The cost of dying: It's hard to reject care even as costs soar

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Every night before putting on his pajamas, Dad emptied the coins from his pockets. The special ones he placed in an album, but most went into a jar to be saved.

So how could the hospital bill for the final days of this frugal man -- with carefully prepared end-of-life instructions -- add up to $323,000 in just 10 days?
That's the price of a home for a struggling family. Enough to put a future doctor through medical school. Hundreds of prenatal visits. Thousands of vaccinations.

My father's story -- the final days of a frail 88-year-old with advancing dementia at the end of a long and rewarding life -- poses a modern dilemma: Just because it's possible to prolong a life, should we?

It's a story of people doing their best in a system that's built to save our loved ones. And it's a reminder of the impossibility, during a crisis, to assess costs and benefits that aren't at all obvious.

This was the lesson of my father's passing: It is easy to get quick access to world-class treatment. It's much harder to reject it.

"If we look at what's coming down the road in technology," said 81-year-old bioethicist Daniel Callahan of the Hastings Center, "we have to realize that this endless fight against aging can't go on.

"What medicine provides is more and more ways to keep people going," he said. "An extra few days, or a month -- it is very, very hard for doctors and families to give that up."

First, two important facts: Stanford Hospital provided great care, and it lost money on my dad. Of his final bill, Medicare only paid $67,800. Like other hospitals, Stanford only collects what its contract with Medicare specifies. Therefore, Stanford wrote off the rest of the expenses, and will recover the money over time through other patients' private insurance and fundraising. While Stanford doesn't make a profit, it needs to break even.

This background helps explain why Americans spent nearly $2.6 trillion on health care in 2010 -- or about $8,400 per person, the federal government reported this month. That's almost double the $1.37 trillion in spending in 2000. As baby boomers age, the climbing cost of health care poses a threat to the nation's long-term solvency.

"The costs are rising at an unsustainable rate," said Virginia Hood, president of the American College of Physicians, which this month issued guidelines urging more cost-conscious care.

"It's 17.6 percent of our GDP (gross domestic product) -- twice that of any other country," she said. "Yet we don't provide care to the same number of people as do other countries, and our health is not as good."

And we don't spend health care dollars equally. Five percent of Americans accounted for half the total. About one-fourth of Medicare spending goes to pay for the care of people in their last year of life -- generally, in a hospital. The average end-of life hospital stay is 12 days; of those, seven days are spent in an intensive care unit, according to data from the Dartmouth Atlas of Health Care.

Death used to be a family affair. Increasingly, it's institutional.

Who's driving big health care spending? People like my dad.

A plan for death

That bill for $323,658 would have angered Dad because he did all the right things. Determined to avoid suffering and costly heroics, he had drawn up "do not resuscitate" and "desire for a natural death" orders.

Kenneth Harris Krieger was a man who sought to give to society, not take. He was a successful engineer with an MBA, a devoted husband and father, an usher at church on Sunday mornings. He grew up during the Depression as the son of a judge. At 19, when war broke out, he was sent to work on the Manhattan Project. Later he traveled to five continents, built Heathkit radios, tutored me through chemistry and perfected a powerful tennis serve. I adored him.

Thanks to modern medicine, he lived decades longer than his father.

But Alzheimer's crippled his fine mind. And his hearing had faded. Frustrated by his inability to hear, comprehend, or speak, he turned silent. There were moments of contentment, but every day he seemed more remote, sad and uncomfortable. He asked for my mom, dead for five years. He hid his wallet and accused caregivers of theft. One night he tried to escape through a window. His back ached. His heart was arrhythmic. And his bones had grown brittle.

When he tripped and broke his hip three months earlier, surgery was traumatic -- he couldn't understand why he hurt, where he was, or how to heal. Increasingly, he just slept.

Should we have quit?

The medical nightmare started, as they so often do, incrementally.
On a lovely Saturday, under a cobalt blue sky, we shared a happy day of gardening. He couldn't remember how to rake, but helped by picking up each leaf by hand. I showed him how to wind a garden hose. He became drowsy after lunch, so I drove him back to his assisted care facility.

He wasn't feeling well that Sunday, and he couldn't say why. Caregivers didn't find a fever. I made a doctor's appointment, then massaged his back until he slept. The doctor prescribed antibiotics.

By Tuesday he was shaking, dehydrated and speaking gibberish. Fear was in his eyes. I raced him to Stanford's emergency room. The diagnosis: septicemia. Bacteria were rushing into his bloodstream, causing shock. At 88, his immune system was weak. His veins were leaking, causing his blood pressure to crash. He needed fluids, antibiotics and a tube to help failing lungs. It was the last time I saw him conscious, the last time I saw his open eyes.

Doctors and nurses in the emergency room jumped into action. The final bill attests to their effort: ER charges ($18,589), catheter to monitor oxygen ($2,125), other catheters ($5,400), chest X-ray ($1,076), and much more.

Should we have quit then? Suddenly, that "do not resuscitate" order seemed unclear; its black-and-white legal language didn't really apply. He needed a ventilator to help him breathe long enough for antibiotics to work. Dad's acute infection seemed treatable. Doctors said there was a decent chance we could turn it around. We'd likely know within a day, they said.

'Who was I to summon his death?'

I was adrift in a sea of conflicting emotions. Even if we saved him, dementia would continue its march. Some other illness, at some later time, would claim him. But he deserved a chance. And in the hospital I felt secure, no longer terrified and helpless. Diagnosis and cure: That's the fuel that drives the clinical engines of places like Stanford.

This was a man who gave me life. Who was I to summon his death?
Proceed, I said. It's a risk worth taking.

So Dad was moved into the ICU, and I got a bedside cot. Daily charge for the ICU: $25,643. There were glimpses of hope; his blood pressure was stabilizing. He held my hand again.

But there was still infection -- where was the source? The search began, with X-rays, Doppler exams and other powerful tools.
Such advances in medical technologies save lives. And they are some of the most powerful forces behind the nation's soaring health care costs. The more tools advance, the longer ill people are kept alive. Each new innovation raises patients' and their loved ones' expectations -- and costs.

Yet by Friday, Dad still wasn't strengthening. I noticed something new -- every time nurses moved him, he winced in pain. Over the hours, we saw why: The infection was in his leg, creating black necrotic patches. This was no routine bacteria. After repeated blood cultures, X-rays and another day in the ICU, we finally had a diagnosis: necrotizing fasciitis, a rare and deadly flesh-eating infection.

Now was it time to stop?
A new Pfizer drug, Linezolid ($1,936), held out hope. A synthetic antibiotic, it targets bacteria resistant to other antibiotics. And it can protect against bacteria-induced toxic shock.

Increased use of medicines is another big driver of costs. The cost represents years of research, and patent protection. And demand is increasing: From 1999 to 2009, the number of prescriptions purchased in the United States grew 39 percent, while the population rose 9 percent.
Exhausted, I felt lost. By some measures, Dad was improving, thanks to aggressive care in the ICU, yet his climbing white blood count suggested a turn for the worse. And he hadn't regained consciousness. Had the initial crisis been too catastrophic?

One last powerful tool

The infectious disease team deployed a powerful, $48,000 weapon: immunoglobulin. Part of a new class of therapeutics called "biologics," immunoglobulin infuses antibodies into patients who can't make their own. It's expensive because it's hard to produce. Each liter of donated plasma yields 4 grams of product, and takes 200 days to make.

Yet even that didn't help.

Now should we quit?
If Dad recovered, what awaited us? Unwittingly, with the best of intentions, we were violating his desire for "a natural death." Was this escalating price -- emotional, physical and financial -- worth it?

Only surgery could turn around this galloping infection, doctors said. Antibiotics weren't enough. I heard the phrases "wound care," "possible amputation" and "skin grafts."

Every year, increasing numbers of old and sick people undergo surgery. That's because we've become so good at it. Improved techniques mean doctors can operate on patients who would have been ineligible in the recent past.
It can be a blessing, prolonging lives. But the cost of elder care can be higher -- and the outcome less certain.

But could an 88-year-old with weak bones, an irregular heartbeat and dementia

survive? And if he survived, then what? When all the specialists left, I summoned my strength and stopped the attending physician: Please, tell me what's ahead of us.

"It's not black-and-white; it's gray," he said, choosing his words carefully. "A long and bumpy recovery, with no guarantee of success."

Complicated forecast

It's difficult to predict a patient's prognosis, said Norman Rizk, Stanford's interim chief medical officer. A national database, APACHE, offers a general prediction of mortality, based on age and other factors, he said. But it can't forecast a patient's future.

The issues of cost and allocation of care are societal challenges still to be tackled, he said.

"It's very complex," he said. "We all recognize the tension between these personal situations and the public good -- the challenge of 'distributive justice,' " or the fair sharing of a limited resource.

"In Congress, and on the campaign trail, some groups believe that life is sacred and we can always support it, forever. Thirty percent of the general public believes that God can bring miracles to bear when patients are hopelessly ill.

"And doctors want to be able to make things better and sometimes overestimate the utility of what they do. They want to be hopeful," he said. And in a crisis, families don't want to hear the price of care, he added. They may sue if they feel care was wrongly denied. "There are very powerful incentives for physicians not to pay a lot of attention to cost."

Feeling alone, I phoned Dad's surviving family and friends. Their wisdom: Let him go.

He is suffering without purpose.

There are far worse things than death.

Now, finally, it was time to stop.

Dad was moved out of the ICU. Over the next four days, his breathing turned shallow, but he slept deeply, sedated by painkillers. A nurse woke me at 3 a.m. Two young doctors rushed in and asked his cooling, pulseless body: "Mr. Krieger, can you hear me?" A chaplain came, with prayers.

Then it was just the two of us, in blessed silence. No more expert opinions, beeping monitors or hissing respirators. No more tests. No more tubes.

I kissed him goodbye, packed my bag and walked into the cool night air.

Modern medicine had carried Dad's body beyond what it could bear. Even the best life is finite.