

Woman's 6-month decline highlights end-of-life care quandary

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A young physician ushered the three siblings into a consultation room at Mercy Hospital St. Louis.

Their mother, Althlee Williams, 89, had fallen into a coma. Her eyes were shut. She couldn't speak. A machine pumped her lungs.

It was time, the doctor told them. They should let their mother die.

For months, they had watched her suffer through rashes and bedsores, heart stoppages and breathing problems. Her weight fluctuated by 100 pounds. Williams' two daughters agonized, but seemed ready. Their brother, Clayton Williams Jr., refused.

"Don't take her off. ... Do whatever you can," he said, before bolting out of the room.

Such wrenching dilemmas test not only family bonds and the frontiers of medicine, but the nation's tolerance for runaway health care costs. In the final six months of her life, Williams' care totaled about \$1.2 million, according to billing records provided by the family.

With the fate of the national health care overhaul now in the hands of the Supreme Court, many experts agree that the ethical

and financial dynamics of dying should remain at the center of the national health debate. Yet few politicians, bureaucrats, insurers and doctors dare even to discuss it. And no one seems to have a clue as to how our society can afford to pay national health costs that approached \$2.6 trillion in 2010 — a tenfold increase since 1980, according to the Centers for Medicaid and Medicare Services.

"With more elderly people coming, as the baby boomers come into Medicare, it's only going to get worse," said Arthur Caplan, director of the Center for Bioethics at the University of Pennsylvania.

End-of-life care issues go far deeper than money. Even two years after their mother's death, Williams' children remain troubled by concerns that all that care did little but prolong her suffering. Beyond political and financial pressures, their mother's case lays bare the ethical complexities of the question that so many families must ultimately face.

For months, the three siblings had rearranged their work and family schedules to help their mother navigate a maze of hospitalizations, blood transfusions, drugs, side effects, infections and dialysis. They looked after her in shifts, with Vivian Ransburg taking most of the day, her sister taking over in the late afternoon, and her brother staying in his mother's room through every night.

They winced with frustration when nurses pricked her fingers to test her blood sugar, and watched her slowly lose her mind to Alzheimer's. When she couldn't swallow pureed food, they allowed doctors to install a surgically implanted feeding tube in her stomach. When her breathing grew short four months before she died, they agreed to put her on a respirator.

Their mother's health only got worse during the repeated hospitalizations, and she often suffered despite extraordinary measures to comfort and save her.

"It was not a comfortable or peaceful death," said Williams' younger daughter, former speech pathologist Teresa Rice Scurlock of University City. "It was just prolonged."

'A BOTTOMLESS PIT'

Cost never appeared to enter into the decisions about Williams' care; the hospital billed Medicare and a supplemental insurance plan.

When the elderly can survive only with aggressive measures, the incentives for all involved tilt toward treatment, regardless of cost. Family members naturally want loved ones to live. Physicians and hospitals get paid well for providing extensive medical treatment — and face legal liability for denying care, even if the patient has scant survival prospects. Insurance companies likewise fear being vilified and sued for denied care, and can preserve profit margins by passing along the costs to employers and their workers. And the Medicare program ultimately reports to Congress, which has shown no willingness to wade into the political deadly arena of near-death care — or curbing federal health entitlements at all.

While steep, Williams' health care tab is hardly unique in an era of rapidly advancing medical technology that hospitals increasingly apply to prolong life.

"A million bucks for an extended (hospital) stay, sadly, is not out of the norm," said Samuel Steinberg, a hospital consultant based in Florida. "Several weeks in intensive care could be a million bucks."

"The bad news is that Medicare is essentially a bottomless pit," he said. "The hospital can keep admitting her and testing her as long as they choose."

The Supreme Court's expected decision this month on the constitutionality of President Barack Obama's health reform law will no doubt affect the cost and delivery of medical care. But regardless of how justices rule, the volatile issues surrounding end-of-life care for the elderly will remain largely unaddressed.

National politicians dropped this hot potato in 2009 after a series of rancorous debates sparked a backlash against government "rationing" of health care and the establishment of "death panels," as Republicans called them, to manage care for the elderly. Democrats dropped efforts to control end-of-life care costs because it threatened to kill the package entirely.

The nation lacks the political will to tackle this issue in part because seniors are such a strong lobbying force. So politicians are unlikely to act until the baby boomers, inevitably, overrun the Medicare system and create a medical cost crisis, Caplan said.

Doctors and hospitals are trained to provide costly medical treatments, even though it may add only a few weeks to a patient's life. Traditionally, their financial success has been closely linked to aggressive medicine and applied technology, from respirators and interferon therapy to dialysis.

But ballooning health care costs are demanding a growing percentage of the nation's resources — threatening the solvency of the Medicare Trust Fund. About 25 percent of all Medicare spending goes to pay for the care of patients in their last year

of life, according to a 2011 study by the Dartmouth Atlas Project.

In fiscal year 2010, the St. Louis division of Mercy Health, which provided care to Williams, reported \$158.8 million in Medicare revenue, according to the nonprofit institution's tax filing. That amount comprised about 17 percent of its annual operating revenue, excluding investment income.

Citing a federal patient privacy law, Mercy Health declined to discuss Williams' case. Mercy officials also chose not to be interviewed in general about end-of-life care, but issued a written statement.

"Mercy encourages all patients to discuss their end-of-life wishes with their family and loved ones and then convey those wishes to their physician," it states. "In cases where there may be a lack of direction or unanimity among patient, family members and health care team, there is always an ethics resource available to facilitate discussion to help reach consensus."

Caplan and other experts say that the problem of spiraling health costs for the elderly is systemic and cultural, cutting to the core of the nation's attitudes toward health entitlements and the essence of life itself. While some bioethicists support the rationing of costly end-of-life care, others caution that health care should never be denied solely on age, condition or even the odds that a patient may soon die.

"We have kind of a religious belief that medicine can save us, no matter what, and that in America, technology makes death an option, not a certainty," Caplan said. "Everyone in the abstract can agree that we're spending too much on people who are dying, particularly elderly people. But when

it comes to your grandmother ... people don't want to say, 'I gave up on my mom.'"

'IS THIS GOING TO HELP?'

Althee Williams was a strong woman with a bright smile.

Williams, a 5-foot-2 former typist at Missouri Printing Co., had high blood pressure, mid-stage Alzheimer's and glaucoma. Still, she remained active and in good spirits. Williams' family was planning for her 90th birthday.

All that changed on March 9, 2009, when Williams, feeling disoriented and nauseous, was taken by ambulance to Mercy Hospital's cardiac coronary unit. Doctors gave her medicine to lower her blood pressure, but it dropped too low and she lost consciousness, Ransburg said.

Nurses called a "code blue" and took Williams to the emergency room, where they revived her 15 minutes later.

"She was never the same again," said Ransburg, noting that, after her mother's initial 3-day stay in the hospital, she could no longer dress herself.

During her final six months, Williams was home for only 10 days. She bounced back and forth between Mercy Hospital and area rehabilitation hospitals and nursing homes. She spent 22 days in an intensive care ward.

"I wish I had never taken her to the hospital the first time," Ransburg said. "I'm going to have this nagging question all my life: Should I have just given her more time that first day to see if she would get better on her own?"

In late March, Williams began a series of blood transfusions. In early April, she started taking food through a stomach tube. Doctors hooked her to a respirator soon after.

“Once they gave her all this medication, it brought her down and made her sick,” Clayton Williams Jr. said. “Everything started shutting down.”

She contracted pneumonia and was diagnosed with Stevens-Johnson Syndrome, a rare allergic reaction that caused her skin to burn and peel. Her hair fell out in clumps. She had terrible bed sores. Her complexion darkened.

The son ached watching his mother each night, confused and suffering, helpless. He recalled that his mother kept asking, “What now? Is this going to help?”

Williams’ hospital and nursing home bills from March 2009 until her death six months later totaled \$1.16 million, even though she did not undergo surgery, chemotherapy, radiation, a transplant or experimental treatments. Her medical care, in essence, was routine — only the volumes were exceptional.

That sum does not include the separate invoices of a dozen specialists, including heart, pulmonary and cardiovascular doctors, ophthalmologists, gastroenterologists, a nephrologist, a plastic surgeon and an infectious disease doctor. Those doctors’ bills are likely to have totaled tens of thousands of dollars.

“The plastic surgeon told the nurses how to wrap her from head to toe,” Ransburg said. “She looked like a mummy, and they had to put gloves on her so she wouldn’t scratch.”

Then another doctor came in and told Ransburg, “She doesn’t need to be wrapped like that. Let’s take it off and let the air get to her.”

Itemized bills for the costs of Williams’ repeated hospitalizations and nursing home stays include about \$285,000 in drugs. But her physicians seemed uncertain whether the severe rash and blisters all over her body were symptoms of an infection or an allergic reaction to medicine.

Williams’ Alzheimer’s, ironically, proved to be a blessing. She often couldn’t remember the pain she had endured the day before. And yet at one point, perhaps instinctively, she started pulling her black-and-blue fingers away from nurses trying to prick them for yet another sugar test.

WHATEVER IT TAKES

Conversations about extending medical treatment to the dying often start late, and the family’s default response is often, yes, do whatever it takes, as Williams’ son said in a moment of despair.

“We could make tremendous gains if we communicated better with patients and did what they want,” said Frank Ingari, president of Essence Healthcare Inc., an insurer based in Maryland Heights. “It’s not just the money, it’s the suffering. Sometimes life extension is no favor to whom it’s extended.”

Under federal law, hospitals have the duty to ask patients whether they have a living will prescribing their medical wishes, and if not, whether they need assistance in preparing one. But even when patients have such wills — and they often don’t — the documents can be vague, and they’re often ignored by hospitals. They may not even be made

available to doctors. And family members, often in panic, can demand more treatment, overriding the will.

Just as doctors may defer to relatives demanding more care, overwhelmed relatives often defer to health care professionals.

“They would tell us, ‘We’ve got to do this, we’ve got to do that.’ They justified everything they did,” Ransburg said. “So we didn’t have much choice but to go along with it.”

On Aug. 26, 2009, Williams’ heart stopped beating while she was undergoing dialysis at Dubuis Hospital in Chesterfield. Once she was resuscitated, one of her doctors asked Ransburg if her mother should be put back on a respirator. Yes, the family decided.

“Are you sure?” the doctor asked Ransburg, seeming to suggest a different path.

Williams was taken back to Mercy Hospital but remained in a coma.

Because of Williams’ Alzheimer’s, the hospital relied on her children to make the tough decisions. Ransburg and her sister had medical and financial powers of attorney regarding her mother’s care. But Clayton, their younger brother, weighed heavily into the discussions.

The Mercy doctors voiced concern. They laid out options. The sisters seemed more prepared for their mother’s death than was their brother, who continued to argue that all measures be taken to save her, Ransburg said.

“My brother wouldn’t let her go, and wouldn’t let us quit,” Ransburg said. “Mother had told us she didn’t want all this,

but we had to live with him after she was gone.”

After he bolted from the room, insisting on keeping his mother alive, the doctor sat Clayton Williams Jr. down alone.

“‘You have to let her go,’” he recalled the doctor telling him. “‘If she was my mother, I would let her go now.’”

The three siblings finally agreed. Ransburg and Scurlock left the hospital. Their brother stayed for several hours, until their mother died at 1:27 a.m. Aug. 27, 2009.

He remains unsure, even two years later, if he made the right call.

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