

# A Good Death?

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“I’ve lived with this for 10 years. I’m hoping for another 2, to make it to my 85th birthday so I can have a big party.”

My patient’s voice was weak, but his goals were clear. He had been transferred to our inpatient palliative care unit overnight for end-of-life care. Having just come on as the attending physician, I was meeting him for the first time.

“Do you ever think about what you might do if time were shorter than you hope?” I asked him.

He looked around the room at the family gathered around his bedside. “We’d all just tell a white lie and pretend I made it. We’d have the party early.”

I left the room relieved and optimistic. We would plan to adjust his medications to control his symptoms and help his family plan one last birthday celebration, complete with cake and perhaps wine (we’d turn a blind eye to hospital policy). My patient would have a “good death,” one of the outcomes that inspired me to choose a career in palliative care.

Over the next week, my patient was surrounded by his large and loving family, who would do anything to support him. They threw him a party, and he had a few bites of cake. Everyone said what they wanted and needed to say to him. Plans for the funeral were ready.

Unfortunately, my patient’s story did not play out according to my script. He had previously undergone an amputation that left him with unrelenting “phantom” pain. Two years earlier, he had had a pump surgically implanted in his back to deliver high doses of pain-

relieving medications directly into his spinal canal. As a result, his tolerance for opioids was far higher than it would be for our average patient. And the cancer that had spread to his lung was rapidly overgrowing his airway. Although he seemed comfortable in the morning, every night his pain and shortness of breath worsened. He became delirious and agitated, moaning and calling for help. His elderly wife, who had her own health issues, refused to leave his side and barely slept.

We did everything we could to control his symptoms and ease everyone’s distress. We increased the medications in his spinal pump and added high doses of powerful sedatives. For days, none of these were enough. His body had held on for a decade, and it would not go quietly.

We finally made headway and gave my patient and his family a modicum of relief. He died the next day, sweaty and exhausted. His could have been a good death. It wasn’t. Rather than being filled with the mixture of quiet laughter and tears of a loving family saying goodbye to their patriarch, the air in the room had been thick with anxiety and suffering. I had felt powerless to help.

We are at an inflection point for palliative care in American medicine and the public consciousness. In recent years, we have seen best-selling books, Oscar-nominated documentaries, and countless articles in the mainstream media about how to live with serious illness and how to die well. Thought leaders are giving TED-style talks and holding

conferences about “disrupting” death. As a palliative care physician in the early years of my career, though, I worry about where we go from here.

Well-intentioned advocates implore the public and our colleagues to rethink how they approach death. The quid pro quo is clear: if people can talk about illness and death earlier, we can help them live and die well. But while most clinicians admit that there is much about dying that’s beyond our control, our rhetoric regarding end-of-life care too often omits this warning. We have grounded our society’s notions of the good death in images of elderly patients peacefully tying up the loose ends of lives well lived. Working at a cancer center, though, I rarely see such patients. The gaping hole that opens in a family facing an unexpected or premature death, such as that of a young parent or a child, cannot be patched by the highest-quality end-of-life care. At best, it can be made less leaky.

And as throughout medicine, the state of our science is imperfect. For some of my patients, death can be difficult to tame. Symptoms may either defy our most powerful medications or force us to give patients doses that prevent them from spending their final hours and days interacting with their loved ones. Just as obstetricians warn expectant parents that birth plans may need to be discarded if labor takes an unexpected turn — and that such twists are not uncommon — we need to add a similar caveat at the end of life.

After my patient died, his

family thanked me for everything we had done. But as I left his room for the final time, I couldn't help but feel disheartened by what he had endured in his last days. His dying process had easily conquered my most effective tools.

Palliative care physicians encourage our colleagues in other specialties, such as oncology and cardiology, to communicate with not only honesty but also humility. We must hold ourselves to the same standard. Whether delivered by generalists or specialists, palliative care improves quality of life and eases suffering for patients with serious illness and their families.<sup>1</sup> Our interventions reduce pain, anxiety, and depression and improve people's ability to cope with a life-altering diag-

nosis.<sup>2,3</sup> In the vast majority of cases, we are successful in mitigating distress. But not always and not completely.

My patient's case was an outlier, but it was not unique. As clinicians in any field of medicine, and particularly in palliative care, we must keep these cases in mind as we navigate our public discourse about the end of life. We should promise to do everything in our power to ease suffering, bringing all our knowledge, compassion, and medical tools to bear. We also need to acknowledge our limitations. We can often make the dying process better and more physically, psychologically, and spiritually comfortable for our patients and their families. But when we set societal expectations for a good death, we claim

a command over nature that we don't always have.

Identifying details have been changed to protect the family's privacy.

Disclosure forms provided by the author are available at NEJM.org.

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