural catheter gave me absolutely no pain relief and the pills did as much good as throwing pebbles at an enraged dragon. I also realized that my right hand

was weak and partially numb, so I diagnosed an ulnar nerve palsy (though this turned out to be a nerve stretch injury from the thoracotomy). This did not add to my peace of mind as I wondered how I would be able to resume being a surgeon. The ICU nurses, doing their jobs, encouraged me to turn and cough to clear my lungs. But, the beast lay astride my chest and I hardly could manage to breathe at all. I shut my eyes and attempted slow breathing, confident that when I opened them after oh-so-long an interval, a sleepless hour or more would have passed. Instead, the minute hand on my clock had hardly moved.

Karen went home to weep, comforted by Sheba, our Great Dane, who placed her enormous head in her lap and gazed soulfully upwards onto her tear streaked face. Even still, the evil dragon evaded identification for several weeks despite review of the pathological slides by multiple local and distant universities, thereby creating yet more unsettling anguish. I was eventually told that the reptile was a non-Hodgkin’s lymphoma requiring

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chemotherapy in case a few of its errant scales had been left floating around inside me. In the wings, the radiation therapists awaited with their tongues hanging out, eager to aim their rays at my chest.

I had heard that open-heart surgery patients were able to return to jogging within a week or two of their thoracotomies, so I put on my running shoes about 10 days postop. Sadly, and oh so deflating for a warrior such as myself, I barely made it to the end of my driveway. However, I had just begun to fight. I girded my loins and was back performing surgery 13 days postop. My oncologist (Lary) put me through a series of tests (one of which was a bone marrow biopsy during which I felt like my innards were being sucked out through the needle) to stage the beastly tumor. I then began a 90 day long trial by ordeal (read chemotherapy). At the onset, Lary asked me how much numbness I could tolerate in my hands to gauge the dose of one of my poisons. I told him that while I was not a concert pianist, I really did need excellent hand sensation in order to function as a neurosurgeon. One of my medications was prednisone at a very high dosage: 100 mg/day. This wonder drug induced steroid mania such that I could barely sleep. I would get out of bed and go down to my stereo, use earphones to listen to music at high volume, and sip scotch in a misguided and ineffectual attempt to fall into the arms of Morpheus.

Besides prednisone I used four other poisonous battle lances to parry the dragon's attacks. One of these was Cytoxan, a cousin of nitrogen mustard used in the mustard gas of World War I. These seemingly produced every side effect known to man other than nausea. Yet, I was able to function well professionally. Karen was my surgical assistant as well as office manager, and she and I had made a pact that if she saw me perform at less than 100% in the office or OR, I would cease all such activity.

The restitution narrative has the basic storyline: "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again." Restitution stories attempt to outdistance mortality by rendering illness transitory. Chaos stories involve being sucked into the undertow of illness and the disasters that attend it. Quest stories meet suffering head on: they accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest. I first saw myself involved in what I now realize was a restitution narrative. This was consistent with the modern period's core social expectation of surrendering oneself to the care of a physician. Lary was brilliant, and he cared for me and Karen, but he could not make eye contact when we spoke and lost me in arcane biochemical explanations when I queried him.

I lost my hair to the Dragon's fiery breath. But, wise warrior that I was, I had anticipated this and had

previously been fitted for a hairpiece to wear beneath my helmet. What an ugly, poorly fitting rag it was, more befitting a peasant than a knight! My face became round from the prednisone with a few wispy strands of beard left upon it. I was amazed that none of my patients questioned me as to the state of my health: was I okay? Was I strong enough to care for them? There was never any sign of them being concerned for me, and I felt hurt by their total self-involvement or perhaps denial. Now, after reading Charon's assertion that "whoever occupies the role of doctor—no matter what his or her actual physical health status—will stand for health to the person diagnosed with sickness,"^[1] I think otherwise.

I was shocked during chemotherapy at how easily every strength I thought I had could be reduced to weakness. I was unmade as my mind sought to hold onto the promise that this treatment was curing me, while my body deteriorated; my intactness, my integrity as a body-self disintegrated. I was being sucked down into the chaos from the restitution narrative. The restitution story presupposes the control that is necessary to affect restitution. The ill person does not have this control himself, but those taking care of him do. The chaos story presupposes lack of control. The chaos plot imagines that life is never getting better and is filled with vulnerability, futility, and impotence. In the mornings when I saw myself in the mirror, I wondered if I would ever be the "old Jim" again and feared this more than the beast dealing me a death blow. Amazingly, "the reality of death is less real than the image of baldness."^[2] My body wasn't mine in view of what it had become and how much control over it I'd ceded to Lary. To my disciplined self my chaotic body represented weakness and inability to resist the serpent. I was in trouble, locked in combat, and uncertain, as never before, of the outcome. The hero who thinks he travels on his own will fail.^[6] Karen was, without a doubt, "the wind beneath my wings." Without her, the beast would have vanquished me. We worked together and she watched over me, assuring both that I was "okay" and able to carry on my work at a high level. Then, we would go home and I would crawl into bed and begin to shake with chills and from weakness. When dinner was ready, she would get me and I would eat. I frequently had the worst of all my side effects, awful mouth ulcers from methotrexate which made this a horrible ordeal. I used viscous xylocaine to relieve the pain; but this caused me to aspirate food on multiple occasions. My pharmacist neighbor developed a cotton candy version of Carafate that alleviated the pain without the risk—what a godsend!

Besides Karen, my support system consisted of my children and most of my friends. I say "most," as a few of them never called once during my ordeal. One later explained "I did not know what to say to you." Was this denial, or was he threatened by his vulnerability if

he acknowledged my infirmity? We have a hard time accepting that life sometimes is horrible, and the attendant denial of chaos only makes its horror worse.^[3]

Methotrexate killed any cells that were quickly replicating including, unfortunately, the essential ones in my bone marrow. To counter this, I had to “rescue” my marrow by taking Leucovorine precisely 8 hours later. This rescue fell in the early morning hours. Lary told me that if I failed to follow his instructions exactly I would die! Aside from the fact that sleep was impossible with this sword of Damocles poised above my head, we set three alarms just to make sure. I also had to take a handful of Tums to alkalize my urine to aid in my rescue; I have not had one since. Toward the end of the match, I became breathless. It was only with great difficulty that I could walk up a minimally inclined ramp in the hospital parking deck. Even after I was no longer jousting with the poison lances, my breathing became progressively more labored. It turned out that, in my vulnerable immune compromised state, I had developed an empyema. After diagnosing the problem by a chest X-ray, my great friend/surgeon (Chuck) needled my chest and withdrew over 5 liters of foul-smelling pus and placed me on intravenous antibiotics. Lord, but the dragon was doing his best to ruin my restitution narrative!

I received my chemo-torture on Wednesday afternoons and took Thursdays–Sundays off from work. Following the trial by ordeal, I returned to full-time work; but my breathing worsened and I weakened, once more. Salman Rushdie in *Midnight's Children* says we all owe death a life, and I wondered if my debt was soon to be collected. It turned out that my empyema had recollectored, so I was rehospitalized and Chuck inserted a chest tube.

At last, the Dragon lay slain at my feet. I was scarred inside and out from the skirmishes, frontal assaults, and physical and mental sieges. I was missing both the upper part of my left lung and the phrenic nerve which controlled this hemi-diaphragm, so this lung would never function the same as before. More significantly, I was missing the delusion that I was immune to the ravages of disease against which I had labored so hard for my patients' welfare.

Auto mythology fashions the author as one who not only has survived but has been reborn.^[4] This applies to me, though not in such a full, grandiose fashion. In the 1991 movie *The Doctor*, William Hurt portrays an egotistical, insensitive, sexist, detached cardiovascular surgeon who teaches his residents and medical students to emulate him. He is treated by an equally cold female

ENT surgeon after he develops vocal cord cancer. When he tells his wife about the tumor, she says “we can beat it” and he replies “WE DON'T HAVE IT! It's Not a Team Sport!” Through becoming a patient, surrendering to a hero-surgeon, enduring the indignities of an ordinary, dependent, hospitalized person, and seeing others around him die, he becomes a mensch (Yiddish for “human being, specifically a person of integrity and honor”). I do not fancy myself as being such a rotten pre-morbid person or such an elevated post-morbid one, but I empathized with him. I cried when I saw the movie first in 1991, and now, again, when I just watched it.

My narrative is still changing as I reflect upon my ordeal, survival, and how it changed me (or did not), and what I consequently think of myself. The restitution narrative really initially fit my approach as that of the fighter who expected to be well again. When I was in the midst of the restitution narrative, I observed myself in a clinical, detached fashion. The dragon's breath and claws swiftly vanquished this aloofness and plunged me into a chaos narrative from which I wondered if I would ever escape. I suffered with pain that almost absorbed the rest of consciousness. Quest and chaos stories call for a shift from the hero of force to the hero of perseverance through suffering.^[5]

I realized that, yes, I was a strong person. This was true for me definitely not because of my biceps or IQ, but because I persevered and became a better person—almost a mensch. When I remember how I was laid waste, it's easy to tremble and cry. The same holds true when I seek anew to share myself through this defining episode with Karen, Chuck, and the rest of my support system. Yet, I congratulate myself for being the #2 hero of my story, Karen being #1. Five years ago I had a party with friends and family to celebrate my 20 year survival.

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