

Futile Care Can Prolong Dying and Increase Suffering

The US health care system is second to none in its ability to prolong life in the elderly and seriously ill. Yet, there is also a dark side to this technological prowess, as both scientific studies and the anecdotal experience of countless Americans suggest. Aggressive medical treatment near the end of life is often futile, costly, and even harmful to patients and their families. The publication of a recent *JAMA* study on the frequency and cost of futile treatment has highlighted these issues in a clinical setting. Meanwhile, a newly published book by Katy Butler describes one family's experience within this system that often opts for aggressive treatment, even at the expense of quality of life - even, sometimes, despite objections on the part of patients and their loved ones.

Two recent articles, one in *The Wall Street Journal* and one in *The New York Times' Sunday Book Review* draw attention to the experience of Katy Butler, who, along with her mother, endured a miserable end-of-life experience as her father suffered from “a crippling stroke [that] destroyed [her] father's independence.” At the insistence of doctors eager to prolong life at any cost, the family agreed to install a pacemaker that allowed Jeffrey Butler's heart to outlive his brain. “The device would keep his heart functioning even as he descended into dementia and almost total physical helplessness over the next five years.”

Butler's mother, Valerie, spent six years as a family caregiver. “Her life stopped,” and everything came to revolve around her comatose husband, kept nominally alive by artificial means. Katy Butler was deeply affected as well, as she ended up making regular cross-country trips to support her mother through this multi-year trial. For both mother and daughter, the ordeal was a wake-up call to the reality of a medical system that is still geared towards delivering expensive health services, often without regard to the real needs of patients and families, which might be met with less aggressive (and less expensive) care.

The *Wall Street Journal* article remarks on the fact that, while 70% of patients' desire to die at home, 40% of patients die in the hospital. “This is an amazing disconnect in a society that prides itself on freedom of choice.” And it comes with enormous economic consequences, because approximately one quarter of Medicare's \$550 billion annual budget paying for medical treatment in the last year of life. Butler describes a medical system that is structurally flawed, geared towards collecting fees for services, and is a system that pressured both of her parents to undergo treatments that they did not necessarily desire.

For the Butler family, though, there has been a silver lining to the difficult experience of Jeffrey Butler's highly medicalized last years. Both women came to understand much better the way that the system currently works, and when Valerie Butler developed serious heart valve problems in her mid-eighties, they were ready.

One surgeon encouraged her to undergo heart valve replacement surgery, telling her that if she survived the procedure, she could live to be 90. “Without it, she had a 50-50 chance

of dying within two years.” To the surprise of her physician, Mrs. Butler decided against undertaking the surgery. She “weighed the surgery’s real and often underplayed risks of stroke and dementia,” and said no. This decision disturbed later cardiologists, who assumed that she should undertake any procedure that might extend her life. Yet, the Butlers were learning that the elderly are often severely negatively impacted by surgery. Butler writes, “I would discover that people of my mother’s age are often like Humpty-Dumpty, seeming vigorous until a mishap, a traumatic surgery or a hospital-acquired infection sets them on a rapid downward spiral.” She recalls how a friend “watched her 87-year-old mother die gruesomely, over three months, after exactly the surgery my mother rejected.”

In the end, Valerie Butler was able to die with dignity. While almost no one gets exactly the death that they plan for, Katy Butler describes her mother’s final moments as a “good-enough” death - not unconscious and attached to tubes, nor in the hospital being defibrillated. Instead, after a night of vomiting, she was taken to an inpatient hospice unit. She died, receiving the palliative and comfort care that she wanted.

Still, things could have easily gone very differently. Butler remarks at how a series of doctors aggressively sought to impose more interventionist, higher-risk, higher-cost treatments on her mother - treatments she later discovered would have cost Medicare “in the \$80,000 to \$150,000 range.” Seeing her mother at risk of “heading down the greased chute toward a series of ‘Hail Mary’ surgeries... each one increasing the chance that her death, when it came, would take place in intensive care,” Butler found it necessary to stand up forcefully to some of her mother’s physicians. In one case in particular, she writes, “Burning with anger, I told the astonished cardiologist that my mother had rejected surgery when she had a far better chance of surviving it, and I saw no reason to subject her to it now.”

While Katy Butler provides a uniquely personal perspective on the challenge that futile care presents to the US medical system, a recently released study in *The Journal of the American Medical Association* lends clinical methodology to the problem. The authors note, “Physicians often perceive as futile intensive care interventions that prolong life without achieving an effect that the patient can appreciate as a benefit.” The goal for the study is “to quantify the prevalence and cost of treatment perceived to be futile in adult critical care.”

In their conclusions, the authors warn that experiences like those of Katy Butler’s family are not uncommon. They say, “Treatment in critical care that is perceived to be futile is common and the cost is substantial.” The three-month study, including “6916 assessments by 36 critical care specialists of 1136 patients,” found that approximately 20% of these patients were perceived as having received treatment described by physicians as either “probably futile” or “futile.” Aside from the human cost of futile care, researchers also found a pronounced economic cost, as well. For the patients studied, “the cost of futile treatment in critical care was estimated at \$2.6 million.”

The authors write, “Treatment that cannot achieve a patient’s goals or that simply maintains a state such as ICU dependence or permanent coma is contrary to professional

values, inappropriately uses health care resources, and creates moral distress.” They recognize, however, that making a determination of when care is futile can be a point of contention, noting, “The determination of futility is often value laden.” Nevertheless, researchers hope that by surveying critical care physicians daily during a three-month period, they have come to a better understanding of what constitutes futile treatment, and how it might be avoided. The *JAMA* article is online at the link below and is free for all readers.

Meanwhile, far too many Americans face the task that Katy Butler faced, and have stories like her story, as noted in the subtitle of The Wall Street Journal article: “How one woman fought the medical establishment and avoided what most Americans fear: prolonged, plugged-in suffering.” Butler has written about her experiences in her newly-published book, "Knocking on Heaven's Door: The Path to a Better Way of Death."

The Wall Street Journal, 9/6,

online.wsj.com/article/SB10001424127887324577304579054880302791624.html#articleTabs%3Darticle

The New York Times, 9/6, www.nytimes.com/2013/09/08/books/review/knocking-on-heavens-door-by-katy-butler.html?pagewanted=all&_r=1&

MedCity News, 9/11, medcitynews.com/2013/09/end-of-life-care-a-great-american-tragedy/

The Marin Independent Journal, 9/9,

www.marinij.com/healthandfitness/ci_24038126/mill-valleys-butler-questions-end-life-care-memoir

JAMA, 9/9, archinte.jamanetwork.com/article.aspx?articleid=1735897

The New York Times, 9/11, well.blogs.nytimes.com/2013/09/11/futile-care-at-lifes-end/?emc=eta1

UPI.com, 9/11, www.upi.com/Health_News/2013/09/11/Study-Futile-end-of-life-care-costs-millions-not-warranted/UPI-79531378928697/

Bloomberg, 9/9, www.businessweek.com/news/2013-09-09/futile-treatment-given-some-as-end-of-life-aid-in-intensive-care