

Humanities: Art, Language, and Spirituality in Health Care

Series Editors: Christina M. Puchalski, MD, MS, and Charles G. Sasser, MD

Finding Ways to Hope, Seeing Beauty

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I want to tell you a story about dying, and doing this returns me to the autobiographical stance that first brought me into this work in the late 1980s. I have no pretense of telling you anything specifically new, but I hope that in hearing me tell this very personal story, you may understand what you do already know from a different perspective and thus know it differently. I believe that much of the best work of social science is not trying to tell people anything new but rather defamiliarizing the familiar and making it differently knowable. What I especially want to defamiliarize is language that can make end-of-life care sound far simpler than it is: words like “denial” and “acceptance” or the idea that matters can be talked through, clarified, and settled. I hope to open gaps between what people know cognitively, what their embodied beliefs are, and how they act.

My title is a quotation of something my father said during one of the most intimate conversations he and I had during the months when he cared for my mother while she was dying. But at the time of our conversation, he would not have thought of this period of their lives as a time of dying. This reluctance to name death was not denial on his part. As I’ll discuss later, it was an affirmation of life as it remained. This idea of affirming the life that remains to be lived is a familiar goal of palliative and hospice care,

but I hope to show how complicated it can get in practice.

My own perspective on all this is slanted in ways I will not try to unpack, but let me offer one observation. When I was starting to write, for the first time, I realized that I had lost my notes from that conversation with my father. Only one fragment remained, in which my father says that he gets through his days by finding ways to hope and by seeing beauty in small everyday things. Even while I was thoroughly annoyed with myself at losing my notes—they eventually resurfaced—I retained enough self-awareness to recognize something ironically symbolic about that loss. The single prospective loss of the person who is dying is fragmented into multiple minor losses. Some of these losses involve physical objects going missing, especially objects that have sentimental or financial value, like jewelry. It seems to me that after the death of every woman I know, her family complains about the loss of some of her jewelry. These are real material losses, but you do not have to be a Freudian to realize that less tangible losses are being displaced onto the jewelry. This same displacement underlay my annoyance at temporarily losing my notes, as a memory of that valued conversation. I still speak from this position of loss, and I’m sure I still engage in various displacements.

When I was a graduate student in the early 1970s writing my dissertation on

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second-person narratives of dying—that is, narratives by spouses and adult children of the dying person—one of my core texts was Simone de Beauvoir’s memoir, *A Very Easy Death*, about the death of her mother. This title, which is both true and also ironic, fits the story of my mother’s dying. I want to tell you some parts of this story.

In telling this story in a medical journal, I act out a tension that seems fundamental to health research specifically and social science generally. This tension is between the particularity and specificity of lives as they are lived and the social scientific and medical impulse to generalize about lives. It is an immediate clinical tension. A friend who runs a hospice told me that the most troubling note she ever received was from a man who basically thanked her for how his mother had been cared for during her death. But then he added: “I appreciate you care for many patients. My mother died only once.” My friend recognized the sad truth of that gentle criticism.

The tension opposes humans’ practical need for simple procedures and universal principles against the existential recognition of fathomless complexity and mystery. Both social science and clinical practice are positioned between practical demands to produce heuristic typifications and, opposed to those demands, the human moral or existential refusal to be typified. Institutions process many deaths. Each person dies only once.

The story I will tell about my mother’s dying rejects types and heuristics about dying but maybe inevitably I am also on my way toward inventing new ones. One can never get outside of this tension, I believe. I will tell my story in four chapters.

Chapter 1: In Which the Hospital Tries to Kill My Mother, and Palliative Care Rescues Her

In August 2012, I found myself cast in the role of the adult-child from out of town about whom hospital health-care workers often complain. They complain because we show up in the middle of an established course of treatment and we complain. My complaint was that nobody seemed to notice that my mother was dying. She had been admitted a

week earlier for pneumonia that had not responded to oral antibiotics at home. She was in Connecticut; I was in Calgary, in western Canada. A couple of days after her admission, I got a call from my father that a CT scan suggested a mass in her lung area, and, on his report, she had cancer. I should note here that my parents were then both 93 years old, they were living in their home of 44 years, and my father enjoyed remarkably good health—his health allowed them to remain at home, where he still is.

I was skeptical about the cancer diagnosis but put off discussion until I arrived a couple of days later. When I got there, my mother had had—or I would say she had been subjected to—a second CT to “stage the cancer.” Her left arm was completely black from wrist to elbow as a result of intravenous jabs. She recognized me and knew where she was, but her grip on reality was slipping in less than subtle ways.

The next morning my father and I met with the attending physician, a hospitalist. I asked why the CT scans had been ordered. The physician said he had “a feeling that something else was going on.” I assumed that meant my mother’s pneumonia wasn’t responding to the intravenous antibiotics. No, he said, it was responding, but he had this intuition and ordered a CT scan, which raised enough questions to lead to second scan. The case was now referred to oncology. I asked to speak to the oncologist. This ended up taking several days, during which a lot else happened.

Meanwhile, my mother was literally leaving us. She was highly agitated and wanted to call various people to say goodbye. Because I had made it clear that no further testing was to proceed, the hospital did something right and requested a palliative care consult—or maybe I asked for that myself; things were happening quickly. When the palliative care physician arrived, my mother was either unable or refused to acknowledge her as a physician. My mother found remarkable energy to go into what I recognized as her most gracious hostess mode. She greeted the physician as if she were a guest arriving at the party and said something very interesting to her. My mother said: “I know you, you’re the one who hurt your arm.” She then refused to respond to any medical questions, simply repeating her “I know you”

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