
ESSAYS/PERSONAL REFLECTIONS

When the path of least resistance is doing everything

ELIZABETH C. ADLER, B.A., M.D. STUDENT

Icahn School of Medicine, Mount Sinai Health System, New York, New York

(RECEIVED June 4, 2016; ACCEPTED June 21, 2016)

The first time I ever saw my grandmother without “her face on” was in a community hospital on Long Island. The only thing stopping this 90-year-old firecracker from penciling in her eyebrows was endocarditis. Or, more probably, it was the IV lines that tethered her to the bed. I made sure not to mention the line of silver at her scalp, growing into the dyed red pieces of hair now plastered to the sides of her face with sweat.

My grandmother was developing pressure ulcers, and I could not turn her by myself.

“I’ll pop out to get the nurse.”

“Don’t bother. She’s probably online shopping, pretending to document something.”

My grandmother barely had the strength to eat, but, damn it, she could still complain. Her eyebrows may have been gray and her skin may have been breaking down, but that was my grandmother lying in that bed.

What deeply troubled me was that none of her armory of doctors seemed to realize that.

My grandma, who came in with an infection of her prosthetic heart valve, now had a pulmonologist and a nephrologist following her in addition to the hospitalist and cardiologist. There was a mild obstructive process going on in her lungs, so she was getting Atrovent treatments every 4–6 hours.

While she had a mask over her face infusing the anticholinergic mist, a care associate entered and asked my father to sign a consent for a procedure to insert a PICC line—a thin hollow tube in the vein above the elbow (she would need better access for long-term IV antibiotics). My grandmother was unaware of the question about the PICC line. She was totally unaware of her care plan in general. Did people assume she lacked capacity? She had just made a snide remark to me that morning about how ditzy her hospital roommate was. Did everyone think she wanted to

begin the dominoes of interventions and wasn’t steady enough to sign on the line?

As my grandmother struggled through the Atrovent Treatment—as this mist that was supposed to help her breath choked her, as the mask smushed her nose, as the elastic bands crinkled her eyes in the wrong direction—my father was signing because, well, that was the next logical step. She needed 20 more days of antibiotics and had terrible peripheral access.

I helped my her take off the misting facemask. “Phew!” She said. “I hate the way that feels.”

I decided to be direct: “Grandma, what are you hoping for?”

One simple sigh and, “I’ve lived my life. My body is giving up, and I think it’s time.” She began to take off one of her rings to give to me, cranking on her index finger, but her digits were too edematous to liberate the ring.

That was shockingly straightforward.

The current plan was to send my grandmother to recover at a skilled nursing facility. (I told grandma about the plan, which I heard about from a case manager as I loitered around the nurse’s station)—a freight train of a plan that would propel her into three more weeks of pureed food and a paucity of fresh flowers and very little real chocolate anything. I surveyed the medical scene: her kidneys were progressively failing even after treating her low-fluid status, she had a solid mass on her chest X-ray that was likely undiagnosed lung cancer, and her prosthetic heart valve was in bad shape. At the skilled nursing facility, she would receive more antibiotics and physical therapy and likely never regain her baseline function.

If we wanted to stop this type of momentum, we first had to know that it was stoppable. Which, had I not just spent the last three months of medical school on a geriatrics/palliative care rotation, we may not have even known was possible. No one brought up the word *palliative* at all. Had I not known to ask for other options, none would have

Address correspondence and reprint requests to: Elizabeth C. Adler, 2111 Easton Drive, Burlingame, California 94010. E-Mail: elizabeth.adler@icahn.mssm.edu.

been presented to us. Had I not asked my grandmother—not heroically but on a whim—what she was hoping for, I'm not sure anyone would have asked.

Unfortunately, this story of intervention dominoes is typical in end-of-life care. Palliative care—specialized medical care for people with serious illness—provides an opportunity to help patients and their families navigate illness. With the goal of addressing the symptoms, pain, and stress of serious illness, palliative care is one of the only inherently patient-centered medical specialties. Palliative care helps ensure that patients are getting the care that is most in line with their needs, the state of their illness, and their values. However, access to palliative care within the United States is limited. According to a 2015 study by the National Palliative Care Research Center and the Center to Advance Palliative Care, a third of U.S. hospitals with 50 or more beds report having no palliative care services. In hospitals reporting palliative care teams, an average of 3.4% of admissions receive palliative care services. However, estimates place the need for palliative care between 7.5 and 8.0% of hospital admissions. Accordingly, between 1 and 1.8 million patients admitted to U.S. hospitals each year could benefit from palliative care but are not receiving it.

Palliative care has the potential to vastly reduce hospital costs via decreased length of stay in the

hospital, decreased use of unnecessary tests, and more efficient care coordination. More palliative care could save our healthcare systems billions of dollars. My grandmother's story, though, illustrates the other savings of palliative care. After a palliative care consult, my grandmother along with her doctors decided that it was time to return home.

If I knew anything about grandma, I knew that the things she loved most included chocolate ganache cake, jewelry, her family, and narrating the PBS Newshour without regard for what the actual reporter was saying (she could talk louder than anybody or any volume setting). We were fortunate that she was so clear about her desires for end-of-life care. She wanted to return home. She was okay with continuing antibiotics but insisted that the Atrovent mist treatment—with the elastic strap that stretched her skin—stop. Her doctors agreed that this was a reasonable desire, given her poor prognosis. The next day, my grandmother was transported home, with a plan for a palliative care nurse to care for her there. She was able to see my grandfather, whose fragility and advanced dementia had prevented him from visiting her in the hospital. He smiled when she arrived and gave her a kiss. My grandmother seemed weak, but she seemed like herself. A day later, she died peacefully at home, wearing all her favorite jewelry.