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Recommended Citation

Awal, Kazi E. and Pagano, Alyssa, "Quality of Death People With Terminal Illnesses are Turning to an Age-Old Method to End it All: Self-Starvation" (2016). CUNY Academic Works.
https://academicworks.cuny.edu/gj_etds/165

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Quality of Death
People with terminal illnesses are turning to an age-old method to end it all:
self-starvation

By Alyssa Pagano and Kazi Awal

On a spring day in May of 2014, Cathy Quinn climbed into her favorite armchair on the patio so she could fall asleep and never wake up again. But it didn’t work.

She thought she had done her research. If stars like Heath Ledger and Anna Nicole Smith could do it—with the right mix of pills and alcohol—she figured she could too. Quinn’s boyfriend, Scott Barraco, found her later that day, slumped in the armchair and unresponsive, but breathing deeply. He saw pill bottles and alcohol on the table, so he knew what she was trying to do. He left her alone for a while, checking on her periodically. He wanted to give her the opportunity to die the way she wanted.

The sun started to set and Barraco didn’t want to leave Quinn outside in the darkness. She was still breathing but he couldn’t rouse her, so he called 911. An ambulance came and took Quinn to the hospital, where she eventually woke up.

In 2012, at age 42, Quinn was diagnosed with tongue cancer and by March 2014 it had spread through her body. She had exhausted her treatment options—death was imminent. Quinn suffered from pain and the anticipation of dying. She was ready to end her life.

“When she made up her mind, she made up her mind. She wasn’t having fun anymore. She had a lot of fun with other people, but at the end it was getting more difficult,” said Quinn’s friend Samantha Asquino.

Asquino described Quinn as someone who loved life. She hosted poker nights, drank margaritas and loved golfing. Just a month before she died, Quinn and Barraco had gone on a cruise through the Caribbean.

But Quinn had become frustrated by her rapidly declining quality of life and she was ready to let go.

Before Quinn’s suicide attempt, she didn’t know there were medically supported ways to die. But afterward, she met with a counselor who talked frankly about the various methods in which terminally ill patients can hasten death. The option that appealed most to Quinn was physician-assisted death. In this scenario a doctor prescribes a batch of pills that, swallowed together, cause first loss of consciousness and then over the course of hours, a painless death.
But physician-assisted death was not legal in New York, where Quinn lived. So she decided on another option, known as voluntarily stopping eating and drinking. The practice, which goes by the awkward abbreviation VSED, is legal nationwide. It is legal for medical professionals to assist because under the law they are respecting the patient's right to deny treatment. That choice to refuse food and water causes death by dehydration—usually within one to three weeks. To ensure that the process occurs with minimal suffering, family and friends enlist the aid of doctors and nurses who help ease the patient's fatigue, hunger and thirst with painkillers, ice chips and other tools.

This concept is not new. In Thomas More’s *Utopia* (1516), a fictional narrative that explores political and social philosophy, More acknowledges the nuanced decision-making that end-of-life health issues bring. Touching on the idea of voluntarily fasting to death, he writes, “Those who are wrought upon by these persuasions [referring to terminal illnesses], either starve themselves or take laudanum. But no one is compelled to end his life thus.”

Of physician-assisted death, More said providing it as an option was part of care. This practice, long taboo in the United States, has been gaining legal footing over the past decade. Americans are becoming more comfortable with the idea that people facing their end should be allowed to choose when and how to die. Surveys show that the majority of Americans approve of physician-assisted death. But while 18 state legislatures are in various phases of considering the practice, it has been approved only in Oregon, Washington, Montana, Vermont, Colorado, California, and D.C. Even in those states it can be difficult to find physicians willing to help a patient die, because many doctors find the practice against their ethos, or find the legislation overly restrictive. And for the 6 million people diagnosed each year with dementia, physician-assisted death is never possible, because by the time death nears they are incapable of making choices for themselves. As the insufficiencies of the physician-assisted method become apparent, intentionally fasting to death—an age-old option—is getting more attention.

The national hospice association recently asked its member hospices to consider developing guidelines for how to manage patients who have made the decision to refuse food and water. And the first-ever conference on VSED took place this year at Seattle University Law School. Though there are no statistics available on how many people fast to hasten death, the practice is likely to gain more adherents as the population ages.

“Perhaps now that it has an acronym, people are paying more attention to it.” said Timothy Kirk, an assistant professor of philosophy at York College and a board member on the Hospice and Palliative Care Association of New York State.

**Problems of Geography**

Like many people who find themselves close-up with death, Cathy Quinn wanted to have some say about how and when it happened. After her unsuccessful suicide attempt she wrote in her blog.
“I hate sitting here, twiddling my thumbs, wondering what new hell the day is going to bring. My death is inevitable. I should say my near death is inevitable, it’s not like I still have years in me and I’m trying to throw them away. I have a month or two at the most. So since it’s inevitable, why can’t I go on my own terms?”

Quinn felt it was unfair that some states allow doctor-assisted death, but hers wouldn’t. Oregon was the first state to pass what they call Death with Dignity legislation in 1994. It took four years for the act to become law because of heavy opposition and an attempt at a repeal. It was another decade before Washington passed its law in 2009. Since then the pace has picked up with California joining the states where physician assisted death is legal last year and Colorado and D.C. this year.

Quinn didn’t have the time or desire to uproot and move to a state where a doctor could legally help her die. So instead, she chose to stop eating and drinking—even though she had serious misgivings. Most advocates and physicians agree that it’s possible to manage the symptoms that fasters experience—thirst, hunger pangs, anxiety, delirium—but Quinn still feared that she might suffer during the process and die in discomfort or even agony.

Nevertheless, she set a date, June 23, 2014, to begin refusing food and water. In the days leading up to it, she hosted gatherings for loved ones to come say their final goodbyes.

Quinn’s throat cancer had advanced to the point that she hadn’t spoken in years and couldn’t eat solid food. Still she spent much of those final days in the kitchen making chicken quesadillas, baked ziti and a dessert lasagna made of chocolate.

“One of the things she loved doing was cook, which is ironic because she couldn’t taste it or smell it,” said Barraco.

On June 22, the day before she was supposed to begin her fast, Quinn had a seizure and went into a coma. Barraco reluctantly took her to a hospice—Quinn wanted to die at home and she wanted to go quickly. At one point, a hospice nurse told Barraco that Quinn might not pass for two to three weeks. He prayed that she wouldn’t wake up, knowing that she would “be pissed.” Fortunately, Quinn died three days later.

“It was peaceful only in the context in the moment that she died,” Barraco said. “I was happy with that, but not at all with what she had to go through leading up to it.”

She never had the control she wanted over her death.

“She wanted to gently fall asleep and not wake up and hold my hand,” said Barraco.

**Doctor’s Dilemma**
As the number of elderly people in the U.S. continues to rise, the health care system will be challenged not only to help them live well, but to help them die well. According to Census estimates, by 2050 there will be twice as many people over age 65 as there were in 2012. That means it will fall to doctors and physicians to inform aging patients of all the options available to them—and when appropriate to provide care that includes hastening death. But even in states where physician-assisted death is legal, many doctors balk at participating.

Some doctors believe that this act goes against the hippocratic oath, the ethical code they swore to upon becoming physicians, because in physician-assisted death, a doctor prescribes a fatal dose of the sedative secobarbital. They actively help patients make their final decision. “There’s no coming back from it,” said Thaddeus Pope, a bioethicist and director at the Health Law Institute at the Mitchell Hamline School of Law. “It’s like if you shoot yourself in the head, you can’t then go and take the bullet out.”

Logistical issues also discourage doctor participation, said Felicia G. Cohn, a bioethicist and professor of medicine at University of California Irvine. California’s death with dignity act, for example, is a 26 page piece of legislation that includes several new forms physicians need to use. “A doctor’s favorite thing isn’t paperwork,” Cohn said. Even some doctors who morally agree with the act do not provide the option to patients because it is too time-consuming and legally fraught. Errors made in following the complicated rules could potentially constitute a felony, punishable by up to 5 years in prison.

By contrast, doctors tend to have a more open attitude toward helping patients who have decided to fast to death. Here, instead of actively hastening death, the doctor is just a spectator, assisting with a natural process. Each day that patients refuse food and water, they reaffirm their decision. The physician assumes a more passive role than in doctor-assisted death—one that tends to feel more comfortable. Their job is to provide support to make the process as comfortable as possible, which is more in line with the physician’s imperative to provide care and improve life wherever possible. Indeed, experts say it’s critical for medical professionals to be involved in the process to ensure that patients receive any medications they might need to reduce suffering.

While fasting to death, patients suffer some common symptoms, according to Sarah Egan, a hospice physician at Hospice of New York. Most patients require extensive oral care because of the dehydration, so nurses and caretakers brush the patient’s teeth to maintain oral hygiene. To combat dryness of the mouth, they use artificial saliva sprays and dampened swabs. Often, humidifiers are also put in the room to help. Thirst is managed with ice-chips or bits of gauze saturated with water. Any pain is subdued using morphine, which also reduces the feeling of thirst. Patients who suffer from agitation or delirium are given anti-anxiety medications.
Egan described the process as often self-reinforcing. Once the patient stops eating it becomes physiologically harder to eat, and the desire to eat abates. Many of Egan’s patients don’t have much of an appetite anyway, because of their disease or age or both, by the time they end up in hospice. Usually within a week after beginning to fast they become bedridden and fall into a coma.

Egan doesn’t see helping someone stop eating and drinking as ethically fraught. Because all of her patients are receiving end of life care, Egan sees her role as providing them with autonomy and respect.

“I wouldn’t call it ‘hastening death,’” Egan said. “They are choosing when to die.”

**Dementia and the Right to Die**

When Phyllis Shacter’s husband of 26 years, Alan Alberts, got an Alzheimer’s diagnosis, neither of them wanted him to experience the late stages of the disease. They had watched Alberts’ mother die of Alzheimer’s after mentally and physically declining from the disease for 10 years.

“You basically die like a fetus, you have no musculature, you can’t swallow, you can’t control your bladder or your bowels, you can’t walk, you can’t sit up straight,” Shacter said. “There’s nothing you could do. You could be in that state for a while before you die.”

Although Alberts lived in Washington state, where physician-assisted death is legal, he wasn’t eligible for a prescription. Death with Dignity laws across the U.S. require that the requesting patient have less than 6 months to live. By the time someone with Alzheimer’s is that close to death, they are typically not mentally competent enough to take the life-ending drugs, another requirement under the law.

Translation: Of the one out of three seniors who die with dementia, zero are allowed to enlist a doctor help them die.

Ironically, when Alberts was first diagnosed with Alzheimer’s, he already had a doctor’s prescription to end his life because he had been recently diagnosed with laryngeal cancer and was not expected to live long. But he recovered and never filled the prescription, which expired after six months. Now, although an even more frightful kind of death loomed, Alberts could no longer receive a doctor’s help to decide when it was time to go.

He decided to fast to death.

“Alan was a very intelligent, conscious man. He had a strong spiritual foundation and he knew he was going to die. He had no investment in suffering and losing one capacity after another, after another, until he was going to die anyway,” said Shacter.
Alberts was diagnosed with Alzheimer’s in November 2011 and died in April 2013, at age 76. To ensure he could follow through with his decision to stop eating and drinking, even if his memory started failing, Alberts gave Shacter an indicator for the “right time” to start the process. He told her that when he could no longer go to the Center for Spiritual Living, a community church they attended, he wanted to start the dying process.

In early April of 2013, Alberts told Shacter he couldn’t go to the center anymore. He was just too tired. Alberts was sleeping at least 16 hours a day and had started losing his balance and memory. He had even forgotten his conversation with Shacter about when to stop eating and drinking. She reminded him of it, and told him if he waited a few months, he might not be mentally competent enough to make the decision. Alberts called his long-time counselor to talk about it. When he hung up he declared he would start his fast the following week.

It took Alberts nine and a half days to die. Shacter was by his side, but not alone. She enlisted two nursing assistant caregivers, a doctor who made regular visits, and an elder attorney to manage the legal documents stating Alberts took full responsibility for his decision.

Alberts had previously created what’s known as an advanced directive, or living will, that indicated what healthcare choices he wanted for the future. He and Shacter were navigating a conundrum that bioethicists say recalls a famous moment in Greek mythology. King Ulysses of Ithaca returning by sea from the Trojan war, knew that if he sailed toward the enticing mermaids known as Sirens, he would be hypnotized by their song and die. But he had such a strong desire to hear their melodies that he told his men to tie him to the mast of his ship and refuse to free him, even if he begged. He was essentially giving orders to disregard his own future orders.

When patients diagnosed with dementia make a living will, they are essentially doing what Ulysses did: planning for how they wish to live and die at a point in the future when they will likely not possess the mental competence to advocate for themselves.

For dementia patients, voluntarily fasting to death raises intense ethical questions. If a patient waits too long to begin, they may forget they wanted to die that way. Then the entire burden falls on the surrogate--often a spouse, sibling or child--to decide whether to trust the patient’s formerly stated wishes or to rely on cues indicating the current desires of the patient. The same goes for taking prescribed life-ending drugs. This is why mental competency is a requirement for both processes.

“It is an exquisite issue of timing,” said Norman Cantor, a retired bioethicist and law professor who taught at Rutgers University.

Twice during the nine day process, both times on the fifth day, Alberts asked for water. The effects of dehydration had set in--his urine turned dark orange and Shacter had to constantly moisturize his skin to prevent it from drying. Before offering Alberts a glass of water, though, Shacter reminded him that he had decided to stop eating and drinking to hasten death, and that
if he drank water it would prolong the process. She then asked if he preferred to have water misted in and around his mouth to relieve the feeling of discomfort, or if he still wanted a glass of water. Both times, Alberts chose the water mist and appeared satisfied afterwards, said Shacter. The discomfort from thirst still made Alberts restless, so his doctor started him on anti-anxiety medication to help him relax.

“Of course I would have given him anything he asked for,” Shacter said. “If he decided to change his mind, he could change his mind. If he asked for a hamburger on the third day that’s what he would have gotten— if that’s what he wanted, if that’s what he really wanted.”

For Shacter, facing her husband’s death and being present and supportive through that process, having it take place at home, without invasive medical machinery, helped her grieve.

“As hard as it was for me, at least I got to witness an organic death, the way a body really does break down and die, which is what’s going to happen to all of us unless we die suddenly,” Shacter said.

To have this death happen the way Alberts wanted took a lot of planning and forethought. He and Shacter started to discuss end-of-life options soon after he was diagnosed. They had ongoing conversations with supportive medical professionals, an elder attorney and counselors. They also did a lot of research, both about Alzheimer’s and about voluntary stopping eating and drinking.

Watching her husband die successfully on his own terms has had a profound impact on Shacter.

“I just feel I’m already preparing to die in how I live my life now,” she said. “As a result of knowing that we have the option to have a good death, we can have a much better life.”