

An Unquiet Death

To cure sometimes, to relieve often, to comfort always.

Usually quiet and stoic, my 89-year-old mother begged for relief. For days her knee had throbbed at rest, and walking was agonizing. My sister took her to a hospital where my mother was put to bed and treated with pain medications for six days. The “observation unit” had no bathroom and was not staffed for usual inpatient nursing care, so my family took shifts as attendants and comforters. My mother was miserable, literally writhing, constantly changing her position to relieve escalating back pain. Her knee pain and swelling increased.

As my sister became more involved in my mother’s hospital care, she grew resentful toward the physician in charge, an orthopedic surgeon. She felt his daily rounds were abrupt and superficial, without time to listen or to explain. My brother, at the bedside during one of the doctor’s visits, reached me on his cell phone and handed the phone to the doctor, who told me the diagnosis was pseudogout and the most effective therapy was being withheld while he explored whether my mother “really needed” her anticoagulation medicine, which might increase the risks of therapy. It was never clear to my family if or when specific medical therapy was initiated, but issues surrounding Medicare “rules” and “length of stay” were discussed in detail, and arrangements were made to transfer my mother to a rehabilitation center. On the day before my mother’s release, when my sister asked about my mother’s many medications, the surgeon told her he did not know because he was an orthopedic specialist.

Very early on the morning of her discharge from the hospital, my mother called and pleaded with my sister to take her home. She did not want to go to a “nursing home.” In a clear strong voice, she said something that at the time seemed entirely inappropriate: “I want to die at home.” After reassuring our mother that no one died from knee pain, my sister came to the hospital and was alarmed to find our mother very different from the way she had been the night before. She knew who and where she was, but her speech was slurred with occasional clumsy choice of words. She was very sleepy yet restless and anxious. “Something is wrong with my mother,” my sister told various nurses in the hallway and the nursing station. When my sister continued to complain about our mother’s growing sleepiness, confusion, and garbled speech, she was told that our mother was just “tired” and that her condition was the result of a generous dose of morphine given to quiet her down for transport. No one came to check her mental sta-

tus or vital signs. Finally, the transport team arrived to move her despite her protests.

My mother died in transit. She left this world alone, essentially abandoned by everyone she had ever met. She started her disengagement in an observation ward, lost consciousness intermittently in an ambulance, arrived awake and in acute distress at a non-acute care facility, and was immediately sent back to die in the emergency ward of the hospital she had just left. Jostled about for three hours by strangers’ hands lifting, pushing, probing, and inserting needles and tubes, she ended her life in a swirl of blaming voices, conflicting commands, frenetic activity, alarms, and mechanical devices.

My mother was familiar with abandonment. Her father had left home when she was a child, and her husband had volunteered for four years abroad in World War II, leaving her with four small children, one of whom died of brain cancer. In his last 20 years, my father, a Southern Baptist minister, was seriously depressed. Although he could rally to perform his duties, dredging up a successful—even charismatic—public face, at home he was agitated, emotionally abusive, angry, and paranoid. During his last ten years, because of increasingly paralytic apathy, he was unable to work or function alone and required my mother’s full-time attention. Twenty-five years ago, my mother took my father to the hospital because he would not eat. Surrounded by his family, he died quietly on the third hospital day with no definitive diagnosis or treatment. Was there a failure in diagnosis and treatment, or had his depression beaten him?

Except for a few activities in church, my mother lived entirely for and through her family. She was a full-time wife and mother, and the closest thing to a profession was her role as a minister’s wife. She knew the lives of her children, grandchildren, and great-grandchildren in detail. She was rock solid in her absolute love and commitment to each member of the family, often expressing acceptance when nobody else would. Her living room and kitchen were plastered with photographs, and she was unflagging about writing letters and about mailing gifts for all birthdays and special events. Three generations were always eager to tell Grandmother about every large and small event in our lives. She made us all feel special. None of us were with her for her unquiet death.

How can I deal with the knowledge that my mother’s life did not need to end the way it did and possibly at the time

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it did? My mother suffered and died in a way that made her and her family feel more like victims of health care than beneficiaries. With righteous indignation, should I investigate and document every decision made by every actor in my mother's care? Being part of the system, I can predict how little that would assuage my angst. Individuals drowning in work and trying to do the right thing would feel wounded and defensive.

As a teacher and student of health care, am I obligated to use my mother's story as a case study? Would that do anything to improve the care in one hospital or better the health care system? Would my complaints help call the frequently unanswered question of who is in overall charge of a complicated patient hospitalized by a specialist managing an acute episode?

Should I feel guilty because I wasn't there? Recently, after taking leave from work to act as full-time coordinator of her mother's care, a physician colleague donated a kidney to her 87-year-old mother with multiple medical problems. She told me about multiple near-miss episodes resulting from medical mistakes and is convinced that it was her vigilance that twice, at least, rescued her mother from death. While my mother's providers might have ignored my sister, would they have listened to a chaired professor at Harvard Medical School? Would my discussions with her physicians and nurses have resulted in more communication among them? If I had been there, would I have participated in decisions about definitive care, assignment to a fully staffed hospital room, and regulation of pain medications? At least I could have checked her pulse and looked for signs of shock before she was removed by the ambulance team.

Our family let my sister carry much of our anger and guilt. She has episodes of shaking and sobbing: "I let them kill my mother." She had relentlessly struggled to find an informed responsible party focused on my mother's acute care. Would she feel better if an individual physician or nurse was held accountable? Does she need an apology or retribution for feeling repeatedly dismissed by a series of busy people? Would she be comforted if some committee found documentation of failure to meet "standard of care" or "best practice"? My sister and her husband quickly sold the home they shared with my mother and moved to another town. The house was too big and filled with too many memories.

My mother was the first to know she was dying and wanted to be in her own bedroom surrounded by her family. Deeply religious, my mother was not afraid of death, and for years she had her small estate, funeral, and burial arrangements completely organized. Her request for a quiet death at home did not fit into our mind-set and was dismissed by all. Instead, the end was clumsy and impersonal. The system had her surrounded.

Should I focus on the benefits of my mother's prior health care? For decades, caring physicians had provided powerful mixtures of compassion and expertise. Modern medicine probably saved her life several times. Had a mastectomy and five years of hormone therapy given her 20 years of borrowed time? The recently implanted pacemaker seemed to protect her from the adverse effects of antiarrhythmia medications. Had her warfarin saved her from an ugly stroke as she was driving her car to her weekly hairdresser appointment?

Should I be grateful that my mother was spared years of decline and loss of independence, dignity, and joy of life? Maybe morphine helped her retire near the top of her game. For her last ten years my mother lived a good life in her own apartment within my sister's home. She had morning coffee with my sister and most dinners with my sister and her husband when they returned from work. She always left the house smartly dressed and carefully made up.

My mother and my sister were also spared the stressful communications and difficult decisions required for end-of-life care at home. One day, in months or years, it would have come to that, and it might have been difficult to manage. A dignified, calm death at home with loved ones is the exception because it requires so much decisiveness, planning, and coordination with health care professionals who are sometimes unfamiliar with the process and uncomfortable with the goals of dying at home.

We had planned a surprise 90th birthday celebration for my mother. Her three children and many of her eight grandchildren and 16 great grandchildren were to be among the guests and family joining us from all over the country. My mother never knew about these plans and never experienced this culminating moment in a life devoted to loving her family. One week after her death, we had the celebration in her absence.

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