

Our Hospice System Subverts the Very Point of Hospice Care

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Credit...Clara Mokri

By [Sandeep Jauhar](#) New

York Times Guest Essay *Dr. Jauhar is a cardiologist in New York who writes frequently about medical care and public health.*

When my siblings and I decided to put our father in hospice care at his home in the spring of 2021, his Alzheimer's was near end-stage. He could barely get out of bed or dress or feed himself. Hospice care seemed to be the best way for him to end his life with dignity.

Nearly all Medicare hospice patients receive care in their residence. So, as is standard, we enlisted the services of a Medicare-approved hospice agency.

We soon encountered a harsh reality, however. Dying at home isn't easy, even with hospice care. The hospice system, we learned, requires family involvement in the dying process to a degree that even we, as a family of

doctors, weren't comfortable with. We were responsible for bathing my father and helping him use the toilet, changing his clothes and, most daunting, administering morphine and other sedatives to treat his pain and anxiety. A nurse was scheduled to come to the house only for about an hour twice a week. Getting an aide to help with basic activities of daily living was nearly impossible.

The main problem was funding. In 2024, the average per-patient Medicare payment to hospice agencies was about \$200 a day, with an annual cap of \$33,500. That outlay would barely pay for a part-time aide, yet it is also needed to cover medications, medical equipment and nurse visits. So hospice agencies are forced to shift the bulk of responsibilities to families as the dying process unfolds over weeks or months.

I remember a Friday evening when we decided that my father, who had stopped swallowing, was severely dehydrated and needed intravenous fluid. The hospice agency wasn't equipped to provide that service, even as a comfort measure, so my brother drove to a hospital to get an IV kit and a few bags of saline and then came back to the house and inserted the IV catheter himself, as my father kicked and hollered. When my brother was done, he tied the bag of fluid to a ceiling fan with some sewing thread because we didn't have an IV pole.

Ironically, we could have put my father in an acute-care hospital bed costing \$3,000 a day without any pushback from Medicare. The Medicare hospice benefit is supposed to provide a cost-effective alternative at home to expensive end-of-life care in hospitals. But by providing so little funding, Medicare too often makes hospice care an unviable option.

Our family was fortunate that we had the resources to provide the care my father needed. My siblings and I divided up responsibilities, and one of us stayed with him at all times. But many families are unable to manage and are forced to move their loved one to a hospital or a nursing home (or in the rare cases that Medicare allows for it, an inpatient hospice facility). Patients themselves may choose to die in an institutional setting for fear of being a burden on their families or not receiving adequate symptom relief.

Sadly, the practice of relying so heavily on families subverts the very purpose for which hospice care was created. When Cicely Saunders, a nurse and doctor, opened the first modern hospice program in London in 1967, she laid out three guiding principles for easing the process of dying: relief of

physical pain, preservation of dignity and respect for the psychological and spiritual aspects of death.

In my family's experience of the hospice system, all these principles were compromised. The care responsibilities we had to shoulder were more than we were emotionally prepared to take on in those grieving final days. And my father's dignity and comfort would have been better served with more guidance from nurse specialists on how to administer his pain medications and sedatives.

Tight hospice budgets can compromise care in even more serious ways. Not long ago, a patient of mine with end-stage heart disease was being moved from the hospital to hospice care at home. I appealed to a hospice director to approve a standard medication for him that helped control his shortness of breath and nausea. My patient had been on the drug at the hospital, and staying on it at home was essential to his comfort. Yet my application was denied. The hospice director said that the medication was too expensive, even if, as expected, my patient had less than a month to live.

I could have tried to get my patient admitted to an inpatient hospice facility, where he could have gotten the drug he needed more easily, but he wanted to die at home. So, reluctantly, I had to send him home without it.

Compounding all these issues is the fact that dying in America is increasingly corporatized. Today, about three-quarters of hospice agencies are for-profit, and many are owned by private equity companies. It is hardly a stretch to imagine that many of these companies skimp on care to protect their bottom line.

The key to a better hospice experience would be more in-home support — a minimum number of hours of aide visits per week, for example. This would require increasing Medicare hospice budgets, of course. In the current political climate, that may be a hard sell, though in the end it would almost certainly save money by avoiding costly hospitalizations.

Fortunately, our family was able to keep our father at home till the end, as was his wish. Yet when I reflect on our experience, I am reminded of what an older woman with terminal heart disease once told me: “My husband said the hardest thing to do is to die. I always thought it would be easy.”

From the comments

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I felt guilty about transferring my dying husband to a hospice facility from the hospital after we'd accepted that death was imminent. He wanted to die at home. Thankfully, the care coordinator described what dying at home would entail. After years of caregiving, I didn't feel up to the task. I was scared! She suggested that we try the nonprofit facility for a few days and go from there. He got great care there, was out of it most of the time, and died peacefully in my arms after 3 days. I'm ever so grateful for that experience. My only concern was when they called me late at night to ask if he had a Do Not Resuscitate order. Of course he had one! He was in hospice after all. But it hadn't been found in the paperwork. I was surprised and appalled that they would be forced to resuscitate without one. There is so much to know at the moment when we are functioning at our lowest level. How I wish that we all had medical aid in dying. We treat our pets better at the end of life.



Sandeep Jauhar

Opinion guest essayist

@TC I'm so sorry to hear about your husband and the choice you felt compelled to make. Sometimes an inpatient facility is the right decision when families cannot provide the requisite care. But inpatient hospice is rare. It accounts for only about 1% of all hospice days in this country. In part, I'm sure, it's because Medicare reimbursement is much higher for inpatient compared to home hospice care.

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