

From Heroic Treatment to Futile Therapy: End-of-Life Ethics for the Coming Millennium

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BETTER LIVING CONDITIONS and improved general health care have added over 30 years to the individual's average life expectancy in this century. By the year 2000, projections indicate that there will be more people over the age of 55 than under the age of 14 living in the United States. Today and every day until the year 2010, approximately 10,000 "Baby Boomers" are turning 55. Gerontologists are beginning to classify individuals under 75 as the "young old." In contrast with life expectancy, life span has hardly changed in the past 200 years; while the percentage of those who reach ripe old age has risen dramatically, practically everybody still dies between 90 and 100.

These demographics predict a rapid increase in end-of-life costs in the coming millennium. The current cost of health care for a person in the last year of his or her life has been estimated at 25-30% of the overall national health care budget. These disproportionately high costs reflect expenses incurred during prolonged stays in special care settings and hospital intensive care units.

The Evolution of Physician-assisted Suicide

In response to the economic and social dilemmas created by these "living dead," the industrialized world has begun construction of the legal scaffolding for mandated "mercy killing" to become a responsibility of licensed physicians. Widely reported court decisions in termination-of-life cases have stimulated public and professional interest in euthanasia and physician-assisted suicide.

As the concept of a patient's right to a "good" death gains acceptance, powers of attorney, living wills, and other mechanisms for terminating life support on demand are becoming routine in most Western countries. In California, the herald of new trends, all patients admitted for surgical procedures are encouraged to compose written instructions concerning life-and-death decisions.

A good deal of empirical research by

political scientists has shown that governmental policies are directly influenced by public opinion when three criteria are satisfied:

1. The public perceives an issue as having profound personal meaning;
2. Public support for the issue is sustained at high levels over several years;
3. Institutional barriers to the implementation of a new policy, in the form of legal prohibitions or constitutional constraints, are gradually removed in the courts and at the ballot box.

The movement to legalize "mercy killing" is close to fulfilling all three pre-conditions for policy implementation.

First, Americans are anxious about future costs of health care. Polls have shown that the single most important factor in support of euthanasia for themselves is the fear of becoming a burden to the family.

Second, according to an analysis of 21 public opinion polls on the subject of physician-assisted death published in JAMA in 1992 by Blendon et al, only 34% of Americans believed in 1950 that physicians should be allowed to end the lives of patients with incurable diseases if the patient and family requested it. This figure nearly doubled by 1977, maintaining a level of 60% to 70% during the next 15 years. More recent data suggest a further acceleration of this trend. The growing willingness to place such vulnerable lives in doctors' hands is all the more remarkable as it coincides with a correspondingly steep decline in public trust toward the medical profession.

Third, legislation rushed through the Michigan state congress in reaction to Dr. Jack Kevorkian's deliberately provocative "assisted" suicides gave juries the opportunity to decline to convict him and to vote out of office the state prosecutor involved in the case. Moreover, three judges declared the Michigan law prohibiting assisted suicide unconstitutional.

These proceedings, combined with the passage of an Oregon initiative legalizing



physician-assisted suicide (presently under court injunction), form a legal foundation for implementing "medicalized" killing in other states. The debate around euthanasia and physician-aided suicide has been put to a public vote twice in California and once in the state of Washington. These initiatives were narrowly defeated: 47% of voters supported Washington's Initiative 119 to legalize physician-aided suicide.

The 2nd and 9th District Courts of Appeal have declared unconstitutional the laws against physician-assisted suicide in the states of Washington and New York. The United States Supreme Court has finally agreed to consider the constitutionality of a right to doctor-assisted suicide early next year (the Court already recognized the existence of a right to die in 1990).

These societal trends raise the possibility that physician-assisted death may eventually gain acceptance as the ultimate therapy for all irreversible, debilitating, and progressive diseases. Inclusion of euthanasia and physician-assisted suicide as legitimate options in well-defined clinical situations places physicians in new roles dictated by social, political, and economic changes.

The impact of these trends on the traditional patient-doctor relationship is not immediately obvious. Few individuals are in a position to truly understand the potential consequences of routine acceptance of physician-assisted suicide. A telling illustration of this point is the amazing transformation within a handful of years of Kevorkian's image in the media and in the courts from psychopathic Dr. Death to gutsy pioneer in the fight for people's rights — specifically, the right to die.

Paradoxically, while the legalization of euthanasia has been rationalized in terms of patient's rights and autonomy, a permit (obligation? power?) to terminate a patient's life may actually enhance the control exerted by physicians over the clinical situation.

At this point, it is important to emphasize that physicians' opinions on the subject of euthanasia faithfully reflect the general consensus. Polls conducted by the California Medical Association nearly 10 years ago indicated that support for both active and passive euthanasia among physicians licensed in the state nearly doubled in the brief period between the two euthanasia referendums. In Oregon, after devising a system for rationing health care, medical leaders avoided taking sides when an assisted suicide measure came up for a vote. The measure was approved in 1994.

Many other observations highlight the profound impact of social culture on clinical practice. Simply put, the culture of medicine cannot exist apart from the general culture. The medical profession cannot take an independent position on "mercy killing" in either of its contemporary guises of euthanasia and aid-in-dying. In a society which perceives death as an enemy, doctors will do all they can to keep patients alive as long as possible; when the general attitude shifts toward acceptance of dying as a natural process, doctors will assist and facilitate that outcome.

We have seen that in our society today, a "good" or "dignified" death is rapidly becoming the main goal of therapy in intractable progressive illness. The new approach requires a new set of arguments and explanations. Indeed, a new professional code of conduct regarding terminal illness is being fashioned at a moment when for the first time in the history of American medicine, the organization and delivery of health care and the character of medical practice have been transformed from a traditional decentralized entrepreneurial model to a centrally administered corporate structure.

The market-driven world of contemporary medical practice has hardly begun to confront the implications of mandated mercy killing. In the new market-driven health care environment, this fateful deci-



sion will undoubtedly join other cost-effective clinical strategies as one more item on a list of recommended therapeutic options. Backed by the authority of the law, the new ethical guidelines will inform both patient and physician on how to comply with the emerging new principles of professional conduct.

The Role of Ethics

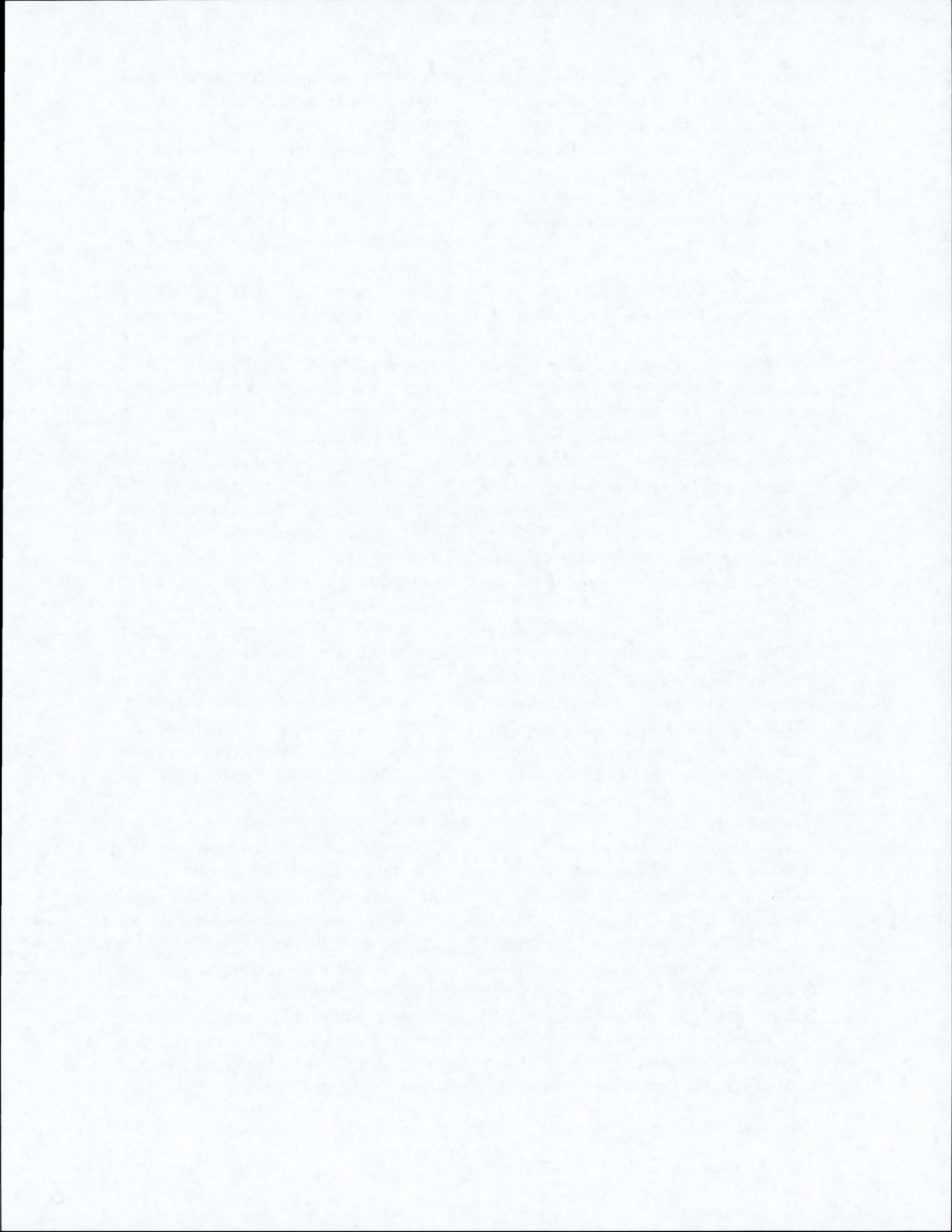
Far from being the bulwark against moral drift for which it is often mistaken, ethics provides the explicit arguments with which to accommodate mutations in communal values. The role of ethicists in our culture is to be harbingers of conformity to "the accepted customs and conventions" as defined by Webster's dictionary. Where the changing values and beliefs of a people lead, there ethicists will follow with philosophic formulations designed to rationalize and hence to justify each particular action in the light of a new day.

The tragic revelations emanating from the Doctors' Trial at Nuremberg in 1947 were codified into ethical principles which were largely ignored by American doctors and ethicists until the time for "patient autonomy" and "informed consent" had arrived with the individual rights revolution of the 1960s. Suddenly, just in time to explain socially correct behavior, American bioethics surfaced at the interface of medicine and society with its "four-fold mantra" of autonomy, beneficence, nonmaleficence, and justice.

Soon, the courts followed. The famous juridical right-to-die decisions from Quinlan (1976) to Cruzan (1990), which legitimized "passive" euthanasia, also established patient autonomy as the moral foundation of modern bioethics. Nancy Cruzan's parents demanded removal of the

feeding tube which had helped sustain her for 5 years in a vegetative state. Physicians and the hospital involved in her care refused to comply with her parents' wishes on moral grounds. Probate court agreed with the parents, but on appeal by the state, the Missouri Supreme Court ruled that the parents' "quality of life" arguments were not as convincing as the state's "sanctity of life" position. On final appeal, the US Supreme Court first recognized the existence of a right to die (1990), basing its decision on the parents' right to determine their daughter's fate. Cruzan's feeding tube was removed against medical advice, and she died 11 days later.

The winds of change are blowing through every pore of health care in America. Medical ethics is no exception. The "heroic treatment" of the post-war era has soured into "futile therapy." The relative positions of doctors and patients in "right-to-die" cases are now reversed: physicians and hospitals presently argue in court that continuation of life support in terminally ill patients violates the ethical principle of distributive justice, whereas patients invoke autonomous rights to their own bodies to insist on full intensive care. A mere 4 years after *Cruzan vs Missouri Department of Health*, the *New York Times* reported the case of a 13-year-old diabetic girl who lapsed into unconsciousness with little or no brain activity. Physicians recommended removing life support after just 1 week. The patient then became "the focus of a conflict between doctors who want to remove life support equipment, as accepted medical practice dictates, and her parents who contend that she can recover." Lawyers for the hospital warned that state law favored discontinuing therapy, but the parents demanded that life support con-



tinue. The child was discharged home on life support in the custody of her parents, because the insurance company would not cover hospitalization costs. The Florida Supreme Court finally ruled that the hospital must invite the local state attorney to arbitrate conflicts between "acceptable medical treatment and the patient's wishes."

An ethics of unalloyed utilitarianism has been introduced in the past few years to legitimize the erosion of patient autonomy. The reported expert opinions of ethicists in the above case are revealing.

Arthur Caplan, a member of the White House Task Force on Health Care, was quoted in the *New York Times* as follows: "The decisions about when someone is dead are not for the state of Florida to make; it's for a doctor to make". Caplan then revealed the rationale for his position: "I find it incredible and mind-boggling that we are talking about rationing health care as part of health reform and at the same time we have a person that is dead that we can't stop treating."

George Annas, director of the Law, Ethics, and Medicine Program at Boston University School of Medicine and Public Health, was even more emphatic: "The law says you're dead when the doctor says you're dead." So much for patient autonomy.

The very next day, the *New York Times* reported a Federal Appeals Court ruling in the case of a 16-month-old infant with anencephalic syndrome, code-named baby K. A hospital ethics committee recommended against treatment. However, baby K's mother insisted that the hospital provide mechanical breathing support during the infant's recurrent respiratory crises, acting out of "a firm Christian faith that all life should be protected."

Dr. Arthur Kohrman, chair of the Committee On Bioethics of the American Academy of Pediatrics, commented "This case

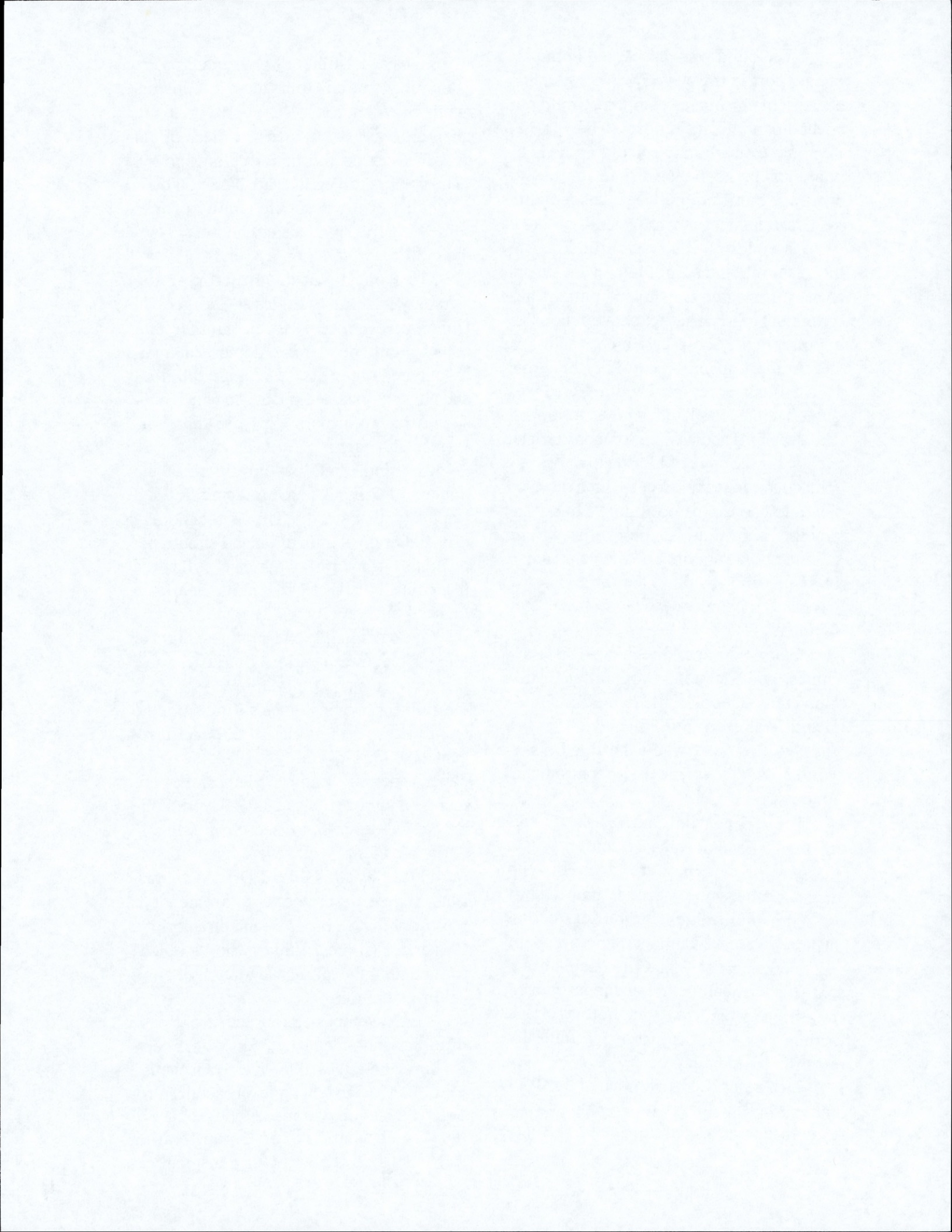
strips away the ability of physicians to act as moral agents and turns them into instruments of technology." In other words, the dilemma was now framed as a clash of the doctor's versus the patient's autonomy. "The doctors' objections are based on their own view of the desirable quality of life, something the law does not address," said the mother through her lawyer.

Dr. Robert Veach, director of the Kennedy Institute of Ethics at Georgetown University, agreed with the mother that courts should not defer to doctors on quality of care judgments. "These are religious and philosophical judgments on which physicians have no more expertise than parents," said Veach.

The immediate past president of the Society of Critical Care Medicine, Russell Raphaely, disagreed: "This is technology driven therapy that is futile and should not be done." A handful of ethicists still argue the point, but the trend seems clearly in favor of the "quality of life" side.

The emerging explanatory paradigm of today's bioethics is priority of distributive justice over patient autonomy. As I write these lines, two headlines spring from the front pages of the *New York Times* in recent days. On November 5, 1996, the newspaper reported "Ban on Medical Experiments Without Consent Is Relaxed." The new regulations for research in vaguely defined patients with severe head injuries introduced by the Federal Drug Administration were described as a "tremendous philosophical change" by the director of a Center for Clinical Ethics who "lobbied" for updating the moral foundation of clinical investigation.

On November 15, another front page headline announced: "In Shift, Prospects for Survival Will Decide Liver Transplants." The decision to alter the procedures for organ allocation was made by the board of the United Network for Organ Sharing (UNOS), a private group of transplant ex-



perts monitored by the U.S. Department of Health and Human Services. Those "prospects for survival" will not be determined by physicians on a case-by-case basis, but according to fixed prognostic categories administered by officials of the Network. The stated rationale for such profound changes in the clinical management of critically ill patients is underlined in the memorandum sent by the executive director of UNOS to liver transplant program directors: "According to the UNOS liver allocation computer model, the new policy will result in a net increase of 200 more transplants over the next 3 years."

Arthur Caplan considers this "a canary in a mine all of us will have to enter." So who lives and who dies? asked the reporter. "It's truly a dilemma," came the answer from a board member, "[We were] trying desperately to balance justice and utility."

Conclusion

The touchstone of medical morality for the past 2,500 years has been Hippocrates' injunction, "Do no harm." Hippocrates also pledged "never to give a deadly drug to anybody if asked for it, nor ... make a suggestion to that effect." We must now decipher how to honor the First Commandment without breaching the Second.

We drift into the next millennium in search of a compass to help us traverse the inevitable cataclysms of human existence. We are all, indeed, canaries in a mine, but it is a mine of our own making and it contains our treasure and our tombs.



Terri Schiavo

From Wikipedia, the free encyclopedia

Terri Schiavo before her 1990 collapse

Born December 3, 1963, Lower Moreland Township, Pennsylvania

Died March 31, 2005, Pinellas Park, Florida

Theresa Marie "Terri" Schiavo (December 3, 1963 - March 31, 2005) was a woman from St. Petersburg, Florida whose medical and family circumstances and attendant legal battles fueled intense media attention and led to several high-profile court decisions and involvement by politicians and interest groups. Schiavo, then 26, collapsed in her home in 1990 and experienced respiratory and cardiac arrest. She remained in a coma for ten weeks. Within three years, she was diagnosed as being in a persistent vegetative state (PVS).

In 1998, Terri's husband and guardian Michael Schiavo petitioned the courts to remove her gastric feeding tube; Terri's parents, Robert and Mary Schindler, opposed this. The courts found that Terri was in a PVS and that she should not be kept alive. In 2003, the matter began to receive national attention.

By March 2005, the legal history around the Schiavo case included fourteen appeals and numerous motions, petitions, and hearings in the Florida courts; five suits in Federal District Court; Florida legislation struck down by the Supreme Court of Florida; a subpoena by a congressional committee in an attempt to qualify Schiavo for witness protection; federal legislation (Palm Sunday Compromise); and four denials of *certiorari* from the Supreme Court of the United States.[1] Despite intervention by the other branches, the courts continued to hold that Schiavo was in a PVS, and would want to cease life support. Her feeding tube was removed a third and final time on March 18, 2005. She died thirteen days later at a Pinellas Park hospice on March 31, 2005, at the age of 41.

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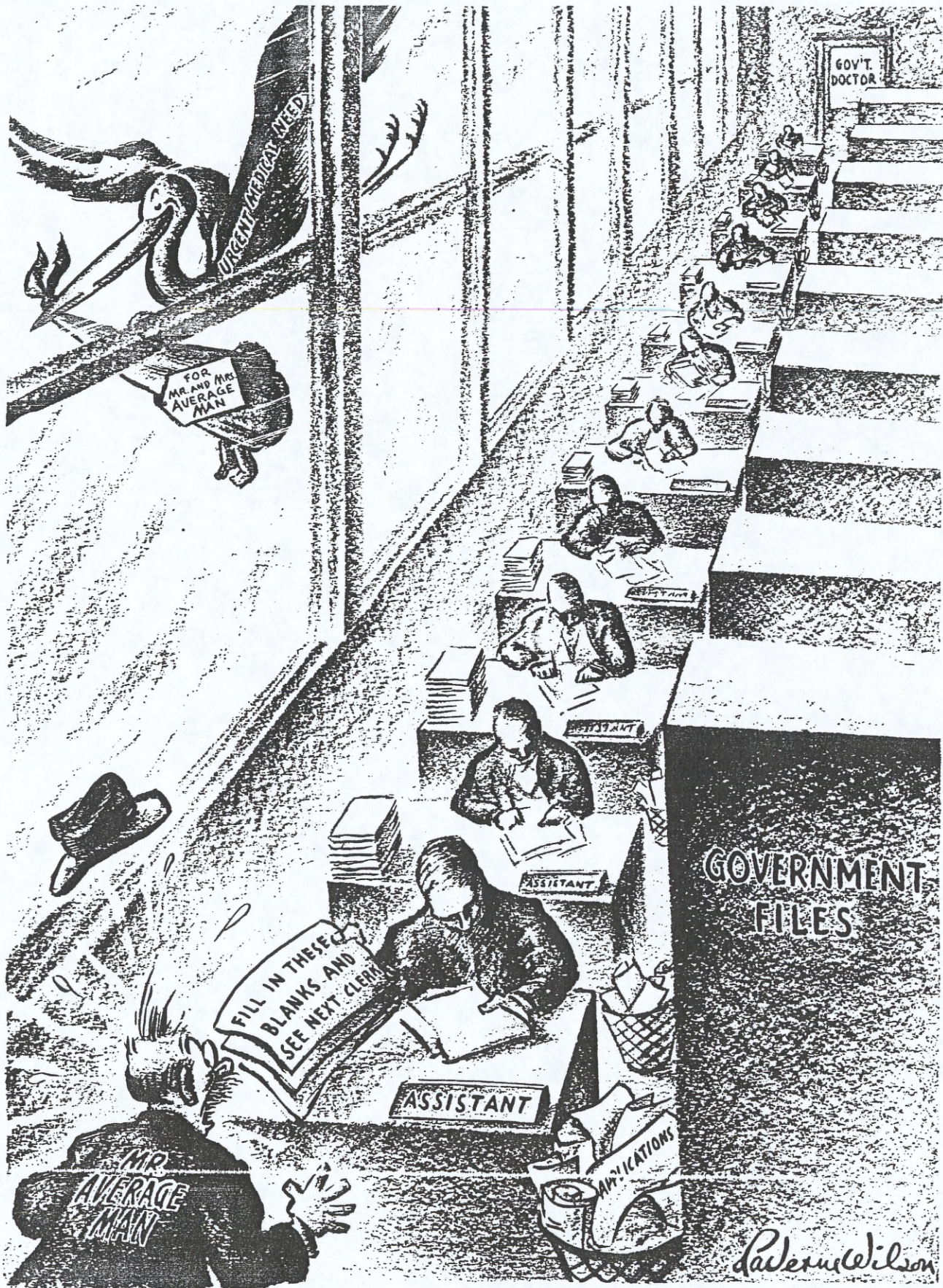


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*There can be but one master in the house of medicine, and that is the physician.
No social framework for "informed consent" or
"patients' rights" until the 1960's.*



Little man, what now?

Informed consent, perhaps?

G.A.M.A. (Nigeria) Sept 1958

Information on the ...

Making Ethics: The Struggle for Informed Consent - Clinical Practice I

Professional Codes

1847 - AMA Code of Medical Ethics - "avoid telling patients of impending death".

1903, 1912, 1957, 1980 - Revisions of AMA Code.

1981 - First mention of informed consent in AMA Code:

"The patient's right of self-decision can be effectively exercised only if the patient possesses enough information to enable an intelligent choice. The patient should make his own determination on treatment. Informed consent is a basic social policy for which exceptions are permitted (1) where the patient is unconscious or otherwise incapable of consenting and harm from failure to treat is imminent; or (2) when risk-disclosure poses such serious psychological threat of detriment to the patient as to be medically contraindicated. Social policy does not accept the paternalistic view that the physician may remain silent because divulgence might prompt the patient to forego needed therapy. Rational, informed patients should not be expected to act uniformly, even under similar circumstances, in agreeing to or refusing treatment."

1. The first part of the document is a letter from the President of the United States to the Congress, dated September 17, 1787. It is a very important document, as it is the first time that the President has addressed the Congress. The letter is a very long and detailed one, and it covers a wide range of topics. It discusses the need for a new government, the weaknesses of the Articles of Confederation, and the proposed Constitution. It also discusses the role of the President and the Congress, and the importance of the new government. The letter is a very important document, as it is the first time that the President has addressed the Congress. It is a very long and detailed one, and it covers a wide range of topics. It discusses the need for a new government, the weaknesses of the Articles of Confederation, and the proposed Constitution. It also discusses the role of the President and the Congress, and the importance of the new government.