



When death came for my Mother

Illustration by Claire Gilmore

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Beautiful, articulate, powerful. A lawyer who worked to defend the underdog, whether they be homeless, mentally ill, or refugees seeking asylum. Who knew she would succumb to a disease I treat every day? It has been 12 years and I still cannot forget the circumstances of her death.

When diagnosed with breast cancer at 64 years of age, she declined chemotherapy. She did not want to go into court with chemotherapy-induced baldness or a wig. Six years later, she had a recurrence. By then she was willing to get chemotherapy if it meant living longer.

Always in a hurry, she was prone to accidents and a simple trip and fall would be her undoing. She broke her hip, a non-pathologic fracture, probably due to osteoporosis. She had to take a several month break from chemotherapy and when ready to tackle it again, the cancer

had gotten the better of her. This was a decade ago, when we still interrupted chemotherapy to let fractures heal.

She spoke glibly and often of suicide and the romance of dying young. Once diagnosed with metastatic cancer, life became more precious and suicide was never mentioned again. I remember talking to her when she was on inpatient hospice care recovering from chemotherapy side effects. A mere 90 pounds, bewigged, with severe hand-foot syndrome and diarrhea from capecitabine, gone was the pillar of strength I grew up with. Yet, she related how looking at the newspaper each morning with a cup of coffee in hand had now become a joy and pleasure, enough to make her want to remain alive.

She told me as long as she could do these things that she did not want to die. But each time she had a round or two of chemotherapy, she became too weak to enjoy even this simple pleasure. Her attending oncologist, nationally respected, tried to tell us that she could not be on hospice and receive chemotherapy. It makes sense now, but not then.

Four days before her death, she called me to ask if I had any ideas to help her extend her life. This was before

publications suggesting aggressive symptom management alone could prolong the life of some patients with stage 4 cancer. She needed the multidimensional care and benefits of inpatient hospice to make her strong enough to withstand chemotherapy but could not get both simultaneously for an incurable illness. Long-term inpatient hospice was not an option for her. Today, patients must choose one or the other, hospice or active care, not both. This becomes a dilemma for patients.

Of course, I wish my mom had never been diagnosed with cancer or developed metastatic cancer. However, once this became her reality, I wished first that we could extend her life with chemotherapy and then that she had not felt forced into accepting what she felt was a premature death. She was a shadow of her former self and led a very limited life—no courtroom drama, no shopping, no outings at all! Yet, she wanted to live another day in a recliner, reading a newspaper!

I was ambivalent. Glad she wanted to live longer even if I was unsure what she was living for since neither a cure nor a life without chemotherapy side effects were in the cards for her. How could I help her? What was the best thing to do? In retrospect, my biggest regret is that she died unwillingly and not at peace.

As a full-time oncologist, I confront this scenario several times a month. I have reflected often on what helps some people accept the end of life with grace and ease, while others fight to the end, defying suggestions from family and health care professionals to stop active therapy and accept comfort or palliative care.

Is it our comparison of cancer treatment to a military battle, where fighting is viewed as courageous and accepting palliative care is viewed as cowardly or surrender? Is it cultural or religious beliefs that make some feel accepting hospice care is tantamount to committing suicide? Is it the desire to wait for an event—a birth, a graduation, a wedding? Or, is it the sign of an unfulfilled life?

As a younger oncologist, I cynically said that the travails and side effects of cancer treatment were part of God's way of making death seem the less unpleasant choice. But with better symptom management and less toxic therapies, this jaded view is no longer true.

We have national conversations about the skyrocketing costs of health care, particularly cancer care. We point out that cancer treatments can cost \$150,000 but only extend life by two weeks. To help curb these costs, we give oncologists demerits for delivering active cancer treatment within two weeks of death. Meanwhile, we document that oncologists who have those difficult

end-of-life conversations receive lower patient satisfaction scores. What we don't talk about or address is how many cancer patients simply want to live—whether another year, another month, or just another day.

In a society that defines living as winning and hides the dying in nursing homes and hospital wards, this is understandable. Death due to illness does not feel natural. We have extraordinary measures at our disposal to postpone death from almost all causes. We instill an expectation that access to all of these life extending measures is not only natural but also a right. We institutionalize our elderly and distance ourselves from the dying process. And, by making it impossible to receive hospice care concurrent with active cancer treatment, we increase the likelihood of inadequate symptom management at the end of life.

Attempts at the impossible feat of death avoidance lead to the desire to stay on treatment long after it is appropriate and results in an ill-prepared death. An ill-prepared death can be a death accompanied by uncontrolled cancer related symptoms without hospice, death shortly after enrollment in hospice, or death in the hospital due to complications of treatment. All of these outcomes are undesirable for patients and perpetuate fear and the vicious cycle of death avoidance.

When death came for my Mom, she was not ready. How can we help prepare our patients for the end? This is the million-dollar question. My hope and goal is not to end life prematurely but to avoid an ill-prepared death full of pain, uncontrolled symptoms, and fear. To succeed at this, we have to change societal expectations so dying is not viewed as losing.

We could achieve this with more national conversations about a natural and dignified death. We could achieve this by introducing (and allowing) hospice care concurrent with active cancer treatment. We could achieve this by better reimbursement for in home care before the end of life. Or, movies, social media, and online classes can normalize the dying process to teach us how to create a good death.

I am still not sure what my Mom wanted, but what I want is for more of my patients to be able to face their death with a sense of closure, acceptance, and peace.

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