

Advance Directives

An oncology nurse's personal experience with end-of-life decision making and its complexities

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Not until I had experienced my own mother's illness and death did I appreciate the complexity of end-of-life decision making. As an oncology nurse practitioner, I had been trained in advance directives. I understood their importance and why they were needed. However, my own family's experience taught me that such planning does not always prevail over the spectrum of emotions, family dynamics, and other realities that accompany death.

My mother, Rebecca, grew up on a wheat farm in post-war Kansas, married at 21 years old, experienced a miscarriage, and had a stillborn and three healthy children in a five-year period. Not long after her last child, her sister took her own life during postpartum depression. My mother herself wrestled with bouts of depression.

With the cultural revolution of the mid-1960s, Rebecca's exuberant and artistic nature seemed to be validated. She played the violin and piano masterfully and was a tremendously talented painter. Her newfound identity was rejuvenating, even life-saving. However, her emotional emancipation was a stressor on her marriage, and my parents divorced when she was 33 years old.

Except for a few short years, she remained single. She worked difficult day jobs, such as bus dispatcher and secretary, while dedicating her evenings and weekends to art and music. These were decades of hardship and exhaustion. She relocated constantly, trying to support herself financially and come to terms with the person

she had been in the past and who she was meant to become. She was 60 years old when she began a position as an early childhood teacher, a job that she loved.

Endoscopy, colonoscopy, and laboratory work all appeared normal. Her symptoms did not resolve, and computed tomography scans showed the ominous signs

"Although our mother was minimally engaged with us, she seemed to want to be kept alive no matter what. It was as though the advance directives were written by a different person."

My mother had an underlying skepticism—even fear—of conventional medicine and its limits. I distinctly remember when, in full health, she articulated to me her recurring fear of being comatose on a respirator, prolonging life past reason or mercy. She also stated these preferences unequivocally in her living will, forbidding a long list of life-prolonging devices and procedures.

At about the same time that my mother was drafting her will and advance directives, I was starting my career as an RN. I had spent months during my clinical rotations on a respiratory intensive care unit, a geriatric floor, and a step-down unit. My first actual job as a floor nurse was tending to patients with end-stage AIDS, patients with wide-ranging illnesses who were receiving palliative care, and patients with end-stage renal disease.

Two months after my brothers and I had held a 70th birthday party for my mother with family and friends, she began having gastrointestinal symptoms.

of omental caking. Exploratory surgery confirmed that her abdomen was rife with metastatic disease. We would never learn the primary malignancy; therefore, the oncologist could not target a specific chemotherapy regimen. Nevertheless, she consented to two rounds of chemotherapy, after which she became septic and was hospitalized.

I provided the hospital staff with her advance directives, which included a do-not-resuscitate (DNR) clause. However, I suddenly feared that the urgency of definitive treatment or care would be lost once she had the DNR label. I remembered my own experiences as a floor RN when the nurse from the previous shift briefed me on the patients in a qualifying tone: "But they are DNR." Soon, my worst fears seemed to conspire against me. It seemed that no one on the medical staff was tending to my mother. Had I ensured neglect by submitting advance directives? In my frustration, I reached my