

Eleanor Roosevelt's Last Days: A Bioethical Case Study



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Because I could not stop for Death —
He kindly stopped for me —

Emily Dickinson¹

When Eleanor Roosevelt died in 1962, she was widely regarded as “the greatest woman in the world” (p. 636).² Despite her celebrity, or more likely because of it, she had to endure a prolonged period of intense suffering and humiliation before dying, which was due in large part to her medical care. Her case reveals a great deal about the evolution of the bioethics of dying and concepts of end-of-life care in America.

CASE SUMMARY

Anna Eleanor Roosevelt was 75 years old in April 1960 when she consulted her personal physician, Dr. David Gurewitsch (Figure), for mounting fatigue. A series of abnormal blood tests led Gurewitsch to diagnosed “aplastic anemia” (although, in retrospect, myelodysplastic syndrome was likely the correct diagnosis; p. 193-212).³ He warned Roosevelt that transfusions could bring temporary relief, but sooner or later, her marrow would break down completely and internal hemorrhaging would result.

Over the ensuing 2 years, Roosevelt was admitted repeatedly to Columbia-Presbyterian Hospital for tests and treatments, which failed to halt progression of her pancytopenia. Premarin produced only vaginal bleeding, necessitating dilatation and curettage, and transfusions temporary

relief of her fatigue, but at the expense of severe bouts of chills and fever; repeated courses of prednisone produced only oral candidiasis, iatrogenic Cushing syndrome, and rectal bleeding. Her “aplastic anemia” continued to worsen, and by September 1962, deathly pale, covered with bruises and passing tarry stools, Roosevelt was begging Gurewitsch in vain to let her die. She began spitting out pills or hiding them under her tongue, refused further tests, and demanded to go home. Eight days after leaving the hospital, *Mycobacterium tuberculosis* was cultured from her bone marrow.

When Gurewitsch suggested that with this new finding, Roosevelt’s chances of survival “had gone up by 5000%,” her family insisted that their mother’s suffering had gone on long enough. Undeterred, Gurewitsch doubled the dose of isoniazid, gave additional transfusions, and ordered tracheal suctioning and a Foley catheter inserted.

Despite these measures, Roosevelt’s condition continued to worsen. Late in the afternoon of November 7, 1962, she ceased breathing. Attempts at closed chest resuscitation with mouth-to-mouth breathing and intracardiac adrenalin were unsuccessful.

Years later, when reflecting upon these events, Gurewitsch opined that: “He had not done well by [Roosevelt] toward the end. She had told him that if her illness flared up again, and fatally, that she did not want to linger on and expected him to save her from the protracted, helpless, dragging out of suffering. But he could not do it,” he said. “When the time came, his duty as a doctor prevented him.”

A BIOETHICAL CRITIQUE

Eleanor Roosevelt became ill and died years before the ethical standards of care for the dying we hold dear today began to be formulated. Most were violated (albeit unwittingly) by Roosevelt’s physicians in their desperate efforts to cure her: that of *nonmaleficence* (ie, avoiding harm)⁴ by pushing prednisone after it had no apparent therapeutic effect; *beneficence* (ie, limiting interventions to beneficial ones)⁵ by performing cardiopulmonary resuscitation in the absence of any

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Figure Eleanor Roosevelt (center) and Dr. David Gurewitsch (left) with 3 unidentified persons in Israel in 1952 (from the archives of the FDR Library, Hyde Park, NY).

reasonable prospect of a favorable outcome; and *futility* (avoiding futile interventions)⁶ by continuing transfusions, performing tracheal suctioning, and (some might even argue) beginning antituberculosis therapy after it was clear that Roosevelt's hematological disorder was terminal.

Roosevelt's physicians also violated what has come to be known as the *principle of respect for persons*⁷ by repeatedly ignoring her pleas to discontinue treatment. However, physician–patient relationships were more paternalistic then, and in 1962 many, if not most, physicians likely would have done as Gurewitsch did, believing that their “duty as doctors” compelled them to preserve life at all cost.

In the 1960s, society had yet to recognize the now generally accepted ethical/legal distinction between killing a patient (ie, creating a new lethal physiological state) and allowing a patient to die (ie, withholding or withdrawing a treatment that interferes with the natural progression of a preexisting lethal pathophysiological state).⁸ Given these definitions, having withheld prednisone or streptomycin and isoniazid or transfusions at the end of Roosevelt's life would have been, by today's standards, morally and legally permissive acts of “allowing to die”—by foregoing “extraordinary means.”⁹

A BRIEF HISTORY OF THE RECENT REVOLUTION IN END-OF-LIFE CARE

Much has changed with regard to medical ethics and care for the dying since 1962. Many of the changes were necessitated by spectacular advances in life-prolonging technology.

“Extraordinary Means”

Initially, physicians unschooled in formal ethics were assisted by theologians in determining how best to apply the emerging life-prolonging technology in the care of dying patients.¹⁰ A watershed event in this regard occurred in 1957 with the declaration by Pope Pius XII before a Congress of Anesthesiologists that ventilator support could be considered extraordinary care in certain situations and might be withheld or withdrawn if its burden outweighed its benefits.¹¹

Shared Decision-making

Patient participation in medical decision-making changed rapidly during this time. In a 1961 survey, 90% of US physicians reported that they would not disclose a diagnosis of terminal cancer to a patient.¹² When the survey was repeated in 1979, 98% reported that they would disclose such information and wondered what was wrong with the other 2%.¹³ This sea change in attitude coincided with a number of broad social reforms emphasizing personal freedom and self-determination.

The Death and Dying Movement

Death and dying became acceptable topics of public discourse, thanks to the work of investigators like University of Chicago psychiatrist Elisabeth Kübler-Ross.¹⁴ No longer a taboo subject, death became an appropriate topic of conversation in venues ranging from cocktail parties to examination rooms.

Court Cases

Eventually, the courts legitimized the distinction between allowing to die and euthanasia through cases such as that of Karen Ann Quinlan.¹⁵ In 1990 the US Supreme Court concurred by ruling that, given proper evidence of the patient's wishes, the feeding tube of another young woman in a persistent vegetative state, Nancy Cruzan, could be removed.¹⁶

Advance Directives

“Living Wills” were introduced in the 1970s as formal documents by which patients might specify their wishes for or against certain forms of treatment at the end of life.¹⁷ These were followed in the 1980s by durable powers of attorney for health care.

Bioethics as a Field

In 1969 the Hastings Center for Ethics and the Life Sciences was founded as an independent think tank¹⁸; in 1971

Georgetown's Kennedy Institute for Ethics became the first university-based bioethics center¹⁹; and in 1983 the University of Chicago's MacLean Center for Clinical Medical Ethics became the first bioethics center dedicated to clinical ethics research and consultation at a medical school.²⁰ Ethics committees followed soon thereafter, along with formal courses, and specialty organizations and journals devoted to medical ethics. A series of bioethics commissions was launched, beginning with the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1974-1978) and continuing to the present with the Presidential Commission of the Study of Bioethical Issues.²¹

Hospice and Palliative Care

In the early 1960s there were no hospice care programs to offer patients like Roosevelt as an alternative to continued futile treatments. Dame Cicely Saunders founded St. Christopher's Hospice in London in 1967.²² The first US program, the Connecticut Hospice, was founded in 1974. Medicare finally made hospice care a covered benefit in 1986, and in 2006, palliative care became a board-certified specialty in the US.²³

Euthanasia and Assisted Suicide

Euthanasia, which was unthinkable in 1962, is now legal in several European nations. Physician-assisted suicide is legal in the states of Oregon, Washington, Vermont, and Montana, thanks to the efforts of activists working to expand the notion of the so-called "right to die."²⁴ These practices, however, remain highly controversial. In a recent survey, 69% of US physicians considered them immoral.²⁵

CONCLUSION

Current bioethical concepts would have dictated a different, presumably more humane, end-of-life care for Eleanor Roosevelt. While arguments can be made as to whether any ethical principles are timeless, Gurewitsch's own retrospective angst over Roosevelt's treatment, coupled with ancient precedents proscribing futile or maleficent interventions (or both),^{4,26} along with an already growing awareness of the importance of respect for patients' wishes in the 1960s,^{27,28} suggest that even by 1962 standards, her end-of-life care was misguided. Nevertheless, one wonders whether a present-day personal physician of a patient as prominent as Roosevelt would have behaved differently. Although Richard Nixon and Jacqueline Kennedy Onassis both had advance directives and died peacefully after forgoing potentially life-sustaining treatments,^{29,30} Nelson Mandela and Ariel Sharon were less fortunate.³¹⁻³³ Both died on ventilators after having been maintained in a vegetative state for prolonged periods as a result of aggressive end-of-life care. Thus, although bioethical concepts and attitudes about end-of-life care have changed markedly

since 1962, even today, those caring for famous patients sometimes find it as difficult as did Dr. Gurewitsch nearly a half century ago "to save [their patients] from the protracted, helpless, dragging out of suffering" at the end of their lives.

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