
ESSAY/PERSONAL REFLECTIONS

Darkness and light: Perspectives in palliative medicine

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Every year, a new cache of medical students is baptized into this ageless art, and with this distinction comes a ceremonial distribution of the white coat. I was exuberant when I received mine—how beautiful! The thick cords of fabric are so neatly woven, reminiscent of chain mail armor worn by Lancelot and his peers. . . . Yes, this is a *suit of armor*, my impervious battle dress against the foes of Disease and Illness. It is replete with knowledge, seething with confidence, keen in choice of diagnosis and treatment—a great garment of ritual and power no different than Merlin’s robe or the shield of Constantine. The brilliant white threads reflect purity of heart and clarity of mind, illuminating the nature of human condition. With this armament, we saw ourselves as the natural optimistic extension of our time—purveyors of medical manifest destiny. I was confident a true understanding of humanity hinged on my education. What an astonishing machine, this Man creature! So intricate, so functionally efficient, so synergistic, the ultimate holistic wonder. And how very reasonable for such a pinnacle in the scheme of natural history to have insight regarding his mechanics, that he might tinker and prod, cut a bit here and there, a tincture of chemical now or again, polishing up the imperfections and peccadillos inherent in producing 6,000,000,000 copies of something, anything.

Beyond this, however, are lessons that cannot be gleaned from formal medical training. Realizations wait for you, lying quietly in their timeless omnipresence throughout medicine, instructing as the personal narrative that is human illness. It was when faces—lives—*people*—began to compete in my

mind with diagnosis and treatment that I gained perspective on what I have really begun, how apocryphal my understanding had been, and in many, many ways, still is. All so very daunting, unexpected; but too late. I could not resist the invitation to attend to my inner self, apart from my scant training, and the inner selves of fellow men both in my position and in positions I will never fully understand. Either end of the stethoscope can be as replete with uncertainty as the other, despite the assumption, if not demand, that one be panacea for the other’s punishment. And how surprising to me that I never really know, in any given encounter, which role ultimately will be mine—despite all appearances to the contrary.

If you look closely, medicine is full of darkness. Any floor of the hospital you choose, at some point or another, carries the long-cast shadows of suffering and losses of all kinds, be they of mind . . . or future . . . or love . . . or of self . . . or life. Your entrance onto the ward then becomes something of a stumble, hands outstretched into the night of this world . . . as though your expedition had gone off course into an alcove of the forest that no one had ever shown you, let alone your abject ignorance of its depth, the secrets it carries, or the querulous centuries spent generating advice on its navigation. An icy wind in this place gently glazes your ear, a mix of wistful longing and dying gasp. It is the voice of many, strangely harmonic with one’s own heartbeat . . . which itself carries the cadence of a war drum too soft in tone to rally one’s spirit or muster any resolve. And indeed, slow is the beat of that drum in the land of the dead, this bleak landscape before you. Too close; this is much too close. Such an intimate portrait, it causes a shudder so deep that one trembles through to the marrow of his bones, to the soul of him; it forces a wayward glance, eyes locked tight and fists yet tighter. The mystery of

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our existence lies here—we, those marvelously proactive sentient animals, having broken shackle from the confines of previous evolution; we, the self-aware, supposed as resplendent in the image of our glorious creator. And in this land that mystery lies flat on its back in a pool of blood and misery, bludgeoned relentlessly by the random caprice of fate, conquered by chance and the minions of barbaric reality, be they missed opportunities . . . or foolish addictions . . . or deeds done in anger or confusion . . . or simply a losing ticket in the lottery that essentially defines our existence.

This land carries the stagnant malodor of decay, both corporal and psychic. It is an old scent, sometimes dry and stale, like that one receives when pushing aside long curtains in a Victorian mansion of many days past, or sometimes damp, like unbarred basement doors to an ancient cellar. Each countenance here shows only the dying embers of life in his eyes, those windows to the interior of a man's heart. Look here; his body is bruised and cachectic, glowing an otherworldly, pallid blue in the moonlight above. He is nothing save a broken bag of bones, having weathered the slings and arrows of others only to be ravaged by his own body. And what is left, then, when one's very own humors would defy him, sentence him to this miserable demise? IV lines feed a futile obsidian fluid into his veins, those diminutive branches on this dying tree, draped in the frigid snow that is his flesh, lifeless. The sable solution crawls into a darkness that is *him*, a darkness I cannot imagine. What loneliness could possibly encapsulate the hell that is *him*? What place could he possibly be, so distant from the familiarity he had known, a vibrant life usurped by this hideous corpse, surely an impostor . . . this ghastly prison I have encountered, and all its attendant horror! Or turn to the madman, for whom you are the enemy always, the latest in a line of conspirators, an alchemist or mesmerist but surely not physician and certainly not healer. His reality is completely other, a relentless maelstrom of lies and deception. He is a slave to his mind and its sickness, gasping at the surface of the world we know, unable to inhale the vapor of sanity we so nonchalantly obtain. Continually drowning below the black tides of disease, forever tumbling in this nightmare . . . until the shore is too distant, with no beacon in sight and no divide between the torrent of this abysmal sea and the impossible infinity of the coal-colored sky. Should he take his own life, this tragic drift will finally end; he will find relief as a memory, an afterthought in the pantheon of our human ancestry. He is no one now, nor has he ever felt like anything other. And what direction might I possibly peddle to the aimless soul that is *him*?

How arrogant of anyone, especially me, lowest of the totem pole, to assume fitness for this role! How boastful to don the white coat of Osler and Father Damian and soil it heedlessly with my specious thoughts on approach and conversation, let alone treatment, God forbid deliverance of dignity or growth! It is then when I realize my white coat is without insulation against the arctic gusts in this land, that it languishes as a dull gray hue in these parts. It is little more than a rag. My knowledge dissipates with each whisp of wintry breath seen against the void, my mind immobilized in these surrealistic surroundings. What their realities are and where I am relative to them—never mind any importance I may delude myself to be present in that relationship—carries a melancholic malaise to it. I am drained to enter their existence, so drained that I lose track of my own. What might I possibly say? What weight might it possibly carry? I want only to flee this vulnerability, this radical departure from the Athenian explorations I had envisioned medicine would be. My own mortality reflects too clearly, too poignantly in the faces of others who, quite easily, would be in my shoes were it not for a lamentable role of the cosmic dice, often times taken by a hand wholly other than their own. How frightening and altogether fantastic to imagine that I will inevitably occupy that role of the condemned, one way or another, perhaps in a manner as disturbing as these; there is no solace or communion in these facts, however, when suffering and death have touched *someone before you* and not everyone, always incongruous, parsimonious for some and unleashed on others. What road must the physician take to alleviate these moribund emotions, self-destructive to the heart of hope itself? What redefinition must transpire to prepare one's self to address these essential happenings of our field, and beyond that, these simple facts implicit in our humanity and sentience?

If you look closely—again—medicine is full of light. There is heroism beyond call, and beauty of human experience. There is brilliance and penetration into darkness, discovery of what previously was not. Ostensibly, this is clearly seen in journals of such-and-such subspecialty, articles by so-and-so describing such-and-such technique or experiment, this drug and that animal model. Wonderful, undeniably. But there is joyful discovery made with far more frequency and of far greater import than any science we may create; it is the consummation of the human-to-human relationship found in medicine, the foundation of our art, sans technological bells and whistles. And imagine my great surprise—again!—that *my white coat has nothing to do with it*, that my heartbeat and

senses and membership in our species made me eligible for participation.

Common themes of self-worth and identity are crucial in palliative care. What have I done/do I do with myself? Was/Is it good? Do I have any worth? Will I leave behind anything worthwhile? Who have I touched? These are common questions, in some form or another, to everyone—physician, cancer patient, and schizophrenic alike. It is the desire to be secure in identity, to know one's self. It is the affirmation of independence, some measure of control over our environment, some facility regarding its manipulation that helps furnish our roles and eventually secures them. When these aspects are threatened and sometimes abolished by illness and dying, the physician then exchanges the texts of disease or treatment and the machinery of vitality for the sound of his own heart, the touch of his own hands, the tears from his own eyes. The physician–patient relationship then becomes, primarily, an event that we all must undergo, an activity that is as much a part of life as death itself. Proper register is given to the events of one's life, a celebration, really, that the physician has the privilege and honor of experiencing. This is an exploration of the depths of another individual's being—who are they? Who were they? Who have they become? And the beauty of this relationship for the physician is that he can in fact deliver dignity through the darkness, illuminate the being of another simply by allowing the patient to describe the happenings and feelings of his own life and their impact on him. The patient must be encouraged to look at himself and his life as a *whole* during a time when illness can deceive us into thinking his essence is somehow transformed, fragmented into cryptic or unrecognized parts, or can be defined only by his current condition. Regrets, triumphs, accomplishments, foibles, and strengths all come to fruition as essential components of giving being human a chance, ultimate praise of Erasmus' human folly.

Discovery is the goal for our patients—discovery of one's best remembered identity, the roles filled in life, some obvious or favorable, some not, and this final role as patient and human coming to close on the chapter that they have written in our history—with as much dignity and control over the circumstances as we are able to give. We must not deny the difficulty and misfortune that fellow humans must endure, be it intractable cancer, psychosis, or anything else. We must accept the profound unfairness of its wanton indiscriminate force as the same catalytic force that has put us here in the first place. They are the governing dynamics of our intricate place in the universe, the same singular

source of beauty and love and life and death. Time and fortune are indeed often blind, often impossible to understand, and often play no favorites, despite the human compulsion to anthropomorphize our will upon the events of life as such. We must not interfere with any belief that offers strength to the patient along these lines; ultimately, the patient is in charge of these sessions. But as the sentient animal, capable of compassion and growth, we can in fact invoke a stronger force, something possibly more satisfying than explanation for misfortune or meaning—a sense of accomplishment, a sense of duty fulfilled, and a sense of thankfulness for whatever vitality one has been able to enjoy. Contentment, in whatever form it ultimately takes, facilitates acceptance and enriches the experience of dying, transforming final moments into opportunities to give themselves to others, albeit in potentially different ways—maybe not as breadwinner or employee or parent as was once, but maybe as confidant or enlightener, confessor or messenger. And it is here that the physician may gain and carry a little piece of each patient's experience, their *sine qua non* that made them only who they could be. It is here that the physician takes full glance at the vulnerable underbelly of our humanity, the wonderful yet transient stint we have in the human spotlight. Perhaps our greatest possible role in service to humanity is found in this fulfillment of human experience, helping to finish brushstrokes on our patient's intimate portrait of self, so intimate that the pain and grief that emanates initially might frighten us. But courage is often found deep in the heart of adversity, indomitable, a function of the life force greater than our own. It is the tireless will of our species not only to evolve, but to flourish. And from this, a wonderful dialectic; patients finish brushstrokes on our own portraits that we are too weak to produce or not versed enough in humanity to understand, that come not from our white coats or years of training, nor from the supposed role we fill as medical authority. They come out of the darkness, from our own hearts and willingness to weaken that we might learn and grow also, that we might next time encounter darkness with understanding. Eventually, the icy air may not carry not so sharp a sting, the palpable blackness may recede somewhat. The timber of the human soul may burn a bit more brightly in the eyes of our patients, and our own portraits might even be a bit more complete. And that portrait will *not* show one man, clad in white coat stained with blood and tears of sorrow over the vacant shell of a withered soul.

It will show a scene of redemption. Two individuals, embracing each other in life, bathed in light.