



Fred J. Schiffman Humanism in Medicine: Reflections

A 'Good' Death

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"I WANT HER TO BE RESPECTED"

"I know she's dying. I just want her to be respected."

My patient's daughter had brought her back to the hospital only a few days after she had been discharged to home hospice, requesting that her mother be admitted for further treatment. Multiple providers, from the Emergency Medicine resident all the way up to the Medicine triage attending, had attempted to parse this sudden change. The patient herself, a frail, cachectic woman in her 90s with severe dementia, an unstageable sacral decubitus ulcer, and chronic obstructive pulmonary disease, lay unresponsive in bed, having received fluids, antibiotics, intravenous steroids, and nebulizers on her way up to the hospital floor. To our eyes, she was clearly dying. Did her family not want her to pass away at home?

I stood across from her daughter, listening to her explain. Her mother had experienced a steep cognitive and functional decline over the past three months, accelerated by a series of admissions for various medical issues, including aspiration pneumonia, sepsis in the setting of an infected decubitus ulcer, and presumed diverticular gastrointestinal (GI) bleeding. She still lived at home but increasingly relied on family to manage her daily needs. She was also no longer able to consistently take her medications.

Given this pattern of decline, the Palliative Care service had been involved during the patient's most recent hospital admission. After discussion with the medical and palliative teams, her family had agreed that home hospice, along with a "Do Not Hospitalize" advanced directive, made the most sense for her. Her chronic medications, including her antihypertensives, statin, and inhalers, had been discontinued in an attempt to decrease medication burden. As-needed sublingual morphine had been provided for pain and air hunger. Home caretaker services had been offered to help offload some of the bur-

Abstract

While medical advancements over the past century have enabled patients to live longer with serious illness, they have also prolonged the dying process while shifting the location of end-of-life care away from home and into acute care settings. This article reflects on what makes certain deaths "good" and "bad" in the hospital setting.

den from her family, but the patient's daughter had declined, since she had always been able to care for her mother before.

Within days of discharge, however, the patient's family had noticed that she was becoming increasingly somnolent and tachypneic. Her family did not feel comfortable using the provided sublingual morphine: they felt that it was only masking the underlying problem at best, and at worst, hastening her death. Her daughter had also grown increasingly concerned that she could no longer care for her mother at home, as the patient had now completely lost the ability to feed or reposition herself. These factors had driven the patient's daughter and son-in-law to bring her to the hospital.

My patient's family knew she was dying, and they did not want any interventions – such as BiPAP or CPR – that would cause suffering in an attempt to prolong her life. However, it was clear to them that her current level of care was not meeting her end-of-life needs. We admitted the patient and continued supplemental oxygen and nebulizer treatments for symptomatic relief. After a careful discussion about the rationale behind morphine therapy, her family was open to its use. She died peacefully the next morning with her loved ones beside her.

GOOD AND BAD DEATHS

What is a good death?

We all have stories of the bad deaths. They are some of the most emotionally charged events we experience in medicine: the COVID-era deaths when we, masked and face-shielded, carried iPads into patients' rooms so their families could say goodbye over video call; the husband who walked away, stunned, after his wife coded unexpectedly in the ICU; the 20-year-old with catastrophic focal segmental glomerulonephritis who died alone in the hospital and estranged from his family.

Studies on “bad” deaths, as perceived by families and providers, have identified several universal themes: dying alone, unrelieved physical and emotional suffering, miscommunication between patients and the care team, and the use of futile life-supporting interventions. Unexpected deaths were traumatic for both families and staff. On the other hand, families also emphasized the stress of a slow decline marked by the dreaded cycle of hospital readmissions, loss of function, prognostic uncertainty, and diminishing hope.¹ When one of my patients died suddenly from an unexpected GI bleed after a prolonged period of cognitive and physical decline, his son told me, “I don’t want to say it, but this is almost a relief. You never met my real father. We lost him a long time ago.”

It is harder to define a “good” death. The concept is both deeply personal and rooted in the broader cultural narrative on when, how, and where death should ideally occur. No event has reshaped the cultural landscape more than the rise of modern medicine, which has turned many previously fatal disease processes into manageable conditions but also prolonged and medicalized the dying process. Until recently, most people could expect to pass away at home, with their family members providing the majority of end-of-life care and support. Now, our patients often spend the last few months of their lives moving in and out of acute care settings, receiving treatment-directed care up until the time of death. “Dying”, as DelVecchio et al. note, “is difficult, particularly in the modern hospital where there are so many treatment options and where relationships are short, discontinuous, without a perspective on the patient as a person, and with little time to acquire it.”²

The modern hospice movement arose in response to a growing realization that aggressive treatment can cause more harm than good for some patients, particularly at the end of life when the benefits of continuing treatment become increasingly marginal. It seeks to reframe the goal away from treating disease and towards caring for the whole patient. Several principles have emerged from the hospice literature on what constitutes a “good” death: consistent communication from the care team, treatment of patients as individuals rather than diagnoses, attention to both physical symptoms and psychosocial stressors, preservation of patients’ dignity and decision-making agency whenever possible, respect for family members as caretakers and advocates, and closure for family after death.^{3,4}

Trends are changing. Over the last decade, deaths at home and in hospice settings have surpassed hospital deaths for the first time since the early 20th century.⁵ For many patients and families, the ideal end-of-life sce-

nario remains a death at home surrounded by loved ones. Applying the same model to every patient, however, can erase the complexities of each person’s situation. With adequate planning, good end-of-life care can be achieved in acute care settings. Dying in a hospital setting may even be preferable under specific circumstances, such as the need for more frequent care or specific therapies. My patient’s family, for instance, was overwhelmed by her relatively rapid functional decline once she was discharged. While the transition back to the hospital in the last hours of her life was not ideal - and may perhaps have been avoided by further exploration of her family’s goals and expectations prior to her return home - it allowed her care needs to be met while freeing her family to focus on saying goodbye. Ultimately, “access to loving, competent caregivers [is] more important than the location of dying”.⁶

Similarly, there is no absolute dichotomy between “natural” and “medicalized” death. Certain medical treatments, such as antibiotics and blood transfusions, can contribute to the dying person’s comfort and their ability to engage with the world around them.⁷ It is best to take an individualized approach to each therapy. My patient’s other chronic medications had become more burdensome than beneficial, but her inhalers were an indispensable part of her end-of-life symptom management. In the appropriate context, even interventions such as chronic hemodialysis may fall under the definition of comfort care. Each person’s needs are different, and only by asking can we begin to understand.

This profession humbles us. For all the power of modern medicine, we can seldom reverse a progressive disease process, and sometimes we cannot even stop the acute decompensations. But we owe it to our patients to explain the medical situation plainly, to listen to their wishes, and to help them delineate a plan so that they live and die as they would have wanted to under the circumstances.

Disclosures

The author has no conflicts of interest to disclose.

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