Palliative and Supportive Care

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First patient

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Essay/Personal Reflection

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My heart skipped several beats as I passed through the wood-paneled doorframe, into the dark room in the large assisted living facility. The space rang hollow, silent, except for the sound of daytime television. The travel channel, perhaps. Or something in the infomercial genre.

Anne, the room's sole occupant, was not expected to live longer than two, maybe three months. Faced with a bundle of psychological and physiological maladies, she had been declining in almost every measure of health for the past year. Her physician recommended hospice care, figuring, not unreasonably, that there was not much left to do.

When Anne's hospice organization first assigned me to her service, I was nervous but ready. For 4 years of college, I had struggled deeply with questions of wholeness, identity, meaning, and how we, as flawed human beings, could ever find solid and stable grounding in these imperfect bodies and unknowable minds. As a former college basketball player, I had struggled to rebuild my identity and sense of self after injuries and anxiety had forced me to leave the game. Around the same time, after being diagnosed with a chronic urological disease (and hearing my physician say, "You're the youngest person I've seen with this disease," as if it were a fun fact) I spent dark, lonely hours confronting insecurities and fears I did not even know I had.

As I faced each one of these struggles and uncertainties, I had trusted in — or rather, relied upon — my intellect, my strength, my capacity for reflection and resilience, to pull me through. There were answers out there to every problem, waiting to be found.

It was in this state of mind — in the belief healing came primarily through wisdom and knowledge — that I came across an academic article on palliative care, filled with patient vignettes centered on the deeper aspects of human suffering. Reading wide-eyed, I wondered how these people found the strength to move through their sufferings while retaining, or even strengthening, their senses of meaning and flourishing. Sitting on an Adirondack chair in my Midwest college campus, poring through these narratives, I knew that I had never experienced anything as demanding, as existentially challenging, as what these people had gone through. And yet, I felt a profound connection to them, as if we existed on a spectrum of human suffering, as if we all had something to endure, something to share with one another, some way to build one another up.

That ineffable connection moved me to think deeply about healing and wholeness, and I resolved to bring healing to others even, or especially, when they felt alone and unknown. I wanted to speak hope into suffering, to use my knowledge and reflections to give others new perspectives on their lives and illnesses. That is how I ended up a hospice volunteer before medical school, and that is how I learned, through Anne, that knowledge and reflection, thoughts and ideals, are nothing without humility.

I learned that lesson very quickly, though not without misstep. In the early months of our time together, I would spend six to eight hours a week in Anne's room — a dark, quiet room, tinged with the smell of stale carpet. Her depression was evident and overwhelming, and she wept often. Loneliness, a sad memory, a disheartening story on the news, pretty much anything could move her to tears. And why not? I could imagine the difficulty in realizing that your body and mind are fragile, fallible, fated to fail you one way or another, and that you will never really be ready for that moment, that it will be like learning a new and foreign language from a scratchy old recording. Like looking at a bleached, fossilized log on the beach, wondering where the time has gone.

On the other hand, it was not difficult to realize that my self-assured, inexperienced idealism would do little for Anne's well-being. What was I to do when she began weeping about her loneliness? Tell her about the meaning to be found in suffering? Recite patient narratives from that academic article I had read? Where I once felt galvanized to support patients in their darkest moments, I now felt insufficient. But with this feeling came another question: How, exactly, was I insufficient? My issue clearly did not stem from a lack of compassion, empathy, or even preparation. I cared deeply about the suffering of others; I saw their wholeness as an avenue to my own; and I had trained for hours with my hospice organization, learning to work in difficult moments and with despairing patients. Looking back, I do not think my early failures meant that I had too little to offer. I simply believe that, in my self-assured idealism, I had tried to offer too much.

"The only wisdom we can hope to acquire," T.S. Eliot writes in his *Four Quartets*, "Is the wisdom of humility: humility is endless" (Eliot, 1943). What I needed to acquire, and what I

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learned through my time with Anne, was humility at the core of compassion, humility at the core of caregiving, and humility at the core of healing. The wisdom I had sought in my readings, reflections, and thoughts had, to that point, been rather ineffective for Anne. So I stopped looking inward and turned outward in humility. Visiting Anne each week, I sat, listened, and talked when she grew tired of talking. I looked at her old pictures, wheeled her to the dining room for company, laughed at the same stories again and again and again. I did this for two years, and every visit felt like the same mundane thing, but by the end Anne was happy and alive and complaining about the cafeteria. Her health improved monumentally, to the point that she no longer qualified for hospice. It was more than we had ever hoped for.

I was somewhat shocked. Anne not only exceeded her caregivers' expectations over our two years together but also achieved lifelong milestones which had once seemed impossible. I remember her telling me early on, in tears, that she would die before the birth of her first great-grandchild. Yet, by the time I left for medical school, she had met not one but two great-grandchildren. And I recall my first impressions of her — sad, still, couch-bound in her room — and the striking contrast, many months later, when she felt well enough to let me roll her in a wheelchair down tree-lined city blocks, bathed in the radiant sun, the fading light cloaking the world in purple-bronze. I can still hear her mentioning those same sunflowers upon our every return.

Two years after I first ventured into Anne's dark and lonely room, our time came to its end. The ending was not, however, the one anybody originally expected. It came not with her death but with my last visit, one day before I was to leave for a new city, a new institution, to begin my formal medical education. The moment seemed an odd confluence of ends and beginnings: the service of my future patients borne from the end of my time with Anne, a time which had taught me more than I ever could have predicted. Yet, far from any profound sense of wisdom, that patient–caregiver relationship had left me with an indelible humility, a comfort with not-knowing, imprinted on my life and caregiving.

When I walked into Anne's room for the final time, I was picturing my future medical career, the mistakes and blunders and growth and victories, peering into a future as uncertain as our first visit together. I was nervous when I first walked through that door. Now I felt only comfort.

"Hi Anne," I said, smiling through the break in my daydreams. "I'm leaving tomorrow for the east coast. For medical school."

"Oh!" she responded, with her own smile. "That's right. I remember. I'll really miss you, you know. Thank you for everything."

Weeks later, staring down the wide river flowing through that new city — its blue water turning black and waxy at the banks, like obsidian — I looked back on the moment, on those two years with Anne. Breathing deeply at the midway point in my afternoon run, I struggled to define what, exactly, I had done for her. Healing had not, after all, come through any hard-wrought or profound wisdom of mine. If anything, it had come through an acceptance that I never had such wisdom to begin with. And now, turning from the past toward the future, toward the vast and pluripotent years before me, I had no idea how healing would come to my future patients.

I stayed in the same spot for several minutes, watching the water break against the rocks. I recalled the wisp of some profound statement from my white coat ceremony weeks before; imagined some vesicular trafficking mechanism I had just learned. The knowledge, the learning, the river — all of it seemed endless.

There was so much power in wisdom. But greater wisdom in humility.

Acknowledgment. The patient described in this essay has had their name and identifying features altered or removed.

Reference

Eliot TS (1943) *Four Quartets*. New York, NY: Harcourt.

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