
ESSAY/PERSONAL REFLECTIONS

A medical revolution in death-hastening decisions

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On one level it was a perfectly ordinary wedding—elaborate floral bouquets adorned the room, the family’s favorite lemon cake was covered in sugar-frosted curlicues and topped with traditional tiny statuettes of a happy couple, the bride’s gown was splendid, and the wedding feast was complete with shrimp cocktail, filet mignon, and champagne. On another level, as the bride’s mother, 58-year-old Amy Plasse slowly walked down the aisle, everyone in the hospital chapel knew that they were participating in an extraordinary event. This was the culmination of Amy’s life; she had achieved her final goal—to witness the wedding of her only daughter. The way was prepared to stop the life-support treatment of dialysis and to end the prolongation of her suffering.

A kidney transplant had given her four solid years, but Hodgkin’s disease and its treatment led to the organ being rejected and to the necessity of hemodialysis. For the past year, she had required nightly home dialysis sessions, but the cancer continued to wreak havoc. Hospitalized with respiratory failure, she spent a month in the intensive care unit before being transferred to the renal ward. There, as is often the case, it was not the physicians, but the nurses, who appreciated that she was inexorably dying. It was the nurses who had learned that Amy’s daughter was to be married in a month’s time, and it was they who acknowledged she would not survive that long. Mobilizing the other staff, they conferred with Amy and her family about moving up the wedding date and holding it in the hospital. The seemingly impossible task of altering the wedding’s logistics began. The wedding dress was fetched from the seamstress, a justice of the peace secured, a wedding ring borrowed from a

nurse’s aide, flowers purchased by the dietitian, and an amateur videographer enlisted to tape the nuptials.

Amy’s son, a reporter from a local newspaper later wrote, “The event turned what could have been a day of despair into a day of hope and joy. And it buoyed us all, mom included, through a weekend of togetherness during which we dwelled not on the unfairness of it all, but on reminiscences and love.” It was a weekend during which dialysis had been stopped, and the family spent the following three days feeding Amy her favorite meals, watching home movies on their old projector, and celebrating her life. On the final night, while her two children slept in the hospital room, Amy peacefully died. During the viewing at the funeral home the wedding video was played, and according to her son, “It tinged the sorrow with celebration.”

In many regards, Amy had a very modern and quintessentially “good” death. Death has undergone a revolutionary change in America, but most of the public remains unaware and uninformed. People are still dying from the same diseases—cardiovascular disorders, cancer, and trauma. Most of us are still dying in hospitals. Death is still inevitably preceded by a final breath and a last beat of our hearts. However, a paradigmatic shift has somehow managed to quietly take place in the practice of medicine; a century of denial is coming to an end, and mortality is beginning to be more openly accepted by medical staff. As a consequence, more and more of us are confronting the need to make decisions that can accelerate our deaths or the deaths of loved ones.

Much of the media attention on death-hastening decisions has been focused on the minuscule number of people in Oregon who request physician-

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assisted suicide. The Attorney General, John Ashcroft, recently marshaled the might of the Federal government in yet another unsuccessful attempt to overturn Oregon's legislation. The Oregon statute has enabled fewer than 70 individuals to die through physician-assisted suicide. Less publicized are the decisions by hundreds of thousands of Americans to die each year following withholding or withdrawal of life-support treatment. Citing studies that found decisions hastening death in 90–95% of intensive care unit patient samples, Emanuel (1997) concluded in a *Lancet* commentary, "The good news is that the withdrawal or withholding of life-sustaining treatments is now standard practice."

My own research interest has been in kidney disease, where this change is also clearly evident (Cohen, 1998; Cohen et al., 2003). A decade ago, less than 1 in 10 deaths of patients maintained with dialysis was preceded by a decision to stop treatment. This year, there were 60,000 deaths of individuals with end-stage renal disease, and 1 in 4 of these followed dialysis termination (Cohen et al., 2000; US Renal Data System, 2002).

This essay represents an effort to better understand and appreciate the complex decisions to stop life support. Deaths, such as that of Amy, have the potential to be transcendent experiences for participants—family, friends, and staff. In the immediate future, they are likely to be emulated by increasing numbers of people. I believe that this medical revolution is both just and correct, but that it also needs to be actively acknowledged and more openly discussed.

In my opinion, most of the baby-boomer generation and their parents grew up with an entirely different notion of dying. The heroes of Edgar Rice Burroughs' novels, be it the indomitable Tarzan or the invincible John Carter, Warlord of Mars, as well as the real-life adventurers and soldiers whose exploits were detailed in newspapers and formed the basis for the fictional accounts, all uniformly spat in the face of death. Caught in the midst of a dire predicament, Tarzan would regularly declaim, "I will fight on with my last breath of life." Burroughs' purple prose enunciated the accepted credo of every Arctic or African explorer who trudged step by step through a hostile wilderness, as well as the heroic figures who fought in World War II and America's earlier conflicts. Death was not a release for them, but rather an implacable enemy to be resisted and overcome. This social context also encompassed the discipline of medicine. Health care was directed entirely toward thwarting death, and each victory was measured by another disease vanquished or by a few percentage points improvement in a five-year survival rate.

However, the second half of the 20th century became punctuated by a series of landmark judicial rulings that signaled a change in the "life-at-any-cost" philosophy (Burt, 2002). Court decisions involving Karen Ann Quinlan and Nancy Cruzan reified the bioethical principle of patient autonomy and self determination—a particularly American perspective of the value of individuals in society. The Supreme Court affirmed that not only must patients agree to participate in treatment, but that they can withdraw their approval at any time and treatment must cease. In our modern legal system, treatment without permission is conceptualized as being an assault and battery by staff upon the helpless body of the patient. This has led to the emergence of a radical idea; it is now up to patients, families, and medical personnel to determine if the suffering associated with treatment outweighs its benefits. "Enough is enough" has entered medical consciousness, and the door has begun to open to facilitate planned dying.

What were the turning points that led to the shift in the American zeitgeist and practice of medicine? Two events worth highlighting are the ascendancy of medical technology in the 1960s and 1970s, and the onset of the AIDS epidemic. The first of these meant that suddenly, organ failure was no longer synonymous with death. Machinery became available that could supplement or substitute for damaged organ systems. Transplantation of heart, lung, liver, bone marrow, and kidneys became possible. Dialysis for renal failure was not only possible, but with the help of government funding through Medicare, dialysis facilities proliferated. Intensive care units became omnipresent, and they epitomized the technological explosion in medicine. The units were settings in which people could be metamorphosed into medical astronauts, surrounded by expensive and sophisticated machinery, dependent on these for monitoring vital functions and substituting in the event of organ failure. If one's heart stopped beating, it could be started or stimulated with medications that were sometimes injected directly into the heart muscle. Alternatively, in a procedure that gave new meaning to the term "aggressive medicine," one's chest could be "cracked" by a surgeon, who reached in with his or her hand and manually pumped the organ until it responded. As the gentle Drs. Kildare and Welby were joined by the grimmer Dr. Casey and finally the frenetic staff of *ER*, the wonder, frustration, and hubris of medicine was revealed to television viewers. One of the remarkable secrets that became manifest was that just because space-age technology could maintain life in the artificial setting of the intensive care unit, dialysis clinic, or surgical ward, this might

have no bearing on whether the individuals who were treated ever returned to anything approximating their formerly satisfying and productive lives.

A backlash was predictable, and the onset of the AIDS epidemic fueled an intense reaction. For the first time since the Great Influenza outbreak at the turn of the century, all of medicine's advances were rendered impotent by a seemingly terminal disease. Medicine's shift from "do no harm" to "do everything" was thrown into doubt by AIDS. Many affected individuals chose to avoid the more aggressive medical interventions, and some were actually barred by intensive care units out of fear of infection and the seeming futility of treatment. After repeatedly witnessing the debility and physical devastation wrought by the disease and its treatment upon friends and lovers, some AIDS patients chose to hasten their deaths. Suicide was brought out of the closet, and it was seen as a means to avoid victimization by the disease. Such suicides were often preceded by "living wakes," in which friends, family, and loved ones gathered to recall the good times, express whatever remained unsaid, and bid farewell. They were often very public affairs.

The idea that one need not wholeheartedly agree to battle death using all of medicine's available technological weaponry filtered its way through American society. One milestone was the publication of *Final Exit*, a book that laid out specific recommendations and a prescription for ending one's life. Another was the legislative struggles over physician-assisted suicide, which culminated in its legalization in Oregon. Not surprisingly, as a "right-to-die" movement took shape, it produced its own backlash. Many of the same groups that objected to abortion are vehemently opposed to physician-assisted suicide and what is perceived to be an American culture of death.

At the present time, a theoretical "bright line" has been constructed, and the majority of bioethicists and theologians condone stopping life support and other actions that accelerate the deaths of terminally ill individuals, while simultaneously condemning suicide and blatant acts of self-destruction (Ganzini & Cohen, 2000). The Catholic Church is particularly clear and outspoken on this subject, and a papal encyclical affirms that the prohibitions associated with suicide are not applicable to the withdrawal or withholding of life-prolonging treatment. Most Protestant and Baptist churches agree with this distinction, as do many Jewish institutions. By contrast, Orthodox Judaism prohibits all acts that accelerate dying, and Israeli medicine has consequently not followed America's lead and has not lowered the threshold facilitating treatment termination.

In the United States, that threshold has been dramatically lowered, and as mentioned above, the great majority of deaths occurring in intensive care units are now preceded by decisions to withdraw or withhold treatment. Furthermore, there is practically no hospital, nursing home, medical clinic, or doctor's office where the option to refrain from aggressive treatments or to stop medical therapies is not discussed, let alone offered. Oncologists may continue to recommend incredibly taxing cancer treatments for their patients, but many of them also now entertain the possibility of potentially less "successful," but less onerous, therapeutic courses.

I am convinced that Rosalynn Carter (1999) was absolutely correct when she wrote in the foreword of *The Handbook for Mortals*, "We often put off what is important in life, and it sometimes takes the shadow of death to make us appreciate that love, family, and faith are things that really matter." As evidenced by the case of Amy Plasse, I am looking forward to more instances where medical personnel recognize the inevitability of impending death and go out of their way to help patients and loved ones take the best possible advantage of the remaining time. I welcome the complexity that this will add to the practice of medicine, and the opportunity it will provide to permit both the relief of suffering and the enrichment of the final phase of life.

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