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### Bulletin of the Park Ridge Center, 1990, V5 N2, May

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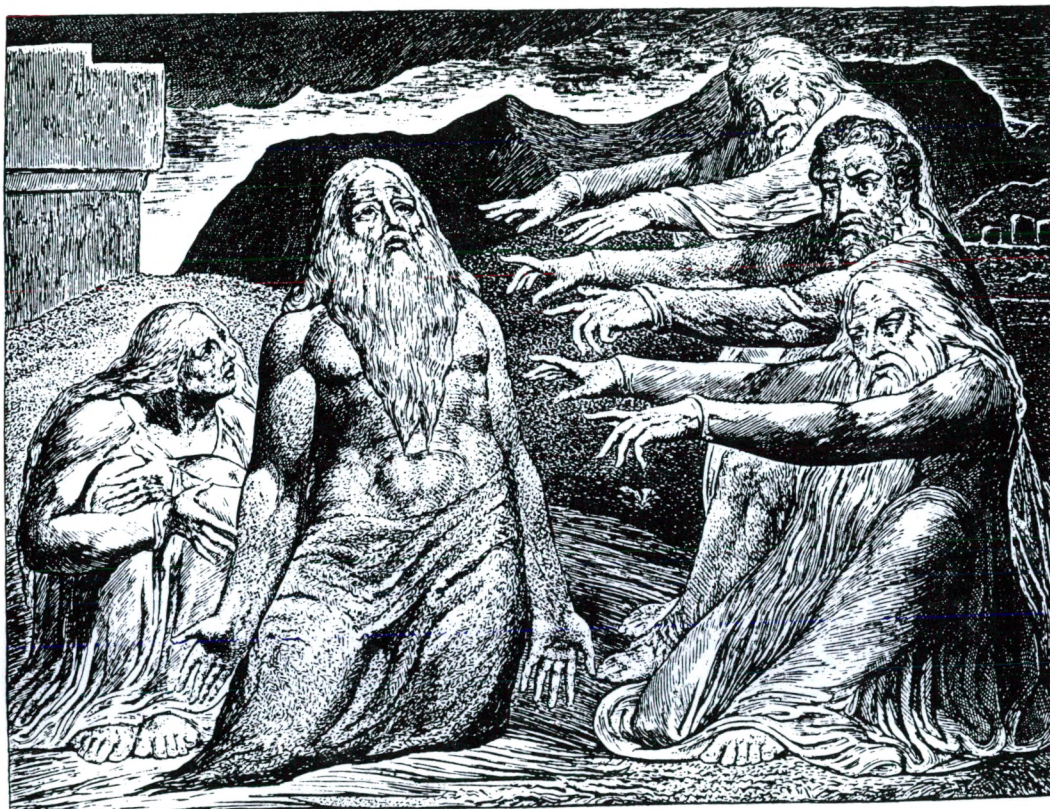
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# BULLETIN

## OF THE PARK RIDGE CENTER

Volume 5, Number 2

May 1990



The Just Upright Man is laughed to scorn

Man that is born of a Woman is of few days & full of trouble  
he cometh up like a flower & is cut down he fleeth also as a shadow  
& continueth not. And dost thou open thine eyes upon such a one  
& bringest me into judgment with thee

A Blake woodcut: Sculp



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# BULLETIN

OF THE PARK RIDGE CENTER

May 1990

Volume 5, Number 2

The *Bulletin of the Park Ridge Center* is published in January, May, and September and sent to all Center Associates. Its purpose is to present accessible, useful information in fields related to health, faith, and ethics and to provide subscribers with a forum for interaction with each other. We welcome contributions in the form of letters to the editor, research suggestions, and manuscripts for review and possible publication in the *Bulletin* or in the Center journal, *Second Opinion*.

Additional copies and back issues of the *Bulletin* (if available) may be purchased for \$3.00 each, \$2.00 for Center Associates. The executive editor of the *Bulletin* is Laurence J. O'Connell, the editor is Ron Hamel, the managing editor is Sandy Pittman, and the copy editor is Barbara Hofmaier. Other contributors include Martin Marty, Micah Marty, Marion Miller, Annalisa Pizzarello, Donna Ray, Jonathan Sande, Mary Solberg, and James Wind. All material copyright 1990 by the Park Ridge Center.

Opinions expressed or implied in the *Bulletin* are not necessarily those of the Park Ridge Center or any organization with which it is affiliated. The *Bulletin* and *Second Opinion* are both published every four months (three times per year); subscribers receive a publication every other month. Here is the publication schedule for the next two years:

May 1990—*Bulletin*, vol. 5, no. 2  
July 1990—*Second Opinion*, vol. 14  
September 1990—*Bulletin*, vol. 5, no. 3  
November 1990—*Second Opinion*, vol. 15  
January 1991—*Bulletin*, vol. 6, no. 1  
March 1991—*Second Opinion*, vol. 16  
May 1991—*Bulletin*, vol. 6, no. 2  
July 1991—*Second Opinion*, vol. 17  
September 1991—*Bulletin*, vol. 6, no. 3  
November 1991—*Second Opinion*, vol. 18  
January 1992—*Bulletin*, vol. 7, no. 1  
March 1992—*Second Opinion*, vol. 19

For an annual subscription rate of \$35 (\$65 for two years, \$95 for three), members receive the *Bulletin* and *Second Opinion*. In addition, subscribers receive discounts on selected Center books and periodicals; advance notice of forthcoming events and publications; and a greater opportunity to contribute to the Center's conversation on health, faith, and ethics.

All inquiries, including editorial correspondence, research suggestions, manuscripts, subscription orders, and requests for information should be sent to the Park Ridge Center, 676 N. St. Clair, Suite 450, Chicago, Illinois 60611. The phone number is 312/266-2222.

**Cover illustration:** William Blake, "The Just Upright Man Is Laughed to Scorn." Courtesy of the Department of Printing and Graphic Arts, The Houghton Library, Harvard University. (See Feature, p. 16.)



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# NEWS DIGEST

## Right-to-die case argued before U.S. Supreme Court

In the Supreme Court's first oral argument over whether there is a constitutional right to die, the lawyer for a Missouri family that wants to let its comatose daughter die said that the 14th Amendment guarantee of "liberty" and "due process" "protects individuals, conscious or unconscious," from invasive medical treatment.

The invasive treatment in dispute is a feeding tube that was surgically inserted into the stomach of Nancy Cruzan a month after she suffered severe brain damage in a car accident in January 1983. Doctors say she is permanently unconscious in a condition called a "persistent vegetative state," without cognitive brain function. No one who has been in that condition for more than 22 months has ever emerged from it. Doctors estimate Ms. Cruzan (now 32) may live for another 30 years if the tube feeding continues.

Her parents, Joyce and Joe Cruzan, are seeking to have overturned the Missouri Supreme Court's refusal to permit the removal of the tube through which Ms. Cruzan has received food and water for seven years. Ms. Cruzan's care, which costs \$130,000 a year, is being paid for by the State of Missouri and the Social Security system.

The Supreme Court will issue a decision before it recesses in June or July.

(*New York Times*, 11/27/89; 12/7/89; *Wall Street Journal*, 12/7/89; *Time*, 12/11/89)

## Fetal tissue implant reportedly helps patient with Parkinson's

An implant of fetal cells into the brain of a man with Parkinson's disease has alleviated his symptoms, according to a report published in

*Science* magazine. The team of researchers, led by Dr. Olle Lindvall of University Hospital in Lund, Sweden, reported data from 11 months before the implant surgery and up to five months after it. Scientists said the report was the first well-documented evidence that fetal tissue implants could be used to treat a disease.

At least half a million Americans suffer from Parkinson's, a progressive disease involving steady deterioration of motor movement. The disease leads to increasing muscular rigidity, tremor, and difficulty in initiating movements.

The researchers in Sweden and Britain report that fetal brain cells implanted into the brain of a 49-year-old man with severe Parkinson's disease not only grew and flourished but also significantly alleviated the man's symptoms, including rigidity and a tendency to freeze in place at unpredictable times. The operation involved taking brain cells from four fetuses that were 8 to 9 weeks old and dissolving the cells in a fluid that resembles body fluids. That solution was passed through a narrow tube directly into the patient's brain to replace brain cells dying as a result of Parkinson's disease. The new cells secrete dopamine, the chemical Parkinson's disease patients lack.

(*New York Times*, 2/2/90)

## Plan offered to stabilize the world birth rate

The world population can be stabilized in the 21st century—if birth control is made universally available by the year 2000. According to a report issued by the Population Crisis Committee, such an effort will cost about \$10.5 billion a year.

The world's population is currently estimated by the United Nations to be 5.3 billion

Distance, in miles,  
average hospital nurse  
in New York City walks  
annually while on duty:

1,272

Source: *Harper's*





Infant mortality rate  
(first 12 months) per  
1,000 live births:

Japan: 5

U.S.: 10

U.S.S.R.: 25

(Among blacks in the  
U.S. the rate is 18 per  
1,000.) In a survey of 11  
industrialized countries,  
Japan had the lowest  
rate, the U.S. ranked  
10th, and the Soviet  
Union was 11th.

Source: U.S. Census  
Bureau



people. The Population Crisis Committee, a nonprofit research group based in Washington, D.C., estimates that the population will increase to 14 billion if birth control is not used much more widely than it is now. Dr. Sharon L. Camp, vice-president of the committee, said that a doubling or tripling of the world's population over the next century "is a preventable disaster."

Population experts have said it would be difficult to sustain the world economy and political order with twice as many people, and impossible to sustain it with three times the current world population. Even wars and disease that would result from the population growth would not slow the rise, according to Dr. Malcolm Potts, president of Family Health International, a nonprofit organization based in North Carolina. "We may kill as many as died in Hiroshima every day, day in and day out over the century, and you would not slow population growth," said Dr. Potts.

The Population Crisis Committee report, "1990 Report on Progress Towards Population Stabilization," sets a goal of making birth control available worldwide by the year 2000 and achieving a worldwide rate of contraceptive use of 75 percent. Recent experience suggests that this goal can be reached. For example, contraceptive use in Zimbabwe has risen from 5 percent in 1976 to 43 percent in 1987. In Mexico, contraceptive use rose from 13 percent in 1973 to 53 percent in 1987; in Indonesia, from 19 percent in 1976 to 48 percent in 1987.

Developing countries spend \$2.5 billion of the \$3.2 billion being spent annually on family planning worldwide. In addition to Zimbabwe, Mexico, and Indonesia, mentioned above, Malaysia, North Korea, Peru, the Philippines, Vietnam, and Botswana are making rapid progress in the use of birth control methods. The Population Crisis Committee report also cited surveys in Asia and Latin America that showed that 75 percent of the women in those regions want modern contraceptives, though they are not always available.

(*New York Times*, 2/26/90)

## Many occupations blacklisted by health insurers

Seeking to avoid losses, many insurance carriers have quietly blacklisted dozens of types of small businesses and professions. A wide range

of occupations, from bartender and gas station attendant to oil driller and dentist, have been declared ineligible for health insurance.

More than 40 industries are listed as "ineligible" by several large insurers. A list under the letterhead of the Phoenix Mutual Life Insurance Company, based in Hartford, Connecticut, includes service businesses like laundries, service stations, hotels, motels, and restaurants; hazardous or seasonal industries like oil drilling and ski resorts; and health care providers. The Hartford Group, a subsidiary of ITT, lists as ineligible for medical, disability, and life insurance the following industries: barber shops, bars, beauty salons, car washes, entertainment groups, fishing enterprises, logging or mining operations, government-financed nonprofit organizations, drilling and exploration operations for oil and natural gas, cab driving, and used car sales. Chiropractors, dentists, education groups, and municipal employees were listed as ineligible for dental coverage.

Insurers say there are a number of reasons for the exclusions. Employees of some businesses that sell alcohol, like restaurants and bars, have higher than average rates of alcoholism, resulting in expensive health problems, which cost insurance companies more to cover. Businesses like lumberyards, munitions plants, and sanitation companies can be unprofitable for insurers because of frequent accidents or illnesses.

Motels, hotels, convenience stores, and hair salons—businesses that tend to have a high turnover and many part-time employees—are ruled ineligible because insurers believe their employees may be in poor health to start with. "Some industries that have high turnover and low pay may be perceived as occupations that attract an employee whose truthfulness and veracity may be difficult to verify," according to Henry Raymond, a director of insurance, managed care, and provider relations with the Health Insurance Association of America, an insurer trade group in Washington, D.C. "It is very difficult to verify what hospital a transient individual went to, or to get a documented health history."

According to Joan Herman, a senior vice-president at Phoenix Mutual, another reason for exclusion is a high incidence of claims by people in the health care professions—doctors, nurses, dentists, chiropractors, and other medical



workers. "Because they are highly aware of health care needs, health providers tend to have a high rate of utilization," said Herman.

Other groups are excluded, according to insurers, because of high administrative expenses. Insurers avoid clients like local governments, which require annual open bidding, and small nonprofit organizations which may lose their financing. Such clients are unprofitable because they may switch or drop their insurance coverage before the insurer can recoup its administrative losses.

Insurance exclusions are felt most acutely by groups of fewer than 50 employees, whose combined premiums frequently do not meet the costs of a single expensive illness. The growing number of exclusions has exacerbated the problem of how to protect 31 million uninsured Americans, more than half of whom are working people and their families.

(*New York Times*, 2/5/90)

### Medical costs rise at almost twice the rate of overall consumer prices

Medical costs rose at nearly twice the rate of overall consumer prices in 1989, capping a ten-year trend in higher medical inflation. According to the Consumer Price Index (CPI), the federal government's inflation barometer, medical care prices increased by 8.5 percent in 1989, compared with a 4.6 percent overall increase in prices. Physician services, one component of the CPI's medical costs measurement, rose by 7.2 percent in 1989.

Unlike other goods and services, demand for medical care is typically not curtailed by cost considerations. "When one is sick and needs medical attention, price is not the first thing that comes to mind," said Daniel Ginsburg, an economist with the U.S. Labor Department's Bureau of Labor Statistics, which generates the CPI. "If you have two operations four years apart, you don't have much choice about whether to do it if the price has gone up. We don't shop around for doctors and hospitals the way we do for new cars."

At the same time, economists say, the flood of health care information aimed at consumers has raised patient demand for costly procedures and treatments. "U.S. society has come to expect the best and want it now," said James

Moser, an economist and director of the Center for Health Policy Research of the American Medical Association. Many consumers can afford the luxury of focusing more on quality than on price because most don't bear the full cost of medical care themselves. "The costs of providing care are often not out-of-pocket payments," according to Moser. "That puts consumers at a distance from cost concerns." Progress in medicine almost always means higher prices, he asserted.

Hospital room costs registered the largest increase in 1989 at 11.1 percent, compared with 9.5 percent for prescription drugs, 8.1 for medical care commodities, and 7.2 for physician services.

(*American Medical News*, 2/9/90)

### AIDS cases reported up 9 percent in 1989

The Centers for Disease Control in Atlanta, Georgia, announced in February 1990 that the number of new AIDS cases in the United States rose 9 percent during 1989, the smallest increase since the CDC began reporting AIDS cases in 1981. But the number of new cases grew faster among heterosexuals, newborns, women, and Southerners, according to the CDC.

What follows is an overview of the most recent CDC statistics on AIDS in the United States:

- 35,238 new AIDS cases were reported in 1989.
- Of these new cases, 56 percent occurred among homosexual and bisexual males, up only 8 percent over the previous year's level. By contrast, the number of new cases attributed to heterosexual contacts rose 27 percent, to 1,562, or 4 percent of the total.
- 547 cases of AIDS transmission from mothers to newborns were reported, up 17 percent from 1988.
- Women accounted for 3,931 of the new cases reported; this is an increase of 11 percent over the previous year.
- The South accounted for the largest proportion of the AIDS cases reported in 1989: 31 percent. The Northeast accounted for 30 percent; the West, for 24 percent; and the Midwest, for 10 percent.

Nationally, the CDC reported a cumulative total

Studies have shown that people often "wait" to die until after a holiday that's important to them. A recent study of 1,300 Chinese women in California found that death rates were 35% lower than usual in the week preceding the annual Harvest Moon festival and 35% higher in the week after the holiday's conclusion.

An earlier study found similar fluctuations in the death rate among Jews around the Passover holiday, and researchers say there is preliminary evidence of "either a dip or peak in death rates around the observance of an individual's birthday or other meaningful occasion."

Scientists aren't sure why "death takes a holiday," but speculate that it could be more attentive care from family or "some as yet unknown psychobiological processes."

Source: *JAMA*





One in 12 hospital beds in New York City is occupied by an AIDS patient, at a total cost of \$1 million a day.

Source: *U.S. News and World Report*



of 117,781 cases since AIDS reporting began in 1981. Sixty percent have occurred in homosexual or bisexual men, 21 percent among intravenous drug abusers, and 7 percent among patients in both categories. AIDS has killed 70,313 people, or 60 percent of all those reported infected in the United States.

(*New York Times*, 2/11/90)

## U.S. halves dosage for AIDS drug

After concluding that a lower dose of AZT—a dose just half of the previously recommended dose—was as effective and caused fewer dangerous side effects than the higher dose, the federal government officially approved the lower dose, reducing the recommended daily dose from 1,200 milligrams a day to 600 milligrams.

Dr. Louis Sullivan, Secretary of Health and Human Services, issued a statement about the Food and Drug Administration's decision on AZT, saying that the "announcement means that fewer patients may have to discontinue AZT therapy because of side effects." As many as half of all AIDS patients cannot tolerate the higher dose because the drug suppresses their bone marrow, the source of red and white blood cells. They often suffer severe anemia and must have frequent blood transfusions to continue taking the drug.

The AIDS Coalition to Unleash Power, or Act Up, an advocacy group for people with AIDS, called the action on AZT "a victory." Act Up has urged the Food and Drug Administration, the National Institutes of Health, and Burroughs Wellcome to recommend lower doses of the drug. Burroughs Wellcome submitted data on the lower dose to the FDA in mid-December 1989, two days after receiving a memo from Act Up.

(*New York Times*, 1/17/90)

## Many hospitals found to ignore patients' rights in AIDS testing

Recommendations made by the federal Centers for Disease Control and the American Hospital Association regarding testing hospital patients for AIDS are not being followed by many hospitals, according to a national survey of 560

randomly selected nongovernment hospitals. Many of these hospitals fail to get patients' consent before performing AIDS tests, do not counsel them adequately about the results, and lack proper safeguards to insure confidentiality.

The survey, the first large study on hospitals' AIDS policies in the U.S., was sponsored by the Robert Wood Johnson Foundation and the University of California at Los Angeles. Dr. Howard Freeman, a UCLA sociologist and one of the report's authors, expressed his concern about the study's results. They show, he said, that many hospitals are not following guidelines provided several years ago by the federal government and the AHA that called for explaining the test to patients and getting their consent for it, counseling them before the test and again after it if the result is positive, and making every effort to keep the results confidential.

Among the results reported:

- Forty percent of the hospitals never or only sometimes counsel patients before testing.
- Informed consent is not obtained from patients in many hospitals, and testing is conducted without the knowledge of patients in some hospitals.
- In 25 percent of hospitals, those whose tests are negative are never told.
- Two-thirds of the hospitals indicate AIDS infection on the patients' charts despite the federal government's guidelines on confidentiality.
- Twenty percent of the hospitals reported at least one instance of a staff member's refusal to treat patients infected with the AIDS virus.
- About 25 percent of the hospitals immediately transfer patients to another hospital if they are found to be infected.

(*New York Times*, 2/17/90)

## Romania's AIDS crisis affects babies most of all

According to statistics gathered by Romanian virologists and confirmed by French doctors, Romania is threatened with an unusual pediatric epidemic of AIDS, concentrated in crowded orphanages and clinics and spread by an old-fashioned practice of giving blood transfusions to newborns. Doctors in Romania have said that of 2,000 children tested so far, 250 have AIDS



and another 200 have tested positive for the HIV virus. Until the overthrow of Nicolai Ceausescu in December 1989, there was no official acknowledgment of any AIDS cases in Romania.

The World Health Organization sent an emergency team to Bucharest, the capital of Romania, in February to verify the earlier findings: 700 children infected with the AIDS virus. According to the head of the WHO program on AIDS, Dr. Jonathan Mann, the number of Romanian children infected is among the world's higher per capita AIDS tolls.

An old practice of injecting blood transfusions into the umbilical cord to stimulate the growth of small infants is one reason for the rapid spread of AIDS among babies. Since the practice requires only a small dose of blood, one pint of AIDS-contaminated blood could be used many times. Also, many less developed countries do not have disposable syringes, and sterilization may be slipshod. The practice of injecting blood from adults into infants and small children was last used in the United States in the 1930s, when parents' blood was injected into children to immunize them against measles. The practice not only did not work but actually caused severe health problems and was stopped by the 1940s.

Blood is now being screened, educational efforts have begun, and emergency medical and testing equipment have been sent to Romania in an effort to stop what WHO officials have called "a preventable tragedy."

(*New York Times*, 2/8/90; *U.S. News & World Report*, 2/19/90)

### East German health crisis worsens as health personnel head for West Germany

East Germany's public health service, once the nation's pride, is in crisis because of a shortage of doctors, nurses, technicians, and other, even unskilled, health workers. The personnel deficit that has existed for several years has drastically worsened because of the exodus of East Germans to the West during the last half year. New regulations allowing free travel between East and West have accelerated the departure of medical employees. As many as 1,000 doctors have already emigrated to West Germany, and more are expected to follow.

"It's purely a question of economics," said Dr. Rudolf Weiner, the medical director and chief administrator at St. Georg, the largest teaching hospital in Leipzig, East Germany. "Ethical questions have, unfortunately, a lesser place in today's society. The doctors in West Germany are among the best paid in the world." Dr. Weiner said that a surgeon in West Germany earns an average of at least \$4,400 a month, compared with about \$75 a month in East Germany.

The shortage of personnel in some areas of East Germany has placed an unusually heavy burden on doctors and mid-level health care workers. Edgar Haring, East Germany's Deputy Health Minister, said that provision of primary care services is most urgent. Routine examinations must be canceled for the time being, Haring said. Other provisions: All doctors must provide medical care; nurses from the ambulatory service will serve in stationary clinics; nonmedical students will forego civil defense training and instead help out in health centers. Third-year medical students are already supporting work in clinics.

Money is not the only reason people are leaving. In East Germany, a factory manager enjoys both much higher social status and higher pay than a doctor. "It's not the high-status profession here, like it is in the West," said a laboratory director at St. Georg's Hospital.

Patients said they were aware of the problems and generally satisfied with the care they were receiving. But the long waits in corridors and anterooms have frayed nerves and in the new atmosphere of political openness, patients were very critical of the system that had created the current crisis.

(*New York Times*, 11/15/89)

### Angioplasty proving lucrative for manufacturers and practitioners

In 1989, analysts estimate, more than 300,000 Americans underwent balloon angioplasty for relief of angina and restoration of blood flow in one or more clogged arteries. Five years before, only 46,000 such procedures were performed. Balloon angioplasty has become as popular as bypass surgery during the last five years.

In balloon angioplasty, as the nonsurgical procedure to relieve angina is called, a thin, balloon-tipped catheter attached to a guidewire

Chances of having a baby with Down's syndrome when the mother is

35 years old:

1 in 365

40 years old:

1 in 100

45 years old:

1 in 32

Source: ABC News





The murder rate among male youths in the U.S. is four times higher than in any other comparably industrialized country.

Source: U.S. Census Bureau

is threaded through the arterial maze to a target blockage originally formed by a buildup of plaque. By manipulating the tip of the catheter outside the patient's body, the cardiologist positions the balloon and inflates it, pressing the plaque up against the wall of the artery.

Margins for improvement in the technological variables of the catheter—the materials of which it is made, the shape and size of its tip, its "torqueability," among others—have made this growing market a fiercely competitive and lucrative one as well. Manufacturers of medical technology are fighting for shares of a market that in 1989 was worth \$510 million.

Some cardiologists, notwithstanding the burgeoning popularity of angioplasty as a procedure and as a market, are becoming concerned by the high recurrence of blockages in blood vessels cleared by the catheters, sometimes just six months after treatment. Dr. Robert Ginsburg of the Stanford Medical Center said he has seen doctors use the catheters as many as nine times on the same vessel.

"That provides an annuity for the physician," he said, "but as a cardiologist, it makes me think twice about what I'm doing with balloon angioplasty." Nevertheless, he argued that the procedure, which is performed by cardiologists in a hospital setting, is far less risky than open heart surgery, which angioplasty may delay or obviate the need for.

(*New York Times*, 1/28/90)

## Changes in life-style can reverse artery blockage, study finds

A vegetarian diet, moderate exercise, and an hour a day of yoga and meditation could produce a reversal of atherosclerosis, a blockage of the arteries that can lead to a heart attack, in men and women who were strict in following the daily regimen. A small but pioneering study reported at the American Heart Association meeting in New Orleans in November 1989 found that strict changes in diet and life-style could not only prevent heart attacks but actually reverse clogging of the arteries without the use of drugs or surgery.

Researchers led by Dr. Dean Ornish, director of the Preventive Medicine Research Institute in Sausalito, California, said that the findings offer patients a low-risk alternative to drugs, surgery,

and angioplasty. "It's not that everyone should make these life-style changes—that's a personal decision—but people need to know they have the option to make informed choices about caring for heart disease."

The 48 men and women in Dr. Ornish's study were chosen from a pool of patients who had complained of chest pains or who had taken treadmill tests that indicated some problems. All were scheduled for angiography, in which a dye is injected into the blood and X rays are taken to reveal the amount of blockage in the vessels. The angiograms, analyzed with the help of a computer, indicated that all patients had arteries at least 40 percent blocked; some were nearly 100 percent blocked.

All patients continued to see their regular physicians. Most were given medication to lower blood pressure or dilate arteries, but none received cholesterol-lowering medication. Half of the patients were assigned to a control group for comparison. They simply followed the standard medical recommendations, including restricting dietary fat to 30 percent of calories, quitting smoking, and getting a half-hour of aerobic exercise three times a week.

The other half were put on a stricter regimen. They ate a vegetarian diet that allowed nonfat dairy products and egg whites, but no other animal products, and they held their dietary fat intake to 8 percent of total calories. Specially prepared meals were provided for those who had trouble cooking the required meals.

Those in the treatment group also spent an hour a day practicing stress management techniques, including yoga stretches and breathing, meditation, and deep relaxation. In addition, they spent an hour three times a week exercising; most went for walks. The participants went for two four-hour sessions each week, where they ate and exercised together and practiced the stress management techniques. They also held group discussions.

After a year in the program, 41 of the 48 people completed the study. Eighteen of the 22 in the treatment group showed improvement in their atherosclerosis; 3 stayed about the same and one who did not follow the regimen got worse. By contrast, 10 of the 19 who received the usual medical care got worse, while 3 stayed the same and 6 showed some improvement.

(*New York Times*, 11/14/89)





## HHS secretary says cigarette makers trade death for profits

For the first time, the Department of Health and Human Services has calculated the economic costs of smoking. Cigarette smoking costs the nation \$52 billion in health expenses or time lost from work each year. In announcing the figures at a hearing before the Senate Labor and Human Resources Committee in February, Secretary Louis W. Sullivan attacked cigarette makers as immoral and irresponsible. "Cigarettes are the only legal product that when used as intended cause death," he said. The companies, he added, were "trading death for corporate profits."

Brennan Dawson, an official of the Tobacco Institute, a trade association for the tobacco industry, took issue with the federal estimates. First, she said, "there are no data to back up claims that smokers overutilize the health-care system." In addition, "people's productivity and life-style are personal matters, and do not result in a cost to society. Smokers pay their own way."

Other commentators disagreed. Dr. John Banzhaf, head of Action on Smoking and Health, a nonprofit antismoking group, estimates that the government underestimated the health risks. The true figure should be closer to \$100 billion, according to Banzhaf. Government figures did not take into account diseases of nonsmokers that could be attributed to the effects of "passive smoking." These include thousands of deaths from cancer and of infants whose mothers smoke, he said.

Senator Edward M. Kennedy of Massachusetts, the chairperson of the Senate committee that heard Secretary Sullivan's report, said that 1,000 Americans die each day from diseases caused by smoking and that the tobacco industry spent \$6.9 million a day in advertising to replenish the supply of smokers who quit or were killed by cigarettes.

(*New York Times*, 2/21/90)

## Are women being left out of federally funded health research?

Three members of Congress are calling for an investigation to determine whether federally supported medical researchers exclude women from clinical tests. "For a variety of reasons, most medical research in this country studies

white males," said Representative Olympia J. Snowe, Republican of Maine, "and we are concerned that the treatments developed might not work for or might actually be harmful to women." Rep. Snowe co-chairs the Congressional Caucus for Women's Issues with Representative Patricia Schroeder, Democrat of Colorado.

Snowe, Schroeder, and Representative Henry Waxman, Democrat of California, have asked the General Accounting Office to determine how many women are being included in research underwritten by the National Institutes of Health.

A 1985 Public Health Service study said that the lack of data on women limited understanding of women's health care needs. In 1987, the NIH said it would begin to encourage the use of women in clinical studies by requiring a grant applicant to explain why it was excluding women from such research.

The lawmakers told the GAO they want to know whether the institutes' new policy was being reflected in clinical studies underwritten by NIH grants.

(*New York Times*, 12/16/89)

## U.S. is decades behind Europe in contraceptives, study shows

The National Academy of Sciences has issued a study showing that American contraceptive research has come to a virtual halt, and that the U.S. has fallen decades behind Europe in developing new techniques. Carl Djerassi, a Stanford University chemist who helped develop the first contraceptive pill, commented, "The U.S. is the only country other than Iran in which the birth-control clock has been set backward."

Methods available overseas but not in the U.S. include an injection that provides two months of protection and a skin implant that can release a contraceptive hormone into the bloodstream for up to five years. European pharmaceutical companies are pursuing research on male birth control pills, reversible vasectomies, and long-lasting vaccines. Even women in many Third World countries have more choices than their U.S. counterparts.

The NAS report said 1.2 million to 3 million accidental pregnancies occur in the United States each year as a result of contraceptive

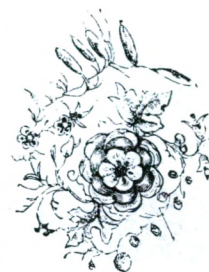
Number of adolescent girls who had babies (U.S.):

In 1960: 600,000

In 1989: 470,000

(Although the number of unwed teenaged parents has increased significantly, the overall birthrate among teens has decreased.)

Source: *Chronicle of Higher Education*





Percentage of American physicians who say that they would "definitely" or "probably" not go to medical school if they were in college now, knowing what they know about medicine:

39

Source: *New York Times*

failures, including failure of the drug or device and use that is too difficult to maintain. The report said that half of all the 1.5 million abortions in the United States result from such failures.

Research in this country has declined, according to the report, because of lawsuits against the makers of birth control devices and drugs for damages caused by their products, political fights over abortion, federal drug approval policies that focus only on the risks of new contraceptives, and a lack of government financing to stimulate such research. Until the 1980s, 17 major companies were carrying on contraceptive development; that number has now dropped to one. No fundamentally new contraceptives have been developed in the last three decades, the report said, and the outlook for new development in this country is not good.

Representative Henry Waxman, Democrat of California and head of the House Energy and Commerce Subcommittee on Health and the Environment, said, "Unfortunately, the debate over the need for improved contraceptive research has been caught up in the debate over abortion. What the anti-abortion forces fail to see is that the way to reduce abortions in this country is to reduce the number of unwanted pregnancies."

(*New York Times*, 2/15/90; *Time*, 2/26/90)

## Abortion notes

### ABA panel supports right to abortion

In February 1990, the House of Delegates of the American Bar Association voted 238 to 106 to approve a resolution opposing government interference with a woman's decision to have an abortion.

It was the first time the bar association had taken a stand on abortion itself. The vote means that the resolution is now official policy of the ABA. The decision could lead the bar association to join with abortion rights advocates in arguments over future abortion cases before the United States Supreme Court.

The resolution was passed by the House of Delegates, the ABA's only legislative body authorized to make policy and issue statements or

to take positions on behalf of the association. The policy statement said that the ABA "recognizes the fundamental rights of privacy and equality guaranteed by the United States Constitution and opposes legislation or other governmental action that interferes with the confidential relationship between a pregnant woman and a physician or with the decision to terminate the pregnancy."

(*New York Times*, 2/14/90)

### Fewer doctors willing to perform abortions

A 1985 poll by the American College of Obstetricians and Gynecologists of 4,000 of its 29,000 members found that 84 percent thought abortion should be legal and available, but only a third of those doctors actually performed them, and two-thirds of those who did abortions did very few. About 4 percent of those polled performed 26 or more abortions per month.

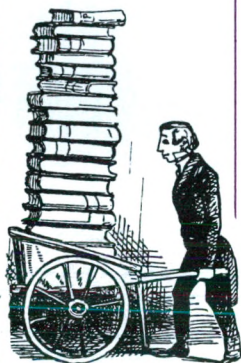
With few incentives to perform abortions, and under siege from protesters, most obstetricians and gynecologists avoid doing abortions, according to medical experts and doctors' surveys. Those who do support abortion rights say the shortage of willing doctors makes it harder for women, who sometimes have to travel hundreds of miles to find a doctor who will perform an abortion.

Dr. Louise Tyrer, vice-president for medical affairs at Planned Parenthood Federation of America, said, "It is getting more difficult to identify doctors" who will perform abortions. "The older doctors like myself," she continued, "who used to see women by the hundreds in hospitals suffering complications of illegal abortions and even dying were highly motivated to change that." But, she said, these doctors are now reaching retirement age, and the younger doctors "have not seen any of that—they're not aware of the horrors."

(*New York Times*, 1/8/90)

### Self-help abortion movement gains momentum

Concerned that abortion rights may be curtailed by the courts or legislatures, scores of self-help groups around the country are teaching women how to perform abortions on them-





selves and each other. Hundreds of women have already given each other abortions or menstrual extractions in a revival of a technique that flourished in the late 1960s when abortions were illegal.

Legal experts say that the states generally allow only doctors to perform abortions, but few prosecutions have been reported for abortions performed by people other than doctors. Carol Downer, director of the Federation of Feminist Health Centers, which operates women's health clinics throughout the country, said that she knew of only two women in the last 18 years who were charged with illegally doing the procedure; in both cases the charges were dropped. Part of the legal ambiguity arises from the difficulty of distinguishing menstrual extraction from suction abortion, the procedure generally used by self-help abortion groups.

Suction abortion involves inserting a flexible tube into the uterus and aspirating the uterine lining. There is no scraping of the uterus, which could cause perforations, and the suction is gentler than that used in abortion clinics because the women are in no rush. While this method can take up to an hour, in abortion clinics it takes five to ten minutes.

People in the self-help abortion movement are also investigating herbs and over-the-counter medications that can induce abortions. They are also publicizing simpler but riskier methods that do not require devices or drugs and that have been used in Chile and elsewhere by women who were raped and imprisoned.

The women in the movement say they were chilled by the Supreme Court decision in June 1989 that expanded the states' right to restrict abortion. "It's really important for women to feel that even if the lid comes down, there are things we can do," said Downer.

(*New York Times*, 10/23/89)

### More federal curbs urged in use of fetal tissue for research

Encouraged by the continued ban on federal financing for transplants of fetal tissue from elective abortions, abortion opponents say they will push to bar all federally financed research using fetal tissue. They say they are uneasy about how some groups obtain and distribute the tissue.

Ordinarily, fetal tissue is discarded after an abortion. Abortion critics say that many abortion clinics do not tell women that their fetal tissue will be used in research. Moreover, there is fear that some doctors, eager to get good fetal tissue samples, have put women at additional risk of complications by altering abortion methods and extending the time it takes to perform an abortion. Since no statistics are kept on the abortions from which fetal tissue is obtained, it is impossible to determine whether this is true or not.

There are no good figures on the number of fetuses used in research, but there are indications that it is substantial. Fetal tissue is widely used because it grows quickly and easily in the laboratory and because fetal cells in some ways resemble cancer cells, enabling scientists to look into what controls cell growth. Fetal tissue can also be used in direct experiments on the causes of birth defects.

Although fetal tissue transplants have not yet cured patients, researchers are optimistic that the transplants might soon cure diabetes and Parkinson's disease and that they might eventually cure other diseases, including Alzheimer's. If the transplant work succeeded, millions of Americans could be candidates for fetal tissue transplants.

The largest supplier of fetal tissue is a non-profit company, the Institute for the Advancement of Medicine, in Effington, Pennsylvania. James W. Bardsley, president of the institute, provides scientists with 300 to 600 specimens a month from 150 to 300 fetuses. About a year ago, Bardsley began insisting that the clinics and hospitals that supplied him with fetal tissue, first ask the women if they wanted to donate the fetal tissue. About half the suppliers refused and no longer provide him with tissue.

A private doctor, Dr. James J. Parks of Denver, who supplies fetal tissue to researchers at the University of Colorado, said that women are glad to donate and that more than 90 percent of his patients give informed consent. "They say, 'Thank God, some good is going to come out of this,'" Dr. Parks said.

(*New York Times*, 11/19/89)

Percentage of journalists who say they would permit their child to have contact with a schoolmate with AIDS:

64

Percentage of scientists who say this:

39

Source: *Harper's*





Adapted from an article appearing in the October 1989 issue of *KOS* and translated by Annalisa Pizzarello

# GLOBAL REPORT

## Bioethics in Italy

Paolo Cattorini

Number of physicians  
per 100,000 population  
(U.S.):

In 1960:

142

In 1987:

237

Source: *New York Times*,  
AMA

In Italy, as in most other countries, interest in the study of ethics has recently been renewed. The development of advanced technical and scientific capabilities in the realm of health care has required that we reflect on the meaning of their application and uses in light of human values. Rational, coherent argumentation and an interdisciplinary approach are necessary in defending a particular position on the appropriate use of a technology; this defense is necessary regardless of one's ideological position. Such an approach can be used to determine a common ethical convergence and a set of norms that could be applied in Western pluralistic societies.

Several cultural currents have influenced Italian bioethics: the bioethics movement in North America, the revival of German practical philosophy, and the Anglo-Saxon tradition of analytic philosophy. The backdrop has been the long and glorious theological-ethical tradition of Catholicism (with its attention to casuistry and its recent lively theoretical debate) together with increased attention to the norms of medicine from within the profession itself. Clearly, the issues are not simple but multifaceted.

Consider, for example, the products of American bioethics. Here we are faced with a multiplicity of ethical theories: neo-Kantianism, contractualism, pragmatism, utilitarianism in its many versions, and the recent modulations of Christian ethical theory. The most striking feature of bioethics in the U.S. is

precisely this wealth of perspectives, encompassing not only philosophies but also religious ideologies. The development of sophisticated conceptual methods has been necessary to facilitate debate between factions and to make eventual agreement possible. This diversity is typical of a young nation whose inhabitants come from a variety of faiths and traditions. They view each other with curiosity; taking very little for granted, they question each other deeply. The principles of American bioethics (autonomy, beneficence, and so on) are extremely useful and easily exported. Any European venturing into bioethics today without fully understanding developments on the other side of the Atlantic would arrive at a sterile synthesis. Another enviable quality of American bioethics is its irony, its lighthearted character, its participants' critical distance from found formulas, their sense of humility about their work, and their realization of the limits of reasoning in the face of human complexity.

In the German tradition, we find the panorama of Husserlian and post-Husserlian phenomenology, hermeneutics, post-Frankfurt schools, and sociological influences with highly theoretical components. Italy is thus faced with the task of critically examining and synthesizing these theoretical positions from both sides of the Atlantic into defensible norms applicable to specific Italian situations.

Several centers for the study, research, and teaching of bioethics now exist in Italy: the School of Medicine and Human Sciences of the Scientific Institute of the Hospital of San Raffaele in Milan, the Center for Bioethics of the Catholic University of the Sacred Heart in Rome, the Department of Human Sciences of the Do-Good Brothers' Hospital in Rome, the Lanza Foundation in Padua, Politeia in Milan,

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the Center for Bioethics in Geneva, and the Anthropology Institute in Florence. The fruits of their labors are displayed in various periodicals and specialized journals. Although we have few formal courses in bioethics, we are seeing a growing number of requests for the teaching of ethics in medical schools. Among the schools offering these courses are the Catholic University of the Sacred Heart in Rome, the University of Florence, the University of Naples, and the University of Siena.

Consulting is gradually assuming a larger role. Italy does not have a national ethics committee as, for example, France does. Rather, ethicists gathered into ad hoc committees consider specific problems (planned parenthood, AIDS, genetics, and so on) as they arise in Italy. These committees are far less glamorous or systematic than a national organization would be, but they have the advantage of being more specific and agile. Some medical societies, like the one in neurology, have their own bioethics commission. Also, several institutes, hospitals, and medical enterprises have ethical committees charged with formulating, recommending, and examining the protocols of clinical and pharmacological research. While not yet perceived at the national legal level, the interest in bioethics evidenced by the above-mentioned centers led to the formation of the Italian Society for Bioethics and Ethical Committees in Milan in July 1989. Its purpose is to promote collaboration between centers and to bring together the results of work done in similar areas. In addition, a secular commission of consultants for bioethics was formed in the autumn of 1989.

What shape is the bioethics movement in Italy likely to assume in the next few years?

First, the Italian legal system, which is not based on case law, will give the bioethics movement in Italy a weak identity. More room will be allowed for theoretical reflection and professional development than for actual consultation. (Magistrates, in fact, currently find themselves having to apply preexisting norms—with all the related problems of interpretation—and they fear penalties for not observing already promulgated laws.) Nevertheless, much can be done by bioethicists in the coming years, mostly in the prelegislative phases of development, critical analysis, and recommendation.

Second, the bioethics movement will be faced with questions about credentials. Who should be called an expert in bioethics, and what rapport must a bioethicist have with existing structures like professional organizations and forensic and juridical experts? We have already witnessed many self-coronations: sociologists who have discovered ethics, meeting organizers beginning to consult, retired clinicians discovering that they had always been philosophers, and so on. In the future, ethicists will have to combine a strict scientific competence with a corresponding philosophical competence, especially because of the theoretical, prelegal nature of the judgments they will have to formulate. Bioethics today witnesses to the philosophical demand which has always accompanied biology and medicine but which in technical times has gone silently underground.

Third, a strictly theoretical analysis is likely to prevail, as opposed to bioethical work that applies theory to a concrete issue, ascertains the problems and relevant facts, recognizes the conflicting ideological positions, and attempts a prelegal mediation. Many issues still await specific attention. This does not mean that we cannot look for new avenues away from an ethic of duty and principle and toward an ethic of virtue or an ethic of natural law and human experience. The more interesting avenues will begin from daily encounters with the patient rather than from rare clinical cases; narration, symbol, and metaphor will not be crowded out by academic, theoretical, juridical language.

Finally, the previous bifurcation of bioethical initiatives into those with Catholic leanings and those with non-Catholic (secular) leanings will begin to erode. Undoubtedly, Catholic clerical theologians can claim leadership of the first phase of the bioethics movement. Today, however, laypeople are also making contributions, and although they realize that their points of view are irreconcilable in certain circumstances, Catholics and non-Catholics are seeking a common engagement and a more profound debate. This debate will lead to the improvement of normative texts, like that on abortion, which many now consider inapplicable.

Percentage of American physicians who are not members of the AMA:

53

Source: *New York Times*





# READERS' LETTERS & COMMENTS

Percentage of people who disagree with the statement "most doctors spend enough time with their patients":

61

Source: *New York Times*

*We want to encourage our readers' contributions to the dialogue on health, faith, and ethics. Please send your letters and comments to the attention of Ron Hamel, editor of the Bulletin.*

## To the Editor:

Congratulations and thank you for the provocative Roundtable feature, "Gender Experience and Fetal Life," in your January 1990 issue. The six participants represent well the plurality of views concerning the weight that should be accorded "women's perspectives" in discerning public policy vis-à-vis abortion. Despite Richard McCormick's efforts at civil discourse in the initial *Second Opinion* article "Abortion: The Unexplored Middle Ground," Bonnie Miller-McLemore's sometimes caustic reflections on that piece and McCormick's impassioned rejoinder seem to verge at times on parody. Each has valid points to make, but both couch their wisdom too often in biting, off-putting verbal assaults. The other four participants offer more insight with less "heat." All in all, it was a stimulating 13-page exposé.

If I may, I'd like to add two brief points to the unresolved and ongoing discussion. First, contrary to Miller-McLemore's stereotyping, Catholic priests (while admittedly male and subject to the formative effects of testosterone, culture, and church structures) are not automatons, monolithic in their every thought and feeling. Ask Charles Curran whether he and Joseph Ratzinger are kindred spirits. Or Matthew Fox, Huns Küng, and Pope John Paul II. Likewise, as Jeanine Czech and Lynn Joyce Hunter aptly

caution, one ought to be careful espousing the women's position, as if all women, from Mary Daly to Phyllis Schlafly, are of like experience and mind in all things. There are surely sexist women, feminist men, and a potpourri of variations between. Disenfranchising anyone for not holding "the party line" bespeaks gnostic arrogance (as Hunter suggests), forestalls any progress toward consensus, and even poorly serves Miller-McLemore's hoped-for rich, conflictual, and heated dialogue.

Second, with due respect accorded to the dignity, rights with corresponding duties, and reproductive freedom that ought to be the heritage of all women, it continually amazes me that so many feminist discussions commence at the point of "being pregnant." It would seem that a woman's rightful responsibility and freedom vis-à-vis reproduction (as well as that of her male mate) begins with decisions about sexual activity itself. Thus when a couple finds that the girl or woman is pregnant several weeks or months later, each is faced not with unbridled freedom but with latent responsibilities for one's prior free acts of sexual intercourse. Rape and incest, from the woman's perspective, are poignant exceptions. As Czech concludes, society (female and male together) must encourage young women "to control their reproductive lives in a proactive manner, by refusing to be sexually active when inappropriate or by using contraceptives consistently and responsibly." Their male partners need similar admonitions.

Let's continue the dialogue, even if heated, and participate in the consensus building. And let's insist on the responsible exercise of rightful freedom . . . *from the outset.*

*Richard C. Sparks, Ph.D.*





**To the Editor:**

The *Bulletin's* discussion of gender experience and fetal life (January 1990) raised many critical points for ethical decision making. I believe that life should be defined in terms of interrelationality, so the problems of new reproductive technologies, fetal life, and birth, particularly, radically sharpen questions regarding appropriate procedure. I also agree with Miller-McLemore that gender formation and experiences significantly affect one's stance in decision making. So stated, everyone sees a situation in her or his own discrete way. Any ethical decision involving more than one person (and every ethical decision, by definition, involves more than one) must satisfy both (all) parties if it is to be functional and enhance all relationships. That is why *every* ethical decision must be made case by case or be determined by "rules" based on a *significant number* of similar instances.

Cases involving fetal life sharply focus for us interrelational decision making because the formations of women and men are intimately involved. Any decision based on the formation and experience of a woman may be unsatisfactory for men. Any decision based on the formation and experience of a man may be unsatisfactory for women. So Miller-McLemore appropriately chides McCormick for advocating decision making based on the male experience. But McCormick also rightly chides Miller-McLemore for supposing the female experience suffices even for decisions primarily involving fetal issues. Given the nature of interrelationality both formations must be considered.

Miller-McLemore argues that, as a "rule," in the early period of their life men are oriented toward production, while women in that period are oriented toward creativity. Issues involving conception, fertilization, abortion, use of fetal tissue, genetic engineering, and the viability of certain newborn life must therefore be resolved interrelationally, yet the formation of males and females, almost by definition, will have created differing sets of ethical values.

Little wonder then that current principles of ethics and law hardly suffice for issues concerning new reproductive techniques. For example, how could Judge W. Dale Young of Maryville, Tennessee, make a useful decision about the

Davises' frozen "pre-embryos"? Mary Davis felt her potential future as a mother was at stake. Junior Lewis Davis felt his moral and legal responsibility as a father was at stake. Young deflected the interrelational problems and decided the case on an ancient principle—the sanctity of life.

Although I share Judge Young's consternation, I do think we need to move into different modes of decision making. When interrelationality is so clearly involved, the final decision ought to include the community (or communities) that has formed the persons involved (which, admittedly, may be only the mother, the fetus, and the family of the mother). In regard to "heroic measures," some courts are now hearing the opinion of the formation community. I believe that soliciting input from such communities should be the next juridical step in handling the complex issues related to fetal life.

*Graydon F. Snyder*

Dean and Professor of New Testament  
Chicago Theological Seminary

Percentage of people  
who consider  
themselves more active  
than others their age:

83

Source: *Hippocrates*





# FEATURE

## Symposium on *Dax's Case: Essays in Medical Ethics and Human Meaning*

(Edited by Lonnie D. Kliever. Dallas: Southern Methodist University Press, 1989.)

The volume contains these essays:

Preface by *Lonnie D. Kliever*

*Keith Burton*, "A Chronicle: Dax's Case As It Happened"

*Robert B. White*, "A Memoir: Dax's Case Twelve Years Later"

*James F. Childress and Courtney C. Campbell*, "Who Is a Doctor to Decide Whether a Person Lives or Dies? Reflections on Dax's Case"

*Richard M. Zaner*, "Failed or Ongoing Dialogues? Dax's Case"

*Joanne Lynn*, "Dax's Case: Management Issues in Medicine"

*H. Tristram Engelhardt, Jr.*, "Freedom vs. Best Interest: A Conflict at the Roots of Health Care"

*Patricia A. King*, "Dax's Case: Implications for the Legal Profession"

*William J. Winslade*, "Taken to the Limits: Pain, Identity, and Self-Transformation"

*William F. May*, "Dealing with Catastrophe"

*Sally Gadow*, "Remembered in the Body: Pain and Moral Uncertainty"

*Stanley Johannesen*, "On Why We Should Not Agree with Dax"

*Lonnie D. Kliever*, "Dax and Job: The Refusal of Redemptive Suffering"

"Don't you see," he said,  
"I am a dead man.  
I can't live."

### Introduction

It was July 23, 1973. What began as an ordinary mid-summer day for Don Cowart ended with his life hanging in the balance and the future he had hoped for cruelly snatched from him. He was twenty-five years old, handsome, athletic, vigorous, recently divorced from his wife of eight months, now in a new and promising relationship, and had been discharged from active duty in the Air Force just three months earlier. Don had been working with his father in real estate since returning to his small Texas hometown.

The accident occurred late in the afternoon. After looking at some property being put up for sale, Don and his father had difficulties getting their car started. On the last try, a flame from the carburetor set off an explosion and fire. A nearby propane gas transmission line had been leaking.

Don escaped from the burning car, spared from the flames of the initial blast. But as he ran to find help for his father, he found himself engulfed in flames. He rolled on the ground to extinguish the flames, picked himself up and continued, but soon collapsed along the roadside as help arrived. "Oh, my God!" was the reaction of the farmer who came upon him. Don asked his rescuer for a gun. He wanted to kill himself. "Don't you see," he said, "I am a dead man. I can't live." His request was not met, and he did live. His father did not.

Life was not without a price. Cowart was transported 140 miles to a burn unit at Parkland Hospital in Dallas, where he spent the next 232 days. He had suffered severe burns over 65 percent of his body; his face suffered third-degree burns. In the ensuing months, in addition



to excruciating pain, Don endured the removal of dead tissue from his body, the application of salves to his raw flesh, the changing of dressings, daily whirlpool tankings to cleanse his wounds, skin grafts, amputation of fingers from both hands, and removal of his right eye. Because of severe damage, the left eye was sewn shut.

Through all of this, Don Cowart reiterated his wish to be allowed to die, but no one acquiesced. He had given his mother power of attorney in the Parkland emergency room, and neither she nor his lawyer friend would consent to the discontinuation of treatment. The doctors and medical team forged ahead.

On March 12, 1974, Don was discharged from Parkland and was transferred to the Texas Institute for Research and Rehabilitation in Houston. After three weeks there, he stopped eating and refused further treatment. His condition rapidly deteriorated; he was near death. On April 15, he was transferred to the burn unit at a hospital in Galveston where his infected wounds were immediately cared for. Don strongly objected to the daily tankings and refused permission for skin grafts. He attempted suicide but was unsuccessful.

A psychiatrist brought in to assess Don's mental competency found him to be very competent. Despite this, his repeated requests to several people to be allowed to die or to be assisted in taking his own life fell on deaf ears. Out of frustration, he gradually became more cooperative in his care and by July 15, 1974, had improved sufficiently to be transferred to the hospital's psychiatric unit. His protests continued, as did his demands to be allowed to die.

On September 19, 1974, after fourteen months of hospitalization, Don was allowed to go home. He was totally blind, his arms and hands were useless, his body was badly scarred, and some of his wounds had not yet healed. He was totally dependent on others for feeding, bathing, dressing, and personal functions. Sleeplessness filled his nights and boredom his days. His relationship with his mother was contentious.

In 1976, Don began pursuing a law degree part-time at Baylor University's School of Law but at great physical and emotional cost. The breakdown of a significant relationship in the spring of 1977 threw his life into chaos. For the second time since he had left the hospital, he

**Are there limits  
to what a  
human being  
must suffer?  
How ought  
we care for  
patients who  
request  
to die  
when their  
lives can be  
saved?**

attempted suicide. The following spring he resumed his studies at Baylor but dropped out again in the fall of 1979. In the spring of 1980, he embarked on a different graduate program at Texas A&M. He continued to be plagued by boredom and sleeplessness and again attempted suicide.

In April 1980 Don was readmitted to the Galveston hospital for psychotherapy under the care of the psychiatrist who had originally evaluated his competency. He was taken off the sleep medications he had been on for years; his sleep patterns and his spirits greatly improved. Two years later, Don Cowart changed his name to Dax. He began a mail order specialty foods business which subsequently failed, bought his own home, and in February 1983 married a former high school classmate. The marriage ultimately failed. Dax resumed and this time completed his graduate program in law. In the summer of 1986, he passed the bar exam. Today he runs a small law practice and continues to be a spokesperson for the right to be allowed to die.

Dax Cowart's story has received considerable attention over the years. It has been the subject of two films, several articles, and countless discussions in classrooms and other educational settings. This issue of the *Bulletin* features reflections upon Dax Cowart's story occasioned by a collection of reflective essays in response to the film *Dax's Case*. The collection includes contributions by distinguished ethicists, lawyers, humanists, physicians, psychiatrists, and theologians.

The Dax Cowart story is provocative and utterly disturbing. Through his experience, the observer/reader is brought face to face in the most graphic and painful way with some of the deepest questions of human meaning and the most complex questions in the delivery of health care: is there any meaning in such tragedies and in such intense human pain and suffering? Are there limits to what a human being must suffer? Does the struggle for continued survival ever become too overwhelming? Is suicide ever justifiable? What limits are there to autonomy, if any? Can beneficence ever take priority over autonomy? Is beneficence always to be identified with paternalism? What constitutes personal identity? What is human death? How ought we care for patients who request to die when their lives can be saved?

Many of these themes are taken up in this



fine collection of essays. It is not possible to discuss them all or to provide a synopsis of each essay. Some of the major themes, however, deserve attention.

Frequently, ethical dilemmas in health care are defined in terms of life and the quality of life. In a most perceptive essay, William F. May suggests that this may well be an oversimplification. Not everyone experiences life as a continuous straight line that sometimes thickens (high quality) and sometimes thins out (less good or poor quality) and eventually ends in biological death. Many who have experienced a severe trauma have died, though they are still alive. What they were prior to the trauma is annihilated; life as it was is terminated. Creation of a new identity and a new life are required. "Don Cowart becomes Dax Cowart. One may criticize such a person, but one cannot rightly patronize him. Should he choose to live, he is not choosing his old life. He must become another man. No parentalist can force him down that road. No mere medical technician ever does enough to assist him along that road. It requires an interior transformation . . . the reordering of one's identity from the ground up" (p. 149). The dichotomy between life and quality of life fails to capture this experience. Perhaps the language of life and death and rebirth comes closer.

Is there any meaning to such an undeserved tragedy and to such apparently pointless and excruciating pain and suffering? The ultimate questions that Dax faces and that his tragedy poses are religious questions. And virtually every religion offers some version of redemptive suffering. But Dax, as Lonnie Kliever notes, never interprets his predicament from a traditional religious point of view. In fact, he categorically refuses any suggestion of redemptive suffering. There is no indication that Dax "has embraced his suffering as an occasion for spiritual growth, heroic courage, exemplary achievement, or even stoic endurance" (p. 206). He continues to protest against his suffering and against those who both allowed it to continue and inflicted more upon him. Yet Dax is not without an interpretation that would allow him to affirm life without trivializing his tragedy. Job offers a mythic pattern for such an interpretation. One reading of Job, claims Kliever, would suggest that "the only answer to life's problems is found in the human capacity

**Is there any meaning to such excruciating pain and suffering? The ultimate questions that Dax's tragedy poses are religious questions.**

to live life over and over again, whatever the pain and whenever the peril" (p. 201). But "torn between a life he cannot achieve and a death he was denied, Dax seems fully committed to neither living nor dying" (p. 208).

Finally, there is the theme of respect for autonomy. Several authors (Childress and Campbell, Engelhardt) take up the cause and even depict Dax's story as a struggle between unjustified paternalism on the part of Dax's doctors, mother, and lawyer-friend and Dax's right to determine his own future. The principle of respect for persons requires that "autonomous patients should have the right to make their own choices to accept or refuse medical treatments, including lifesaving medical treatments, as long as their choices do not impose serious harms or burdens on others. To deny or override this right is disrespectful because it insults the autonomous patient by imposing on him or her someone else's conception of patient benefit and of the good life and death" (p. 25). Other authors, however, come at the autonomy/paternalism dichotomy from a different angle. Zaner argues that the language of rights polarizes the parties and breaks down the dialogue when what is needed is mutually enabling discourse. Winslade makes similar observations, drawing attention to the autonomy of Dax's mother and doctor and their interest in preserving the basis of Dax's autonomy for future choice.

In this issue of the *Bulletin* several people reflect on Dax's story or on one or another of the essays out of their own experience; one individual has herself suffered a tragedy similar to Dax's. We invite our readers to ponder these reflections and to join the conversation here in the pages of the *Bulletin*.

—Ron Hamel  
Editor, the *Bulletin*

(I am indebted to the essay by Keith Burton in Kliever's volume for the information contained in my abbreviated account of Dax's story.)



## Response: Charles Ceronsky

Lonnie Kliever notes in his essay that ordinary people ask very different questions than do medical, legal, and ethical professionals when faced with tragic suffering (p. 187). They ask "meaning" questions. My experience as a hospital oncology chaplain, hospice coordinator, and ethics case consultant during the past seventeen years has given me many memories. My memories are of other questions ordinary people ask when patients refuse heroic treatments and then are forced by third parties to endure that same morally optional "care." Ordinary people, those of us who fear we might someday be vulnerable to powerful third-party medical decision-makers, ask: "Who do they think they are? How can I protect myself from them?"

Unlike Stanley Johannesen (p. 176) I do not find allowing a desperately ill or injured individual the option of refusing extended, extremely painful treatments an "assent to the death of another as a good." The patient's death is not a perceived good simply because I am willing to honor a refusal of extremely heroic treatment in such a tragic situation. I can commit myself to support the patient in the long struggle for life, if he or she chooses heroic treatment, and be "glad [that person] is still with us" (p. 185). But in faith I can also support that same patient as the illness or injury takes its course, if he or she concludes that the burdens of treatment outweigh the benefits. Some argue that if treatment is attempted some will survive, as did Dax. Yet the right to refuse excessively burdensome treatment is not limited to the terminally ill. And from a Christian perspective, death is neither the greatest evil nor our ultimate end.

How can health professionals, committed to healing yet not wanting to abuse the power of position, be there for tragically ill patients and their loved ones? Joanne Lynn (pp. 67-71) describes appropriate care beautifully. I too have experienced good outcomes from time-limited agreements regarding treatments with well-informed patients or their surrogates. I have also observed and sometimes shared in the wonderful experience of relating in a caring, commit-

**We abuse family members when we put them in a position of decision making rather than the appropriate role of representing the patient's wishes as they know them.**

ted, and open manner to patients who wish to die rather than engaging in a power struggle, only to see them respond as Dax did to Dr. White's empathic care marked by respect (pp. 16, 18, 122-23, 166). They chose treatment once they received adequate symptom control, they were treated with respect, they and their family were both attended to, and they could be confident that the health professionals would not try to force them to agree to treatments they found too burdensome. Of course, the care I describe, which Dr. White attempted to provide and which Dr. Lynn espouses, is identical to hospice care. Richard Zaner erroneously identifies hospice care as available only to those who are "terminal, dying in spite of treatment" (p. 50). Once a patient refuses overly burdensome treatment without which they cannot live, they are terminal, dying without treatment, and thus eligible for hospice. Hospice provides both a philosophy of care and a system of care for the tragically ill or injured who choose to refuse excessively burdensome though potentially lifesaving treatment. And, happily, when appropriate care and support are offered, some will change their minds and choose a heroic attempt to live using the marvels of modern medicine. Others, finding treatment still too burdensome, will help us appreciate that death need not be feared overmuch nor does it need to be hastened by euthanasia.

We abuse family members time and again when we put them in a position of decision making rather than the appropriate role of representing the patient's wishes as they know them. This is still common practice, and though it usually doesn't precipitate the patient-family conflict of Dax's case, it still creates significant unnecessary pain in already heavily burdened individuals. We owe them a great deal more than that. Unfortunately most of us providing direct care are guilty at one time or another of trying to elicit decisions from the family so that we can avoid the more difficult experience of informing patients and respecting their wishes as stated at the time or previously.

I have found that ordinary people generally want protection from vitalists. They also struggle to make sense of life when pain, suffering, limits, aging, or mortality move beyond the news into their personal experience. At that point many believers find themselves stripped of the American measure of self-worth, inde-

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pendent productivity, with little to fill the void. How can the church proclaim more clearly that our call is to unveil the presence of God in the midst of human experience not just when we are young and healthy, but also when we are old, sick, limited, or dying?

## Response: Ruth Purtilo

Compelling ethical issues are raised by Dax's story, and *Dax's Case: Essays in Medical Ethics and Human Meaning* provides a rich resource to aid my thinking. I also draw, inevitably, from my own years of working as a physical therapist. (The only time I fainted at work, in fact, was while trying to debride a screaming, severely burned boy in a Hubbard tank.) I focus my comments on Dax's health care team: first, to address some problems raised as a result of the way the "team" is portrayed in the film *Dax's Case*, and second, to highlight the importance of team-related issues in the moral assessment of such cases.

I've used the film scores of times. And over the years I've become more acutely sensitive to one artificial element in the portrayal of Dax's situation, namely that with one exception he is alone, and the health professionals themselves appear "solo" on the screen. The faces of both Dax and his health care team appear on the screen only as a moving trainload of faces pressed against the window. The collaboration, when it is acknowledged at all, is conveyed as taking place in succession, along Dax's time line rather than around his Hubbard tank or wheelchair. Most of the essays, however, acknowledge the importance (and supposed presence) of teamwork. For example, Childress and Campbell cite a classic study of a multidisciplinary burn team at work, suggesting its approach as one way to help the reader assess how well Dax's team worked to maximize autonomy (p. 30). Lynn makes a case for "attending to all the patient's concerns, not just his patho-

**Kant most closely ties the idea of autonomy to respect, urging that we ought to regard individuals "as persons with the same rights to their judgments as we have to our own."**

logical derangements." She believes that professionals should give a competent patient like Dax the authority to stop lifesaving treatment after a trial, in the patient's estimation, has failed: "A care-giving team would be unfair not to follow through on its promise" (p. 69). King applauds the film's placement of Dax "at the hub of a *series of relationships*" (my emphasis), evoking images of the line-up I mentioned, but elsewhere she talks about his team as a "web of interactive relationships in which the conduct of one affects all" (p. 98). And Johannesen critiques the team's handling of Dax in proposing that "the social tragedy of Dax's life is not the system that treated him against his will, but one that supplied him with no other language than the language of 'rights'" (pp. 175, 176). Taken together, these commentaries on the team of health professionals highlight at least two themes: (1) the team itself is viewed as an agent in the course of Dax's treatment, and (2) there is disagreement or at least confusion about whether the team was a winning team and about what rules or criteria can legitimately be used to judge the team.

Several commentators note correctly that autonomy provides one obvious framework for discussing the moral implications of Dax's predicament. But Childress and Campbell reveal the underside of autonomy-governed analyses: "without [a] social context of care, acquiescence in the patient's wishes may be (rightly) perceived as indifference rather than respect" (p. 39). Since World War II, the health care team has been adopted as a necessary though perhaps not sufficient means of creating a social context of care by which respect for the patient and family can be fully expressed. Two explicit goals of a team approach are to provide *comprehensive* and *individualized* care. In the former the complementary roles of specialized competencies among modern professionals are acknowledged, and the latter is based on the assumption that many voices and ears are required for grasping the rich complexity of each individual's story (T. Brown, "An Historical View of Health Care Teams," in *Responsibility in Health Care*, ed. G. Agich [Boston: Reidel, 1982], pp. 603-778). With both goals in mind, the team can give a patient the respect humans deserve.

Kant's interpretation of autonomy most closely ties the idea of autonomy to respect, urging that we ought to regard individuals "as

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persons with the same rights to their judgments as we have to our own . . . not for a utilitarian or any other reason except that another is a person and therefore rightfully a rational determiner of his or her own destiny" (T. L. Beauchamp and J. E. Childress, *Principles of Biomedical Ethics* [Oxford: Oxford University Press, 1979], p. 59). No other group of health professionals takes this highly specialized and personalized approach to treatment more seriously than rehabilitation specialists. Rehabilitation is designed explicitly to foster each individual's highest possible level of functional independence and appropriate interdependence given the constraints imposed by illness or injury (R. Purtilo, "Ethical Issues in Teamwork: The Context of Rehabilitation," *Archives of Physical Medicine and Rehabilitation* 69 [1989]: 8–13). Rehabilitation teams (usually including physicians, physical therapists, nurses, occupational therapists, psychologists, vocational counselors, social workers, recreation therapists, speech and language pathologists, and dietitians) may be distinguished from other health care teams in part because they are directed toward broad psychological, social, and vocational outcomes as well as toward the more narrowly defined goals of medicine and nursing.

How do we know if the rehabilitation team members, who most certainly were performing the majority of interventions in Dax's rehabilitation, were acting in their appropriate capacity as creators of a supportive social context and ardent protectors of individualized (respectful) care? We don't. Winslade remarks on this black hole in the Dax story:

If any serious effort at either understanding Dax's feelings or counseling him was made, no evidence for this appears in the film. . . . [There was hardly created] a climate of reciprocity and mutual respect.

Winslade then recalls the short film clip in which nurse Leslie Kerr (the only nonphysician health professional interviewed), appearing solo, reflects on her worry about Dax's request to die. Winslade concludes, "and no one was willing—as far as I know—to assist his suicide while he was in the hospital" (p. 127, emphasis added). Without at least the benefit of the team's presence, an observer lacks critical data required to make moral or existential sense of

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Dax's situation. The brilliant commentaries by May and Gadow highlight how this oversight or neglect becomes moral complicity.

The film frequently brings the viewer back to the picture of Dax crying out to an ultimately unresponsive listener. One can hardly fault the succession of persons in the film who, each from his or her own private understanding of the request, agonizes over the appropriate response to Dax's own anguish.

May situates the quandary within the context of Dax's life quality and assumes that a call for assistance in dying can also be the call for that which is beyond death, namely rebirth. It follows that "the responsibility of the community has but begun if it has imposed continuance [of life] upon an individual." The appropriate social context is therefore one that moves the person into "rebirth":

Concretely the language of rebirth and reconstruction requires the community to invest much more heavily in rehabilitative and chronic care. It would also enlarge the relevant interventionists from purely medical staff to other healers, including nurses, social workers, physical therapists, occupational therapists, chaplains, and other patients who have survived similar ordeals. The technical interventions of the surgeon and physicians do not begin to touch the problems that the patient and the patient's family face. Technique supplies means to ends; but the patient faces a crisis in the ends themselves. . . ." (p. 149)

Reconstruction requires guiding a person into a new reality, not carrying the person across as a parent carries a child. The guidance must come from many avenues, May concludes. But how can health professionals skillfully provide such guidance?

Sally Gadow helps the reader to answer this question. She begins by forcing the reader to gape at the unthinkable in Dax's story. Here's what we have, she says. The health care professionals are inflicting excruciating pain over many months on a person whose body requires constant attention. It is, however, a body naked, even to the point of being without skin, of a person who is blind, without hands, and physically powerless to resist, flee, or even shield his body. No one can imagine wanting for one's own body the body one sees looking at Dax. His presence itself acts as a divider.



Why is it important to acknowledge the degree of otherness that such a body invokes?

The inflicting of pain for any purpose requires a certain dissociation from one's own body in order not to suffer with the person in pain. The relief that dissociation affords accounts for the experience in which it can be easier to intervene in someone's pain by increasing it (as in child battering) than simply to witness it and suffer in response. (p. 159)

The health professionals' dilemma of having to induce pain as a necessary part of appropriate treatment for patients such as Dax requires that they use every resource available to them. As Gadow further observes,

Making moral sense of Dax's pain by either interpretation, beneficence or torture, is a costly means of resolving ambiguity. Both frameworks succeed in dispelling confusion about the intention behind his pain, but at the price of distancing the two sides so extremely that ambiguity is clarified into antagonism and moral uncertainty becomes a fight to the death. . . . Having seen the extremity, then, to which moral understanding is driven in situations predicated on that gulf, we must return to it now and consider how it might be crossed. (p. 163)

The remainder of Gadow's article emphasizes the possibility for bridging the gulf through communication. Many commentators on Dax's story agree that the only hope for crossing this great divide is to risk communication with him.

But can a *team* ultimately aid in this task of communication? Elsewhere I have detailed some cautions concerning team dynamics and its effect on patient autonomy: the psychology of teams may lead its members to link arms *against* the patient rather than include the patient on the team. The length of the rehabilitation process itself creates a nexus of interdependencies in which desires stated by the patient are taken less seriously over time rather than more seriously. At the same time, the personal and professional perspectives brought by the members, along with the opportunity for checks and balances on each other's perceptions, are time-honored strengths of the team (Purtilo 1989: 8-12). In short, the team is *primarily* a communication-enhancing device. Therefore the team arrangement is critical to a

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positive outcome for Dax.

I conclude that we are missing one critical synthesizing element in Dax's story. Without the benefit of the rehabilitation team's discussion, the interactions that led to the final action (unacceptable to Dax) can be viewed simply as each person's column of opinions. The communication among them is the missing keystone. One can also conclude that without this fundamental piece moral questions concerning the appropriateness of his autonomy or their paternalism cannot be answered.

David Thomasma maintains that a concert of moral interests are attainable within a team, but that several steps are necessary ("Moral Education in Interdisciplinary Teams," *Surgical Technologist* 2:17):

1. The team must develop a common moral language for discussion.
2. Team members must have conative and practical training in how rationally to articulate their feelings about issues.
3. Values-clarification exercises are needed.
4. The team must have common experiences.
5. The team must develop a moral decision-making method.

I would add that at each step the patient's well-being must be the standard against which the success of each step is measured. Neglect to do so becomes complicity wrapped in silence. At least on that point I am certain that Dax and I are on the same team.



## Interview: Linda Webb

In March Editor Ron Hamel spoke with Linda Webb, who suffered severe burns in a fire 15 years ago.

**Bulletin:** Can you begin by telling about your own experience as a burn victim?

**LW:** I was in a fire, trying to save someone else, and I got caught in the fire myself. I don't think anyone knew that I was even in there.

I tried to get out, and I called for help, but soon I passed out from the smoke. When I came to, I didn't realize that I was burned.

**Bulletin:** How long were you in the hospital?

**LW:** Two weeks and a whole year. I was at Loyola and then at the Rehabilitation Center.

I remember being taken from one hospital to another. I was in severe pain, and they were trying to take pictures—I thought they were crazy. For the next few days or weeks I remember things only vaguely, probably because of all the medicine. I couldn't talk—I had inhaled a lot of smoke.

**Bulletin:** Can you describe your treatment?

**LW:** Well, I was so severely burned that the plastic surgeons did not think I would even make it. I had a tracheotomy for a while and then just whatever treatments could be done in my bed, like baths three times a day.

**Bulletin:** And then you had the Hubbard tank?

**LW:** Yes, and that was very scary. They would take me off my bed and put me on something like an ironing board to whirl me down. At the time I still had the trach, and they would have to keep the airway free. Then they would lift me up and put me into the Hubbard tank. It was very painful. I still didn't realize how badly I was burned. I remember what looked like eyebrow tweezers, which they would use to pick at my face. I would see them putting things down, and I'd wonder, "What is that?" I never saw my

*Linda Webb is a mother and grandmother living in Oak Park, Illinois.*

**"They wouldn't tell me how badly burned I was, and when I started wanting to see myself, they wouldn't let me."**

face, but it was my nose and my ears that were coming off—I had no idea. But all of it was painful.

**Bulletin:** Did they ever talk to you about your condition, tell you how badly burned you were?

**LW:** No, and I really couldn't ask questions because of the tracheotomy. I would get very upset. I was helpless. There was nothing I could do for myself. Then when I started wanting to see myself, they wouldn't let me.

**Bulletin:** When did you find out how badly burned you were?

**LW:** Not for quite a while. I knew I was burned, but I guess I didn't really. I guess the Lord kept it from me. There was no way to see myself, but probably I began to realize that all those things they were putting down were part of my face.

**Bulletin:** What was going through your mind? What were you feeling?

**LW:** It was very terrifying. I was helpless; I didn't have my family; I couldn't get up or run in and out when I wanted to. My feet didn't even hit the floor for what seemed like four months. I wondered if I would ever get out of there.

**Bulletin:** Did you think about that often?

**LW:** Yes, but I just kept fighting it. I said I've got to get out of here; I know I'm going to get out of here. I've got to so I can be with my son. I don't know—I might not have fought so hard if I hadn't had my son. I didn't know who would take care of him.

**Bulletin:** What did you think about Dax's case, and what did you think about the book of essays?

**LW:** I was very angry at him. First of all, refusing treatment only makes situations worse. The pain he talked about would have been just as bad or even worse without treatment. He got infections, and so did I. That's why I lost my fingers, even though I didn't refuse treatment. I think I also got angry with him because he had his family, and he treated them pretty bad. His mother was loving and cared about him. And



besides, I truly don't think that he really wanted to die.

**Bulletin:** *What do you think he wanted?*

**LW:** Well, he went through the anger stages. I can't say I didn't do that. You know for months I couldn't eat. After one bite I felt like I had eaten a whole coffee cake. One time I ate a couple of bites and that's all I wanted. The girl said, "Well, you're not going back to bed until you finish." I don't usually get very angry, but I just pushed the tray off the bed onto the floor. So I think you go through angry situations.

**Bulletin:** *Was he just an angry person lashing out at people in every situation, or was something else going on when he said he wanted to die?*

**LW:** Well maybe at the time he thought he did, but I believe that if he had wanted to die he would have. If I had truly wanted to die, there's no way that you or a nurse—or anybody—could have kept me alive.

**Bulletin:** *Do you think anyone has a right to ask to be allowed to die?*

**LW:** No.

**Bulletin:** *Why not?*

**LW:** Because people could decide one minute that life's not worth living and then take their own life, or try to. And that would be very wrong.

**Bulletin:** *Do you think Dax was well treated by the doctors? Were they listening to him? Or do you think they were just ignoring him, going about their own business?*

**LW:** They were probably listening to him. But the doctors are there to save life, not to help people destroy life.

**Bulletin:** *He said several times during his recovery that his quality of life would not be good. He didn't want to live as a blind and handicapped person.*

**LW:** Well, I could say that about myself. I'm not blind, but my vision was affected. And every day there is trouble. But I can do almost every-

"It was very hard for my friends to accept me after the accident. I had no friends—well, maybe one."

thing, and if I can't, I'll figure out some way. But it's a struggle. I also have a lot of respiratory problems, which he doesn't mention having. And I know that without those I could do a lot more than I do now. I know he has to be struggling too, but—

**Bulletin:** *Even though it's a struggle, it's worth it.*

**LW:** I think it's worth it. I mean the Lord kept me alive for some reason. Obviously I have a lot more work to do.

**Bulletin:** *Dax does not seem able to give his experience or his life any meaning. Do you ever ask yourself about the meaning of this suffering in your life? How did you ever make sense of the whole thing?*

**LW:** Well, I didn't. I wished I hadn't experienced it, but there's nothing I can do except keep trying.

I mean, I lost a lot. I was very young. I could be married today and have more children, which I would have loved. I can't really work and do things that I would like to do. But I did grow closer to the Lord, figuring it must have been something for him to keep me alive.

**Bulletin:** *That's pretty positive . . . In one essay the author talks about a sense in which the old person dies, and a new person emerges out of an experience like Dax's. Did you have any of that?*

**LW:** Well, all I can say is that it was very hard for my friends to accept me after the accident. I had no friends—well, maybe one. It seemed like they just couldn't accept it. And I've had problems even with the family.

This is a picture of me. They see me now and think I'm not the same person. Once when my son was about fourteen—you know those teenage years, when they just rebel—we were having a discussion, and I was trying to lay down some rules. He said to me, "You're not my mother." He did it a couple of times, and I finally said, "Well who do you think I am?" He said, "My mother left." That's how he was thinking about it at that time. Or maybe that's what he wished—that his mother was just going to walk back in the door.

**Bulletin:** *How old was your son when the accident happened?*



**LW:** He was eight. He'll be 23 in May.

**Bulletin:** *Did that force you to rethink who you are? Your son's reaction as well as your friends' and family's reactions? And even your own experience? All those losses?*

**LW:** Well, you think about a lot of things. If I'd show people pictures, I would say, "Well, that was me." But really, that *is* me.

**Bulletin:** *If Dax were in the room right now, what would you say to him?*

**LW:** I don't know. I'd probably be nice to him. Who knows? Maybe he'd have something useful for me, and I'd have something useful for him. I did get very angry reading the book. But each person's different.

**Bulletin:** *Dax just didn't want to put up with what you were willing to put up with?*

**LW:** Well, I don't know if he's had a lot of surgeries, but I've been in and out of the hospital for about fourteen years since the accident. I've had a lot of plastic surgery. I had a good plastic surgeon and got back most of my nose. And most of one ear was gone. . . . They don't want to put me to sleep because of my lungs. So during most of the surgery I had done on my face and neck and hands, I was awake. And that's very stressful.

**Bulletin:** *And painful.*

**LW:** Yes, it was painful. But I had a good doctor. He'd keep me calm and talk to me. That was important. I did see some doctors who weren't very nice. But when the doctors have empathy for the patients, I think the patients respond better.

**Bulletin:** *There was clearly great tension between Dax and the doctors. Do you think anything might have been done differently?*

**LW:** It's hard to say unless you were there. You don't know if they tried really talking to him.

I can tell you one experience when I was in rehab. They put me in the whirlpool. First I refused to go in, because it was like the upper

**"They'd expect me to button myself, and I'd get very angry. Angry because I wanted to do it and was fighting to do it but just didn't have the strength to do it."**

tank, which had burned so much. But on the third day they made me go in. They opened up all my wounds, and then they just put a gown on me. Of course they had to get a doctor because of all the infection. So the plastic surgeon came over, and he had to do things that weren't very nice. But I could see that he was really trying to help me, and then we became friends. Maybe Dax was just remembering all the pain and not really giving them a chance. That's what I could have done to this doctor. But he was really trying to help me.

**RH:** *Did it bother you when they forced you to do this?*

**LW:** Well, it was always very scary when they put me in the whirlpool. Yes, I was angry that they forced me to go in. My wounds were starting to heal, but the water just opens all the wounds again. I'd be screaming in the night when they changed my dressings and probably woke half the patients up. But all in all it turned out fine.

**Bulletin:** *What was the process of your rehabilitation like?*

**LW:** At the Rehabilitation Center, because I'd lost my fingers, I had to relearn to do things like dress myself. It was like going to school again—getting up early and going to class.

**Bulletin:** *How did that feel?*

**LW:** It made me angry. I got so tired, because of my lung problems. Plus I was right-handed and had to try to do things left-handed, without full use of my left hand. One of the worst things was trying to button. And of course they'd expect me to button myself, and I would get angry. Angry because I wanted to do it and was fighting to do it but just didn't have the hands and the strength to do it.

**Bulletin:** *One of the questions raised in the Dax case is whether Dax understood enough about his situation to be able to make a life and death decision about himself. What do you think? Were you capable mentally and emotionally of making a good decision about your future during the early part of your treatment?*



**LW:** No, I don't think so. There wasn't anything wrong with my mind. It's just at the time you can't make a decision like that. If I'd been able to make a decision, do you think I would have let them come in there, knowing they were pulling off my nose? No! I'm sure I wouldn't have.

**Bulletin:** *So you would say that it's probably better for the doctors, at least early on, to make those decisions?*

**LW:** Yes, definitely.

**Bulletin:** *What pulled you through? You mentioned your son earlier.*

**LW:** Well, yes, my son. I had some neat experiences too. One lady came to my hospital room. She said that she had wakened in the middle of the night in her bedroom and been told to come see me. Now this woman didn't know me from anybody. So I believe her story was true. She read the Bible a little bit and prayed for me and said I'd be off that machine [the ventilator]. I had been on it for quite a while and didn't think I'd ever be off it.

**Bulletin:** *Are there any lessons to be learned from experiences like yours and Dax Cowart's?*

**LW:** Well, everybody should take life seriously. It's something to be cherished. A lot of people look at life as being miserable. I mean, I could be angry and bitter, and sometimes I feel like I may be, but what good would it do? I've got to make the best of what I still have.

**Bulletin:** *What was the worst thing about your experience? What do you think might have been the worst for Dax?*

**LW:** Well, the pain was bad, but maybe for him it was blindness. I don't know.

The accident affected my eyes a lot. I have to wear pretty powerful glasses. I just have to thank the Lord I can see at all. I don't know if Dax experienced this, but I couldn't close my eyes for a long time. I had things—cysts, I think—scraped off my eyes, which was very painful. I was awake while they put something that felt like barbed wire in to hold my eyes open so they could scrape them.

**"I had to wear a jug mask, and people would say things. Once I went out for ice cream and a guy said, 'Oh, do you want to go to a Halloween party?' That was hard."**

**Bulletin:** *So is pain the worst thing in your experience? Or are there other things?*

**LW:** Pain was hard. But there were other things, too. I had to wear a jug mask for quite a while, and people would say things. My son would get very angry because people made remarks. Once when I was in the nursing home and was wearing the jug mask, another woman decided to go out for ice cream. I hesitated, but then I decided to go along. I figured I wasn't going to live my life just sitting in an apartment looking at the walls. While we were out, a guy got out of his car and said, "Oh, do you want to go to a Halloween party?" That was hard.

**Bulletin:** *So, getting used to living your life—*

**LW:** Well, right. That guy was probably handsome, and I used to be beautiful. And then all at once, in one day—all that's gone. You just have to adjust.

**Bulletin:** *How do you do that?*

**LW:** Well, for a long time I wouldn't look at myself. I'm probably still here just because the Lord keeps me in peace, and because of new friends.

**Bulletin:** *Do you think the doctors and nurses and nursing assistants had any idea what you were going through?*

**LW:** Well, I'm sure they must have. I often wondered how they could do it. But I guess each person has different talents. I don't know how some of them did do it. Just taking a bandage off my grandson is too much for me if he starts to scream a little bit. So you can imagine it had to be very stressful for them.

**Bulletin:** *Did you think they were sensitive to what you were experiencing and feeling? Were they taking you seriously?*

**LW:** Well, some of them did, and some didn't. I recall one doctor who was doing something with the bandage. I was crying and screaming, and he made some remark about it not being that painful. Some doctors are there because they care about the patients and want to help.



Same with the nurses. But some get into it because of the money. One person who worked with the nurses at the Rehabilitation Center was very mean to her patients. She did not have any kind words, and she didn't handle the patients gently. Once I told her she didn't have to be so rough, and she said, "I wouldn't be here if I could make better money or had a better job." But a lot of nurses did care and were more calm.

**Bulletin:** *What's it like—just being totally helpless, not being able to speak or move?*

**LW:** It was terrifying. I wanted somebody to stay in the room with me all the time, but of course they didn't. I just liked having somebody there with me.

**Bulletin:** *Did it make sense to you that Dax said he just wanted to die?*

**LW:** Well, maybe Dax saw himself. If I had seen myself in the mirror, I might have said the same thing. But I didn't see myself.

**Bulletin:** *You must have had a pretty strong hope that someday this would all be behind you and things would be OK, more or less.*

**LW:** Well, for a while I thought, "If I live that's OK, and if I don't that's OK." Then after that lady visited me and I had a couple of other experiences, I started to think that God had kept me here for a reason. I got to saying, "Well, I'm going to fight this, going to make the best of it."

**Bulletin:** *So your religious faith may have played some role in your fighting to keep going?*

**LW:** I know it did. But now Dax—he's still saying he'd rather have died. I just feel bad that he still feels that way.

**"I've learned  
that life is  
something to be  
cherished.  
I mean, I could  
be angry and  
bitter, but what  
good would it  
do?  
I've got to make  
the best of what  
I still have."**

## Response: Angela Schneider O'Connell

... behavior can communicate various levels of meaning. . . . Often the important message may be disguised and difficult to discern and quite different from the apparent meaning. . . . So the surface message, 'I want to die,' might not be the whole story. (White, p. 17)

My reflections on the case of Dax Cowart will focus on the inherent meaning of medical treatment. Medical treatment entails an active and a passive dimension: a therapist inflicts often painful treatment on the patient, while the patient suffers the pain, undergoes the treatment. The patient allows the therapist to enter his or her body, the core of privacy. This intimacy, however, is one-sided. In itself it does not establish the unity of medical treatment. As Elaine Scarry has observed, "Whatever their spatial proximity, there are no two experiences farther apart than suffering and inflicting pain" (quoted by Gadow, p. 153). The unity of medical treatment is only established when there is a unity of meaning between the intentions of the therapist, on the one hand, and those of the patient, on the other hand. Both intentions must be directed toward doing good for the patient.

Since the time of Hippocrates, the meaning of the therapist's actions has been to do good for the patient. Whatever objective pain the therapist might inflict on the patient during treatment, the therapist's intention is "above all, to do no harm." The meaning of the patient's objectively painful treatment lies in its redemptive character. In this secular sense of redemptive suffering, the patient quite literally buys back—to a greater or lesser extent—a lost state of health. The beneficence of the therapist and the redemptive nature of the patient's suffering are thus two sides of the meaning of medical treatment. Inflicting pain and suffering pain can find meaning when they are directed toward the good of the patient.

How is this meaning established? Meaning is constituted in the relationship between a sign and what it signifies. In this relationship three

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elements need to be distinguished: first, there must be something that is apparent. (In the case of a verbal expression, for example, it is the sound of the words, a physical phenomenon.) Second, there must be an act of consciousness which establishes the relation between the physical phenomenon, or its equivalent, and that which is meant. Third, there must be that which is meant.

For example, the action of the nurses submerging Dax Cowart's severely burnt body in the pool of searing chlorox water despite his anguished screams would be the equivalent of the physical phenomenon. Somebody watching the procedure will understand it as meaningful only if he or she can relate this infliction of pain to the good the nurses intend to achieve. In the same way the nurses can understand their actions as meaningful only if they can relate the physical actions and the hidden good, the ultimate effectiveness of the treatment.

What do Dax Cowart's continuous demands to die and his repeated suicide attempts tell us about the meaning of this treatment for Dax himself? Dax's refusal to give meaning to his suffering, which Kliever (p. 190) rightly calls his "categorical refusal of *redemptive suffering*," breaks the unity of meaning. I disagree with those who say that Dax Cowart destroyed the unity of meaning. The unity was torn apart by his mother's self-interest and his medical team's ambivalence about the effectiveness of the treatment.

Throughout the narrative it is stated that Dax Cowart's mother, Ada, insisted on aggressive treatment for her son because of her religious beliefs (pp. 6, 7, 8, 10, 17, 36, 120, 126, 184, 191). Admittedly, Ada Cowart's faithful observance of her religious precepts carries its own important message, and an important meaning can be discovered beneath it. Yet this important meaning is of value to her, not her son. By pursuing her own good rather than her son's, Ada Cowart robbed the medical treatment of its beneficent meaning.

At times during the crucial early period, the therapists also robbed the treatment of its meaning. As Winslade noted,

many people who encountered Dax in the early years of his treatment were ambivalent about whether they wanted him to live. . . . In fact one might wonder whether the vigorous treatment of Dax *masked the unconscious ambiv-*

**Cowart realized that part of him had died and that a new self had been born of his own labor pains. By naming this new self Dax, he ritualized and celebrated his death and resurrection.**

*alence* the staff felt towards him; they consciously used all their skill to save him while, perhaps, secretly wishing that he would die. (p. 122, emphasis added)

Ambivalence and ambiguity are part of our everyday lives. Neither, however, indicates that meaning is present but rather that it is sadly absent. In the absence of meaning, painful treatment is nothing but pain. Pain without the promise of meaning—a meaning perhaps hidden at present but to be revealed in the future—is agony without an imagined future. The absence of a future is death.

According to Robert Jay Lifton, death, future, and suicide stand in a powerful relation:

the suicide can create a future only by killing himself. That is, he can reawaken psychic action and imagine vital events beyond the present only in deciding upon, and carrying through, his suicide. And for that period of time, however brief, he lives with an imagined future. (Quoted by Winslade, p. 128)

Cowart did not kill himself. He realized that part of him had died and that a new self had been born of his own labor pains. He named the new self Dax. William F. May reminds us that

not only traditional societies but also Christianity uses the language of death/resurrection to emphasize the sharpness of the break between the old and the new. The metaphor of undressing and dressing expresses both ceremonially and substantially the alterations demanded of the self. (p. 144)

By naming himself Dax, Cowart ritualized and celebrated his death and resurrection.



## Response: Patrick Staunton

It is difficult and may very well be presumptuous to undertake any further commentary on Dax's case. Yet because of the disagreement even today about the correct course of action, the case offers an invaluable lesson to those interested in health care. Jerome Brunner talks about different kinds of knowledge. Facts and figures lead to the kind of knowledge that the scientific movement has compelled us both to accept and to respect. The other kind of knowledge, though, is best communicated by means of the story or parable. The parable or story contains truths that the scientific method cannot grasp. To me, Dax's case is such a story.

As a psychiatrist, I employ knowledge acquired through the scientific method to diagnose my patients and prescribe treatment. Yet I would be a poor psychiatrist if I did not know that each of my patients has a unique story that cannot be incorporated into any diagnostic category. The meaning of this story I must try to grapple with and understand, for my ability to help a particular patient depends on that understanding. A story is by its very nature ambiguous, with different nuances and levels of meaning. Not everyone gets the same message from the story, and a message sent is not necessarily a message received.

So what has this got to do with Dax's case? According to one interpretation, a young man in the prime of life is exploring many attractive options when he suddenly loses most of his manhood and his father on the same day. His initial reaction is an expressed desire to end his life. This expressed desire is repeated on several occasions, presumably as he reflects on the enormity of his losses and the painful consequences of continuing treatment.

The lesson that Dax wants to leave with us is that he should have been allowed to die. He has become a passionate advocate for the competent individual's right to make that choice despite objections from family, friends, or physicians who may claim to have his best interests at heart. This lesson appeals to those of us who view individual rights and the freedom

**Despite the many successes of modern medicine, the physician's reputation in our society appears to be steadily declining.**

to exercise those rights as the preeminent value in a free society. Yet this is not the only message in the story.

Another interpretation might well be that a young man was happily saved from an untimely death through the near-miraculous interventions of modern medicine and the dedicated support of his mother and lawyer-friend. His ability to become a practicing lawyer and thus a contributing member of a community might be cited to justify this interpretation. His periodic protests that he be allowed to die could be viewed as transient responses to his suffering, not to be taken literally—perhaps as when Jesus on the cross asked that "his cup" be taken from him. Some years ago in this country (and perhaps still in some countries), this interpretation of the story would have a large following, but not today. While most of the essayists are unwilling to accept the first interpretation as the whole story, none supports the second. Determining why that is so can, I believe, throw some light on the troubled nature of the relationship between the physicians and the society they serve.

My father was a practicing general physician in the west of Ireland where I grew up, so I have had a good opportunity to observe the changing nature of the physician's role over many years. During much of his professional life, the justification for his existence depended on his ability to give accurate diagnoses and prognoses. At the same time, he did what he could to alleviate suffering and provide support to patients and their families. There were few occasions when it could have been said that he cured a disease. Yet like most physicians of his time, he was well respected as an important member of the community.

Since World War II, the medical profession and the hospitals have greatly expanded their ability to intervene in the natural course of disease. They have new powers to restore health, alleviate suffering and disability, and prevent premature death. Despite the many successes of modern medicine, however, the physician's reputation in our society appears to be steadily declining. On the one hand, we are expected to perform miracles, and on the other, we are criticized when the results are less than perfect. All want access to the benefits of modern medicine, yet they complain about the increasing cost of health care. Physicians are frequently fingered

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as the chief culprits. Medical malpractice awards continue to escalate, which appears to be society's way of sending a message to the profession that we are making more money than we deserve. We are also perceived to be cold and impersonal as we institute more efficient business practices to bring our costs down.

Finally, when a patient complains that his or her individual rights have been compromised in any way in the physician-patient relationship, the complaint is increasingly accepted at face value; the physician no longer receives the benefit of the doubt. The popular interpretation of Dax's story is a good example.

A profession's role in society is not determined simply by the profession itself but also by the culture in which the physician practices. Physicians, members of one of the oldest professions, have enjoyed an eminent position in most societies throughout recorded history. What does a change in their position (and the Dax case suggests that it has changed) mean for the profession and society as a whole? This important question needs to be addressed both within the profession and outside it, because the health of the medical profession is important not only to its individual members but also to the larger society. It is ironic that in my father's day, when physicians had little ability to alter the natural course of disease, they were generally held in high esteem by those they served. Today, when our capacity as physicians to intervene successfully is at times nearly miraculous, the profession is regarded with distrust. Being a good physician has never been more difficult.

**Basic to Dax's case is one very broad question: what (if anything) do human beings by virtue of their existence owe to others and the world?**

## Response: Carrie Nelson

Basic to Dax's case and our reactions to it is one very broad question: what (if anything) do human beings by virtue of their existence owe to others and the world? Are certain principles so fundamental to the human condition as to be inarguable obligations of the privilege of existence, or does the serendipitous nature of existence and history make any duties to the world and those who exist in it absurd?

Most would agree that there are certain rights of existence as well as obligations. The rights, however, are seemingly confined to one's immediate self, whereas the obligations apply when one's actions more directly involve others. According to this view, one has no obligations when the goals or behaviors are perceived to affect only oneself. One likewise has the right to any self-actualizing act or thought if it does not directly have a negative impact on others, including those to whom one has a fiduciary responsibility.

With this framework of thought I offer some specific personal comments on points and questions raised in this volume of essays on Dax's case.

Childress and Campbell present an eloquent and edifying discussion of paternalism and beneficence. Their thoughts concerning potential future ratification by the self of paternalistic actions is particularly helpful. Decisions in the present must be made by the self and not mocked unfairly by the selective memory of the future self.

Dialogue, in this case the dialogue between patient and caregiver, is the essential vehicle of informed consent. Although Zaner validates and clarifies this concept, he errs in saying that Dax failed in his part of the dialogue with his caregivers. Even today, the physician still tips the power scale in his favor, and this imbalance was more pronounced 17 years ago. The vulnerability and powerlessness of Dax was such that effective dialogue could have occurred only if his caregivers had sought unusual means to enhance his powers of self-actualization, while at the same time increasing their vulnerability.

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Gadow's essay speaks poignantly about the issue of vulnerability in this case.

Engelhardt's essay is very helpful, particularly his discussion of Texas law and the state's interest in protecting life. One cannot help wondering whether the change in suicide law in Texas just before Dax's accident fostered some legal paranoia which influenced his case. One can only speculate whether his lawyer, Rex Houston, fostered the perverse conflict of interest by "treating the attorney" instead of the patient.

May's very compassionate discussion of individuals in the face of catastrophe should be part of the essential education of all health caregivers. He does well to remind us that parents acquire their authority over children in part because they have "been there," causing us to reflect further on the origins and validity of paternalism.

The difficulty of maintaining both compassion and intellectual integrity alongside the constant danger of losing emotional and intellectual objectivity is an important theme of Gadow's piece. Finding the maximally therapeutic amount of mutual vulnerability of patient and health caregiver is part of the art of medicine that can be shaped to some extent but that relies largely on the essential substrate of the would-be healer. Dr. Johannesen's view of Dax's life presents another side. Johannesen seems to scorn Dax for not fitting into a societal ideal. Dax is not a noble figure but rather a transient, "sentimental" popular figure whose motives Johannesen finds quite suspect. This view of Dax's human tragedy seems extraordinarily distant and cold, bordering on cruel.

Finally, Kliever's analysis of Dax's case using the story of Job is instructive. Certainly Dax could be a Job—but he is not. The analogy is not quite perfect because the certainty of Dax's continued "chronic sorrow" and "limitless grief" highlighted by May outweighs the struggles of the mythical Job, for whom a turn of events could restore him to his former body and life.

Although this book is a stimulating collection of essays, it lacks a selection by Dax himself. Surely his thoughts, too, have evolved since 1973, and the reader yearns for an opportunity to hear from him. A continuing dialogue with him, as Zaner states, would bring us closer to being "free from ignorance and freed for truth." His catastrophe can provide for the rest of us an

occasion for the rebuilding of our own worldview.

## Response: James P. Wind

One by one the essential pieces of late-twentieth-century conventional wisdom about suffering, quality of life, individual rights, and medical care are rendered inadequate by Dax Cowart's experience. The films about his tragedy and the collection of essays treated here unmask a health care situation bearing the weight of many inadequate paradigms. We weigh life against quality of life; we approach medical ethics cases with an eye toward autonomy vs. beneficence; we attempt to resolve our deepest questions and dilemmas in the "language of rights"; we shape our healing relationships around the axis of professional power and knowledge; we decontextualize our ethical quandaries and then package the most troublesome of them as "celebrity cases"; we avoid the religious and philosophical zones of these quandaries if at all possible; we place our premium upon the doing rather than the talking side of care.

The collection of essays edited by Kliever demonstrates the consequences of our conventional wisdom. It also points to alternatives. At the practical level of patient care, for example, Joanne Lynn, a physician, raises questions about the way Dax's physicians responded to their patient's repeated requests to die. She suggests mediating strategies which seemed to have been overlooked by these doctors as they acted in opposition to clear expressions of their patient's preference. She also explores options for dealing with the incredible pain suffered by this most famous burn victim. Patricia King makes similar moves in discussing the behavior of Dax's lawyer. She warns against conflicts of interest that emerge when attorneys are friends of patients *and* their families and then suggests that the practice of law could be strengthened by learning lessons about informed consent (to legal advice!) from medicine.

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**One by one the essential pieces of conventional wisdom about suffering, quality of life, individual rights, and medical care are rendered inadequate by Dax Cowart's experience.**



Several essays challenge us to explore the meaning behind a patient's refusal of treatment. We can be tempted to decide that the conversation is over once we have determined that a patient is competent and that a decision has been made; we then respond with grudging acceptance or benevolent disregard. But Richard Zaner views Dax's intended last word on his future as the first word of a much needed dialogue in which the patient and those who provide care "collaborate in each other's freedom" (p. 57). Zaner would have us move beyond the "language of rights" to a different kind of discourse, one much more mutual than adversarial.

Sally Gadow takes us deeper into the chasm separating patient and carer as she explores the difference between being trapped within a body (Dax) and being free to transcend the body's limits (all those who surround such patients). Her analysis helps us ponder the paradox that healing can seem to be torture, that care can be received as cruelty. Like Zaner she would have those who provide care participate in mutuality. To do that physicians and other members of the health care team must learn to value the patient's voice as often the only means left for transcending the imposed limits of tragedy. At the same time these carers must find ways to share their vulnerability, to take a step across the patient-provider gap, by bringing some of themselves into the relationship.

Two essays probe still deeper levels of our health care situation. Stanley Johannesen and Lonnie Kliever examine the public and private myths that shape Dax's decision and his providers' responses. Powerful images of the body, the healthy young male, and the good death work together to limit the imagination of both patient and physicians. Especially interesting is Johannesen's discussion of the way the image of the "accident" diverts our attention from the cultural values that allow events like the one that struck Cowart to happen. The result is that our rage, frustration, and ethical debate are directed to those who care for the victim rather than to those who build pipelines like the one that left Dax blind and maimed.

Kliever and William May make the most direct challenges to the language of rights when they re-perceive Dax's case through religious lenses. Kliever rereads Dax's case alongside the biblical account of Job and challenges our con-

**Dax steadfastly refuses—like the Job of the poetic sections of the biblical account—to accept the conventional attempts to make suffering redemptive.**

ventional wisdom about redemptive suffering. Dax steadfastly refuses—like the Job of the poetic sections of the biblical account—to accept the conventional attempts to make suffering redemptive because of its contribution to some greater or future good. And May suggests that the Western habit of viewing life as unilinear narrows the possibilities for care that could be made available if one read each life as sequences of birth, death, and resurrection. According to May, Dax did not just suffer a diminishment in the quality of his life. Rather the experience of his tragedy and the ordeal of healing were a time when an old self, Donald Cowart, died. What had to happen in the time of his treatment (and what the health care team and Dax seemed not to perceive) was the emergence of a new person, Dax.

These essays challenge our current American approach to catastrophe in still other ways, but what are some implications? First, despite attempts by James Childress, Courtney Campbell, and H. Tristram Engelhardt to clarify the essential role of the principle of autonomy in medical ethics, these essays present powerful claims that this cherished principle alone is not sufficient to guide us through cases like Dax's. We need to take seriously Engelhardt's diagnosis that in our culture neither revelation nor reason succeeds in grounding a society-wide consensus on a hierarchy of values. We have turned to autonomy by default, as a minimal bulwark to protect people from imposition of values they do not affirm. But this collection of essays as a whole shows us that more is needed.

Second, the reader of this book gradually begins to see a catastrophe like Dax's as what William James once called a "full fact." The perspectives employed here bring different dimensions of Dax's story into view. None of the authors comprehends the entire case; each contributes different ingredients. Far more was involved in this catastrophe than burned flesh. Identity, the values of a surrounding culture, the unacknowledged death of a self-conception, the revulsion that most of his carers felt but did not express to Dax, legal conflicts of interest, and the goals of medicine were all entangled in this one critical incident.

Third, these essays provide a fresh and powerful encounter with the mystery of human life and death, and great paradoxes emerge. For Dax, living became a burden, and death seemed



to be relief. His own new identity and his ability to take control of his life could be expressed only through his request to be allowed to die. In Dax's case we glimpse the powerful impulse toward life—both in Dax's body which survived an indescribable assault and in those who tried to care for him. We puzzle over whether Dax's survival was partly the result of his determination to pursue his right to die. At the same time we are forced to think again about death. Is it only our enemy, or can it be a friend?

The fact that the conversation about Dax's case continues undermines facile claims that an individual's death or choice of death is a private affair. Instead, the ongoing argument between those who champion Dax's violated rights and those who oppose his position reminds us that one person's fate is part of a complex human

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web. These essays give us a glimpse of the web and raise anew questions about the meaning of compassion and the responsibility of individuals for each other, forcing us to realize the critical need for depth in our approach to cases like these. There is much more to Dax's story than our conventional bioethics debates attend to. The challenge before us is to assemble a repertoire of options like those contained in these essays and to fashion new models of caring and thinking. To Dax, his care providers, and to these commentators we owe a great debt: they have made it possible for us to stop and think about what is really going on in such extreme cases and in everyday decisions where our routines of thinking and acting are seldom held up for such searching and constructive analysis.



## BOOKS

Daniel Callahan, *What Kind of Life: The Limits of Medical Progress* (New York: Simon and Schuster, 1990). 318 pp. \$19.95.

For the second time in three years, Daniel Callahan has stirred the waters of discourse about the American health care system with a book that is every bit as provocative, unsettling, and stretching as was *Setting Limits*. Yet in many ways this new volume, *What Kind of Life*, is more satisfying and even more successful. What had been in the background of *Setting Limits* is exposed. The core problem is brought to the foreground. The core problem is exposed. The sickness that afflicts our health care system is not at root economic, political, organizational, or managerial, nor does it reside solely within health care. The fundamental illness is moral, and it inheres in the heart of the nation.

Ultimately at issue is our vision—our vision of what it means to us as individuals and as a society to live a life and to live it together, and of how understandings of health and illness, finitude and decline, disease and death fit in. To grapple with vision will necessitate conversations about the human good (what ought we pursue?) and human ends (which ones are worth having?). Ignoring these questions and the values embedded in them is a prescription for continued failure at reforming the health care system. Precisely because most efforts at changing the system have been piecemeal and have been attempted within the framework of dominant cultural values, they have not succeeded. What is the "reigning vision" that has perpetuated the problem? Callahan identifies three major components: our identification of good health with complete physical, mental, and social well-being; the satisfaction of a vast array of subjectively determined individual "needs"; and a strong belief in human rights in

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general and, more particularly, in the right to make (almost unlimited) claims upon society to have one's health "needs" met. When these factors are combined with a strong commitment to autonomy and free choice, the pursuit of unlimited medical progress and an ever-higher quality of life, the eradication of pain and suffering, and an inability to accept finitude and decline as part of the human condition, the system begins to spin out of control. Further compounding the problem is the belief that attempting to meet all individual health care needs and cure all disease would be economically feasible if there were greater efficiency in the delivery of services. Callahan argues compellingly that these premises of the present system are fundamentally flawed.

His own proposal hinges on two basic reorientations. The first is a shift away from an individual-centered to a society-centered approach to health care; the second is a shift from an emphasis on curing to an emphasis on caring. Each poses a serious challenge to the reigning vision and represents the radical re-visioning that Callahan calls for.

A societal approach to health care involves reconceptualizing the good society and the place of health in that society, as well as determining our communal health needs. Within this perspective, health is understood as a common benefit, something essential to our life together, but also as one need among many and probably not the most important. In effect, our priorities are shifted from meeting individual needs to meeting communal health needs. "The primary goal, the highest priority, of the health care system as a curative effort should instead be that of fostering the common good and collective health of society. . ." (p. 110). Clearly, then, good health is not an end in itself but a means to achieving the primary goals of society. Calla-



han himself suggests several societal ends: the maintenance and good functioning of political and legal systems; a sound economic order; national defense; pursuit and transmission of knowledge and culture; and maintenance of the institutions that undergird a society.

The goal of a health care system should be to promote enough health so that we can adequately carry out the main functions of our society and so that the great majority of citizens are healthy enough to carry out their respective social roles and interpersonal relationships (Callahan calls this the "principle of sufficiency"). To accomplish these goals, Callahan believes that an "average" level of health is sufficient for society as a whole; in fact, he contends that we have already reached this level. Neither perfect nor increased health (individually or socially) is necessary or even necessarily desirable; no direct correlation exists between better health and human happiness or a better society. The level of health in some social groups, however, is below average, which does impede their participation in social existence. This is where health improvement efforts should be directed. At the same time, there should not be so much spent on health that other basic social needs are neglected. A "full accounting" of the range of societal needs and of the total long-term costs of saving patients from a particular disease is required before any determination of how much to spend on health care.

If achieving an adequate level of social health takes priority in a health care system, what becomes of individual needs for curing? How are we to balance societal health and individual well-being? What claims can individuals make upon society regarding their personal health care? If every individual need for care cannot be met, then what is to be the contribution of a health care system to the individual? Callahan proposes that it be the provision of "care." While curing is almost always uncertain and the need frequently unlimited, caring is always needed and is far more finite in its requirements. By *caring*, Callahan means "a positive emotional and supportive response to the condition and situation of another person, a response whose purpose is to affirm our commitment to their well-being, our willingness to identify with them in their pain and suffering, and a desire to do what we can to relieve their situation" (p. 144).

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But can the individual hope for anything beyond care? Callahan does not rule out curative medicine but argues that heavy emphasis should be placed on setting limits. The first limit has to do with age. Limits on expensive, life-extending curative medicine are necessary for those beyond a full biographical life-span. The other limit is to be placed on our aspirations. "What is important for our present societal purposes . . . is to devise a set of reasonable aspirations, ones that combine technical feasibility, a thoughtful understanding of what is most conducive to human happiness and welfare, and economic good sense" (p. 155). Callahan suggests these aspirations for curative medicine: (1) a full life-span and the avoidance of premature death (hence, curative medicine would focus on efforts to understand and then cope with major causes of premature death and morbidity within them); (2) a psychologically stable and emotional state (hence, the availability of effective psychiatric and psychological therapy); and (3) a state of adequate functional capacity (hence, the availability of rehabilitative therapy). These ideals must always be balanced against the reality of limits.

In order to achieve this balance, Callahan argues for an allocation policy with two key ingredients. The first is a perspective on technology assessment and the research imperative, and the second is a strategy for deriving priorities. "Priority," he argues, "should be given to the development of technologies that promote long-term benefits, that seek a good balance between life extension and quality of life, and that seek also to minimize the impact of illness on those already afflicted" (p. 165). All technologies should be judged in light of the moral, societal, and cultural ends we want the technology to serve. When it comes to investment in research, the main considerations should be whether it will eventually contribute to health care savings and whether it will contribute to relieving the onset and burden of chronic illness.

Callahan's societal view of health care clearly informs his determination of priorities, which he describes employing the image of a pyramid. At the bottom are the first four levels: basic caring for all; then public health and preventative measures (including accident prevention and prenatal care); then immunization and protection against infectious diseases; followed



by emergency medicine and primary care (limited to routine and inexpensive forms of diagnosis and therapy). Callahan believes that resources invested in these levels of care "will produce the greatest impact on mortality and morbidity, and will do so at the lowest cost per capita" (p. 177). The result will be a level of health and dignity sufficient to ensure the functioning of societal institutions and a system that is reasonably just. The burden of proof for *not* providing these levels rests with government and its elected representatives.

At the top of the pyramid are levels five and six: general, advanced forms of medical cure or restoration (advanced surgery, chemotherapy) and highly advanced, technological medical therapy such as dialysis, open heart surgery, organ transplants, and total parenteral nutrition. These two levels are increasingly concerned with individual curative needs and consequently require severe limitations. Here the burden of proof is on the individual to show that the particular need should be met in the face of limited resources and other societal needs. The degree of "burden of proof" will vary with economic conditions.

Such individual, institutional, and societal changes are massive, requiring central government planning and legislative decisions as well as cooperation from the private sector. The legislative agenda will need to be preceded by public forums, hearings, and educational programs. The time frame is envisioned to be about a generation.

Callahan proposes "an alternative way of thinking about health that will lead into the devising of a reasonable and just health care system" (p. 12). He views the book as an "elaborate outline, an extended sketch, rather than a detailed blueprint. . . . I am seeking coherence and wholeness, even at the cost of failing to explore in needed detail the many difficulties and puzzles the discerning reader will readily discover" (p. 13).

In this, he has succeeded, and his proposal will likely change the terms of the debate about health care reform. He perceptively identifies the flaws in the standard approach as well as their causative factors, and he forces us to grapple with them.

Although Callahan claims to be painting a mural rather than a microscopically detailed miniature, it seems reasonable to point to areas

**When Callahan speaks of a vision of the good, of life's meaning, of human finitude, he is touching not only upon philosophical issues but upon religious ones as well. Yet he seems to have no place for religious answers.**

where the mural needs more detail. Callahan's proposed shift to a societal perspective and to a greater emphasis on the common good is a major social task which extends beyond health care. Because it is antithetical to reigning cultural values, it will require major efforts at social transformation. A far more detailed and persuasive rationale than that given in *What Kind of Life* will probably be required to bring about this change. Callahan's argument speaks to those who are already converted, but it may do little to penetrate the deep-rooted individualism of American society. Furthermore, the just balance between the common good and the good of the individual is virtually always difficult to achieve.

The mural will also need to flesh out the implications of a shift in focus from curing to caring—for scientists and medical researchers, for those parts of the health care industry that cater to high-tech medicine, for specialists devoted to the application of advanced technology, for medical education and the ethos and self-understanding of the medical profession as a whole. What will health care for the individual look like in this kind of system? What will be the likely impact on mortality? Will pain and suffering actually increase or decrease? And will society be able to see the benefits of a system based on Callahan's proposal (as they are now able with high-tech medicine)? If not, a shift from curing to caring, from extending life to increasing the quality of life may not be sustainable in the long run. Without tangible results in an alternative system, society may not be able to pass up dialysis and heart transplants when they are facing certain death and know that technology is available to save them.

Another detail for the mural. Given the length of time it will probably take to implement a proposal like Callahan's, what happens in the meantime? How do we address the current health care crisis? Are there interim measures for dealing with our current structural and allocation problems?

Finally, when Callahan speaks of a vision of the good, of life's meaning, of human finitude, illness, suffering and death, he is touching not only upon philosophical issues but upon religious ones as well. Yet Callahan seems to have no place for religious answers. But from where will these answers come? Are we to believe that philosophical reflection itself will be adequate?



Callahan's book is an important piece of work. It is lucid, generally compelling, often eloquent, decidedly visionary, and undoubtedly daring. Future discussions of health care reform cannot afford to ignore it, whether or not the participants find themselves in agreement. Probably no other treatment of the American health care system is as encompassing in its approach or frames the debate as it should be framed, that is, as a question of values.

—Ron Hamel



James F. Drane, *Becoming a Good Doctor: The Place of Virtue and Character in Medical Ethics* (Kansas City: Sheed and Ward, 1988). 211 pp. \$12.95.

During certain third-year rotations, groups of medical students at our university attend weekly ethics conferences. At these meetings students are asked to make presentations on patients they have dealt with during the week whose care has led to ethical questions. Discussion of the cases and the ethical issues follows. Frequently, however, new students report that they have encountered no ethical questions during the week. By "ethical questions" the students understand "moral dilemmas." Where there is no crisis of conscience, they assume, there is no occasion for ethical reflection.

That students associate medical ethics with moral dilemmas is not surprising. The popular press, the medical literature, and most medical ethicists have tended over the years to focus their attention on "hard choices": withdrawing life support from patients in persistent vegetative states, choosing who will receive a scarce but lifesaving medical therapy, determining the fate of defective newborns, and so on. To some, however, this focus is disturbing, especially if one shares the classic view that ethics is above all about character. James F. Drane is such a person.

Drane argues that doctoring is ethical through and through. Every encounter with every patient is an inherently ethical one, in that physicians' characters inevitably manifest themselves in what physicians perceive, how they think, feel, and act, and what they say. Each

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physician is distinctive, and that distinctiveness is traceable not only to differences in knowledge and technique but to the kind of person the physician is. Drane invites us to reflect on the character traits of good doctors, and in part thereby, perhaps, to become (or to assist in the education of) better doctors.

Medical ethics over the past several decades has tended to focus on hard choices and to employ the language of principle, rules, and rights. Drane, conversely, draws our attention to the everyday relationships between physicians and patients, employing the language of character, virtues, and "styles of being." His professed aim is not to do away with the principled approach but rather to redress an imbalance between attention to principles and attention to character. In calling for a reexamination of the place of excellence of character in medical ethics, Drane joins the company of recent commentators like Henry Beecher, Leon Kass, William F. May, and Renée Fox.

Rather than making a theoretical case, Drane begins by exploring the virtues of good doctors. He begins with a direct appeal to the reader's faculty of ethical perception. No amount of principled argument can convince a reader that good doctoring is a matter of character unless the reader first perceives that there is such a thing as good doctoring. Once we recognize good doctoring, we can then go about investigating it: its essential characteristics, its sources, and its significance.

Drane turns first to the patient. What wants and needs do patients bring to the physician? In the context of what relationship is the physician best able to respond? Medicine is a response to the experience of illness, and good medicine begins with what it means to be ill.

Eschewing a catalog of medical virtues, Drane derives the traits of good doctors from the essential medical acts: diagnosis and prognosis and the virtue of benevolence; medical communication and the virtue of truthfulness; decision making and the virtue of respect; inevitability of feelings and the virtue of friendliness; access to medical help and the virtue of justice; and doctors as priests and the virtue of religion. While I have quarrels with Drane's taxonomy and with some of his positions, his account of the virtues succeeds in inviting the reader to reflect on the traits of good physicians.

Drane then attempts to justify considerations



of character and virtue in medical ethics, raising some important questions. How has American medical ethics reached its present state, which Drane characterizes as a loss of the ethical self? Why is medical ethics dominated by medical law? Why does ethics so often resemble technical knowledge, a methodology for making decisions? Why do Americans tend to make considerations of character into private matters? Drane argues that we must get in touch with our ethical selves, recognizing that our thoughts and actions inevitably create a self, that virtues and vices are nothing if not expressions of self, and that goodness may entail giving serious thought to the kind of self we wish to be and express.

The book concludes with an overview of the "philosophical foundations of an ethics of character" (a title that may promise more than the text delivers). Ethics is essentially personal (character is an attribute of persons), personality is fostered, defined, and expressed in relation to others (one's patients, colleagues, family, community, and culture), and therefore the ability to see and understand others is essential to ethics. In medicine, the patient is the primary other, and it is in relation to the patient above all that the character of the physician is defined. In treating the disease, the virtuous physician attends to the biological, psychological, and sociological aspects of the patient and the patient's world, of which the physician and the medical profession are an important part.

Readers of Drane's book may wish to explore further the relationship between medical excellence and human flourishing. In some respects, medicine is a privileged calling; for example, it fosters the development of certain virtues—discernment, compassion, moderation—to an extent that many other occupations do not. Yet perhaps medical virtuosity also exacts a human price. Perhaps good medicine sometimes requires maintaining a certain distance between oneself and one's patients; perhaps the conditions of contemporary medical practice do not always foster excellence of character; and perhaps good doctors genuinely suffer because of their calling, through intimate contact with disease, decay, death, pain, sorrow, and loss of hope.

As a call to examine character and virtue in medicine, Drane's book is a worthy addition to the literature of medical ethics. The book is not,

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however, and does not purport to be, a "self-help manual," at least not in the sense that reading it will make one more virtuous. If we aim to become better physicians, we can best use the book as a supplement to shared experience with a virtuous physician, or perhaps in conjunction with selected readings of medical biographies, medical essays, and imaginative literature. A theoretical account of virtue does not inform practice in the absence of sustained attention to virtuous persons in action. In redirecting our attention to such actions and the character they express lies the greatest virtue of *Becoming a Good Doctor*.

—Richard B. Gunderman

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Kevin D. O'Rourke, O.P., and Philip Boyle, O.P., eds., *Medical Ethics: Sources of Catholic Teachings* (St. Louis: Catholic Health Association of the United States, 1989). 335 pp. \$33.00.

This volume is a unique and important contribution to the medical ethics literature, particularly in the Roman Catholic tradition. Under one cover, O'Rourke and Boyle have assembled excerpts from a variety of ecclesiastical documents that are representative of church teaching on over 50 topics relating to ethics in health care. The topics, arranged in alphabetical order, range from abortion and AIDS to genetic testing and counseling, hydration and nutrition, national health insurance, pain relief, suffering, and withdrawal of treatment. In all, there are 129 selections drawn from statements of the Second Vatican Council, papal encyclicals and addresses, pontifical commissions, and bishops' conferences. With the exception of a significant number of statements of Pope Pius XII (pontificate, 1939–1958), the selections are from the Second Vatican Council and post-Vatican II sources. Within each entry, the statements are arranged in order of authoritative import.

Two essays introduce and provide a context for this "compendium" of ecclesiastical teaching on medical moral matters. The first is a discus-



sion of Catholic Christian understandings of the human person, health, sickness and death, and sexuality. This theological anthropology, intended to lift up the fundamental values underlying church teaching, is informed by biblical sources, the tradition, and theological reflection. The essay is positive and balanced in its approach, though not beyond question or disagreement. The second essay focuses on the nature of Christian conscience, its proper formation, and its relation to faith and to official church teaching. The clarity and balance here, as well as the fidelity to the best of the Catholic tradition, are commendable.

O'Rourke and Boyle set out to provide a collection of church teachings for health care professionals that would not only give the substance of official teaching on medical-moral issues but also provide the theological grounding for those positions. In this aim their volume succeeds very well. Given the intended audience, however, a brief descriptive and interpretive introduction to church teaching on each of

**The editors set out to provide a collection of church teachings that would give not only the substance of official teaching but also the theological grounding for those positions.**

the topics might have been desirable. While there is merit in allowing texts to speak for themselves, and there are the ever-present constraints of space, such introductions might have further deepened readers' understanding, particularly for those not well versed in the Catholic moral tradition and method of moral reasoning. Also, bibliographical information on additional sources of church teaching not included in the collection would have further enhanced the volume as a reference work.

One need not be a health care professional or Catholic to find the volume useful. It is a handy reference work for anyone who wishes to become informed about Catholic church teaching on issues in health care. And it may serve as a worthy supplementary text in medical ethics courses seeking to consider the Catholic perspective and to employ primary sources, whether in a university or parish setting.

—Ron Hamel



# LITERATURE DIGEST

## Nutrition and hydration for the permanently unconscious

Germain Grisez, "Should Nutrition and Hydration Be Provided to Permanently Unconscious and Other Mentally Disabled Persons?" *Issues in Law and Medicine* 5, no. 2 (1989): 165-79.

Kevin O'Rourke, "Should Nutrition and Hydration Be Provided to Permanently Unconscious and Other Mentally Disabled Persons?" *Issues in Law and Medicine* 5, no. 2 (1989): 181-96.

These companion articles explicate two opposing Catholic positions on the provision of nutrition and hydration to patients in a persistent vegetative state (PVS). Grisez holds that it is not morally acceptable to withdraw food and water from PVS patients because even they benefit from care. O'Rourke believes that it is morally acceptable to withdraw nutrition and hydration from such patients.

Grisez argues that the benefits of feeding a permanently unconscious individual outweigh the burdens. It is often argued that the cost of providing nutrition and hydration to a PVS patient is a burden that far outweighs any possible benefits to the patient, who has no appreciable mental life. Yet, Grisez points out, the actual cost of the food and water provided is negligible; discontinuing feeding indirectly eliminates the costs of care by facilitating the death of the patient. The question, therefore, is not so much "Should we discontinue feeding the patient?" but rather, "Should we discontinue caring for the patient?" In Grisez's words: "In our affluent society, can we justify abandoning the comatose in order to save the costs of caring for them as we care for others who cannot care for themselves?" (p. 172). Grisez answers this question in the negative because the costs of

**Grisez argues that life is a good in itself and thus should be maintained regardless of the cognitive capacities of the patient.**

care are justified by two benefits: (1) care maintains the patient's life, and (2) care maintains human solidarity with the patient.

The author argues that life is a good in itself and thus should be maintained regardless of the cognitive capacities of the patient. Several ethicists have argued that life is good only insofar as it allows us to pursue other human values, to encompass the goods this physical existence makes possible such as relationships, the pursuit of a career, and so forth. Once such goods are no longer attainable, as in the case of the PVS patient, then physiological life is no longer considered valuable. Grisez disagrees:

In denying that "mere physical existence" is inherently good . . . [we] presuppose that a person's life has only the status of instrumental good—something which human persons have and use for their specifically human purposes, but, nevertheless, something which remains really distinct from what human persons are . . . But a person's life is not merely an instrumental good. It is the very actuality of his or her living body, and—although human persons also have spiritual powers and acts which cannot be reduced to bodily capacities and functions—a human being's living body is the bodily person. . . .

. . . So a human person includes a body; one's living body is an intrinsic part of one's personal reality; one does not merely possess, inhabit, and use one's body as an instrument. Human life, which is the very actuality of a person's body, is a good intrinsic to the person . . . Therefore . . . human life is inherently good, so it does not cease to be good when one no longer can enjoy a degree of cognitive-affective function or attain other values (pp. 172-73).

Caring for PVS patients also maintains human solidarity with them, affirms their dignity as persons, and expresses benevolence toward



them. Comatose patients are benefited by being cared for out of a love that respects their dignity.

One can maintain the bond of human communion with permanently unconscious persons, even though they cannot enjoy the good experiences normally characteristic of this bond as it exists among conscious persons. This bond is a moral reality, which is maintained essentially by fidelity of will and action. . . . families and larger communities that faithfully care for their comatose members maintain human communion with them and thereby benefit not only themselves (by continuing to be loving families and genuine communities) but their comatose members. (p. 175)

No official church statements regarding provision of artificial nutrition and hydration to people in permanent unconscious states exist. Kevin O'Rourke applies two statements about the use or withdrawal of life-prolonging therapy in general to the case of PVS patients and concludes that withdrawing food and water from such patients may be morally acceptable.

O'Rourke summarizes the substance of the Catholic church's teaching on the provision of life-sustaining treatment in seven points taken from Vatican II and statements by Pope Pius XII. First, we have a positive obligation to preserve life and make it fruitful. Second, intentionally causing the death of oneself or another is wrong. (Hence, murder, suicide, and euthanasia—or any action or omission that of itself or by intention causes death in order that all suffering may be eliminated—are contrary to the moral good of individual persons and community.) Third, because inducing the cause of death is prohibited, only when a naturally caused pathology is present does one have an ethical right to determine whether to remove, circumvent, or alleviate that pathology. Fourth, if the means to remove or circumvent the pathology are effective and do not involve a grave burden for the patient, then there is a moral obligation to use them. If they are ineffective and do impose a grave burden on the patient then they need not be used. Fifth, burden can be defined in several ways; it can be physical, economic, psychological, or spiritual. Sixth, the application of church teaching must be carried out on a case-by-case basis with a view to the "circumstance of persons, places, times and culture" (p. 187). Finally, "the most significant norm for determining whether life support should be uti-

**O'Rourke contends that because the mind is necessary for spiritual function and the PVS patient has no possibility for cognitive-affective function, we are not obligated to sustain physiological functions in these patients.**

lized is that the spiritual goal of life is the ultimate criterion to measure whether means are proportionate. . . . When the potential for spiritual function is no longer present, then it seems that all treatment or care efforts which sustain the physiological function are ineffective" (p. 188). Because the mind is necessary for spiritual function, at least the potential for cognitive-affective function in some degree must be present to justify sustaining physiological function. Since the PVS patient has no possibility for cognitive-affective function, it would seem that we are not obligated to sustain physiological functions. Although the church's position does not allow intentionally causing the death of this person, it does allow the removal of treatments that prevent the fatal pathology from taking its natural course. Since the fatal pathology "affecting the homeostasis of a PVS patient is the inability to chew and swallow" (p. 182), artificial nutrition and hydration constitute a form of life support. Hence, if the treatment is either useless or burdensome as defined by the seven points above, it may be withdrawn.

—Annalisa Pizzarello

### Caring alternatives to euthanasia

Richard M. Gula, "The Virtuous Response to Euthanasia," *Health Progress* 70 (December 1989): 24-27.

In response to the growing debate on euthanasia and increasing pressures toward its acceptance, Richard Gula proposes a "virtue-informed" approach for the Catholic community. (His suggestion is surely applicable to other religious communities as well.) In essence, this approach places more emphasis on the witness of the community and its embodiment of basic moral convictions, its moral character, than on argumentation. Three virtues in particular should shape the character of the community—interdependence, care, and hospitality.

The individualism that so characterizes American society fosters the pursuit of independence, self-reliance, and individual autonomy, and support for euthanasia is a natural outcome of these societal values. It allows one



to retain control even in one's dying and to be neither dependent nor helpless. The challenge for the Catholic community is to model interdependence on an individual and institutional level. Practically, in the area of health care, this might mean being a catalyst for collaboration among various subcommunities in providing outreach programs for the sick, elderly, and dying. Local congregations might institute a ministry for health care services. And the community as a whole might contribute its religious perspectives on life, aging, suffering, family obligations, social justice, and death to the euthanasia debate.

So much of modern medicine's focus has been on curing. This sometimes results in prolonging life beyond what is reasonable and in turn generates fears of overtreatment and prolonged suffering. This situation further fuels support for euthanasia. The Catholic tradition, however, has emphasized caring rather than curing. "Caring reflects the Catholic tradition's clear and steady insistence that individuals are not morally obliged to bear burdens beyond their capacity. The Catholic tradition values life as a basic condition necessary to achieve all other values. But it does not demand an idolatrous reverence that makes physical life an absolute value. . . . Caring includes curing when possible, but it also entails simply accompanying in a faithful and loving way those whom medicine cannot cure" (p. 26). If patients were assured that they could set limits on their treatment, much of the need for euthanasia could be eliminated.

Behind the idea of "hospice" is a philosophy of caring that could infuse all health care thereby creating communities of hospitality. Here the dying would be able to live as free from pain and as much in control over their treatment as possible. An ethos of hospitality alters the ministrations of health care personnel. Time spent with the sick and the dying, assuring them that they will not be abandoned, assumes greater importance. Hospitality, or supportive care, would also need to be directed to care givers and family members.

By becoming a virtuous community of interdependence, care, and hospitality, Catholics can address many of the concerns that motivate people to consider euthanasia, ultimately provide better care for the sick, elderly, and dying, and visibly express the convictions that under-

**Much of modern medicine's focus has been on curing, but the Catholic tradition has emphasized caring.**

lie the church's opposition to euthanasia. Together with sound arguments, this approach may well be far more persuasive and effective in stemming the tide against euthanasia than arguments alone.

—Ron Hamel

### **Policy and attitudes on advance directives**

S. Van McCrary and Jeffrey R. Botkin, "Hospital Policy on Advance Directives," *Journal of the American Medical Association* 262, no. 17 (November 3, 1989): 2411-14.

Kent W. Davidson et al., "Physicians' Attitudes on Advance Directives," *Journal of the American Medical Association* 262, no. 17 (November 3, 1989): 2415-19.

Living wills and durable power of attorney, known collectively as advance directives, are becoming an increasingly important component of medical decision making for previously competent patients. Living wills permit individuals to formally express their preferences for health care should they later become incompetent, while durable power of attorney allows individuals to appoint a substitute decision maker to implement their preferences. Thirty-eight states and the District of Columbia have enacted some type of living will, durable power of attorney, or "natural death" legislation. A 1988 telephone survey by the American Medical Association indicated that 15 percent of the population have prepared living wills and that 58 percent have informed their families of treatment preferences should they become incompetent. This evidence indicates a general public awareness and concern with having their wishes respected should they no longer be able to express them. Furthermore, doctors, especially doctors who have had actual clinical experience with them, express positive attitudes toward advance directives. In a survey of Arkansas physicians currently engaged in general practice, family medicine or internal medicine 80 percent of the respondents expressed a positive attitude toward advance directives; only 1.5 percent expressed a negative attitude (Ar-



kansas was selected because it was one of the first states to pass legislation on advance directives). Fifty-five percent of respondents had had actual experience with advance directives, and 83.5 percent of these said their attitude became more positive as a result. Generally, they felt that advance directives were a good way for patients to influence their medical treatment should they lose the ability to verbalize their preferences. After completing an advance directive, patients were less worried about receiving unwanted treatment and doctors were less worried about the legal consequences of withholding treatment. Advance directives also help to reduce family discord over treatment and help to contain medical expenditures.

There is a gap, however, between the receptive attitude of doctors and the public toward advance directives and the actual implementation of such documents in the clinical setting. Of 219 randomly selected hospitals polled in a recent study, only two-thirds had an official policy on advance directives. The study was undertaken to answer these questions: What proportion of U.S. hospitals have formal policies on advance directives? Among hospitals with policies is information about advance directives actively requested, or is the burden of notification on the patient? What role do hospital ethics committees play in the formulation of such policies? Sixty-seven percent of the hospitals surveyed had official policies on advance directives, but only 4 percent actively inquired whether such documents existed. Ethics committees were not significantly associated with the formulation of these policies; of 69 hospitals that had both a formal policy and an ethics committee, only 43 percent had the policy reviewed by the ethics committee.

McCrary and Botkin recommend that all hospitals formulate and implement formal policies on advance directives. They further suggest that these policies include the hospital's asking whether the patient has formally expressed his or her treatment wishes. Advance directives safeguard a patient's autonomy and minimize conflict in a critical care situation, yet they are useless if the doctor is unaware of their existence. A competent patient who enters the hospital might forget to mention that he or she has formally stated his or her treatment wishes; hence a formal policy that routinely asked patients whether they had advance directives

**Advance directives safeguard a patient's autonomy and minimize conflict in a critical care situation, yet they are useless if a doctor is unaware of their existence.**

would bring all existing documents to light. Furthermore, if the physician knew an advance directive existed, she could discuss with the patient his expressed wishes before a crisis arose, giving the patient the opportunity to revise those portions that no longer accurately expressed his treatment preferences.

—A.P.

### **Church and government differ on new reproductive technologies**

Lisa Sowle Cahill, "Moral Traditions, Ethical Language and Reproductive Technologies," *Journal of Medicine and Philosophy* 14 (1989): 523-40.

This article attempts to mediate between two different ways of viewing new reproductive technologies designed to help infertile couples. The author critically examines the Vatican's *Instruction on Respect for Human Life in Its Origin and on the Dignity of Procreation: Replies to Certain Questions of the Day*, which focuses on the rights and welfare of the embryo and the protection of the family, and she examines the federal Office of Technology Assessment's (OTA) report *Infertility: Medical and Legal Choices*, which focuses on the rights of couples. After exploring the similarities and differences between these two approaches, the author presents a theory of the morality of reproductive technologies incorporating the conclusions of both papers.

The Vatican's instruction focuses on the rights and status of the embryo and on the integral connection between sex, marital commitment, and parenthood. It derives from the norms set forth in *Humanae Vitae* that each and every act of sexual intercourse must represent the values of love and procreation. The *Instruction* insists not only that conception should not take place outside of marriage, but that even in marriage it should take place only through an act of sexual intercourse. Even if the loss or destruction of superfluous embryos could be avoided, all techniques of laboratory conception are prohibited whether or not they introduce a third party as a donor. "Couples have a duty not only to respect the lives of embryos, but to respect and preserve the nature of mar-



riage and family as grounded in the psychospiritual and procreative partnership of one woman and one man" (p. 496). The *Instruction* takes the view that the new reproductive technologies endanger human welfare and rights.

In contrast, the OTA's *Infertility* focuses on the freedoms, interests, and rights of would-be parents, accords the embryo negligible moral status, and sees the role of the government primarily in terms of quality control and enforcement of reproductive contracts. Although donor and surrogate methods raise questions about the conditions necessary for parent-child bonding, these questions are not prohibitive. The document offers extensive information on the medical, legal, and financial aspects of reproductive technologies. It concludes that any means available should be used to help an infertile couple realize their free choice to have a child.

Despite their opposing conclusions the documents share some similarities. Each uses the mechanism of "rights" language to attempt to establish common ground, to advance moral claims, and to attempt to build consensus. "The authors of each seem to assume that their arguments about rights are self-evident and are grounded in values so basic and indisputable that the only prerequisite to agreement is elucidation and restatement" (p. 499).

Cahill believes that although both documents make valid moral points, neither pays significant attention to the other's perspective. Each document, by using a terminology of rights that assumes each point to be self-evident to all careful enough to follow the logic, is locked into its conclusion. To reach some consensus between the two opposing viewpoints, she rejects this use of rights terminology, replacing it with some fundamental observations about the relationship of marriage. First, the relationship of marriage has both a physical and a psychic dimension. The psychic dimension is realized in the partners' intentional commitment to one another; the physical dimension is realized in the sexual union of spouses, the possibility of biological parenthood, and in their sharing material goods and arrangements. If we focus attention so fixedly on either body or spirit that the importance of the other is disproportionately diminished or seen in a wholly negative light, then we split this basic union of marriage. Second, while both the ma-

**The definitive character of marriage is a commitment by each partner to share both physically and spiritually in the life of the spouse.**

**Parenthood, as an expression of this sharing, comes second to the fundamental commitment.**

terial and spiritual dimensions are essentially human, it is the spiritual dimension that is distinctively human and, as such, deserves more protection in cases of moral conflict. Finally, the definitive character of marriage is a commitment by each partner to share both physically and spiritually in the life of the spouse. Parenthood, as an expression of this sharing, comes second to the fundamental commitment. Any method designed to help the infertile couple produce children must attend to these aspects of the relationship of marriage if it is to be morally acceptable. The author concludes that homologous methods protect these values because they keep the procreative function within the partnership of marriage without introducing a third party: "In homologous techniques, the physical relationship of sexual intimacy and the biological relationship of parenthood are both preserved within the marital relation of the couple . . . the limit of justified compromise in linking marriage, sex and procreation ought to be drawn where one's physical procreative capacity is realized outside the spousal relation and within a relation of reproductive cooperation with a third party" (p. 516). Furthermore, homologous methods preserve the spirit of both *Infertility* and *Instruction* by maintaining the unity of marriage and still allowing an infertile couple the choice to have a child without falling into the absolutism and rigidity evident in both documents.

—A.P.

## Euthanasia still illegal in the Netherlands

M. A. M. de Wachter, "Active Euthanasia in the Netherlands," *Journal of the American Medical Association* 262, no. 23 (December 15, 1989): 3316-19.

Despite misconceptions to the contrary, active euthanasia remains a criminal offense in the Netherlands and the question of whether it deserves legal protection remains a subject of public debate. However, cases of active euthanasia do occur, and a precedent set by a 1973 court decision makes prosecuting a physician who practices active euthanasia difficult as long as



he or she abides by certain guidelines established to protect the patient. The purpose of this article is to assess the frequency of this practice in the Netherlands and to explain the mechanism that allows it to take place despite its status as a criminal offense. As of October 1989, no official statistics on the incidence of active euthanasia in the Netherlands exist; estimates range from 2,000 to 10,000 cases per year. Of 396 respondents to a national survey in 1986 of 900 randomly selected physicians, 48 percent had received one or more requests for active euthanasia, and, in these cases, 37 percent of the requests had been honored (most non-respondents cited time constraints as their reason for failing to participate; only two said they did not respond because they opposed active euthanasia). According to a 1986 report, 25 family physicians in The Hague were faced with 17 requests for active euthanasia during 1985. These requests were carried out in 9 of the 17 cases. The 25 physicians treat about 500 patients each year, and about 2 percent die through active euthanasia. However, reporting rates for the incidence of active euthanasia may be inaccurate for several reasons. "Permission for burial or cremation is given only after the physician has issued a death certificate declaring that the patient died of natural causes. Physicians who participate in euthanasia want to avoid questioning by police and coroners, and they also want to protect the patient's family from official inquiries" (p. 3317).

The current Dutch penal code states that anyone who takes another person's life, even at their explicit request, can be punished by imprisonment. However, the same penal code also states that someone is not punishable "if the person who commits that act is driven by an 'overwhelming power'—a sudden conflict of duties or interests in a situation in which a choice must be made" (p. 3317). Actual practice with regard to punishing physicians who participate in active euthanasia was shaped in 1973 when the first Dutch physician was prosecuted for taking the life of one of his patients. The physician was convicted and given a suspended sentence of one week in jail and one year's probation. The court stated, however, that euthanasia would have been acceptable if six conditions had been fulfilled, among them, that the patient be incurably ill, that the patient be experiencing unbearable suffering, that the

**Although a certain professional and legal tolerance of active euthanasia has been established in the Netherlands, it is not based on a comprehensive ethical or legal framework.**

patient request the termination of his or her life, and that the patient's physician perform the euthanasia. In a 1984 court decision, consultation with a colleague was added as a necessary criterion for active euthanasia to be morally acceptable and legally pardonable. Court decisions in the 1970s and 1980s established the three conditions of the patient's request, the hopeless situation, and collegial consultation as necessary conditions for the acceptable practice of active euthanasia. Despite a permissive court policy, no change has been made in legislation concerning active euthanasia. Physicians and health care institutions have established policies of review and guidelines to be followed if a patient requests euthanasia. These checks include review of the case by a team consisting of the attending physician, the chief of service, and the head nurse, and also referral of the case to the department head and the director of the hospital before any action is taken. The author notes in conclusion that although a certain professional and legal tolerance of active euthanasia has been established in the Netherlands, it is not based on a comprehensive ethical or legal framework.

—A.P.

### **Ethics of fetal tissue transplantation**

Council on Scientific Affairs and Council on Ethical and Judicial Affairs, "Medical Applications of Fetal Tissue Transplantation," *Journal of the American Medical Association* 263, no. 4 (January 26, 1990): 565–70.

Richard B. Miller, "On Transplanting Human Fetal Tissue: Presumptive Duties and the Task of Casuistry," *Journal of Medicine and Philosophy* 14 (1989): 617–40.

Fetal tissue transplants have been attempted in the treatment of several clinical disorders including Parkinson's disease, diabetes, and immunodeficiency and metabolic disorders. Fetal tissue has intrinsic properties—it grows faster than transplanted adult tissue and is less likely to be rejected by the immune system—that make it attractive for transplantation research. Studies on animals indicate that the therapeutic



value of these transplants is promising. For research to continue, however, ethical questions regarding the use and procurement of fetal tissue must be addressed. Specifically, there is concern that the potential for transplanting fetal tissue will influence a woman's decision to have an abortion. A woman might become pregnant with the sole purpose of donating tissue to a sick relative, or an ambivalent woman might be swayed to have an abortion by the potential good to be derived from donating the tissue from her fetus. These two articles provide guidelines for procuring fetal tissue for transplants ("Medical Applications of Fetal Tissue Transplantation") and an ethical defense of this practice ("On Transplanting Human Fetal Tissue: Presumptive Duties and the Task of Casuistry").

The Council on Scientific Affairs and the Council on Ethical and Judicial Affairs of the American Medical Association assert that the retrieval and preservation of usable tissues cannot become the primary focus of abortion. To prevent such an abuse they recommend three prohibitions: (1) fetal tissue cannot be donated to a designated recipient, (2) fetal tissue cannot be sold, and (3) the request for consent to use the tissue for transplantation cannot be made before the final decision regarding an abortion has been reached. Since the abortion process may also be influenced inappropriately by the physician, "measures must be taken to ensure that decisions to donate fetal tissue for transplantation do not affect either the techniques used to induce the abortion or the timing of the procedure itself with respect to the gestational age of the fetus" (p. 568). Also, to avoid conflict of interest, physicians and other health care professionals involved in performing abortions should be prohibited from receiving any direct benefit from the use of tissues taken from the aborted fetus. The council asserts that the "principal ethical concern in the use of human fetal tissue transplants is the degree to which the decision to have an abortion can be separated from the decision to donate post-mortem tissue" (p. 569).

Richard Miller attempts to provide an ethical defense for using fetal tissue in transplants. His arguments rest on two analogies. First, for a general ethical framework, he draws from just war reasoning. Such reasoning provides a justification for overriding a prima facie duty. Sec-

**The duty to the health of others—present or future, individuals or groups—may justify overriding the duty not to use persons as instruments.**

ond, for the specific case of transplanting fetal tissue, he relies on the ethics of organ transplantation and the use of cadaverous tissue. He argues that the justification for transplanting fetal tissue begins by overriding the prima facie duty not to use others merely as means to ends; the limitations surrounding such use parallel those governing harvesting organs from the dead. Central to these limitations are safeguards against conflicts of interest.

Prima facie duties must be satisfied unless they conflict with other goods in a carefully defined set of circumstances. They are not absolute, but they require justification to be overridden. For example, a just war constitutes an exception to nonmaleficence, in which the duty not to harm may be overridden by the obligation to protect oneself and others from danger. In the case of fetal tissue we begin with the prima facie duty not to use persons—dead or alive—as means to ends. This duty is overridden in those exceptional cases in which other lives may be saved or great advances made in medical knowledge for future generations. The duty to the health of others—present or future, individuals or groups—may justify overriding the duty not to use persons as instruments. Though we may find justifications to override these prima facie duties, the original duty imposes restrictions on the resulting practice. In the case of war not all means are allowed toward the end of reestablishing peace; killing innocent civilians, for example, is not allowed no matter how much it contributes to ending the war. In the case of fetal tissue transplants, the restrictions are found by studying the prohibitions on harvesting organs from the dead.

The fetuses used for tissue transplants are dead; the respect we owe to them is an extension of the respect for nascent life and of the general respect for the dead. Using dead fetuses should be governed by the same canons that govern the use of cadaverous tissue because the primary factor in not using either as a means to an end rests in attending to the conflict of interests. In the case of organ transplants our desire to put the dead or dying individual's organs to good use does not interfere with our duty not to use persons dead or alive as a means to an end. In the case of using fetal tissue, it is essential to keep the decision to abort separate from the decision to donate the fetus's tissue. The use of cadaverous tissue is governed by the Uniform



Anatomical Gift Act, and these stipulations apply in the case of fetal tissue transplants: (1) there must be no financial exchange; (2) there must be a clear separation, in timing and procedure, between the abortion decision and the decision about using fetal materials; (3) someone other than those procuring the tissue should determine the death of the fetus; and (4) anonymity between donor and recipient must be preserved (p. 625).

The inseparability of abortion from the issue of fetal transplants goes beyond mere conflicts of interest, however. "Fetal material is provided by induced abortions some of which may be morally questionable" (p. 627), and this raises the issue of complicity. Complicity can take several forms. First, in using the tissue from elective abortions does the researcher put himself or herself in cooperation with the abortionist? The author argues that the researcher need not be in moral cooperation with the abortionist because those procuring cadaverous tissue are not assisting in the deaths themselves. The abortions would be occurring anyway; they are not a means to the end of fetal research. As long as the criteria cited above are met, the researcher is separate from the abortion process.

Second, does the possibility of a beneficial use of fetal tissue make abortion more acceptable? The author counters: "The safeguards listed above are designed to remove any incentive on the part of the woman to abort for purposes of gain, be it financial or otherwise. Such safeguards, especially those separating the decision to abort from decisions about subsequent use of fetal material, are designed to remove any incentive to abort for reasons other than maternal well-being" (p. 632).

The third form of the complicity question is raised by Richard McCormick and focuses attention on the relationship between procuring fetal tissue from elective abortions and cultural attitudes about nascent life: "Is the progress achieved through such experimentation not likely to blunt the sensitivity of Americans to the immorality of the procedure that makes such advances possible, and thereby entrench attitudes injurious to nascent life?" (p. 632). The author asserts that the relationship between medical progress and negative attitudes about nascent life would be difficult to determine. More important, however, those questions should be faced head on by reconsidering the

**Does the possibility of a beneficial use of fetal tissue make abortion more acceptable?**

morality of abortion. "Policy about research and transplantation ought not to carry the weight of . . . attitudes about abortion" (p. 632).

The final version of the complicity question concerns the weakening of moral integrity. In the case of fetal transplants, "does the collection, dissection, and transplantation of fetal tissue brutalize the women and men who perform these procedures lowering their respect for life? Does the taint of abortion deleteriously affect moral expectations surrounding biomedical research? Does the taint of association . . . imply approval?" (p. 633). Again, the author believes these objections do not hold so long as the individuals involved in the research are careful to avoid abuses: "Transplanting fetal tissue is an instance, at most, of indirect scandal in a culture in which abortion remains a highly emotional and controversial issue. Given the putative benefits of transplanting fetal tissue, at least at this experimental stage, the alliance between abortion and procuring fetal materials would seem justified by proportionate reason" (p. 634).

—A.P.



# POINT OF VIEW

## Politics of Abortion Stifle Promising Areas of Research

Myron Genel and Sarah Carr

For a decade, federal policy on fetal research and in vitro fertilization has been dictated by opponents of abortion. Today, although many observers sense a shifting of public opinion and political will regarding abortion rights, prolife groups maintain a firm grip on these aspects of federal biomedical-research policy. With federal funds already barred for in vitro fertilization and certain kinds of fetal research, antiabortion forces recently have managed to stifle yet another promising area of therapeutic medical research: the transplantation of fetal tissue obtained from elective abortions into patients with incurable diseases, such as Parkinson's and juvenile diabetes.

The failure to invest federal resources in these areas of research has serious consequences for fetal and human health. Even more troubling, however, is what abortion politics has done to the government's ability to develop public policies in a rational manner. Promising research will continue in a limited way without federal money, but a national policy and strategy for such research are badly needed.

In the current climate, no sensible way exists to discuss differences of opinion and to search

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for a common ground. Critical issues are either left unresolved or are swept into the courts—an often woefully inadequate place for the consideration of weighty ethical matters.

Federal policy on fetal research and in vitro fertilization is defined in regulations established in 1975, based on recommendations of the National Commission for Protection of Human Subjects of Biomedical and Behavioral Research. In addition to setting ethical parameters for conducting fetal research, the regulations created an Ethics Advisory Board in the Department of Health and Human Services to provide guidance when special problems arose in interpreting or applying the rules. Unfortunately, the advisory board has not operated since 1980. Antiabortion groups never supported the board's existence, and they have made its continued suppression one of their important political objectives.

In Congress, where antiabortion sentiments have been deeply entrenched for two decades, the bioethical stalemate also has paralyzed its deliberative processes. A congressional Biomedical Ethics Board and a companion advisory committee authorized in 1985, in part to review fetal-research policy, have never functioned because of disputes over potential members and their views on abortion.

The issue of transplantation of fetal tissue—the most recent area of political conflict—first arose in the fall of 1987, when researchers at the National Institutes of Health were preparing to conduct an experiment involving the implantation of aborted neural tissue into the brain of a patient with Parkinson's disease. As with all human-subjects research, the proposed experiment was scrutinized by scientific and ethical review boards at NIH. Although the research

*Myron Genel, M.D., is professor of pediatrics and associate dean for government and community affairs at the Yale University School of Medicine. He has served as chair of Connecticut's Transplant Advisory Committee since its inception in 1984.*

*Sarah Carr is a legislative analyst with the Association of American Medical Colleges.*



involved the use of postmortem fetal tissue, which is permitted by current regulations in accordance with "applicable state or local laws," HHS officials refused to approve the research until ten questions about the ethical, legal, and scientific implications were resolved.

NIH convened a panel of 21 experts in the fields of science, medicine, law, ethics, and religion to study these questions. Following presentations by biomedical experts and public testimony from both proponents and opponents of the research, panel members debated what public policy should be concerning the use of aborted fetal tissue. Their deliberations were not without discord, but 17 members of the panel did conclude that the use of fetal tissue from elective abortions in transplantation research was "acceptable public policy."

While finding that abortion created "a set of morally relevant considerations," the 17 panel members concluded that "the possibility of relieving suffering and saving life cannot be a matter of moral indifference to those who shape and guide public policy." They went on to recommend guidelines for such research. One of the main arguments against tissue transplantation research is that it might encourage or sanction abortion. The recommended guidelines therefore isolate a woman's decision to undergo abortion from consideration of how the resulting tissue would be used.

The panel's report, including statements of dissent from four members, was approved by the NIH director's advisory council in December 1988. The advisory council unanimously recommended that the moratorium on federal funding of research with fetal tissue be lifted. Recently, however, Dr. James O. Mason, the Assistant Secretary for Health, announced that HHS would continue the ban indefinitely. Thus the government has rejected a thoughtfully developed policy that respects widely divergent views, to accommodate the inflexible views of one segment of the American public.

Despite the moratorium on federal funding, research at some institutions will undoubtedly continue with private support. After years of basic research into the usefulness of transplanted fetal tissue and the establishment, by investigators throughout the world, of a primate model for Parkinson's disease, investigators from Yale and the University of Rochester have demonstrated that tissue from monkey

fetuses can restore neurological function in adult monkeys with induced Parkinsonism. Yale investigators have also shown that human fetal tissue, obtained from standard abortion procedures, could be transplanted into monkeys and produce the same results. Much of this research, save that involving human fetal tissue, was supported by NIH.

Scientists and physicians at Yale felt a compelling need to pursue a human trial of this potential treatment for Parkinson's, a disease with ominous long-term consequences and no effective long-term therapies. Before proceeding with clinical trials, however, investigators, ethicists, and administrators at Yale deliberated for 21 months over the ethical and scientific issues involved. The final experimental design is consistent with the guidelines developed by the 21-member NIH panel. In December 1988 the first implant of aborted fetal neural tissue into a patient with incapacitating Parkinson's disease was performed: a two-year study involving 20 patients is under way.

Still, the applications for cell replacement therapies will not be determined with one or two pilot studies. Developing alternatives to the use of fetal tissue, through cellular and genetic engineering techniques, very likely depends first upon understanding the capacities of fetal cells. For the universities sponsoring such research and the scientists conducting it, absence of federal funding exacts a toll financially and discourages other potential donors from supporting such studies. Moreover, in the current climate, few institutions not already involved are likely to initiate similar studies in the future.

Discouraging research in this and other controversial areas has troubling consequences for academic institutions, but the costs to society are even greater. Potential therapies for sufferers of certain chronic diseases may be lost. Progress in treating a number of congenital disorders and diseases of pregnant women and developing fetuses will be slower than necessary. Research into the profound effects of crack cocaine on the developing fetus and the tragic prenatal transmission of AIDS will be delayed.

Furthermore, when federal money is not available, federal oversight and scientific peer review on a national level also are absent. A recent example of what can result is the unguided development of an in vitro fertilization industry that has no identifiable or verifiable

**One of the main arguments against tissue transplantation research is that it might encourage or sanction abortion. The guidelines therefore isolate the decision to undergo abortion from consideration of how the resulting tissue would be used.**



standards. Social equity is also an issue. A government unwilling to support research is unlikely to pay for treatments, yet the benefits of fetal research and research employing fetal tissue, if substantiated, will surely be available to the more privileged of our society (if not in this country, then overseas).

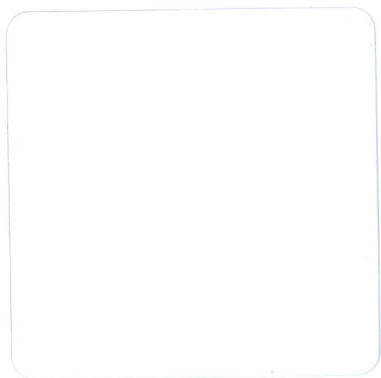
Promising avenues of research will be stymied until the bioethical stalemate confounding government and lawmakers is overcome. Public policy must be decided in a rational manner that recognizes and respects the diversity of beliefs and values held by American citizens. That will not happen, we fear, unless the public rejects, and our political leaders confront, the moral absolutism of antiabortion forces—or

**Discouraging controversial research is troubling for academic institutions, but the costs to society are even greater.**

until the movement itself tempers its unyielding posture.

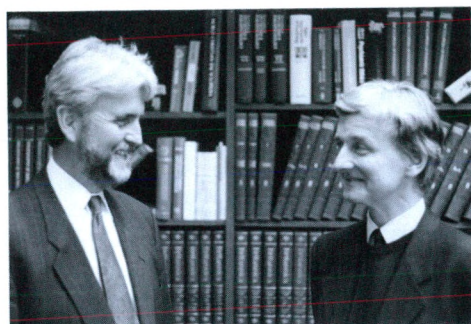
*Condensed from an article that appeared in Chronicle of Higher Education, 15 November 1989, p. A56.*

*In the Point of View section, we will print original or already published opinion pieces on issues related to health, faith, and ethics. This section is not intended to reflect the opinion of the Park Ridge Center. Readers should submit such pieces to the editor of the Bulletin.*





# CENTER NEWS



Center president Laurence O'Connell (left) with Professor Dietrich von Engelhardt of the University of Lübeck.

## Center forms alliance with institute in West Germany

The Park Ridge Center is beginning to make international linkages. On March 8, 1990, Laurence O'Connell, president of the Park Ridge Center, and Dietrich von Engelhardt, director of the Institute for the History of Medicine and Science at the Medical University of Lübeck, West Germany, entered into a formal alliance to further their mutual interests in the areas of research, publication, and education. Founded by Professor von Engelhardt in 1983, the institute's purpose is to promote research and education in the history of medicine and natural science considered within their social and cultural contexts. In addition to carrying on a full program of research, the institute offers medical students courses in medical terminology, the history of medicine, medical sociology, and medical ethics.

Professor von Engelhardt has recently published *Ethik im Alltag der Medizin* (Ethics in Everyday Medicine). The volume examines the historical setting and systematics of medical ethics and its relationship to law, philosophy,

and theology as well as to research, therapy, and a wide range of theories of medicine and natural science—all with reference to concrete situations and problems.

In an effort to promote greater international scholarship and dialogue in medical ethics, both institutes are currently discussing as their first cooperative project an ongoing series of international yearbooks in bioethics. The first is tentatively planned for January 1992.

## Television series features Center books

A three-part television series produced by the Catholic Telecommunications Network of America is based on the Center's Health/Medicine and the Faith Traditions book series. The programs, directed by Fr. Robert Bonnot of CTNA, illustrate how three major religious traditions deal with contemporary issues in health and medicine. Each program features a single tradition: Judaism, Islam, and Roman Catholicism. Center president Laurence O'Connell and Senior Associate James Wind are participants in the television series along with Center authors Rabbi David M. Feldman and Richard A. McCormick, S.J.

## Ethics panel creates document on invasive life support

In May 1989, Center president Laurence O'Connell participated in the Consensus Panel on Ethical and Moral Guidelines for the Initiation, Continuation, and Withdrawal of Intensive Care, co-sponsored by the American College of Chest Physicians and the Society of Critical Care Medicine. According to James L. Breeling, director of education for the ACCP, the resulting report will be "a landmark document."

Minimum speed at which nerve impulses move through the body (in miles per hour):

135

Source: *In Health*





A University of Minnesota survey found that clinically depressed people are much less likely to believe in God than is the population as a whole. Only 75% of those with anxiety disorders and 88% of those with major depression believe in God, compared with 95 percent of the general population.

The psychiatrist conducting the survey wondered, "Are they depressed because they don't believe in God, or do they not believe in God because they are depressed?"

Source: *Context*



It will be published in *Chest*, the official journal of the ACCP. Panelists were chosen for their expertise in medical, theological, legal, or economic aspects of critical care medicine.

## First Council of Europe Symposium on Bioethics held

The Council of Europe, comprising 23 Western European states, strives to promote European unity, protect human rights, and facilitate social and economic progress. In recent years problems posed for law, ethics, and human rights by progress in the biomedical sciences have emerged as a central concern at the Council. The First Council of Europe Symposium on Bioethics (December 5-7, 1989) was directed toward opening discussion on these critical problems as they affect member states.

Center President Laurence J. O'Connell was invited to the symposium in Strasbourg, France, to deliver a presentation on ethics committees and ethics consultation in the United States. Other speakers addressed the topics of bioethics in the medical school curriculum, international regulations governing biomedical research, bibliographical resources, and research in bioethics. Focusing on the dissemination of general information, the symposium steered clear of policy debates. The Council of Europe promises to become a central participant in international discussion of bioethical issues.

## Nursing experts join in colloquium

A colloquium on "Ethics and the Nursing Profession," designed by Senior Associate Ronald P. Hamel in cooperation with Senior Fellow Judith Ryan, was held April 4-5, 1990, in Chicago. The colloquium brought together ten of the country's top thinkers in the nursing profession and several experts in related fields to consider the theory and practice of nursing ethics and the state of the profession in the present health care system.

## Linares principals meet with journalists

Four principals in the Linares case recently participated in a seminar at the Center with twelve William Benton Fellows in Broadcast Journal-

ism (University of Chicago). The focus of the discussion, held on November 16, 1989, and moderated by Center staff, was the media reporting of the case in which Rudy Linares held a nursing staff at bay with a pistol while he removed his permanently unconscious infant son from a respirator. Participants in the Center's discussion included the attending physician, the vice president and general counsel at Rush-Presbyterian-St. Luke's Hospital in Chicago, the director of public relations, and the hospital spokesperson who handled press relations in the case. Benton Fellowship director Peter Herford described the content of the seminar as "the toughest and most important we are likely to tackle all year." The Center has been asked to host another session.

## Abortion report distributed—and revised

The Center's special report "Abortion, Religion, and the State Legislator after *Webster*" was distributed in January 1990 to Center Associates and all 7,500 state legislators and has received much favorable response.

One reader, however, pointed out that the report's summary of the Roman Catholic position on abortion could be misunderstood. A revision, which is being inserted in all copies now being sent out, reads as follows:

Of all religious faiths, Roman Catholicism probably takes the most restrictive position. All direct abortion is prohibited, even to save the life of the mother. This moral prohibition lies in the belief that abortion intends the unjustified destruction of innocent human life. Although the church has never officially stated when the fetus receives a human soul (i.e., whether at conception or later), the operative theological assumption since 1869 has been that it occurs at conception. From that moment on there is a person. This is the position reflected in recent church documents dealing with abortion. For example:

"The human being is to be respected and treated as a person from the moment of conception; and therefore from that same moment his rights as a person must be recognized, among which in the first place is the inviolable right of every innocent human being to life" ("Instruction on Respect for Human Life in Its Origin and on the Dignity of Procreation," March 1987).



Extra copies of the report are available for \$1.35 each for fewer than ten, and \$1.00 each for ten or more. For any quantity, please add \$2.50 for shipping and handling. Orders should be prepaid and sent to the Park Ridge Center.

### Center co-sponsors AIDS conference

An international conference, "AIDS and Justice: Ethical, Legal, and Economic Issues in the International AIDS Epidemic," is being co-sponsored by the Center with the Kaiser Permanente Foundation of Northern California, the Bioethics Consultation Group in Berkeley, California, and Hospital San Raffaele of Milan, Italy. The conference will study issues concerning justice, public awareness, minorities, distribution of resources, access to care, and discrimination. (For information on dates and place, see the *Bulletin Board*.)

### Second interdisciplinary seminar convenes

A seminar entitled "The Park Ridge Center Interdisciplinary Seminar in Medicine, Faith, and Ethics" is the second such seminar coordinated by Research Assistant Jonathan Sande. Participants are students, fellows, and faculty in health care, theological ethics, and related disciplines. The group meets monthly to discuss a common text, present papers, or discuss their research. The theme for this year's seminar is "Toward a More Human Medicine." At the first session, in January, the group viewed and discussed the film *Dax's Case*, about Texas burn victim Dax Cowart.

### Three Center books published

Three Center-sponsored books have come off the press in the last few months. *Healing and Restoring: Health and Medicine in the World's Religious Traditions* (Macmillan) is a companion volume to *Caring and Curing: Health and Medicine in the Western Religious Traditions* (Macmillan 1986). Two more volumes in the Health/Medicine and the Faith Traditions series have also appeared: Prakash Desai's *Health and Medicine in the Hindu Tradition* and Stanley Harakas's *Health and Medicine in the Eastern Orthodox Tradition*, both published by Crossroad.

### Center co-sponsors genetics conference

The Center is co-sponsoring a two-part conference on genetics, religion, and ethics with the Institute of Religion at the Texas Medical Center in Houston and others. The first of the two national conferences, "Implications of the Human Genome Mapping Project for Medicine, Theology, Ethics, and Policy," was held at the Texas Medical Center on March 29-31, 1990. The second will be held in 1992.

### Second Opinion distributed to church leaders

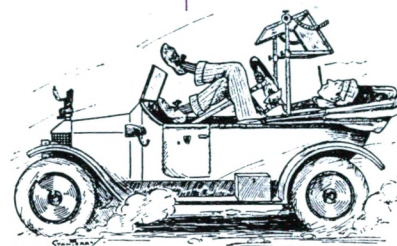
Sixty-five hundred copies of *Second Opinion* Volume 13 are being distributed by the Wheat Ridge Foundation to church leaders and others who participated in the conference featured in that issue—"Striving for Fullness of Life: The Church's Challenge in Health." The conference, co-sponsored by the Wheat Ridge Foundation and the Carter Center of Emory University, included speeches by C. Everett Koop, Jimmy Carter, Rosalynn Carter, Martin Marty, Carter Center Executive Director William Foege, and Assistant Secretary for Health James Mason. The speeches are published in *Second Opinion* Volume 13.

### Boards plan for bioethics certification

The Center recently hosted a joint meeting of board members of the Society for Bioethics Consultation and the Society for Health and Human Values. The group, including Center president Laurence O'Connell (who is also president of the Society for Bioethics Consultation), is working together on a proposal for certification of bioethics consultants.

A recent study in Iowa found that the average hospital bill for motorists injured in auto accidents was \$2,462 among those who were not wearing seatbelts vs. \$753 among those who were.

Source: JAMA





## BULLETIN BOARD

Mean debt of indebted medical students upon graduation (about 80% are indebted):

\$42,200

Source: *New York Times*

*Readers are invited to submit announcements of meetings, conferences, and seminars of likely interest to their colleagues in the areas of health, faith, and ethics. The announcements as well as calls for papers and other items of general interest to the Bulletin's readership will be published in the Bulletin as space permits. Please direct such announcements to Sandy Pittman, managing editor of the Bulletin.*

### Center positions open

The Park Ridge Center is accepting applications for two positions. The first is Senior Associate for Religion, Health, and the Humanities. Candidates should hold a Ph.D. and be recognized scholars in the field of American religion with a significant publication record. They should bring proven ability to design, lead, and evaluate research that probes the deep relationships among religion, culture, and modern health care.

The second position is Associate for Theology, Ethics, and Clinical Practice. This is a three-year full-time appointment. Candidates should hold a Ph.D. in theological or philosophical ethics or in medicine and health care, and possess evident research, writing, and organizational abilities. This person will work closely with the Senior Associate for Theology, Ethics, and Clinical Practice and will be responsible for assisting in the development of research projects and particularly for coordinating and administering those projects, monitoring selected literature, and carrying out a research project of his or her own.

Letter of application and current vita should be sent to Laurence J. O'Connell, President, The

Park Ridge Center, Suite 450, 676 N. St. Clair, Chicago, Ill. 60611. Applications will be accepted until June 15, 1990.

### Staff openings at the Hastings Center

The Hastings Center, a medical ethics research center in New York, expects to have two openings on or before September 1, 1990: Center Associate, who will work under the director and provide significant intellectual and managerial leadership for all facets of the Center's work, and Editor of the *Hastings Center Report*. Letters of inquiry should be directed to Personnel Office, The Hastings Center, 255 Elm Road, Briarcliff Manor, NY 10510-9974. Phone: (914) 762-8500.

### Conferences

*International Conference on AIDS and Justice*, June 24-27. San Francisco Marriott Hotel. This conference on the ethical, legal, and economic issues in the international AIDS epidemic is co-sponsored by the Park Ridge Center (more information in "Center News"). Contact: Conference Coordinator, Bioethics Consultation Group, P.O. Box 10145, Berkeley, CA 94709. Phone: (415) 486-0626.

*National Association of Residential Care Facilities*, May 26-29. Bedford, Mass. Contact: Harve C. Horowitz & Associates, 11620 Vixens Path, Ellicott City, MD 21043. Phone: (301) 997-0763; in D.C. dial 596-3028.

*Society for Disabilities Studies*, June 13-16. Quality Hotel Capitol Hill, Washington, D.C. Contact: Harve C. Horowitz & Associates, 11620 Vixens Path, Ellicott City, MD 21043. Phone: (301) 997-0763; in D.C. dial 596-3028.





**American Association for the History of Medicine**, May 10–13. Sheraton Inner Harbor Hotel, Baltimore, Md. Contact: Dr. E. C. Atwater, Department of Medicine, University of Rochester Medical Center, Rochester, NY 14642. Phone: (716) 275-2903.

**American Hospital Association**, May 31–June 2. San Francisco, Calif. Contact: S. Purdie, 840 N. Lake Shore Drive, Chicago, IL 60611. Phone: (312) 280-6650.

**International Conference on Missionary Medicine**, June 2–5. Epworth by-the-sea, St. Simons Island, Ga. This conference is sponsored by MAP International and entitled "The Cost of Commitment: International Perspectives on Christian Health and Healing." Contact: S. Davis, 2200 Glynco Parkway, P.O. Box 50, Brunswick, GA 31521-0050. Phone: (912) 265-6010.

**Pastoral and Ethical Issues in Genetics**, June 25–29. Georgetown University Medical Center, Washington, D.C. This summer course is open to clergy, educators, and caregivers of all faiths and is taught by faculty from Georgetown Medical School, the Kennedy Institute of Ethics, and the National Center for Education in Maternal and Child Health. No scientific or formal counseling experience is required. Course activities include lectures, discussion, and clinical observation. Tuition is \$260. Scholarships and three CEU's are available, as well as on-campus housing. For a detailed brochure on the program contact: Frank D. Seydel, Dept. OB/GYN, Georgetown University Medical Center, Washington, DC 20057. Phone: (202) 687-8810.

**European Society for Philosophy of Medicine and Health Care**, June 15–16. Bochum, Federal Republic of Germany. The theme for this conference is consensus in medical ethics. Contact: Professor H. M. Sass, Zentrum für Medizinische Ethik, Ruhr-Universität Bochum, Postfach 102148, 4630 Bochum 1, FRG.

**International Society of Technology Assessment in Health Care**, May 20–23. Marriott Medical Center Hotel, Houston, Texas. Contact: Ms. Jan Glover, Program on Humanities and Technology, University of Texas Health Science Cen-

ter, P.O. Box 20708, 6431 Fannin Street, Houston, TX 77225. Phone: (713) 792-5140.

**Health and Spirituality: The Abundant Life**, October 12–14. Danvers, Mass. (just north of Boston). Conference speakers will include poet Maya Angelou and psychiatrist and best-selling author M. Scott Peck. Contact: Rev. William Cuntiz, Office of Development, Andover Newton Theological School, 210 Herrick Road, Newton Centre, MA 02159.

Annual deaths from  
substance use and abuse  
(U.S.):

Tobacco:

346,000

Alcohol:

125,000

Alcohol and drugs:

4,000

Heroin/morphine:

4,000

Cocaine:

2,000

Marijuana:

75

Source: *Utne Reader*





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## **THE PARK RIDGE CENTER**

**FOR THE STUDY OF HEALTH, FAITH, AND ETHICS**

The Park Ridge Center for the Study of Health, Faith, and Ethics exists to study the deepest questions that confront people as they search for health and encounter illness. Its programs of research, publishing, and education explore dimensions of these fundamental human experiences that are frequently overlooked in an environment of specialization and technology. For this reason the Center gives special attention to the religious and secular expressions of faith that are present in all health care situations, bringing faith into conversation with more frequently heard medical, philosophical, and legal voices. In doing so the Center seeks to contribute to ethical reflection on a wide range of health-related issues—from clinical medicine to the formation of public policy. As it makes and disseminates its discoveries, the Center seeks collaboration with representatives from all religious communities, all health care professions, and all academic disciplines that share our commitment to ever more adequate forms of care.

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