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Second Opinion

health, faith, and ethics



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Second Opinion, as its name implies, recognizes that the complexities of modern health care make it increasingly difficult to find the single “correct” action, thought, or method. Each situation is open to a variety of apparently legitimate and appropriate interpretations and applications. But such confrontations with ambiguity need not lead to discouragement. They can instead elicit greater research, discussion, and thought.

By inviting contributions from a wide range of perspectives, *Second Opinion* stimulates interdisciplinary conversations between members of fields relating to health, faith, and ethics. While other publications deal with one or two of these concerns, *Second Opinion* distinctively seeks to address all three. The Park Ridge Center created this publication in the hope that it will help form one public out of a number of related constituencies. This public will not only wish to relate ethics and faith to health issues, but should also, through lively and enlightened interchange, be better equipped to do so.

Second Opinion

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Initial Comment

Ineluctable Forces

The *Oxford English Dictionary* defines *ineluctable* as “that from which one cannot escape by struggling.” Perhaps, like the word *oxymoron*, *ineluctable* will become a buzzword in our contemporary conversations. There’s a delicious crunchiness to it; its users sound as though they mean business.

It also carries ominous overtones that resonate with much of our experience. Besides death and taxes, so many dynamisms in life seem beyond our control. Although our daily odysseys may abound with choices, life beyond our everyday realms often seems implacable. American society ages, our institutions follow their own bureaucratic impulses, our pervasive cultural confusion about values deepens. In the face of such ineluctability, retreat to private spheres becomes an attractive option. Yet those forces grind on.

Consider the “ineluctable forces” that worry medical economist Eli Ginzberg. “The high cost of introducing and perfecting new technology; the opportunities for corporate enterprises to attract and retain both young and mature physicians who will be available, even eager, for salaried employment; the current unbundling of services, which is likely to accelerate as entrepreneurial physicians see opportunities to improve their earnings by undertaking more diagnostic work and other procedures in their offices, in preference to the hospital; the introduction of DRGs (reimbursement based on diagnosis-related groups), which will inevitably lead

to tighter hospital controls over modes of physician practice, mediated by ever more elaborate computerization; and the recent emphasis by both for-profit and non-profit hospitals on marketing policies and diversification, which are leading to links with other health care providers, particularly physician groups, nursing homes, and hospices, and intensifying the need for skilled management if the hospitals are to survive and prosper” (*American Medicine: The Power Shift* [Totowa, N.J.: Rowman and Allanheld, 1985], p. 18).

Ginzberg believes that this formidable phalanx of developments has led health care into the “vortex” of the money economy, creating an unavoidable conflict between moneymaking and the proper caring goals of medicine. But Ginzberg offers little hope in the face of this conflict. What’s needed for our response—political leadership, professional cooperation, and the commitment of Americans to enhance their health by changing their personal behavior—is “not yet visible on the horizon” (pp. 19, 27). The odds all seem to favor the ineluctable forces.

Although economic developments may have preoccupied us in the Reagan era, these are not the only ineluctable realities that concern health care providers and consumers. Medical science has its own dynamism, always pushing us further into the realms of experimentation and complexity. Technology rushes ahead, following (like the artificial

heart) its own relentless rhythms. And the human body harbors its own ineluctability. We learn of genetically encoded diseases, and we watch our bodies age. What can we do in the presence of all this inevitability?

We can begin by seeking to understand the larger shaping forces in our life. We can, as several authors in this issue attempt, explore the mystifying and frequently forbidding worlds that all too often remain the private preserves of the economists or the medical researchers. We can call attention to the troubling implications of our present actions. We can search for patterns and trends in the midst of modernity's chaotic sprawl.

Occasionally we can set aside our fear of the unknown and peer with wonder at vistas—like the one offered of DNA on this issue's cover—which possess qualities of the beautiful as well as the ineluctable. Once in a great while we can unravel another piece of the mystery of our existence. Perhaps, as the geneticists hope, with understanding and appreciation will come the possibility of reshaping what had previously been sheer ineluctability.

More likely will be the recognition that some things in life remain inescapable. Then our task shifts to a search for appropriate ways to live in the presence of things that cannot be changed even when we struggle. People with AIDS cannot—at this time—get rid of their disease. Instead they have the greater challenge of learning how to live and die with it. At such intersections with inevitability, or fate, or destiny, humans must step into the realm of imagination. Are there different ways to understand what is really going on? Are there different ways one can behave in the presence of the ineluctable? Are there resources available that can

assist one in reentering the struggle against what seems insurmountable? Can I find ways to let go of the struggle and redirect my life more meaningfully? Is life's meaning to be found in struggle or in resignation, and how will I know which to embrace?

The ineluctable can be a place of convergence for science and religion. At its best, science seeks to penetrate the mystery, to solve the problem. Our religious traditions, on the other hand, provide alternative frameworks, perspectives, ways of imagining what is being encountered. Although frequently without referring to each other, science and religion are co-investigators in the fundamental human effort to comprehend the ineluctable. Can their common encounters open the two cultures, as C. P. Snow called them, to each other?

Each article in this issue of *Second Opinion* seeks to help us approach the ineluctable. The journalist, churchman, historian of medicine, social ethicists, and theologians who write here offer differing assessments of our encounter with some of the dominant forces in our lives. They select different forces for us to consider; they suggest different ways to understand our situation; and they provide alternative imaginative avenues for us as we make our common way. They make us ask if things are as predetermined as they feel. They goad us to find fresh solutions. And they challenge us to think about how we should live in the presence of things we cannot control.

A handwritten signature in dark ink, consisting of a large, stylized 'J' followed by 'P. W.' in a cursive script.

James P. Wind

Experimenting with Humans

Part 2: Innovation or Exploitation?

OVER THE PAST four years, a small religiously affiliated hospital on the edge of the Mojave Desert has captured attention worldwide by audaciously testing the ethical boundaries of research on human subjects. The hospital, Loma Linda University Medical Center, has successively (1) transplanted a baboon heart into a baby suffering from a fatal cardiac defect; (2) pioneered a series of human-to-human heart transplants in newborns and drawn fire for initially denying such lifesaving surgery to one boy because his unwed parents were felt to be unsuitable care givers; and (3) harvested a heart from a hopelessly deformed newborn kept alive solely for the purpose of organ donation. Together with other news-making phenomena like the implanting of artificial hearts that induce paralyzing

strokes and the spread of potentially dangerous new microorganisms into the environment by geneticists without federal approval, these events have created a public perception that the field of human research remains imperfectly regulated, that a Wild West mentality prevails in which researchers make their own laws. Indeed, Loma Linda was able to act because of the lack of a national consensus on whether such activities as cross-species organ transplants and the use of malformed infants as sources for organ donations are medically and morally justifiable. As a Seventh-day Adventist hospital, Loma Linda places theological priority on the holistic health of the body in preparation for the day of Christ's return, so it was, in part, following an idiosyncratic and metaphysical agenda. Yet because



Four mothers and their babies celebrate with surgeon Leonard Bailey, who performed heart-transplant operations on the infants.

UPI/Bettmann Newsphotos.

each proposed procedure was scrutinized by the hospital's institutional review board (IRB), however homogeneous and doctrine-oriented that board may have been, Loma Linda was abiding fully by the letter of federal regulatory law. Thus the larger society receives the message that it is entirely possible for one maverick institution to undertake the most radical, even outlandish, medical interventions—and do so with complete impunity.

The perception that there exists a research Dodge City, however, is false. Experimental medicine has come a long way since 1803, when Thomas Percival drafted the first modern code of ethics pertinent to human research. That code counseled that the pursuit of new treatments should be governed by “sound reason, just

analogy, or well-authenticated facts” and that “no such trials should be instituted without a previous consultation of the physicians and surgeons, according to the nature of the case.” In our own time we have seen two national commissions grapple with the problem of reconciling society's collective need for medical progress based on human experimentation with the ethical imperative that we protect individual test subjects from abuse and exploitation. Very real fears prompted this exercise. Preceding the creation in 1974 of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, Americans had witnessed stark examples of scientific investigators preying on the poor, the incapacitated, and the uninformed in the pursuit of research goals (see Part 1 of this



Loma Linda University Medical Center, Loma Linda, California, has been the site of many innovative, and concomitantly controversial, medical procedures. (Photo by Dick Schaefer; courtesy of Loma Linda University Medical Center Community Relations Office.)

article in *Second Opinion*, vol. 6). Revelations concerning the U.S. Public Health Service's notorious syphilis study involving rural black men (Jones 1981), the Willowbrook State School experiment in which mentally retarded youngsters were intentionally infected with viral hepatitis (Rothman and Rothman 1984), and the Jewish Chronic Disease Hospital case in which twenty-two enfeebled patients were given injections of live cancer cells without their knowledge (Langer 1964), had troubled public, medical professionals, and policy-makers alike.

Over a four-year period, the National Commission pondered the issues inherent in research involving vulnerable populations, focusing on such subsets as fetuses, children, prisoners, and the mentally ill. The work culminated in a series of voluminous reports, including an ethical manifesto entitled the Belmont Report (U.S. Dept. of Health, Education and Welfare 1978). These documents elaborated policy goals which placed the rights of research subjects above all other considerations and enshrined in the research discipline such principles as respect for persons, beneficence, and equitable distribution of rewards and risks among all segments of society. From these principles were derived three requirements for human experimentation: (1) mandatory informed consent; (2) a determination that the anticipated benefits of a procedure outweigh its risks; and (3) a fair selection of research subjects, so that no group is disproportionately burdened. Paralleling these guidelines was the establishment of a system of advance

review of research proposals. The vehicle is a nationwide network of locally based institutional review boards. These IRBs are jointly monitored by the National Institutes of Health (NIH), which oversees all federally funded research, and the Food and Drug Administration (FDA), which, regardless of the source of funding, regulates research involving new drugs, devices, radiation materials, and biologicals (serums, vaccines, and other pharmaceutical preparations derived from animal products and other biological sources). These changes, together with voluntary observance of internationally accepted ethical guidelines like the Nuremberg Code and the Declaration of Helsinki, have made possible the realization of Percival's dream of professional review, with the addition of one new player, the experimental subject himself.

The apparently smooth functioning of modern research controls has led some to assert that such rigid vigilance is not necessary. But the danger of abuse has never been greater. Technology is fast-paced. Medical progress operates with a kind of manic license—the equivalent, in a way, of manifest destiny, the nineteenth-century doctrine used to justify American territorial expansion. To relax controls as we push scientific frontiers into ever newer realms would encourage in the medical setting the same kind of evils that occurred in this country's imperialistic epoch: expedient disregard for the rights of weak or exploitable populations in the name of the greater good—as the expansionists interpret “good.”



"Doctors still approach patients as if they were children, by virtue of their being sick and . . . of their alleged inability to participate in decision making because of medicine's esoteric knowledge."

—Jay Katz, professor of law and psychoanalysis at Yale University

Photo courtesy of
Yale University Law School.

But to ensure the sound regulation of cutting-edge medical inquiry is but half the job, for we have not yet resolved some of the basic questions involved in human research. How, for example, do we differentiate between a minor deviation from everyday therapeutic practice, to be performed without prior review, and a departure so significant that it constitutes outright research, requiring submission of formal protocols to an IRB? The distinction is not always clear. And how well is the principle of informed consent being observed in experimental practice? It is the purpose of this article to survey these and other challenges facing contemporary research on human subjects.

Innovative Therapy versus Research

Jay Katz, professor of law and psychoanalysis at Yale University and a trailblazing commentator on human experimentation, tells of attending a conference at which a researcher delivered a paper on leukemia chemotherapy in young children. The investigator informed the audience that he had performed more than six bone marrow biopsies in a two-week period to assess the effectiveness of the drugs. During the subsequent discussion period, Katz asked how the man had obtained IRB approval for something so discomfiting to infants as bone marrow biopsies. "He responded that committee review had been unnecessary because his was not a research project, but a therapeutic interven-

tion. I pressed him for an explanation and he told me that he had employed these procedures only in order to be more helpful to his infant patients in the therapeutic management of their disease" (Katz 1987:4).

As this illustration shows, the rise of the IRB system has been accompanied by a disturbing tendency to pass off as therapy what ought to be labeled research. This is not necessarily a deception to avoid IRB scrutiny. A gray zone does exist between what is clearly therapy and what is obviously experimentation. This is due in part to the inherent experimental nature of all medicine, as articulated by physician Thomas Chalmers in the legislative dialogue that led to establishment of the National Commission: "It is extremely hard to distinguish between clinical research and the practice of good medicine. Because episodes of illness and individual people are so variable, every physician is carrying out a small research project when he diagnoses and treats a patient" (Kay 1975).

Two definitions are most widely used to mark this boundary: *research* as activity intended or designed to yield generalizable knowledge, and *therapy* as activity intended or designed to yield benefits to an individual patient. But confusion reenters the picture because what a physician tries on one patient usually becomes, if it works, a candidate for use on similar patients. Thus the identical action can be viewed as both a form of therapy and a form of research, and in reality, clinicians are often motivated by the twin goals of helping single patients and an entire class of patients at the same time.

It is a necessary condition for medical progress that physicians have the latitude to seek creative solutions to clinical problems, based on their specialized knowledge, experience, and judgment. The National Commission recognized this need when it identified a category of IRB-exempt activity which it labeled *innovative therapy*. The term refers to the introduction, during the course of treatment, of novel procedures that modify common practice. For example, after giving a patient the recommended dosage of a given drug and observing no improvement, a physician may decide to increase the dose by some unspecified amount. Or he may use on a small child a device that has been previously approved by the Food and Drug Administration for use in adolescents or adults. Both of these activities would constitute innovative therapy. Clearly, though, at some point the deviation from standard practice becomes so great that one leaves the realm of treating patients more aggressively and moves into totally uncharted waters of experimentation. In principle, IRB approval of the planned activity would then be required. But at what point has the practitioner crossed the line?

"I would define *innovative therapy* as established, effective therapy used in a related but novel way," says William Weil, Jr., professor of pediatrics at Michigan State University and former chairman of the American Academy of Pediatrics Bioethics Committee. "For example, I know penicillin works very well against infections in children, and now I want to use it in infants. That's innovative therapy. But say I'm going to use it in heart

attacks. That's not innovative therapy, that's research." But confining innovative therapy to incrementally different but related activities still leaves ambiguity. For example, if it is innovative therapy to hike the patient's dose by 10 percent or 20 percent, what about raising it by 50 percent? Or doubling it?

Surgery presents special problems, and surgeons have indeed been a target for those who argue that a good deal of research is disguised as innovative therapy. In surgery, of course, there are generally no incremental issues. You either try a new technique or you don't. But how dramatic must the departure be to qualify as research?

"Suppose that in the middle of the night, in my brilliance, I decide I've got a new way to perform a liver transplant. And the next morning I go in and hook up all the blood vessels in different ways," says Arthur Kohrman, director of Chicago's La Rabida Children's Hospital and Research Center and chairman of the institutional review board at the University of Chicago. "That's undoubtedly research. It's easy to define the outrageous example. But on the other hand, let's say I want to experiment with other than standard settings on the heart pump for a subset of coronary bypass patients that I think will do better with slightly different settings. Is that research, or am I simply taking an already approved procedure and, because we know more about it now, making a modest improvement that deserves a try? Or say I cut open a patient in order to do an arterial graft and find an anatomical variation where

the artery branches off that I've never seen before. The patient is lying on the table with his insides hanging out, and I have only moments to decide to respond to something unique. Is that innovative therapy or research? A surgeon has to be able to respond to the unexpected. If I had to get an emergency consult with the IRB every time I was presented with a novel situation, or likewise if I had to do so every time I wished to change a nuance in a procedure, it would paralyze the practice of medicine."

Although surgeons are frequently criticized for failing to submit research protocols, Weil believes they are actually less likely to get away with unethical behavior than are other specialties. "What surgeons do is pretty obvious," he says, "whereas what a lot of other specialists do gets swept under the rug because no one's watching. You can't be in the operating room for hours separating Siamese twins or doing an intestinal transplant without drawing a lot of publicity. But if it had been a medical problem you'd never hear of it. Suppose you wanted to use cyclosporine or intravenous gamma globulin to treat diabetes. It would be hard for me to think of that as innovative therapy, and in fact, both of these are the subject of research protocols in this country. Yet if I wanted to try them in a surreptitious way, there would be nothing to stop me except a local whistle-blower."

Robert J. Levine, professor of medicine at Yale and a nationally acknowledged authority on experimental ethics, believes surgeons are acting less impulsively

these days. “More and more commonly,” he says, “surgeons are going to their IRBs. For one thing, they are increasingly getting reminders from their colleagues and others, namely nurses. Another factor is the influence of journals. Surgeons wishing to publish their new techniques must comply with the journals’ insistence upon evidence of review and approval from an IRB.”

Kohrman’s solution to the problem is first to recognize that there is no solution. “There is always going to be a gray area,” he says. “Eliminate creativity, and by definition you’re saying we can’t move forward. The people who are involved need to be made aware that there *is* a debate, and that when in doubt it is better to seek counsel than to make the assumption that everything should be subsumed under innovative therapy. In other words, err on the side of caution.” The best secondary line of defense is the requirement that all significant departures be given a formal controlled research trial subsequent to the initial use. The National Commission specifically addressed this point:

There is concern that innovative therapies are being applied in an unsupervised way, as part of practice. It is our recommendation that significant innovations in therapy should be incorporated into a research project in order to establish their safety and efficacy while retaining the therapeutic objectives. (Levine 1977:367–83)

Unfortunately, it is a requirement that is frequently ignored.

Neonatal Medicine

Nowhere has the distinction between innovative treatment and research been so blurred as in the field of neonatology. For many years, paralleling the meteoric development of neonatal intensive care, low-birth-weight and otherwise compromised newborns have been the subject of a great many medical procedures performed without restraint, without prior review, and often without parental consent. Based on empirical evidence of their worth, these procedures have been widely emulated by neonatal centers throughout the world, entering everyday practice without any formal proof of efficacy or safety.

“In years past, those in the field took some desperate measures to get children to respond,” says Audrey Brown, director of pediatric hematology and oncology at the State University of New York Health Science Center at Brooklyn. “Many things have become part of the armamentarium without having been properly tested.”

Particularly distressing is the growing realization that many of these innovative and unverified measures have had serious iatrogenic consequences, that is, the treatments themselves have been responsible for causing illness. The earliest example came in the 1940s and early 1950s, when oxygen was first used systematically to relieve the respiratory difficulties of premature infants. Thousands of children were blinded as the result



"It's almost inconceivable that research proposals which violate ethical principles could now be funded, carried out, or published."

—Audrey Brown, M.D., director of pediatric hematology and oncology, State University of New York Health Science Center at Brooklyn

Photo courtesy of SUNY Health Science Center at Brooklyn, Public Relations.

of an oxygen-induced condition known as retrolental fibroplasia. Had any clinical trials been undertaken, as finally were in 1954, this side effect would almost certainly have been discovered (W. Silverman 1980). Somewhat later in the 1950s, an attempt was made to employ with infants certain antibiotics that had been proven safe and effective in adults and older children, namely sulfa, mycins, and chloramphenicol. A number of premature babies died or suffered damage before studies disclosed the incompatibility of such drugs with preterm physiology.

In our own time, the universally accepted practice of airway suctioning in intubated newborns has been recently linked to the development of intraventricular hemorrhage, a common cause of brain injury and death in the nursery (Perlman et al. 1983:204–8). So has the therapeutic use of bicarbonates. Atropine and calcium, once thought to enhance neonatal heartbeat, have been found actually to decrease cardiac output. Mothers' milk, long assumed to be best for infants, has been shown to have the capacity to carry viruses that are dangerous to preterm infants, yet it continues to be dispensed from milk banks on the assumption that the benefits outweigh the risks. At least 38 infants recently died due to the intravenous administration of Vitamin E, a substance believed by some to prevent retrolental fibroplasia; simple safety studies might have averted this tragedy (Phelps 1981:924–26).

There has been an explosion in the use of extracorporeal membrane oxygenation to help ailing newborns

breathe, even though there have been few properly conducted experiments on the value of this dangerous technique. ECMO, as it is called, is the use of a heart-lung machine to drain blood from the infant's body, add oxygen and remove carbon dioxide by means of an oxygenator membrane, and then return the blood to the body. The diuretic furosemide, overaccumulations of which can cause hearing loss, has been widely administered to newborns even though no safe neonatal dosage has been established and evidence exists that neonates excrete the drug three times more slowly than do older people (Peterson et al. 1980:139–43). A controversial 1984 study raised the possibility that phototherapy, used routinely to combat neonatal jaundice and occasional brain damage associated with it, can destroy DNA in cultures of human cells (Rosenstein and Ducore 1984:3–6).

Meanwhile, it has been a common practice in this country to perform surgery and other invasive procedures on neonates without the benefit of anesthesia, based on a fear of anesthetic toxicity and the dubious theory that newborns, particularly preterm babies, don't feel pain. Instead, they have been routinely paralyzed with curare-based drugs, which have no role in pain reduction whatsoever. "The issue of how much pain can be justifiably inflicted is easy to overlook in infant surgery since the baby cannot state his preferences," notes Helen Harrison (1987:53), author of *The Premature Baby Book* and a frequent critic of nursery policies. The practice appears to be in rapid decline in the face of safer

anesthetics and new physiological evidence that newborns feel pain as intensely as anyone (Boffey 1987). But how could the medical community have taken so long to appreciate such a self-evident fact?

The National Institute of Child Health and Human Development (NICHD), an arm of the National Institutes of Health, recently came to the candid conclusion that neonatal medicine has introduced a number of innovative methodologies "without rigorous use of the controlled observation necessary for the objective evaluation of many of these innovations" (Request for Cooperative Agreement Application 1985:2). The agency further declared in a startling admission that

a major problem in neonatal medicine is the balance between assuring prompt implementation of new technologies, procedures, treatments, and drugs, and adequate assurance of their safety and efficacy. Indeed, because of the urgent demands of sick patients, care is often based on limited knowledge of new modalities not subjected to critical studies prior to introduction and acceptance. In a critically ill baby, an innovative idea may be tried which, if the baby's condition improves, can rapidly set a new trend and become routine. Therefore, the worth and/or safety of such new neonatal care modalities at times are not evaluated scientifically and their incorporation into the [neonatal intensive care unit's] arsenal of therapies is often based on limited experience.

In the view of George Cassady, director of the neonatal intensive care unit (NICU) at the University of Alabama at Birmingham, "New treatments ought to be treated as guilty until proven innocent." Says Cassady: "When, in the clinical setting, you are called upon to care for a dying baby and you know from several other institutions that a treatment has been shown to be helpful, you would hardly be comfortable denying the treatment to that dying baby. But we should be pressuring each other and the funding agencies into performing subsequent formal multicenter studies." Cassady believes that the issue becomes more critical as drugs and treatment become more powerful; he likens medicine's position to that of nations whose weapons are becoming ever more potent. "With our new therapies we can work miracles, but we can also do irreparable harm."

William Silverman, the near-legendary conscience of neonatal medicine, believes the specialty has been marked both by disasters and by tremendous successes. What price, he asks, are we willing to pay for success? Silverman argues that physicians cannot avoid making mistakes when they expose infants to new treatments, because they can't foresee what will happen. But he advocates the use of the controlled clinical trial "to minimize the magnitude of those mistakes."

Silverman contends that the standard of evidence for newborns must be higher than for other categories of patients because the consequences of error are so much greater. An entire lifetime hangs in the balance.

"In some cases," he says, "the health of several generations may be at stake, as was the case with diethylstilbestrol (DES). It's Russian roulette. You can win five times out of six, but that one disaster is enormous."

Very belatedly, NICHD has set in motion a program to reassess more than two decades of neonatal practice. A network of seven Level III nurseries (the most sophisticated of three levels of neonatal treatment centers) in the United States has been established to carry out simultaneous randomized controlled tests of both long-accepted and newly proposed therapies. Such treatments and procedures as high frequency ventilation, exchange transfusion, the feeding of mother's milk to premature infants, hyperalimentation, delivery room intubation of preterm newborns, DPT injections in infants with history of neonatal seizures, and the use of vitamin E have all been proposed for scrutiny. Among the first items to be looked at is whether intravenous gamma globulin administered to low-birth-weight infants is in fact effective in protecting them against infection. The initial phase of the program is expected to take five years.

Recombinant DNA

Gene therapy, the alteration of a person's genetic code to cure inherited disease, has been a dream of medical science as long as the nature of genes has been understood. The theory calls for the ingrafting of healthy

genes into a sick person's DNA, using viruses to airlift the genes into cells. But those who would monitor the development of this momentous technology are all dressed up with no place to go. "In all the history of human research," says Charles McKay, of the Office for Protection from Research Risks, "this is only the second time that ethics has been out in front of technology, where we've had the ethical implications covered before the actual research was under way."

The first occurred in the early 1970s when then-President Nixon authorized preliminary investigation of a nuclear-powered heart. The work never got beyond the discussion stage because of the ethical controversy it triggered: no one wanted to spend \$10 billion on a therapy that would benefit only a handful, and everyone was put off by the quality-of-life implications, the risk-benefit ratio, and the need to sacrifice early volunteers in order to perfect the concept. Ironically, these same concerns, as well as some of the technology involved, later became applicable to the development of other kinds of artificial hearts.

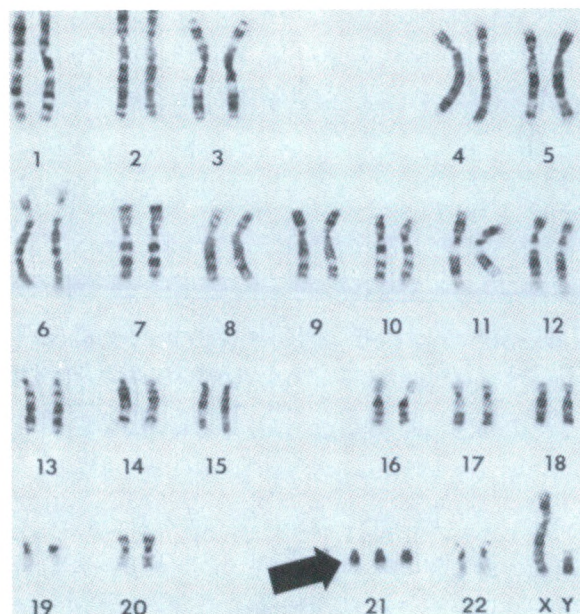
With gene therapy, no one is backing away, but after some exhilarating giant steps early on, progress has been disappointingly slow. Investigators have had only limited success at transferring new genes into animals and getting the genes to function. Awaiting the day when the breakthroughs come, however, are some impressive regulatory controls. NIH, which has sway because of its funding power, has established a Recombinant DNA Advisory Committee (RAC) to review all

proposals for genetic experimentation on human beings. The committee has published a definitive list of ethical points for researchers to consider. Also watchful is the FDA, which will share joint authority with NIH over the new technology.

"There is great caution," says McKay, "because of what happened in 1980," when UCLA researcher Martin Cline jumped the gun by attempting a gene transfer on two human beings with the inherited blood disorder beta thalassemia, even though previous animal experiments had been a flop. Cline went to Italy and Israel to try the procedures, circumventing his university's IRB, which had refused him authorization. The experiments failed, and Cline returned to the U.S., where he met with severe professional reprimand, losing his grants and the chairmanship of UCLA's genetics department (Lyon and Gorer 1986).

Cline is not the only DNA researcher to ignore the regulatory process. In 1987 a Montana State University plant geneticist introduced genetically altered bacteria into elm trees in an effort to control Dutch elm disease. He acted without waiting for approval from federal agencies and later admitted that he had done a similar experiment in 1984 (*Chicago Tribune*, 2 and 4 September 1987). The examples of two such distinguished researchers acting in so cavalier a manner with a volatile technology have given the government good reason to be wary.

Yet the vast majority of geneticists seem to appreciate the need for caution. "Since the Cline episode,



In Down's syndrome, there is an extra chromosome number 21 (three rather than the normal two). The extra chromosome is usually the result of the incomplete separation of the chromosomes during the formation of an egg cell by the ovary. More than 3,000 disorders attributable to a defect in a single gene or a chromosomal error have been identified.

researchers in the U.S. have been quite willing to abide by the set of national standards regarding gene therapy," says the chairman of the RAC, LeRoy Walters, director of the Center for Bioethics at the Kennedy Institute of Ethics, Georgetown University. "They will, I'm convinced, submit protocols before attempting gene therapy, not only to their local IRBs, but also to the RAC." Samuel Gorovitz, dean of the college of arts and sciences at Syracuse University and former member of the RAC, is similarly confident. "Neither the Cline nor the Montana State affair worry me very much," he says. "In both cases, the violations were followed by a great fuss. No set of regulations will guarantee compliance by all the players, but we do have a situation in which the end run is not likely to succeed."

Gorovitz is far more concerned about the issue of somatic gene therapy vs. germ line gene therapy. These two rather opaque terms embrace a simple distinction. *Somatic cell therapy* refers to putting genes into a patient in such a way that the sex cells, sperm or ova, are left untouched. Most experts believe that, from an ethical standpoint, this is not appreciably different from any other form of therapy designed to benefit an individual patient. *Germ line therapy*, on the other hand, alters the sex cells as well, so that the new genes will be passed along to the patient's descendants. Two fears loom large: (1) that the procedure, like any medical treatment, will engender mistakes, and that germ line therapy would allow such mistakes to get into the human gene pool; and (2) that there will be great temptation to

change traits unrelated to illness (such as those for intelligence), raising the specter of eugenics if carried on through the germ line.

"There is a consensus in the genetics community that germ line therapy is not appropriate and that protocols will not be approved without clear assurance that they will not involve sex cell modification," says Gorovitz. "The fear involves a concern about the quest for perfection. When techniques go beyond correcting deficiencies of a medical sort, and instead try to enhance normal human capabilities, an intolerance of normality is fostered."

Genetic engineering raises other ethical questions. Newly acquired DNA markers and probes will permit early screening for genetic predisposition and gene carrier status. Will it be an unqualified boon for people to learn that they are going to get certain illnesses later in life? Huntington's disease, for example, or Alzheimer's disease? Could such knowledge perhaps trigger a suicidal depression? Meanwhile, tests that reveal genetic susceptibility to occupational and environmental hazards could backfire. Such screening might alert those susceptible to the dangers of exposing themselves to sunlight, certain chemicals, and other substances that could trigger disease; but conversely, data about one's vulnerabilities might make it impossible for one to get a job or purchase insurance. Genetic engineering offers a "mixed blessing," says Charles McKay.

Fetus and Embryo

The most hotly debated subject in experimental medicine at the present time is probably research involving the fetus and the embryo, particularly the use of fetal tissue for purposes of transplantation. Fetal tissue is an attractive donor source. First, it can be transplanted more easily than adult tissue because it incites a weaker immune response, reducing the possibility of rejection. Second, it is biologically active, as one might expect from the tissue that is still developing. Thus, it has a unique ability to grow and develop in the postoperative period.

The potential of fetal tissue grafts engenders some disturbing thoughts. In one reported case, a woman with severe diabetes proposed aborting her baby and using its pancreatic cells for a transplant to help her own condition. In another case, a woman wished to be artificially inseminated by her father, who had Alzheimer's disease. Her objective was to abort the fetus and have its cells transplanted to her father's brain. The cells, a near-perfect tissue match, would theoretically replace essential chemicals lost in the course of the disease. In both cases, the proposals were rejected as unethical and medically unfeasible (Reuters 1987).

Yet researchers have already transplanted fetal tissue into human beings in at least three cases. In January 1988 a team of neurosurgeons in Mexico City reported taking tissue from a spontaneously aborted fetus (one resulting from a miscarriage) and implanting

it in the brains of two patients with Parkinson's disease. The procedure, which brought a marked improvement in the patients, followed previous work both in Mexico and the U.S. in treating Parkinson's with implants of tissue from patients' own adrenal glands. Such autografts restock the brain's depleted supply of the critical substance dopamine. But fetal tissue is thought to be a superior source of dopamine, and its use eliminates the need to put an elderly patient through separate operations to retrieve adrenal tissue and then transplant it. Meanwhile, investigators at the University of Colorado have reportedly used cells from fetal pancreases to stimulate increased insulin production in mature diabetics, and Dr. Robert Gale is known to have instilled fetal liver cells into six victims of the Chernobyl nuclear disaster in an attempt to get healthy bone marrow to grow. Successful fetal tissue transplants in animals suggest that even wider application of this troubling new technology is coming. For example, in California, elderly mice suffering from a condition approximating Alzheimer's disease have been treated by an implant of fetal mouse cells. The cells secrete the memory-enhancing chemical acetylcholine, bringing improvement in learning and recollection. And joint research carried on by Case Western Reserve University and Columbia Presbyterian Hospital in New York has succeeded in repairing crushed nerves adjacent to the spinal cord in rats. Fetal cells are used as a matrix, or bridge, to guide regrowth of the injured nerves, whose function is to connect the spinal cord to the extremities. It is be-

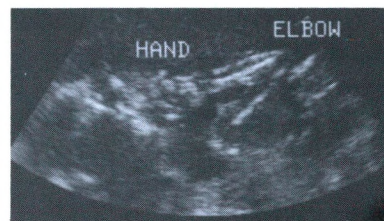
lieved doctors will one day call on the technique to repair neurological damage caused by accidents and ruptured disks, and perhaps even employ it to repair injuries to the spinal cord itself (Kolata 1987). Moreover, fetal cells may hold the key to correcting certain birth defects, such as spina bifida (a defect in formation of the spinal cord) (Fine 1986:52) and hypogonadism (a condition marked by slowed growth and sexual development) (A. Silverman et al. 1986:2090). Some even suggest it could be used to regrow portions of the brain and cure congenital brain damage.

But for all its promise, fetal tissue research presents a confusing legal picture. At the state level, everything is clear enough. Some forty-two states permit gifts of tissue from dead fetuses for research or therapy, under terms of the Uniform Anatomical Gift Act. Only six states expressly forbid such use, in cases involving elective abortion. At the national level, however, a moratorium on federally funded fetal research was approved by Congress in 1974, shortly after the U.S. Supreme Court's historic decision legalizing abortion. And although the National Commission later published guidelines favoring certain kinds of fetal research, so long as there is parental consent, the research has not proceeded. Under Department of Health and Human Services regulations, such experimentation must first be reviewed by a national ethics advisory board, which at present does not exist, despite attempts to establish one. This in effect bans federally financed research on the fetus that isn't of direct therapeutic benefit to that fetus

(regulations do permit experimental procedures that are helpful to a fetus, for example, prenatal surgery to correct intrauterine hydrocephalus and hydronephrosis).

If the legal picture is clouded, it is because the ethical climate is unsettled. There are strenuous objections to using fetal tissue for transplants and other research because of the obvious link to induced abortion. The necessary tissue can, of course, be obtained from spontaneous abortions, but these most frequently occur in the first trimester of pregnancy, when the tissue is more immature and possibly of less therapeutic value. Moreover, spontaneous abortions occur with little warning, with the fetus often suffering from defects that decrease its desirability as a donor. The preferred fetal donor is healthy and succumbs at a predictable time, so that preparations can be made to use its tissues while they are still fresh. The scenario which best satisfies the criteria is an elective late abortion of a normal fetus—not so late as to produce a viable fetus, however. The National Commission's guidelines defined such abortuses as premature infants and expressly proscribed using them for research.

Among the disturbing possibilities is coordination of efforts between the transplant surgeon and the physician performing the abortion, so that termination of pregnancy is foisted upon a woman to satisfy the demand for fetal tissue, or so that a method of abortion is chosen which is not necessarily in the mother's best interest but which improves the chances of getting high-



New techniques for detecting fetal problems may spur demand for more effective treatment of those problems. Series of ultrasound images of an eighteen-week-old fetus. (Courtesy of Ultrasound Department, Lutheran General Hospital, Park Ridge, Illinois.)

quality tissue (that is, a prostaglandin-induced procedure, which damages the fetus least but causes a labor-like delivery). Such potential evils can probably be averted, however, by separating the personnel involved in the processes of obtaining and utilizing fetal tissue, as the people involved in transplant surgery have no part in declaring the donor brain dead.

A prospect of even greater concern is that women may turn to conceiving fetuses for the sole purpose of selling them, creating an industry in which fetuses are intentionally cultivated for their commercial value. Richard McCormick, S.J., professor of Christian ethics at the University of Notre Dame, calls this "the complete reduction of the fetus to the status of a thing." But such trafficking could, and likely would, be prevented by the passage of laws. McCormick is far more troubled by the banal use of fetal tissue derived as the byproduct of customary abortion practices. "Then you get involved in a form of cooperation with a practice that you regard as morally wrong. For me, the problem is profiting medically from a morally wrong act, which would eventually blunt our sensitivities and tend to provide a supportive atmosphere for the practice of abortion."

However, many others reflect the more pragmatic view of Georgetown's LeRoy Walters that using fetal tissue obtained by elective abortion is no worse than and no different from procuring organs from any decedent. In common transplant practice it is immaterial whether the cause of death is murder or motorcycle accident. The salient medical fact is that an organ with

lifesaving potential is available. It should be likewise, Walters argues, where a mother has made a personal decision to abort. "Research involving dead fetuses should not be controversial," he says. "If it is clear that the fetus is dead, then its remains should be accessible to provide new life or a better life for an individual who is going to live on for the foreseeable future."

Another issue is raised, however, by the case of a living but nonviable fetus, as may be produced in a very premature delivery or occasionally in a prostaglandin-infusion abortion. The child may live for some hours and in fact can be placed on life support to continue the perfusion of organs with oxygenated blood, until such time as a transplant team can arrange to harvest the infant's tissue. The National Commission recommended that nontherapeutic research on a living nonviable fetus be allowed only where (1) vital functions are not artificially maintained; (2) procedures that would cause cessation of fetal heartbeat or respiration are not used; and (3) the research goal is acquisition of knowledge not obtainable by other means (National Commission for the Protection of Human Subjects 1975). Obviously, one cannot undertake to remove brain tissue or vital organs such as the heart without violating these provisions.

Some have nonetheless proposed use of nonviable donors. A recent article in the *Hastings Center Report* argued that if the "fetus ex utero," as a living nonviable fetus was called, "is not a person, obligations to the abortus are less binding than those we have towards donors who are persons. Because of its closer approxi-

mation to uncontroversial personhood, a viable abortus is more likely to be counted as a person than is a non-viable fetus ex utero or a viable fetus in utero." Although noting that retrieval of essential organs or tissue from dead fetuses is preferable to retrieval from living non-viable abortuses, the authors, who included a nationally renowned fetal researcher, nevertheless said: "We believe . . . that use of essential organs or tissue from nonviable fetuses is morally defensible if dead fetuses are not available or are not conducive to successful transplants" (Mahowald et al. 1987:9-15).

The moral questions raised are formidable. Can one rationalize inflicting pain and discomfort on a dying fetus any more easily than one can excuse painful procedures on an elderly person just because that person is near death? And how does one justify expunging one life, however fragile and fleeting, to preserve or enhance the life of another?

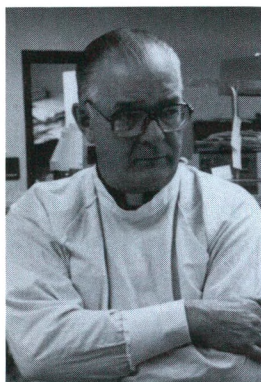
Experimentation on embryos generated by in vitro fertilization poses a different but related set of problems. This line of research has been facilitated by improvements in cryopreservation, the freezing of spare embryos for future use.

Embryo research has important applications. The study of fertilized ova in the earliest days of life, when most birth defects develop, can conceivably shed light on what causes such defects and contribute a great deal to our understanding of the process by which a few primordial cells differentiate into a full human being. This in turn could assist cancer researchers, because it

has been theorized that the runaway growth of malignant cells is caused by embryonic genes which, for unknown reasons, suddenly switch on in later life. The knowledge gained could be useful in improving reproductive technologies, and the effect of new drugs and toxic substances on early prenatal development could perhaps be tested.

But some would argue that embryonic life is as sacred as any other form of human life and should not be subject to what amounts to lethal experimentation. Any embryo used in research can be presumed to have been compromised. It is therefore unsuitable for implantation in the uterus and destined to be discarded in favor of another of the embryos mass-produced by superovulation techniques. Hence, the experiment ipso facto forecloses any chance the research embryo has to develop into a full-fledged human being. Is such an arrogation on the investigator's part, even with parental consent, appropriate? What rights has a nonconsenting, nonsentient organism consisting of only a handful of cells? Is it contradictory to forbid destruction of an embryo but permit abortion of the same preterm creature when it has become more mature?

In its condemnation last year of reproductive technologies, the Vatican singled out embryo research, noting that "the practice of keeping alive human embryos in vivo or in vitro for experimental or commercial purposes is totally opposed to human dignity" (Ratzinger and Bovone 1987). Richard McCormick sees no moral difference between the embryo, the fetus, and a



Richard A. McCormick, S.J., professor of Christian ethics, University of Notre Dame, Notre Dame, Indiana, visits the neonatal intensive care unit at Lutheran General Hospital, Park Ridge, Illinois.

born human being; they are all at essentially the same point on the continuum. "I'm inclined very strongly to say that there should be no embryo research under any circumstances," asserts McCormick. "There are persuasive reasons for going a very protective route. We are obviously dealing with human life, life that has the potentiality for flowering into full personhood. Therefore, it demands respect. Once we start relaxing that respect, allowing tampering and experimentation, it's hard to draw a line and say this far and no farther."

Although he does not subscribe to the Vatican position regarding in vitro fertilization, McCormick believes there should be no surplus embryos available for research. "I don't share the Church's judgment," he says. "I believe in vitro is a legitimate technological procedure for infertility. But I want it surrounded with types of protection that will keep us from getting in trouble. Discarding embryos in my view is inappropriate. If you are going to fertilize three ova in the test tube, you ought to implant them in the uterus. I have problems with freezing surplus embryos anyway. Thawing itself is not a benign procedure. Forty percent of them die in the thawing process, so it's rather crude."

In contrast to the Roman Catholic perspective is the view of many Jewish and Protestant theologies that life does not commence until the moment of live birth (Gregoratos 1986:977). Rabbinical teaching has held that the fetus is part of its mother and cannot be considered an independent entity until thirty days after birth, or "unless a full nine-month pregnancy is definitely

known to have been completed" (Feldman 1974:253). Such a belief would appear to permit procedures not only upon the embryo but on the fetus as well.

Michigan State University's William Weil believes we should proceed with embryo research. "Personally, I feel the embryo is not something that has inherent rights," he says. "It is incapable of sensing things, of feeling pain. It is alive in the sense that if you cut out my kidney it will be alive for a while. Its cells will use oxygen. But my kidney has no life of its own. Neither has the embryo a life of its own. It will die unless it's put in someone's uterus. Some would say the embryo, if nurtured properly, could become a person, whereas a kidney could not. But you have to consider what something is at any given moment in time."

Weil observes further that "the major benefit of working with embryos is that we lose close to 50 percent of all fertilized embryos in the normal process of reproduction, many because they are so severely deformed they can't survive. But what if we could discover how that happens? We might not only find out how to save some from dying but also prevent many other embryos from developing lifelong deformities. For me, that benefit outweighs the objections."

Parents would obviously express a multiplicity of views. But a revealing comment was carried last summer in the news media. "Before I started going through in vitro I thought, why not do it [embryo research] if it's going to help everyone?" recalled a thirty-one-year-old Boston woman. But, she said, as she beheld the em-

bryos produced by her eggs and her husband's sperm lying in a petri dish awaiting implantation, she had a change of heart. "I felt just so sentimental about them, and I thought I wouldn't want anybody messing around with them" (Saltus 1987).

Public policy on the issue remains to be settled. In Britain, where in vitro fertilization has progressed much more rapidly than in the United States, an official board of inquiry, chaired by Oxford philosopher Lady Warnock, recommended in 1984 that investigators be allowed to do research on embryos in the first fourteen days following fertilization. After that, it recommended that such research be regarded as a criminal offense (Committee of Inquiry 1984). On the fourteenth day of life one sees the first sign of the formation of the central nervous system. It is believed that prior to this time, the organism is unlikely to have any sensations, thoughts, memories, or relationship with the environment.

According to a survey published in the *Hastings Center Report* in June 1987, similar committees in Canada, West Germany, Spain, the Netherlands, and France have approved some form of embryo research. However, while two Australian committees also agreed, four others categorically recommended banning such experimentation. Among countries approving the research, there were sharp differences in attitude. For example, committees from Germany, Spain, Australia, the Netherlands, and France felt research should be confined to spare embryos left over from the clinical care of an infertile couple. But committees in Britain and

Canada would go further and allow the deliberate creation of embryos, using in vitro techniques, for the sole purpose of research. And although the majority of nations agreed that fourteen days was the proper limit of time for embryo research, the French committee recommended a seven-day limit, and the West Germans would permit it during the first cell divisions only. Among the various committees, special concern was expressed about particular lines of research: interspecies fertilization, genetic alteration of embryos, cloning, and gestation in a nonhuman environment (Walters 1987:3–9).

Embryo research is now being performed routinely overseas. Australian researchers have successfully microinjected individual human sperm into female eggs. They seek fertility help for men whose sperm are chronically unable to penetrate the ovum. Meanwhile, scientists in Scotland and Britain are screening the DNA of new embryos for purposes of sex determination and genetic diagnosis.

In the United States, however, embryo research is stalled. To date, only one governmental body has considered the issue: the Department of Health and Human Services' now-defunct Ethics Advisory Board in 1979. It concluded that research on embryos within fourteen days of fertilization was permissible but did not rule on the question of deliberate breeding of embryos for research (Ethics Advisory Board 1979). The recommendation has not been acted upon by Health and Human Services, primarily because of political ten-

sions surrounding the abortion issue. Meanwhile, the board has since gone out of existence, creating a de facto prohibition on federally funded research involving in vitro fertilization. This is scarcely an absolute prohibition, however. A number of U.S. centers have established active in vitro fertilization clinics operating with private funds. Presumably, such centers could attempt embryo research, although the social and ethical restraints would be powerful.

Anencephalic Organ Donors

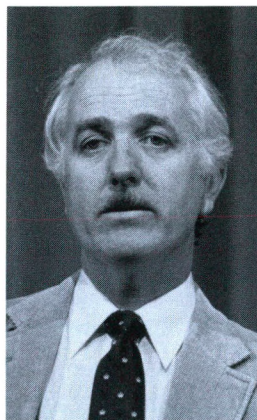
In 1986 I participated in a perinatal ethics conference sponsored by Georgetown University School of Medicine. One of the speakers created a stir by informing the audience that a Canadian institution was about to experiment with keeping an anencephalic child—a child born without all or most of a brain—alive on life support for the purpose of harvesting its organs for transplant. The idea of using anencephalic babies to satisfy the critical need for pediatric organs was not new. Legislators in two U.S. states had proposed bills that would open the door to such a thing. But this was the first time I had heard anyone in North America announce actual plans to try it.

Little more than a year later that promise was fulfilled. An anencephalic girl born in Orillia, Ontario, became the donor in a heart transplant conducted at Loma Linda University Medical Center by Leonard

Bailey, the surgeon most known to the world for implanting a baboon heart into Baby Fae. The girl, who was named Gabrielle, had been diagnosed prenatally as suffering from anencephaly, a defect in the formation of the neural tube. The defect, which is invariably fatal, occurs in the first twenty-eight days of life, preventing development of the brain and the top of the skull. All the children possess is a brain stem, which will conduct breathing and a few other primitive functions for a few hours to a few days before death finally occurs.

Gabrielle's parents reportedly wished to give their child's demise some meaning. They agreed to have her kept alive on a ventilator so that her organs could benefit someone else. Meanwhile Gordon and Alice Hulc, a couple from British Columbia, had learned through prenatal diagnosis that the son Mrs. Hulc was carrying would have a fatal cardiac defect called hypoplastic left heart syndrome. The best chance of treating the condition is acknowledged to be the neonatal heart transplant procedure pioneered by Bailey.

When Gabrielle's potential as a donor became known, a series of events was set in motion. Mrs. Hulc was flown by air ambulance from Vancouver to Loma Linda, where she underwent a Caesarean section. At the same time, doctors began stopping Gabrielle's ventilator every few hours to see if she could breathe on her own. When it was determined that she could not, Gabrielle was declared brain dead and, still attached to a ventilator, was flown to California, where her heart was removed for implantation into the Hulcs' son. As of



Dr. Leonard Bailey appears at a press conference to describe the fatal complications that ended the life of a three-year-old boy on whom Bailey had performed two heart transplants in two days.

UPI/Bettmann Newsphotos.

this writing, the boy, named Paul, was doing well.

The full-scale use of anencephalic donors would solve a major problem in this country—the lack of available pediatric organs. Each year, an estimated 400 to 500 infants need a new heart or kidney, and another 500 to 1,000 need a new liver. The most desirable source of organs for transplantation are those who have sustained mortal damage to the brain but whose visceral tissues are unscathed. In older individuals this prescription is mainly filled by gunshot victims and by people who have been involved in traffic accidents, particularly motorcycle accidents. However, relatively few infants and young children die this way. The most common causes of pediatric death involve conditions that render the internal organs unsuitable for transplant. As a result, there is an acute shortfall. Between 40 and 70 percent of youngsters under two who are on the transplant waiting list die for want of a size-matched donor organ.

The possibility that anencephalic children might fill the need comes from the fact that, despite their gross cerebral anomalies, their internal organs tend to be normal. As many as 3,500 anencephalic babies are born in the U.S. every year, which would fill most of the need, even presuming the current 15-percent rate at which potential organ donors become actual organ donors.

The problem arises in satisfying the accepted legal standard for procurement of any cadaver organ, that is, that the donor must be brain dead. In the case of anencephaly, that means waiting until the brain stem has

died (although it is difficult in any case to pinpoint brain death, even in normal infants). But the organs of newborns are more perishable than those of older people. By the time the brain stem ceases activity, the body parts have deteriorated too far for medical use. This can be in part alleviated, as it was with Gabrielle, by hooking the child up to a ventilator and feeding her a sugar-water solution to keep the body's tissues well-oxygenated and nourished. But once brain death has occurred, the deterioration is quite rapid. The transplant must be initiated in a very short time. Or so it has been believed.

This state of affairs has led to proposals that the definitions of death and donor suitability be changed to embrace live anencephalic infants. A bill proposed in early 1986 in the California Senate sought to amend the Uniform Determination of Death Act (recognized in forty-two states as the model articulation of neurological death) to stipulate that "an individual born with the condition of anencephaly is dead." The impulse for this, of course, was the belief that an absence of brain hemispheres is equivalent to brain death. In New Jersey, meanwhile, a state assemblyman introduced a bill to revise the Anatomical Gift Act, allowing anencephalic infants to become donors prior to brain death, with the approval of their next-of-kin. The end result in each case would have been organ retrieval from infants who were biologically alive. Both bills were defeated.

Alexander Capron, professor of law, medicine, and public policy at the University of Southern California, strongly criticizes the thinking behind such proposals.

To declare anencephalic infants dead while they are still alive and breathing could, in Capron's view, lead to even further broadening of the category of people considered deceased. Included, for example, might be those in permanent comas, whose medical status—dying and unconscious—is similar to that of anencephaly. It is dangerous, he says, selectively to let down the barriers against organ removal from living donors. "If society wants to adopt a policy of sacrificing living patients for their organs, it seems very strange—and a very bad precedent—to start with the most vulnerable patients." Capron concludes by suggesting that energies should be turned away from redefining death and toward finding better ways to care for dying anencephalic infants "so that when they become brain dead they can be organ donors" (1987:9).

William Weil is deeply disturbed by the apparent disregard being displayed toward the dignity of the anencephalic child. He voiced suspicion that in Europe, where anencephalic infants have previously been used as donors, there have been occasions when the children were not completely brain dead by accepted criteria. "We must remember these are children who happen to have anencephaly," Weil says. "A child without a kidney is a child without a kidney, not a kidneyless thing. Just because in anencephaly it's the brain that is missing doesn't take the infant out of the category of child. It is true that this society tends to put more emphasis on brain function, but from the moralistic point of view, it's



"What a lot of other specialists do gets swept under the rug because no one's watching."
—William Weil, Jr.,
professor of
pediatrics, Michigan
State University,
East Lansing

Photo courtesy of Michigan State
University News Bureau.

hard to see why the brain should be a more important determinant of identity than a kidney. These children are living children until they are dead. I don't think anyone should be taking organs out of living children."

Arthur Kohrman is wary of the tendency to subordinate one patient's rights to those of another. "What upsets me is the idea that the recipient is more important than the donor," he says. "We could be opening Pandora's box. Is it just a matter of time until we start making relative judgments in other areas? Grandma is more important than Aunt Tillie, and so on? The utilitarian, of course, would say we already make those judgments all the time, whether it's on a *de jure* or *de facto* basis. We make sure the president gets better medical care than a child on the Navajo reservation. The question is, is it right?" Kohrman finds reason to fear the thought of making anencephalic infants a special category of living donor. "Once you open the door and say that medicine is able to take a life as part of its charge—no matter how we may justify it in terms of benefits to one or another party, we have altered medicine's role."

Richard McCormick is encouraged by the Loma Linda precedent, because he thinks it makes the living donor controversy moot. "The case proved wrong the standard medical orthodoxy which says you can't use the organs of dead children because they have deteriorated too much. If the recipient child survives, they will have shown that's not true. The whole idea of changing the definition of death becomes unnecessary. Here was

a child who was pronounced dead legitimately, by standard brain death criteria, and then was flown to Loma Linda. With consent, there's no problem about using the organs of a child that's dead."

The transplant community is watching closely.

Informed Consent

The general feeling among long-time observers of human experimentation is that much progress has been made in ensuring that the informed consent of potential human subjects is obtained. "It is still a problem," says Robert Levine, "but it is mostly a matter of fine tuning." Alexander Capron concurs: "Informed consent is much closer today to what one would call adequate."

To Jay Katz, the area in which informed consent is "still on shaky ground" lies in the relationship between doctor and patient during therapeutic interventions. "There are three major reasons that the informed consent procedure is meaningless in the therapeutic setting," says Katz. "First, doctors still approach patients as if they were children, by virtue of their being sick and by virtue of their alleged inability to participate in decision making because of medicine's esoteric knowledge. Therefore physicians view the informed consent requirement as a pointless and onerous obligation imposed upon them by law. Second, physicians haven't given sufficient thought to their obligation to communicate medical uncertainty to their patients so that

they can make a meaningful contribution to the medical decision staring them in the face. Finally, if doctors inform their patients about anything, they tend to inform them about the risks and benefits of the treatment they think best for the patient. They do not take the time to inform the patient about alternative procedures available to them."

This information gap can have crucial consequences in the gray area where therapy and research intersect. Often, as we have seen, a physician's goal of treating a patient can coincide with a desire to test a new therapy. But under such circumstances, how often is the patient fully informed about the experimental nature of what is being tried? Are the risks and the alternatives spelled out?

Katz is disturbed by this twilight zone of innovative therapy, in which IRB review, which might ensure full disclosure, is not required. "I don't know how widespread the problem is," he says, "but I think many physicians try to consider intervention as innovative therapy so that the informed consent process promulgated by federal legislation does not have to be complied with." Katz scoffs at studies showing patients to have little understanding or retention of information given them. He cited one such study, conducted in New York upon patients undergoing cardiovascular surgery, in which the informed consent session was tape recorded. A month or two later, patients were asked what they remembered about the consent process. Few recalled much, giving ammunition to those who consider in-

formed consent a waste of time. "I asked the person who conducted the study, 'What do you make of the fact that you did this study the night before the operation, when some of the patients had already received preoperative medication? All the patients had agreed that the next morning they would undergo serious and complex surgery. Then you came in and informed them about the risks of the procedure. If I were the patient I would listen with half an ear and say, 'Who wants to listen to all that? I've already made the decision.' If you want to conduct this study well, the information should have been given to the patients before they entered the hospital. As is, it's a questionable experiment.'"

Some of the people I talked to in connection with this article cited the case of Baby Fae as an example of how, even now, the informed consent process sometimes breaks down in the experimental setting. As most people will recall, Fae was a newborn suffering from hypoplastic left heart syndrome. Her parents were unmarried, separated, uneducated, and poor. The father was not present for the session in which Dr. Bailey outlined the baboon transplant procedure for the baby's mother. There is no evidence that either parent read or comprehended the consent forms. Doubts have been expressed concerning whether Dr. Bailey would have been able to sell his experiment to more affluent, better-educated people. Would he even have tried?

"I believe the consent form itself was defective," comments Richard McCormick, one of the panel members who subsequently investigated the Baby Fae case

under the auspices of the National Institutes of Health. “It held out hope of long-term benefits in a way that, for that couple, could easily have been coercive. It appears they were told that there was no other available procedure for a child with hypoplastic left heart syndrome, and that the surgery offered the possibility of long-term survival, a claim that was not justified because it had no medical foundation.”

Fortunately, the Baby Fae case appears to be a notable exception to an improving picture with regard to informed consent.

Proposed Relaxation of IRB Review

Ask how widespread unethical practices were in human research twenty years ago, and you will get considerable disagreement. To David Rothman, director of Columbia University’s Center for the Study of Medicine and Society, the state of affairs presented in Henry Beecher’s famous 1966 article in the *New England Journal of Medicine* was an accurate reflection of the truth. In that article, Beecher cited twenty-two cases of serious experimental abuse which he said proved “unethical or questionably ethical procedures are not uncommon” in medical research (1966:1354–60). Beecher, apparently not wishing to embarrass the parties involved, did not name the investigators or their hospitals. By being deliberately vague, he left room for critics to argue that the cases cited did not represent the medical main-

stream. Rothman, however, recently obtained Beecher’s papers and undertook a detailed analysis of the journal articles from which Beecher drew his cases. He concluded that the research was mainstream indeed, financed by such entities as the Surgeon General’s office, NIH, and the Public Health Service, and carried out by such respected institutions as Harvard Medical School, New York University, and Northwestern University. Said Rothman, a “utilitarian ethic,” fostered by defense research needs during World War II, “continued to govern human experimentation—partly because of the war precedent, partly because the benefits seemed so much greater than the costs, and partly, too, because there were no groups or individuals prominently opposing such an ethic” (Rothman 1987:1198).

But Robert Levine sees that era in a different light. “It wasn’t all that bad,” he contends. “There were only a handful of incidents that were the object of exposés in the 1960s and 1970s. I think the serious improprieties represent a very small minority of cases. Measured against Beecher’s twenty-two cases were tens of thousands that no one saw fit to comment on.”

Virtually everybody today agrees that human subject research has become an essentially sensitive and conscientious enterprise. So confident are many people that there is increasing sentiment in certain quarters for a reduction in the intensity of IRB surveillance. Levine, one prominent exponent of this view, has written what is generally regarded as one of the definitive texts on human experimentation, *Ethics and Regulation of Clinical*

Research (1986). Levine argues that IRBs divert much of their energies to such trivial matters as record keeping and waste inordinate time reviewing research that may never be done. IRBs are required to approve research proposals *before* the Department of Health and Human Services considers whether to fund them, and HHS funds less than two-thirds of the applications it receives.

Levine also cites figures showing that in 1978, IRBs at the more than 650 institutions then conducting research spent \$130 million a year to perform their tasks. "What do we think we are buying with all this money?" he writes. "Impetus to developing the statutory requirement for IRB review was provided by a mere handful of cases that were brought to the attention of Congress in the early 1970s. . . . Certainly we should not tolerate such violations in the name of research. I suggest, however, that we can purchase adequate defenses at much lower cost by changing our approach to regulation" (1986:360–61).

Levine makes three suggestions: (1) make it clear that there are certain offenses our society will not tolerate and that those offenses will be punished in specified ways, as is done with felonies like murder, rape, and arson ("Researchers, unlike arsonists, are obliged to publish an account of their activities in order to earn their rewards; thus it should be much easier to apprehend wrongdoers"); (2) reconstitute IRBs as advisory committees available to provide consultation and guidance, so that investigators might reassure themselves that they are not going to commit any punishable

offense; and (3) submit all research proposals to some licensing agency capable of judging the scientific design and the competence of the investigators. He concedes that in certain classes of ethically problematic research prior IRB review and approval should be mandatory. These include research on all persons who are either incapable of consent or not reasonably autonomous (for example, prisoners); research involving deceptive strategies; research involving the risk of physical or psychological injury; and proposals designed to introduce, test, evaluate, or compare therapeutic, diagnostic, or prophylactic procedures.

"Things are not perfect now," argued Levine in a recent interview, "but we've created a climate in which episodes like Tuskegee, the Jewish Chronic Disease Hospital affair, or Willowbrook, for that matter, are extremely unlikely. We don't see the kinds of exposés that we used to."

Levine's sentiments are echoed by Audrey Brown of the State University of New York. In a 1987 address commemorating the centennial of NIH, Brown said:

In recent years, many in the research community have come to feel that the quality of research proposals has been improved by the requirement of prior review. There is a general impression that the very existence of the IRBs has raised the general consciousness of medical researchers concerning the ethical principles that must guide research practices. There is, in fact, the sense that this has been the major impact of IRBs and that

the effect of this impact is a lasting one and would continue even if the IRBs no longer functioned. It's almost inconceivable that research proposals which violate ethical principles could now be funded, carried out, or published.

Alexander Capron counters that the IRB system should be left untouched. "In a large sense," he says, "the system works pretty well, and it accomplishes what it is supposed to accomplish." Capron does recommend, however, that the FDA and NIH commission on-site peer evaluations of individual IRBs. "At the moment, we have no such thing—only governmental inspectors from the FDA, who are not interested in any nuanced view of how an IRB performs, but only in following a paper trail, say, making sure procedures were followed in approving the testing of a certain drug. Site visits would be a valuable tool. Then we would be in a better position to say how the IRB system is working."

Rothman defends vigorously the importance of IRBs as a first-line defense against abuses:

Some critics argue that the committees are poorly administered, time consuming, and uneven in performance, and that most patients are unable to give informed consent, making it preferable to trust to the integrity of the researcher. But in policy terms, this remains the minority view. The memory of the postwar record precludes a return to a hands-off policy, and institutional review boards are now regarded as symbolically and ac-

tually valuable. . . . No matter how favorable to deregulation the political climate may be, it is likely that researchers will continue to operate under close supervision and in the glare of committee lights. (Rothman 1987:1199)

National Review Commission

Another recommendation frequently heard is the call for establishment of a national review commission to consider broad categories of research, particularly those involving new technologies, which present complex technical, social, and ethical questions that may be beyond the capacity of local IRBs to resolve. For example, Loma Linda's IRB gave its imprimatur to the Baby Fae experiment, even though thorough analysis of previous attempts at cross-species transplants in animals and humans would have shown that the procedure had only the most remote chance of success. There is a strong likelihood that Loma Linda's religious homogeneity, its insularity from the medical mainstream, and the strong personality of Dr. Bailey combined to lead the IRB to approve a procedure that would have been turned down by most IRBs elsewhere. Can we afford such pluralism where life and death issues are at stake? Would it not be preferable for a national body to assess and regulate not only xenografts, but other troubling and complex issues like fetal and embryo research, testing of AIDS vaccines, genetic manipulation, and artificial organ implants?

"A national ethics advisory board would be an excellent idea," says LeRoy Walters. "Many other countries have them. Australia does. So do Denmark and France. It wouldn't take Congress to establish one. It could be set up by the secretary of HHS with just a stroke of a pen."

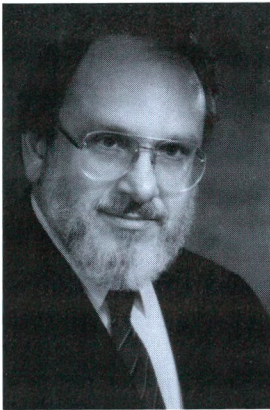
There have been several false starts toward creation of a standing national research commission. In 1978, Joseph Califano, then secretary of Health, Education and Welfare under President Jimmy Carter, established the Ethics Advisory Board. Funding problems, a change in administrations, and the formation in 1980 of a somewhat redundant body, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, conspired to put the advisory board out of business. When the President's Commission itself died in 1983, it left a large vacuum. Then Congress, in the Health Research Extension Act of 1985, set up a twelve-member bioethical policy board consisting of six senators and six representatives, divided equally between Republicans and Democrats. The board in turn was to appoint a biomedical advisory committee, thirteen of whom were finally named last summer. Reportedly, no staff has been hired, nor has either the board or the advisory committee started to work. The delay has been caused by political division among members of the board over the first issue the group is scheduled to consider: fetal research.

Some commentators appear cautious about the

value of national commissions. "The up side," observes Charles McKay, of the Office for Protection from Research Risks, "is that without national oversight, we run the risk of introducing new technologies erratically, without the means of assessing them in a measured, reasonable way. The down side is that it can really slow down research. It's very easy for things to get politicized, for boards to become stacked with ideological points of view. Then, too, the idea may not always work. Would all new technologies get forwarded? What procedures are there to force someone to comply with commission decisions? Do you have to go to court? NIH has the power to withhold funding, but our enforcement authority in other areas may not be so strong."

Remarks Arthur Kohrman, "I can imagine a national review commission for the extremes. But on a day-to-day, nitty-gritty level, a commission would drown. Merely deciding what fits into the domain of 'new technology' is difficult. Where would you put segmental liver transplants, for instance?"

"And would you accept all of a commission's conclusions? What would be their reasons for saying no? Would they reject using animal hearts for human transplant because they got 10,000 pieces of mail from animal rights people? Would they say no because the idea is aesthetically revolting? Or would they take a more sophisticated scientific approach and decide that not enough animal research had been done to justify moving into humans? Even if that were the basis, what would they do with the argument that there is a limit to



"Once you say that medicine is able to take a life as part of its charge—no matter how we may justify it—we have altered medicine's role."

—Arthur F. Kohrman, M.D., director of La Rabida Children's Hospital, Chicago

Photo courtesy of La Rabida Children's Hospital.

how much you can extrapolate from laboratory work and we'll never know about something until we try it in humans? I'm not sure those arguments can be solved any better by a national commission than at the local level.

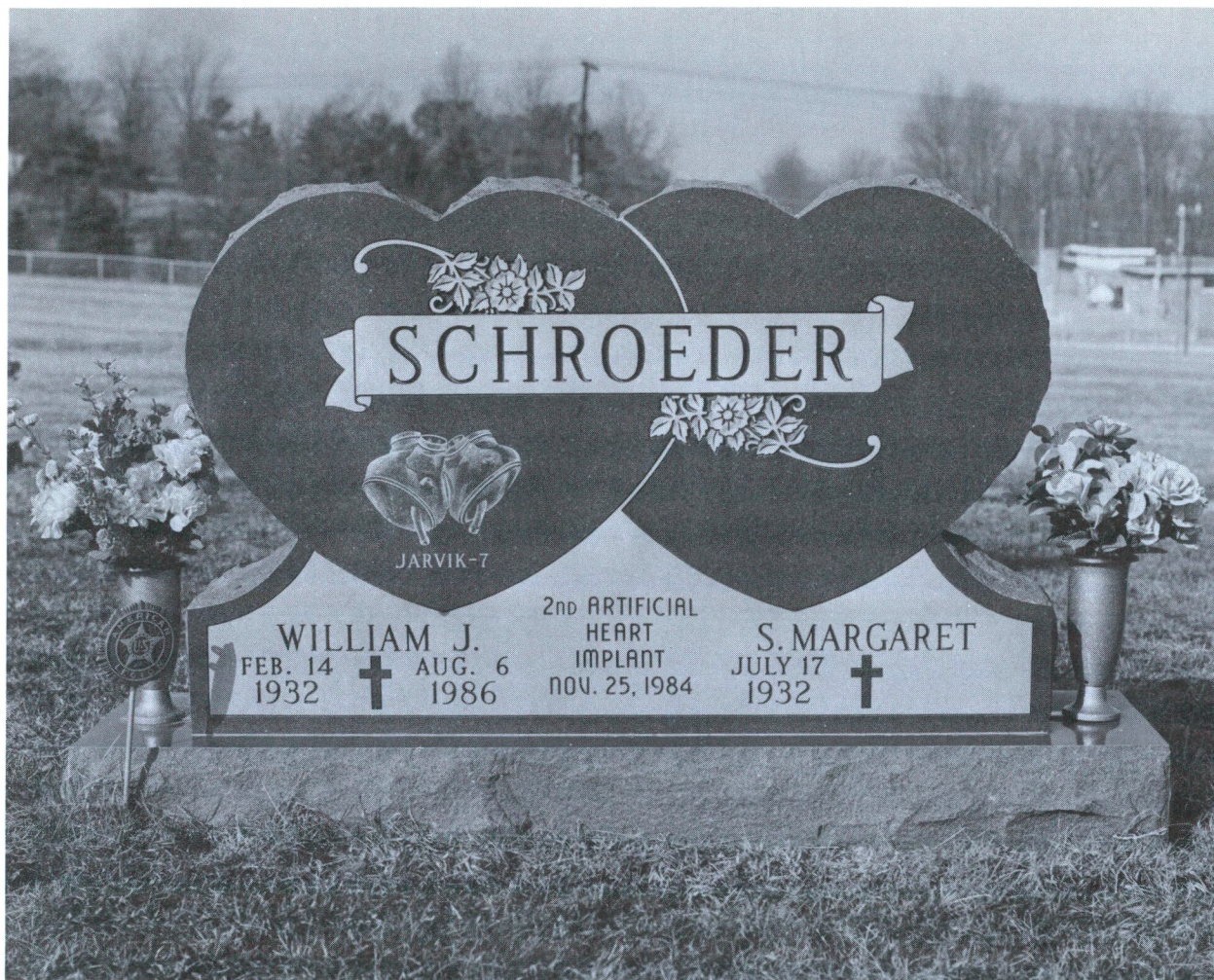
"My own sense," continues Kohrman, "is that the best thing we can do is create IRBs and other local agencies that are adequately staffed and adequately diverse in their talents, providing wide cross-consultation. Beyond that, the goal is to educate, to raise consciousness about issues of human dignity, and set criteria (in particular, nonmaleficence and respect for persons) by which one might judge proposals. The best you can do is ensure adequate process, not prescribe outcomes."

Kohrman sees an inevitable and constant tension "between those in medicine who would move ahead by leaps and bounds and those who would nail their feet to the floor. Often the boundaries of human endeavor are pushed forward by audacious individuals. Can they be allowed to rush forward without seriously violating the rights of human subjects? I was at Stanford the day that Norman Shumway did his first heart transplant. I remember the scene. The national feeling was that we had entered a domain in which we didn't belong, that we had gone too far. Today, heart transplants have become standard therapy. But we would never have had the door opened had not Christiaan Barnard and Norman Shumway kicked it out."🌐

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The tombstone of William J. Schroeder (the world's second recipient of a permanent mechanical heart), Fairview Cemetery, Jasper, Indiana. Engraved on the black granite is a picture of the Jarvik-7 artificial heart implanted in Schroeder's chest at Humana Hospital–Audubon, Louisville, by Dr. William C. DeVries. The heart, which relied on a 323-pound air compressor (about the size of a small refrigerator) to provide pumping power, sustained Bill Schroeder's life for 620 days.

Photograph by Robert McCarty

The Social Context of Medicine

Lessons from the Artificial Heart Experiment

Images

Salt Lake City, Utah, secluded in the valley, framed by the snow-clad peaks of the Wasatch Mountains, its skyline pierced by the spires of the Mormon Temple that dominates the dazzling whiteness of Temple Square. Nearby, in the animal barn of the University of Utah's Division of Artificial Internal Organs, a young calf named Alfred Lord Tennyson stands mutely in his stanchion, tethered to the Utahdrive system that powers his Jarvik-5 artificial heart for a record-setting 268 days in the calf and sheep implants that precede the first human experiment with

Dr. Barney Clark . . . A conference room at the University of Utah Medical Center, August 1986. Members of the Institutional Review Board (IRB) gather to talk with medical sociologist Renée Fox and me, eight years after they began to struggle with the artificial heart protocol and the many things it represented. Eventually, they say, they transmuted it into “a scientific protocol we could accept,” and Barney Clark, the “avuncular astronaut,” became a medical pioneer. The IRB members are a pensive group, still deeply affected by their experience. One likens this meeting to a wake rather than a reunion. “Everyone hoped [the heart] would work,” a member reflects, “and it got in the way of better judgment.”

Louisville, Kentucky, on the banks of the Ohio, its skyline dominated by the soaring rose granite and green marble tower of the new Humana building, headquarters for one of the country’s leading for-profit hospital corporations. After simmering mutual disaffections, Dr. William C. DeVries and his artificial heart program moved from Utah to Louisville’s Humana Heart Institute in August 1984. . . . November 1984. Hundreds of print and electronic media reporters jam a suite of rooms at the Louisville Convention Center, used as Humana’s media center during William Schroeder’s implant. It is, say some veteran reporters, one of the best organized public relations efforts since NASA’s early space ventures. Over and over in the background, against the hubbub of voices and phones, plays Louisville’s newest hit song, “Plastic Heart.” . . . The lavish Humana building has been hailed as an architectural masterpiece and as an art deco extravaganza. In the image-filled dreams of members of DeVries’s artificial heart team, during the long days and nights they care for Bill Schroeder, Murray Haydon, and Jack Burcham, the Humana edifice appears again and again as a mausoleum.

Fairview Cemetery in Jasper, Indiana, where William and Margaret Schroeder raised their six children in a close-knit German-Catholic community. The grave of Bill Schroeder, who died in August 1986, is marked by a heart-shaped black granite tombstone. Engraved in the shining granite is a picture of the Jarvik-7 artificial heart that sustained his life for 620 days.

Voyages: The Inner and Outer Worlds of Vital Organs

Such images reflect the interplay between medicine and the society of which it is a part, and they help to explain why my colleague Renée Fox and I have spent five years on the trail of the artificial heart.¹ The development and first clinical uses of artificial hearts, both as a hoped-for permanent replacement or as a device temporarily implanted until the securing of a donor heart (a bridge-to-transplant), is an intrinsically interesting chapter in the history of biomedical research, bioengineering, and therapeutic innovation. But solely from that angle of vision, the artificial heart would not have engaged us so intensely or for so long. It did so because we soon found it to be a microcosmic case, involving many complex and interacting phenomena, issues, and social systems.

As such, the artificial heart has been part of a long-term, larger case study of the development, use, and medical and social implications of organ transplants and artificial vital organs. Individually and collaboratively, Renée Fox and I have spent years examining medicine's drive to replace failing vital organs because it has served as a paradigm of larger, medically transcendent social and cultural themes, including "essentially moral and religious problems with which modern Western society is grappling" (Fox and Swazey 1978:380).

Analogous to the processes of field research and running analysis involved in studying the artificial

heart, this paper moves back and forth between micro- and macrolevels of phenomena and issues. I first sketch the individual and institutional participants in the initial experimental permanent artificial heart implants, both to highlight dimensions essential to an understanding of this particular medical episode and to indicate some of the "small system" components involved more generally in medical research and care. Next I consider four themes illuminated by the artificial heart story: (1) the bearing of medicine on our attitudes and actions concerning life, death, and personhood; (2) distributive justice issues with respect to the fair allocation of finite material and nonmaterial medical care resources; (3) the effectiveness of the professional and external "social controls" that govern medical research and care; and (4) the explicit and latent shaping of biomedical research and care by sociocultural values. I conclude with some brief reflections about the lessons that such a detailed case study can offer to our understanding of health, illness, and medicine in American society.

Tin Men, Wizards, and Emerald Cities: A Cast of Characters

The "real" artificial heart story would provide superb grist for a playwright or novelist, far more dramatic and intricate than the entertainment provided by the fall 1987 "St. Elsewhere" television series on the "Craig 9000" artificial heart implant under the aegis of the

“The heart is just a pump,” conventional biomedical wisdom has held for many years, and therefore, like any pump, it can be duplicated and replaced.

“Ecumena Corporation.” From a literary perspective, the quintessentially American characteristics of the artificial heart story echo themes found in Herman Melville, Arthur Miller, Theodore Dreiser, Frank Baum, and Isaac Asimov, with a touch of Neil Simon. The cast of characters—individual and institutional—involved in the implants captures many of the values and systems, small and large, that shape the world of American medicine and its subworld of biomedical research and therapeutic innovation.²

To begin with, though least amenable to broad generalizations and abstract principles, there are *people*. Their personal and professional biographies, motivations, and overt and covert roles cannot be factored out. For instance, the artificial heart is not atypical with regard to the factors that move a new drug, device, or procedure from laboratory studies to human use. This process involves far more than judgments that the bench and animal data warrant the shift to clinical application and that potential benefits to patients outweigh known risks. The careers, convictions, and hopes and fears of those most centrally involved in the first human trial of the Jarvik-7 heart illustrate other factors in the process. In this instance, these influences included quests for priority and prestige, a deep-seated conviction that “bionic man” is desirable and attainable, economic and political concerns and stratagems, a strong belief that life is always preferable to death, and an abiding commitment to human progress through science and technology.

The cast of characters also includes *institutions*, each of which is an intricate social system in its own right. Devices like the artificial heart are designed, engineered, and tested in university and private research laboratories. In this case there is the University of Utah’s Institute of Biomedical Engineering and Division of Artificial Internal Organs, where two young men, William DeVries and Robert Jarvik, joined the research group gathered around artificial organ pioneer Dr. Willem Kolff. Kolff formed his own independent research company in 1976, with close ties to the university; that company became Symbion, Inc., when Jarvik wrested control from his former mentor.

There are also, of course, hospitals in which clinical research takes place and medical care is rendered: in Salt Lake City, the academic medical center of the University of Utah; in Louisville, the Humana Corporation’s Humana Hospital Audubon and its private group practice Humana Heart Institute. To be sure, these institutions display striking differences. But at a deeper level, the primary differences—academic and nonprofit vs. community and for-profit—are diminished by their hospital-as-a-social-system similarities.

Other institutions, religious and secular, private and governmental, also play major roles in the artificial heart story. These include the Mormon Church, which permeates the life and culture of Salt Lake City and, though most principals are reluctant to admit it, seems a major influence in the Jarvik heart’s development and implant into Dr. Barney Clark (Fox 1984). On the secular

side, also a strong presence in its local community of Louisville, is the Humana Corporation, embodying what its proponents and opponents respectively see as the promise and peril of the “new health care for profit” in American medicine (Gray 1983).

Remote from Utah and Kentucky, but omnipresent in the artificial heart story by virtue of both its actions and its inactions, is the Food and Drug Administration (FDA), one of the legion of agencies that shape medicine through their regulatory powers. The FDA has the duty to regulate new medical devices, especially those like the artificial heart that are judged to pose a “significant risk” to patients. In concert with the hospital institutional review boards for the protection of human subjects, the FDA has had primary responsibility for authorizing experimental clinical use of artificial hearts.

Then there is the *media*, for better or worse surely one of the most powerful shaping forces in American society. The ways that the media have reported the artificial heart, and by virtue of that reportage significantly influenced both public and professional perceptions and judgments about the device, illustrate how print and electronic journalism can affect the content and contours of medical research and care in America (Altman 1984; Blakeslee 1986; King 1986).

Finally, this partial cast of characters must feature the *heart*. Actually, several hearts with different meanings and implications have a place in the story. There is the “natural” biologic heart. “The heart is just a pump,”

conventional biomedical wisdom has held for many years, and therefore, like any pump, it can be duplicated and replaced. Other experts in the cardiovascular system see this as an overly reductionistic view, arguing that the heart is an organ in a complex feedback system. The “Jarvik heart,” one eminent cardiac surgeon said emphatically, “is a cow pump,” not a functionally adequate replacement for the human organ.

Artificial has many connotations, especially in our disposable-plastic society. What does *artificial heart* connote, and is it the most apt synonym for an organ replacement device? There is also the heart that for thousands of years has been symbol and metaphor and quasi-mystical repository of human attributes in so many religions, societies, and cultures. Despite our modern knowledge and professed absence of magico-religious thought about the heart, it is doubtful that so much attention would have been riveted on the device had it been a Jarvik-7 pancreas or any organ but the heart. Said one reporter to us, recalling what it meant to cover the Barney Clark implant: “It’s just totally amazing to me that they can take out the organ of all feeling and all emotion and replace it! The fact that they did it and that he felt the heart ticking and was alive is overwhelming.” Nor are surgeons totally immune to thoughts that the heart, at least symbolically, is more than a pump. In December 1987, DeVries did his first bridge-to-transplant procedure, partially ending the moratorium in effect since April 1985 on his use of artificial hearts (Swazey, Watkins, and Fox 1986). Some

What does artificial heart connote, and is it the most apt synonym for an organ replacement device?

two weeks later, as a donor heart was being transplanted into Walton Jones, Jr., DeVries, in an adjacent operating room, began to examine the device he had just removed from his patient's chest. "I hate to cut this thing in half, I really do," he said. "It's almost like sacrilege" (Gil 1987). The artificial heart wizards have reversed the Tin Man's quest, but the heart has lost little of its deep-rooted meanings and centrality in human life.

Life, Death, and the Ends of Medicine

Values, attitudes, and beliefs about the nature, causes, and meanings of health and illness, and about the roles of healers and the healing arts, are deeply embedded in all societies and cultures. So, too, are views about defects and the wearing of body and mind, aging, mortality, and death, and about what it means to be "fully human" or a "person" (*The Problem of Personhood* 1983).

American society in recent years has been much preoccupied with dying and death, biomedically, ethically and religiously, legally and legislatively, economically, and on very personal levels. This preoccupation with death—when and why it occurs, what it means, how we respond, whether and for what reasons we should strive to avert, accept, or perhaps hasten it—is part of a long Western history of attitudes toward death, with an overlay of particularly American attitudes (Ariès 1974; Mitford 1963). Our advanced technologic medicine is only one component, albeit significant, of

our response to serious illness, dying, and death. The replacement of failing vital organs, by transplants or man-made surrogates, at once epitomizes the achievements possible through basic and applied clinical research, the yield and limitations of "half-way technology" (Thomas 1974), and the extent of our ignorance about the workings of the living organism. These treatments also raise questions about what it is, in an ultimate or metaphysical sense, that we seek to accomplish or avoid through our medical dealings with the body human and the human condition.

Humanly poignant and socioculturally profound questions are contained in our efforts to give, receive, and reciprocate for the "gift of life" of a transplantable organ (Fox and Swazey 1978:chap. 1; Swazey 1987).³ There is much to ponder in the title of a March 1988 symposium sponsored by the Cleveland Clinic Foundation: "Life after Death through Organ Procurement." However much we have medically and legally codified "brain death," we still feel deep unease and uncertainty about it, and about who or what the donor is from whom organs are to be "harvested." To wit, a common entry in the surgical notes that record the condition of the brain-dead organ donor is "beating heart cadaver" (Younger et al. 1985).

The seemingly relentless determination to replace failing vital organs causes some to question whether there should be limits on our efforts to avert death through such interventions. Or do we feel an unbounded imperative to offer the hope, if not the guarantee, of

life? In October 1987 Dr. Thomas Starzl and his colleagues at the University of Pittsburgh transplanted five organs (liver, pancreas, small intestine, and parts of a stomach and colon) into three-year-old Tabatha Foster. "There was no other choice," her father said. "We had to go along with it. We knew if she didn't get it, she would die" ("Transplant Recipient Nears One-Month Mark" 1987).

In recent months, prospects of using anencephalic infants (lacking all or a major part of the brain) as organ "sources" has further sharpened questions about the meaning of giving an organ, our definition and understanding of death, the attributes of being a "person," and the moral implications, both religious and secular, of the drive to save lives through transplants. Debate among physicians, lawyers, and ethicists is exemplified by the contrasting and strongly held views of legal scholar Alexander Capron and biochemist Arthur Caplan:

Capron argues persuasively that breathing anencephalic newborns are dying, not dead, and [that] it would be misguided and destructive to amend either our brain death laws or the Uniform Anatomical Gift Act to permit harvesting organs from [these] live . . . newborns . . . Caplan [believes] that anencephalic newborns should be considered a separate category of human ('living but brain absent') and that parents should be able to donate their newborns' organs prior to their death. He justifies this position on the basis that

the anencephalic child can never develop even 'a semblance of personhood,' that the 'need for these organs is real,' and that ' . . . many parents are eager to have their dead or anencephalic child used as a donor in the hope that something good might come of a tragic situation.' (Annas 1987:36-37)

This highly charged, volatile debate went public in 1987 with extensive print and television coverage of two cases. In October Dr. Leonard Bailey at Loma Linda University Medical Center transplanted the heart of an anencephalic infant, "Baby Gabriel," flown from Canada to California, into newborn "Baby Paul." Then, in December 1987, a California couple, knowing their soon-to-be-born baby was anencephalic, decided the mother would carry him to term and have him maintained on life-support systems until he could become a donor. "I don't want to make this baby a total waste," Mrs. Winners explained in a public appeal to have a hospital accept the offer of their baby's organs ("Using Brain Deformed Babies as Organ Donors Spurs Debate" 1987). Some 118 hospitals, on ethical and legal grounds, rejected the couple's plea that their baby might "live on somehow," but their offer was accepted by Dr. Bailey and Loma Linda. (The infant, a few days later, was delivered stillborn.)

The effort to maintain life or postpone death through the use of an artificial heart raises many of the same more-than-medical questions, framed with extra intensity by this early "Model T" stage of the device. In

The replacement of failing vital organs epitomizes the achievements possible through basic and applied clinical research and the extent of our ignorance about the workings of the living organism.

many ways, the quest for an artificial heart fits into the tradition of technological utopianism in American culture (see Segal 1985) and its antecedents in Western European thought; it is part of the conviction that humans can bend and master nature and create the environment of their choosing and design. The strong element of hubris in this conviction cannot be overlooked, at least in the way that it is being played out in the development of artificial vital organs. “Willem Kolff,” one of his colleagues reflected, “has a vision of a totally replaceable body.” “As we stood on the threshold of taking the artificial heart to the clinic,” he continued, “everyone sensed the dilemma that [the device] was not yet ready to support real human existence. . . I too had misgivings, but I didn’t want to stand in the way of progress. A whole symphony of technology gave us the feeling that maybe the heart was going to work.”

For most, the promise and lure of a permanent artificial heart faded dramatically, at least for now, with the accounts of Barney Clark’s 112 days, and of William Schroeder’s lying semiconscious in his hospital bed, slowly succumbing to the series of strokes and recurrent infections that finally ended his life after 620 days with a Jarvik heart. For all those days and nights, the artificial heart efficiently pumped his blood and perfused his body. “Bionic Bill,” as Schroeder was dubbed by some members of the press in the euphoric first eighteen days after the implant, was alive, but his mental and physical impairments—caused at least in part by the device—led many to wonder, at what price life? “A dying man needs

to die, as a sleepy man needs to sleep,” Stewart Alsop wrote of his own terminal illness and the experimental treatments he underwent, “and there comes a time when it is wrong, as well as useless, to resist. . . . That time has not yet come for me. But it will. It will come for all of us” (Alsop 1973).

Medicine and the (Un)Just Society

Another project I embarked on while studying the artificial heart took me throughout Maine to study issues in health care needs and services for the elderly.⁴ Maine is a vast and sparsely populated state, largely rural and poor, with a higher percentage of elderly residents than the national average. Meeting with senior citizens and their families and with health and human service planners and providers, hearing their concerns about matters like health care costs and the availability of services, especially for the rural and poor frail elderly, posed stark contrasts with the world of the artificial heart. It was psychically disjuncting to move between the medical care issues confronting Maine’s elderly, which mirror the enormous sociomedical problems being posed by the graying of America, and the ambience of academic medicine and high-tech bioengineering in Salt Lake City and the corporate largess of Humana in underwriting DeVries’s artificial heart program. These small but intense encounters open onto the large questions about distributive justice: how a society chooses to

allocate its scarce material and nonmaterial resources, and how those choices bespeak the values undergirding that society.

Dollars for health care and illness care, equipment, facilities, transplantable organs, and the personnel who give care to the ill and dis-eased are resources that are finite, even in an affluent society, and decisions on their allocation must be made at many levels. Is it right or fair, for instance, to move a bridge-to-transplant patient to the head of the queue, giving him or her priority for the next available human heart because he or she is living with a device that may cause irreparable damage if it remains too long in the body? If we have chosen to provide organ transplants to those in medical need, should that “gift of life” be predicated on an ability to pay for its high costs? Conversely, should we have made this choice to offer very expensive interventions for a relatively small group of people given the scope of more basic medical needs? Why, as a nation, do we endorse, or at least passively accept, the investment of hundreds of millions of dollars in developing and deploying expensive halfway technologies that may palliate a disease and extend life, but not cure or prevent, while the plight of the medically indigent and underinsured mounts and their access to care steadily deteriorates? “Who shall live when not all can live?” (Childress 1970). And, short of these life or death decisions, we wrestle with a question no less difficult: who is responsible for “protecting the medical commons” (Hiatt 1975)?

Many such moral questions about resource alloca-

tion are clear and vivid, but the sharpness with which they can be posed does little to help us answer them. It seems particularly difficult for our highly individualistic and pluralistic society to confront, much less resolve, the issues of distributive justice that arise in health care and medicine.⁵ Indeed, we delude ourselves about having any sort of comprehensive social policy and structures for delivering health maintenance or illness care by talk of our “health care system.” We deliver a great deal of illness care, particularly of the acute variety, but much less in the way of health care. “Health maintenance organization” is another misleading term for a delivery mode concerned largely with controlling costs, and thus extremely reluctant to enroll subscribers who do not have a good past, present, and prospective health status.

Congruent with our prevailing socioeconomic policies, we have multiple ways and tiers of providing, receiving, and paying for health and medical care. If there is a “system,” it can be seen only after one has put the jigsaw pieces together, especially in this era of marketplace competitiveness and signs of increasing destabilization in American medicine (Kinzer 1988).

Our current ways of giving medical care, which have long involved implicit rationing, contain moral dilemmas that are captured by the extensive resources given to a William Schroeder or a Tabatha Foster, and, in counterpoint, by the desperate efforts of a Maine area agency on aging to find the resources (human and economic) to meet the needs of an ill, debilitated couple

The seemingly relentless determination to replace failing vital organs causes some to question whether there should be limits on our efforts to avert death through such interventions.

in their nineties, being cared for in rural poverty by their children past the age of seventy.

Do these cases represent unacceptable or tolerable inequities in a society that purports to be just and egalitarian? Given the heterogeneity of our values, and our collective unwillingness to confront the reality of rationing decisions, we lack a framework within which to reach consensus on an answer. Economics, in the form of the ethos of cost containment, has dominated “health” care politics in recent years. But as Norman Daniels points out, “Economic incentives such as those embedded in current cost-containment measures are not a substitute for social decisions about health care priorities and the just design of health care institutions. These [measures] . . . will not ensure that we will meet the needs of our aging population over the next several decades in a morally acceptable fashion or that we will make effective—and just—use of new procedures” (1986:1383).

Perhaps, as ethicist Karen Lebacqz suggests, we have had so much trouble, and so little success, deciding on whether and how to provide socially just modes of medical care in the United States because we have focused on the wrong questions. “If injustice is the beginning point”—as indeed it seems to be when dealing with health, illness, and medicine in American society—“then we may need different theories of justice” (1986:123).

Who Shall Guard the Guardians?

As our study of the artificial heart unfolded, interviews, observations, and published and unpublished sources gave Renée Fox and me more information and viewpoints about the Jarvik heart’s laboratory testing, the initiation of the first clinical implant, and the subsequent uses of the Jarvik device and other models for permanent and bridge use. Especially when an innovation may benefit desperately ill patients, the move from the laboratory to the clinic is an inherently premature, uncertain, risk-laden step. Beyond the patterns common to early stages of therapeutic innovation and human experimentation, however, other more troubling patterns emerged in the artificial heart story.

The case of the artificial heart thus became a vehicle for examining the systems of social controls that govern, or fail to govern, physicians and other professionals (Swazey and Scher 1985). The topic of professional social controls is a necessary part of any attempt to understand the systems shaping health care and medicine. Attention must be focused on how researchers and physicians are trained and socialized, why they feel that as professionals they have a right and a duty to exercise individual and collective self-governance, and how such self-governance is exercised with respect to technical and moral competency (Bosk 1979).

Concerning the artificial heart as a species of therapeutic innovation, *social controls* refers to the informal and formal means that medical professionals and

external agencies (for example, law, regulation, public opinion) can employ to assess and approve or disapprove the development, clinical testing, and widening use of a new drug, device, or procedure. At a bare minimum, three questions should be asked about initiating and continuing a clinical experiment:

1. Is the move from the laboratory to the clinic warranted by the *in vitro* and *in vivo* data on safety and efficacy of the new drug, device, or procedure?
2. Is the clinical research protocol soundly designed? Does it ask scientifically valid and answerable questions and use sound and appropriate methods of gathering and analyzing clinical data?⁶
3. Does the investigator and his or her team have the clinical research knowledge and skills to implement the protocol?

Various participants in the decisions to initiate and continue clinical experiments with the Jarvik heart, and close observers of those decisions, felt both at the time and in retrospect that all three questions could or should be answered “no.” Why, then, did the experiment begin and continue, along with the proliferation of bridge-to-transplant procedures? Who were the gatekeepers, and why did they seemingly fail, on balance, to exercise the range of social controls at their disposal?

Two points about these questions merit emphasis.

First, sociologically, explanations for what transpired do not involve casting the various actors in the roles of villains or heroes. Second, these questions transcend the particularities of the Jarvik-7 heart. For example, there are questions about whether the way that artificial heart research has been reviewed may or may not be typical of IRB and FDA regulation of significant risk medical devices more generally, and also may or may not be illustrative of the way that research with such devices is conducted. In addition, some of the problematic aspects of the clinical research on the artificial heart reflect more systemic alterations in patient-oriented clinical research and in the training of physicians to do that research (Feinstein 1987; Maurice Strauss 1960).

An array of social control agents had (and have) options to endorse and facilitate, delay, or halt the clinical use of the artificial heart. These agents include the laboratory and clinical investigators and their immediate colleagues; the wider professional community of cardiovascular and cardiac surgeons, especially those involved in clinical investigation and cardiac replacement; institutional officials; institutional review boards; the FDA's Division of Cardiovascular Devices and its advisory panel; and, more indirectly, the media and more distant proponents and critics (Swazey and Fox 1970; Swazey, Watkins, and Fox 1986). Some of these social control agents, individually and collectively, have remained advocates of the artificial heart experiment. Others have had grave reservations about the circumstances, nature, and results of the device's clinical

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use. Among this latter group, with one or two exceptions, countervailing factors—personal, professional, and political—have stilled a more than private expression of their concerns and dissuaded them from taking any steps to institute a moratorium on clinical use, especially as a permanent replacement for the human heart.

The silence and inaction on issues concerning the artificial heart—for example, whether patient outcomes medically and ethically justify continued use of this generation of devices, and whether implants qua clinical research can be justified—involve familiar, recurrent, sociologically explicable social control patterns in medicine and other fields. One can analyze this silence in relation to professional socialization, societal norms governing the roles of the powerful professions, and the dynamics that can occur in clinical research. However, such understanding does not readily translate into remedies and does little to resolve the deeply unsettling issues of moral agency embodied in the case of the artificial heart, including the obligations and responsibilities of participant observers. *Quis custodiet ipsos custodes?*

“Made in the U.S.A.”

Perhaps the most important lesson that Renée Fox and I learned in our study of the artificial heart was the importance of recognizing and understanding the social and cultural contexts of medical research and care. If

any one theme came to dominate our study, it was the quintessentially American character of the artificial heart experiment. This is not to say that the development and testing of an artificial heart could take place only in America—indeed, such work is proceeding in several other countries. But there is a very American cast to the scope and pace of work on artificial hearts in the United States since the 1950s (of which the Jarvik heart is only part), their clinical deployment, the ways in which the device’s developers and clinical users have acted and have been perceived and portrayed, and the types of ethical and social policy concerns that the device has evoked.

The American tapestry of the artificial heart story has many threads. Woven in, for example, are the mix and tensions between academic and corporate medicine, between government-funded, university-based research and development and private, for-profit research and development, and the new alliances between universities and private industry.

The types and blends of bioethical, legal, and social policy concerns that have been raised about artificial hearts (particularly during these early clinical phases of their use as experimental permanent devices and as “rescue medicine” interventions for patients awaiting a heart transplant) also have a particularly American cast (Fox and Swazey 1984). This is seen, for example, in the content of ethical debate about implants as human experimentation: its focus on issues of autonomy and informed consent, the special vulnerability of the dying

patient as research subject, risks and benefits, quality of life, and the moral and legal implications of “turning the key” to end the experiment.

Temporary “emergency” use of the device as a bridge to transplant has also stirred debate, with concerns being registered about informed consent issues, the adequacy of IRB and FDA approvals and monitoring, the use of risky experimental devices with little prior evaluative clinical research, and allocation of resources with respect to the imbalance between donor hearts and transplant candidates. And for over twenty years, studies for the artificial heart program of the National Institutes of Health have raised questions about what we will or should do, societally, if a safe and effective artificial heart is developed. These “what if it works?” questions, sometimes framed with reference to the history of chronic dialysis, have centered on the individual and aggregate costs of artificial heart implants for thousands of persons a year and on the determination of who should have access to the device and by whom the costs should be borne (National Heart, Lung, and Blood Institute 1985).

“We Shall Overcome.” The history of American culture has been marked by strong convictions about a “dream of progress” and an often boundless optimism about the fruits of science and technology. In contrast to the more Gallicly somber beliefs of a René Dubos about our pursuit of the “mirage of health,” for instance, there is the “we shall overcome” optimism of a Lewis Thomas, strongly convinced that there is a finite list of

human diseases which, with the development of a truly scientific medicine, we will be able to understand fully and effectively prevent or treat (Dubos 1971; Thomas 1985). The visions of “spare parts” medicine and “bionic man” represented by the artificial heart are of a cruder, more mechanistic genre than Thomas’s vision of the conquest of disease through the fruits of basic biomedical research. But both visions are part of the same culturally patterned beliefs in our eventual ability to conquer illness and infirmity and perfect imperfect human bodies. This belief, to be sure, antedates American culture, and it is not untainted by strands of pessimism or fears, but it has been more pronounced and played out more fully here than in other places.

The conviction that an artificial heart can, should, and will be perfected thus is a perhaps hypertrophied exemplar of American beliefs and values about the yield of science and technology. As enacted in the artificial heart story, these convictions are laden with hubris—an arrogance about our ability to “slay the dragon” of nature that is not unique to the artificial heart. As Stanley Reiser has written, “The machines we build are highly directive. For we build into them not only mechanical or electronic powers but our own aspirations. . . . Machines . . . can become key agents of a view developed through the Scientific Revolution that nature should be mastered, not lived with. What greater act of domination could we as humans devise than to substitute a machine for the most conspicuous agent of life, the heart?” (Reiser 1984:172-73)

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“The Right Stuff.” The media’s reports on the artificial heart provide a rich portrayal of the attributes that this innovation, and the people and places connected with it, is seen to embody. When Renée Fox analyzed a small sample of press files, for example, she found certain patterns in the characterizations of some of the lead figures—Drs. William DeVries, Robert Jarvik, Willem Kolff, and Allan Lansing (head of the Humana Heart Institute) and artificial heart recipients Barney Clark, William Schroeder, Jack Burcham, and Murray Haydon and their families. These depictions, she noted, represent “highly traditional American values, virtues, and images,” often with a “mythic and legendary quality”:

- Small-town feeling
- Traditionally conceived roles of male and female, husband and wife
- Celebration of family: many children and grandchildren; an idyllic marriage
- The work ethic as a virtue
- Individualism, in the form of self-reliance, self-confidence, inner and outer strength, and the determined pursuit of a goal
- An “admirable tension” between the work ethic and individualism, on the one hand, and familial and community values, on the other (particularly in the case of the super-dedicated doctors)
- Youthful, robust, gifted, irrepressible, pioneering, inventive, restive, innovative spirits
- Dedication to a larger-than-self, collective purpose in the service of humanity

- Patriotism: community, military service, school, church, “civic religion”
- Emphasis on achievement, competition, and success (humble origins; hard work; desire to excel; youthful dreams; attainment of respect, wealth, occupational and professional recognition; community leadership; “winning”)
- Grace, gallantry, and equanimity in the face of life and death.

Behind the Scenes: The Artificial Heart and Mormonism. From the time of our first visit to Salt Lake City, Renée Fox and I were struck by the ways that the artificial heart was sociologically “the same but different” from other cases of therapeutic innovation we had studied over the years. A striking difference was the largely latent influence of Mormonism on the Jarvik heart’s development and first clinical use. Mormonism, as Thomas O’Dea has written, is “in many respects the most American of religions.”

[Mormonism] has been “an America in miniature.” The chief processes of American history [the original colonization and breaking of the wilderness, the development of political self-government and the conflict with the mother political institutions, the development of group self-consciousness, the attraction of immigrants from Europe and the utopianism associated with it, the process of assimilation to a native English-speaking culture, and the experience of westward

movement] have been repeated within the smaller context of the peculiar Mormon experience. . . . When we add to these historical processes the fact that in its values Mormonism offers an analogous spectacle of distinction and similarity, the strange combination of peculiarity and typicality stands out as the most striking Mormon characteristic. (O'Dea 1957:117-18)

When Renée Fox and I discussed our initial impressions about the influence of Mormon religion and culture with members of the artificial heart team in Utah, they argued that it was American values, not the Mormon faith, which had helped shape the artificial heart story. But this, we observed, was precisely the point: it is a blend of at once religious and secular sociocultural values (Fox 1984). Thus the themes noted above in press stories about the artificial heart express congruent Mormon and American values. So, too, does the eulogy delivered by Elder Neal Maxwell, a member of the Mormon Church's Council of Twelve, at Barney Clark's funeral. "True scientific research," Elder Maxwell observed, "is but the carefully ordered expression of that mortal drive and hunger and quest to know more of what God knows." Dr. Clark's days with an artificial heart, he said, were "a unique second salute to God in gratitude for the gift of mortal life. . . . To a world increasingly filled with hopelessness and despair, he stood quietly but resolutely for an entirely different view of life" (Van Leer 1983).

Our encounter with the artificial heart story in Utah, then, revealed that "in largely implicit and unintended ways, Mormonism played a role in shaping the heart team's values, vocabulary, and imagery; its conception of itself; its leadership and organization; and its relationships—to colleagues, to its special patient Barney Clark and his family, to the IRB, to the press, and to the American public. Mormonism in this sense added certain dimensions of meaning and mission to the implantation of the artificial heart in Barney Clark" (Fox 1984:86-87).

Lessons from the Field

On Methods and Values. I have suggested in this paper that a particular mode of social science research (an in-depth case study based primarily upon fieldwork) and a particular topic (the artificial heart) can illuminate the myriad events, phenomena, and processes that shape the ways a society deals with health, illness, and care. I have sketched some of the themes and issues captured by the artificial heart story but have offered little in the way of conclusions and recommendations about matters like professional social controls, the uses of halfway technologies, and methods for redressing inequities in our allocation and delivery of health and illness care.

Just as one makes trade-offs in choosing what to take up in a paper of circumscribed length, one makes trade-offs in choosing research methods. On the one hand, for example, case studies and qualitative ethno-

Apart from some attention to the religious dimensions of particularly controversial topics like abortion, there seems to be a pattern of avoiding the religious dimensions of health and illness and its care in American history.

graphic work are subject to questions about validity and generalizability, compared to quantitative methods involving large data sets and statistically based conclusions. On the other hand, journeys into the field can provide a depth of information and understanding—the “thick description”—that enables a researcher more approximately to penetrate the “lived in reality” of a situation, event, or social system.

Because this paper has dwelt so much on value patterns, it is important to note that a critical though largely latent factor in one’s choice of research topics, methods, and lines of analysis is the values that a researcher brings to his or her work. Whether one is developing a survey instrument or working in the field, social science research, like any other area of scholarly inquiry, is not value free; the researcher’s mind is not a tabula rasa which neutrally selects topics, receives and processes data, and generates results. Thus social scientists as well as theologians need to explore their own perspectives critically, examining and articulating how they ground their values as researchers, and giving attention to the ways and extent to which those values inform their work. That, too, is an important lesson to take into and bring back from the field. It is one that Renée Fox and I will be discussing at length in a book in progress on the artificial heart, particularly as we reflect on the ways our personal and professional values have figured into a decision that it is time for us to “leave the field” of transplantation and artificial organs.

On Structured Silence. In concluding, I would like to

reflect briefly on the “structured silence” that seems to shroud public discussion of the role of religion in medical research and care in America. Renée Fox and I were struck and somewhat surprised, for example, by the responses, ranging from denial to anger, of Mormons and non-Mormons in Utah to this part of our perspective on the artificial heart. As another example, the massive media coverage of “happenings” like the Barney Clark implant, the Baby Fae baboon heart transplant, or Loma Linda’s donor program for anencephalic infants contained almost no mention, much less discussion, of their Mormon and Seventh-day Adventist contexts. The reasons for such silence, I think, are complex and important and have to do with far more than the fact that these two religions are not in the American mainstream. Apart from some attention to the religious dimensions of particularly controversial topics, such as the “pro-life/pro-choice” debates about the beginning and end of life, there seems to be a pattern of avoiding or ignoring the religious dimensions of health and illness and its care in American society.

The relative lack of public discussion should not be confused with a lack of interest in the religious dimensions of health, illness, and medicine. Time spent in the small worlds of hospitals, for instance, reveals that a great deal of private reflection and discussion goes on, between individuals and in small groups, among patients and families, physicians and nurses, chaplains and others who daily experience or encounter illness and the beginnings and ends of life. Such private

discourse does not readily translate into public dialogue. The pluralism of American society, with its many and diverse faith traditions, mitigates against the ready surfacing and discussion of religious values. So, too, does the fact that our society, as embodied in the separation of church and state, considers religion a private affair. Correlatively, many become uncomfortable when faith is “displayed” outside the home or place of worship, deeming it to be somehow an emotional, inappropriate expression of a personal matter. And, too, ours has been an increasingly secularized society, in

which morals and values, religious and secular, become transmuted into ethics, sometimes with mocking acknowledgment of their “former” religious groundings (Fletcher 1987).

If these impressions are sound, further exploration of them could yield important insights into the value-tapestry of contemporary America as glimpsed through the windows of public and private discourse about the religious dimensions of health, illness, and medicine. There are many voyages to be made into the field, and many lessons to be learned. ☸

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NOTES

1. The study begun in 1983 is our second on the artificial heart; the first was a detailed analysis of Dr. Denton Cooley's controversial 1969 implant (Fox and Swazey 1978: chap. 6).
2. A full account of the artificial heart story and its participants begins long before the events surrounding the Jarvik heart (now, since Dr. Jarvik's ouster from Symbion in 1987, beginning to be called the J-7 or Symbion heart). The long history of efforts to develop a man-made replacement for a failed human heart can teach a great deal about the technical, political, economic, and human forces that drive therapeutic innovations. In June 1938, for example, *Time* magazine's cover pictured Charles Lindbergh, "the lone Eagle," and the perfusion pump he had developed for the brilliant and controversial French surgeon Alexis Carrel: a device the *New York Times* christened an "artificial heart" (Hallowell 1985). Descendants of that invention included the prototype hearts developed in the 1950s by physician-researchers like Adrian Kantrowitz, Michael DeBakey, and Willem Kolff. The device that bears Robert Jarvik's name, for example, represents over twenty-five years of work by Kolff and some 247 co-workers (Kolff 1983). The hoped-for clinical applicability of those devices, in turn, was one basis for the beginnings of the National Institutes of Health artificial heart program in 1963 (Bernstein 1984; Michael Strauss 1984; U.S. Congress 1982).
3. Our society's definition of transplants as a "gift of life" has embedded this treatment in the complex phenomenon of gift exchange, which, in all societies and cultures, is governed by the "triple norms" of obligations to give, to receive, and to repay a gift. The deep meanings of offering a possible gift of life to a dying family member or stranger, the pressures to accept such a gift if it is offered, and its inherent reciprocity have made organ transplantation an especially intricate and value-laden endeavor.
4. The Acadia Institute's Maine Health Care Decisions project was one of the six "community bioethics" demonstration projects funded by the Prudential Foundation from 1985 to 1987. Ironically, one of the foundation's press releases for this program pictured the Jarvik heart, with a caption asking, "It's ready, but are we?"
5. One example of cultural influences on philosophical concerns and ethical debate was provided to Renée Fox and me during a research and teaching trip to the People's Republic of China in 1981. In a conversation with a group of Chinese physicians about the imminent opening of their country's first chronic dialysis facility, we asked how they would handle the problem of patient selection and what guidelines they would use. Their repeated response was "No problem." What they meant, we finally discovered, was that they saw "no problem" with what we, as Westerners, viewed as a major distributive justice issue, because their dialysis unit had not yet opened. For the Chinese, we were told, such speculative worrying about what might be a problem is "playing with emptiness."

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6. Institutional review boards still debate whether their duties should include assessment of a protocol's scientific design. If, however, a protocol is so poorly designed that it cannot produce meaningful results, then benefits to subjects can never outweigh risks; therefore, no matter how fine the consent form, the experiment is not ethically acceptable.

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Economics and Medicine

Theological Reflections

ETHICISTS AND THEOLOGIANs have devoted an enormous amount of attention to biological and medical issues in the past two decades. Issues like abortion, euthanasia, and the meaning of informed consent have claimed attention for a longer span, while others have come to prominence as the result of more recent scientific and technological breakthroughs. Organ transplants, prenatal testing, in vitro fertilization, the artificial prolongation of life—these developments pose new moral dilemmas and challenges to existing bodies of ethical wisdom.

But in the new literature on biomedical ethics, less attention has been devoted to the ethical examination of economic and social systems for health care delivery. This is all the more surprising since the system as a whole affects virtually everybody, while the particular problems with which the literature is more preoccupied

touch the lives of comparatively fewer people. Whether or not one ever needs to use the system, almost all of us help pay for it through taxes, health insurance premiums, and higher prices for products from industries with health care plans. Moreover, the systemic organization and funding of health care in a society both influences and reflects relationships, attitudes, and values of all sorts.

The Troubled American Health Care System

Is the health care system in the United States functioning well? If so, ethicists, like mechanics, might follow the maxim “if it ain’t broke, don’t fix it.” Indeed, in many respects the system is a notable success. The advances

of medical technology are little short of phenomenal, with spectacular victories over once-dreaded diseases like smallpox and polio, with steady gains against even cancer and heart diseases, and with dramatic surgical breakthroughs to improve the well-being of victims of arthritis and accidents. The victories and breakthroughs have begun to register statistically, with small but significant recent increases in life expectancy which appear to reflect both medical advances and improved nutrition and disease prevention. According to the World Bank (1987), life expectancy in almost all of the industrialized countries has gone up four or five years during the period between 1965 and 1985; in the U.S., male life expectancy advanced from 68 to 72, and female life expectancy from 74 to 80. Gains in some of the underdeveloped countries were even more impressive.

But despite these sources of encouragement, not all is healthy in the American health care system. Its overall cost, as a percentage of the gross national product, has increased from around 3 percent to over 10 percent in the period since World War II—with costs in current dollars reaching beyond \$400 billion. Two decades of Medicare have provided unprecedented medical security for the elderly, and the Medicaid system has greatly improved the access of many poor people to better-quality health care. But many other poor people and the large majority of the population who are neither elderly nor rich nor very poor have a more troubled relationship to the system. On the one hand, they carry the lion's share of the costs of the publicly supported

systems. But on the other hand, they also confront the rising costs of their own health insurance programs and doctors' fees. In a period of shrinking personal incomes, in real dollars, the increased health care costs diminish the income available for all other purposes.

It is also a difficult time for health care professionals and hospitals. The increase in the number of physicians, although a promising development in some respects, leads to greater insecurity in the profession as a whole. That is compounded by the burgeoning costs of liability insurance—in itself ominous evidence that the relationship between doctors and their patients has to some extent soured in recent years. The system has also created a larger supply of hospital beds than the country really needs—perhaps by as much as 30 percent. And the competition among hospitals for patients has become correspondingly acute.

The country has not had a full-scale debate about health care since the Carter administration, when various forms of national health insurance were under consideration. The serious federal budget deficit has put a damper on consideration of costly new governmental programs. But that very deficit may itself soon make necessary more serious consideration of alternatives for containing the growth of the health care portion of national income. The churches need to be prepared to contribute to the debate over health care delivery when it returns to greater prominence on the political agenda—as it surely will. It may even be a responsibility of the churches to help precipitate that debate.

The large majority of the population who are neither elderly nor rich nor very poor carry the lion's share of the costs of the publicly supported health care systems.

Basic Theological Considerations

What perspectives can Christians bring to bear upon the health care system?

It is debatable at the outset whether Christians, or the adherents of any other faith tradition, have anything *unique* to offer to the ethical discussion of the health care system. Insofar as the literature of biomedical ethics deals directly with systemic questions, it tends to reflect philosophical, not theological, modes of thinking. Much of that literature is contributed by nontheologians, often by persons whose primary training is in medicine, economics, law, or sociology and not in ethics (Walters and Tamar 1986). Substantive works are largely grounded in the thought of major moral philosophers, not theologians (Churchill 1987; Veatch 1981). That is understandable. Both factual expertise and conceptual clarity are indispensable as we seek to sort out moral issues, and theology certainly cannot proceed without them. Moreover, factual and philosophical ground tends to be common ground on which persons of all faith traditions can meet in reasonable discussion. If issues are cast in theological terms, how can they be understood by persons who do not share the theological views by which they are defined? It certainly is no wonder that most ethical discussion of issues related to systems of health care delivery is framed in factual and philosophical rather than theological terms.

Theological traditions, however, also supply an indispensable element: what we believe to be ultimately

real and good. Ethics, as H. Richard Niebuhr (1960) has pointed out, rests finally on our "center of value," on the basis of which all other values are measured. Everyone has some "center of value," some ultimate norm, which governs all lesser values. For many of us the norm is a diffuse self-centeredness that finally, in Niebuhr's view, disintegrates into an embrace of many values at once—which he terms *polytheism*. For others it is *henotheism*: treating one's own group (such as one's family, one's country, one's race, or even humanity as a whole) as the center of value. In the Jewish, Christian, and Moslem traditions it is *radical monotheism*, which identifies the center of value with the center of all being.

Religious traditions are traditions about ultimate beliefs and values. It is possible to discuss ethical problems without reference to ultimates, but such discussion can never be rigorous or complete. Often, of course, it is possible for people simply to assume a common ultimate frame of reference. And it is also true that some questions do not hinge upon ultimates. For example, in the United States there is general agreement among people of all religious persuasions on the need for adequate urban sewage systems. Practically speaking, many issues can be resolved without invoking religious faith and thereby risking the intrusion of unnecessary divisiveness.

But religious ground is finally the ground on which value conflicts must be resolved, and clarity about the religious ground on which one stands often helps clarify lesser points of difference. Furthermore, the

introduction of religious discourse does not invariably introduce divisiveness into ethical discussion. When we discuss the implications of our religious views at the deepest levels with people of different traditions we sometimes find a firmer basis for real unity and cooperation than when we restrict the conversation to a lowest common denominator of practical values.

Theology attempts to express faith traditions intelligibly and apply them appropriately. How are we to apply theology to such ethical issues as the critical evaluation of health care systems? We certainly cannot do so simply by citing biblical passages. Theologians and ethicists of the Judeo-Christian traditions ground their faith in Scripture, but scriptural materials are at different levels of importance and are sometimes even in conflict with other parts of Scripture. The primary question is always, what is the *heart* of the matter? What is the underlying faith to which the biblical materials point? Necessarily this core of faith will always be presented metaphorically, as we interpret what transcends knowledge on the basis of those experiences or symbols we trust to provide the most dependable insight into what we cannot know directly.

I have argued more extensively elsewhere that Christian theology rests upon personal and covenantal metaphors: Christians understand reality to have God as its source and sustainer and God to be in deep personal relationship with humanity (Wogaman 1985). The character of that relationship is understood by Christians to be disclosed in the event of Jesus Christ's incar-

nation, which expresses boundless love and ultimate hope in the goodness of God. Christian faith is thus a very optimistic religious outlook: it expresses and celebrates the hope that the very center and source of all being cares personally and deeply about every human being and that, despite all human vicissitudes and tragedies, including the tragedy of death, good will ultimately prevail. This outlook may be shared by people who would not describe themselves as Christian, just as it may be repudiated by some who do. But for those who hold it, it is profoundly important in shaping all other perceptions and values. The problem for theological ethics is discerning how to apply such a basic outlook intentionally and reasonably.

Theological "Entry Points" for Moral Problems

Given the vastness of the theological tradition, with its rich tapestry of doctrines and symbols and narratives, it seems desirable to look for the theological "entry points" most fruitful in dealing with certain kinds of problems. Some particular doctrines or stories may be more applicable than others in applying the central core of faith to an issue at hand, though the choice of theological entry points should not be arbitrary. Ultimately, any point of application has to be consistent with the core faith and with other theological entry points.

When St. Paul speaks of the priority of “grace” over “works of the law,” we are reminded that God’s love comes first, before we do anything to deserve it.

Thus when St. Paul speaks of the priority of “grace” over “works of the law,” we are reminded that God’s love comes first, before we do anything to deserve it. And we are given an entry point into every moral question that hinges on human deserving. That is, this faith outlook is in conflict with every tendency to make ultimate judgments about who does and who does not deserve to be treated as a child of God. Such a theological entry point surely does not provide us with immediate guidance on social policies of reward and punishment. But it definitely relativizes the judgments about human beings upon which such policies depend. We might, for instance, find ourselves reacting to welfare recipients a bit less moralistically when we remember that we are all sinners standing in the need of grace.

Or, as another theological entry point, the doctrine of creation holds that the physical universe is an expression of God’s loving purposes and not irrelevant or hostile to them. Thus we can be spared a false spiritualism that denies the importance of this world and its material contents. The doctrine of creation affords an entry point into questions of economics or physical health, requiring us in each instance to ask how the physical circumstances of life can better be structured to further God’s gracious purposes. We could not dismiss the suffering of the poor or diseased by airily calling them to count their spiritual blessings.

The doctrine of creation also suggests the great subtlety with which physical, spiritual, and relational aspects of human life are interconnected. The purposes

of human existence are never purely physical (we do not “live by bread alone”), but neither are they purely spiritual or relational. The most suggestive account of these interrelationships may well be that of Karl Barth ([1945] 1958), who characterizes “creation as the external basis of the covenant” and “covenant as the internal basis of creation.” For Barth, the physical or tangible world serves as external support for the true ends of human life. The latter are expressed as the divine-human covenant, manifesting God’s loving grace and establishing the true basis of human community. Thus physical questions are important because they can support or impede the fulfillment of the human spirit and God’s intended community of loving persons. Such an entry point leads to the basic theological interpretation of the importance of economic life and health care.

The entry point of the doctrine of original sin prompts us to remember our natural tendency toward self-centeredness. It helps illuminate questions of social privilege, power, and injustice, reminding us that we are awfully prone to rationalize our own self-interest and that all people should have some share in the distribution of social power as a protection against injustices. It also reminds us of the spiritual dangers of professional pride and paternalism.

Obviously the list of theological entry points could go on. Such points may be nonsense to those who do not share the basic religious outlook, but those who share that outlook must wrestle more seriously with applying them to real problems. If one takes a theological

outlook seriously—if it really *does* express one's center of value—then one will try to apply it as directly as possible. One will deviate from an obvious, direct application of one's religious outlook only for the sake of remaining faithful to it at a deeper level.

Basic Presumptions Guiding Christian Moral Judgment

I have argued elsewhere that we do most of our moral decision making by placing a burden of proof on those holding any position that seems to violate our basic commitments (Wogaman 1976). Only for good reason will we set those commitments aside—a good reason being understood as an exception made necessary by practical circumstances so we can keep faith with the commitments at a deeper level. Thus Christians have a presumption against war, because war seems so directly contrary to love. But they may make an exception of a particular war if it can be shown that failure to wage war would have results even more contrary to love.

For purposes of ethical application, we can express the Christian theological perspective in the form of presumptions that we will follow as directly as possible. These are abstractions expressing the core of the tradition, and as abstractions they may well be shared by adherents of other religious traditions. Nevertheless, their meaning to Christians will be based upon the

Christian theological tradition. For present purposes, I wish to speak of five such presumptions.

1. *The goodness of creation.* This follows from the doctrine of creation. The physical world and the fulfillment of life within it are taken to be good, not evil. Such a presumption would, among other things, suggest that suicide and euthanasia face a severe burden of proof. It would suggest that relevant medical care should be exercised to save life and improve physical well-being in every possible instance unless substantial reasons exist for not doing so. Some heroic medical interventions may only prolong agony, in which case—if the point is indisputably established—termination of some treatments might be morally advisable. Some medical interventions might be too costly—that is, might threaten the ability of society to meet even more compelling needs—in which case a moral judgment must be made in favor of meeting the other needs. Such a presumption would not in itself settle the medical facts. But it could help us sort out the implications of the facts. And as a general proposition, the presumption of the goodness of creation could well lead us to affirm advances in medical technology, it being understood that such advances would be no substitute for observing normal rules of good health and preventive medicine.

2. *The value of each individual life.* The Christian grounds this presumption in the faith that God, the center and source of all being, loves each of us without reservation. Nobody, according to this presumption, could be written off as of no value. Obviously this

Physical questions are important because they can support or impede the fulfillment of the human spirit and God's intended community of loving persons.

presumption would exclude exploitative use of human beings for medical research, such as that practiced by Nazi doctors. But it would also place a burden of proof on those who wished to exclude any patient from needed care.

3. *The unity of humanity in God.* The relationship we have with God establishes our kinship with one another, so that the metaphor “family” is appropriately applied to humanity in general. We belong to one another because we belong to God. The commonality of human beings can be grounded in other perspectives—for example, in those of biology and rationality—but the theological grounding is probably the most profound. Although we cannot even be acquainted with the vast majority of our human sisters and brothers, they are still related to us as seen in theological perspective.

As a presumption, then, the unity of humanity stands against any actions, policies, or institutions that foster unnecessary alienation among people. Racial segregation or apartheid would be obvious illustrations, as would policies flowing from sexism or national chauvinism. Economic policies can also contribute to unity or to disunity.

4. *The equality of human beings.* Grounded in the limitless love of God for each person, this presumption affirms that we are all of equal ultimate value. And if we are of equal value, the presumption is that we should all be treated equally. The factual differences among human beings make this presumption impossible to implement fully, but it still places the burden of proof on

those advocating any particular inequalities of treatment. All human societies must use incentives of some kind in a complex structure of rewards and punishments: it is necessary to motivate socially constructive forms of behavior, including creative productivity. A just society will set up structures in which incentives favor justice and are against injustice, and such structures, although they may institutionalize some inequalities, can often meet the burden of proof. Sheer need can legitimately override the presumption of equality—some people need more medical care or educational assistance to be equal to others. Still, the presumption should favor equality. Inequalities of circumstance often lead to a false sense of pride among the privileged and an equally false sense of inadequacy among the disprivileged. And inequality places a great strain upon community relationships. It is difficult to feel close kinship with those who are considerably more or less wealthy than oneself—particularly if the culture places a high premium upon material success as a mark of human fulfillment, as ours obviously does. So this presumption is closely related to the unity of humanity.

5. *Human sinfulness.* This is a different kind of presumption, reflecting not a value but a theologically based perception of the human condition. The doctrine of original sin, as we have already noted, is an important theological entry point into issues of human power and privilege. Stated as a presumption, it at least means that the burden of proof falls on those who would treat anyone as morally perfect. It is a hedge against human

pretension in all its forms and a reminder that due allowance must always be made for the pervasive tendencies toward self-centeredness. Thus the presumption of human sinfulness should lead us to preserve institutions that protect people from those who are more powerful but not necessarily less sinful.

Such a list of Christian moral presumptions is certainly not exhaustive, and other Christians might wish to deal differently with even these. Nevertheless, the list shows how theological traditions can be “boiled down” into more manageable form for purposes of ethical analysis. Those who disagree with the particulars of this presentation can at least locate the points of disagreement with greater clarity.

I wish now to consider the problem of the economics of health care delivery in the United States more directly. Is the U.S. health care delivery system fundamentally in accord with theological insight, or is there significant conflict between Christian faith and the way this system is organized?

The Economic System of Health Care Delivery in the U.S.

Health care in the United States is so varied and complex that one could even question whether the term *system* is appropriate. Certainly no single master plan has been developed by conscious intention. Nevertheless, I use the term here because the various aspects

of health care in this country are interrelated with systemic effect.

One notices immediately that the American system is entrepreneurial. Health care is bought and sold, just as other goods and services are placed on the market. Some health care delivery is charitable (as in “free clinics” organized in inner city areas). Some is publicly managed and delivered (as in the network of Veterans Administration hospitals and various other public hospitals and clinics). Some is funded by government (as in Medicaid and Medicare). And, of course, government is deeply involved in the financial support of medical education. Still, the market governs most medical transactions—a fact that even governmental funding tends to confirm, because governmental interventions in the health care system generally entail the purchase of services offered privately or the funding of the purchases by individuals covered by public programs. American health care delivery presents a mixture of private and public, but the private sector with its entrepreneurial economics is clearly dominant.

But that is not to say that truly *competitive* free market principles dominate in every respect. Despite the private and entrepreneurial character of most American medicine, the system is sharply criticized by Milton Friedman and others who are most deeply committed to free market economics. Friedman’s objection is that although American medicine is mostly private, it is not sufficiently competitive. A free market is one in which all who wish to provide goods or services are free to do

The presumption of human sinfulness should lead us to preserve institutions that protect people from those who are more powerful but not necessarily less sinful.

so, with consumers equally free to buy from whom they will. Friedman cites the American Medical Association and other related professional bodies as acting to limit competition and innovation in health care delivery. By developing a governmentally enforced system of licensure which is essentially controlled by the profession, a monopoly in restraint of trade is developed and maintained. Friedman (1962:158) argues that "licensure has reduced both the quantity and quality of medical practice; that it has reduced the opportunities available to people who would like to be physicians, forcing them to pursue occupations they regard as less attractive; that it has forced the public to pay more for less satisfactory medical service, and that it has retarded technological development both in medicine itself and in the organization of medical practice." He concludes that "licensure should be eliminated as a requirement for the practice of medicine." In a more recent book, he accuses the American Medical Association of having "kept down the number of physicians, kept up the costs of medical care, and prevented competition with 'duly apprenticed and sworn' physicians by people from outside the profession" (Friedman and Friedman 1979:221).

Friedman's own vision of economic ethics is itself troubling from a Christian theological perspective, principally because of its exaggerated emphasis upon individualism. But in the case of medicine, he has pointed to the curiously split consciousness of the American medical system. On the one hand, that system is an expression of traditions of selfless competence and caring;

on the other hand, it is an expression of frank—even crude—economic self-interest. Seen from the standpoint of the patient—the "consumer"—the contradiction is all the more perplexing. The patient truly is a consumer, a purchaser of medical services from those who sell them, and is ostensibly free to choose among competing "sellers" on the basis of quality, price, and other considerations. But the patient is also dependent upon the health care practitioner for expert judgment on questions of basic physical well-being. On such matters, the patient often feels utterly incompetent to second-guess the expert—which may simply mean turning the actual decisions of health care over to the practitioner. Insofar as the practitioner is also an economic actor, "selling" a service to a customer, it is a matter of the salesperson being in a position to make the sales decision. Few other salespersons are in so enviable a market position! That position is enhanced by whatever relationships of personal support and trust have been established, though such relationships may also serve to underscore the noneconomic aspects of health care delivery in the mind of the practitioner. Occasionally debates over altruism and self-interest break forth within the profession itself (Tiemstra and Pellegrino 1988).

This combination of economic circumstances effectively shields medical practice from many of the normal restraints of a market economy and the effects of inflation. The 1985 median net income of physicians in the United States was reported to be \$102,520 (Holoweiko 1987:70), which represented a gain of 34 percent

between 1979 and 1985. This figure, which represents net income *after* such costs as liability insurance have been subtracted, roughly parallels the rise in the cost of living for that period (Holoweiko 1987:69). It is interesting to note that such increases have occurred despite an increase in the number of doctors (a lowering of the number of patients per doctor) and a decrease in the number of patient visits per general practitioner (from 175 per week in 1974 to 134 per week in 1986) (Holoweiko 1987:82). This can only mean that large numbers of doctors have met the economic challenge of increased competition by advancing their fees commensurately. Even Friedman, who supposed that removing restraints on the number of new entrants in the medical profession would lower medical costs through increasing competition, did not expect this development.

But one must not simply equate the traditional fee system with free market economics. Friedman himself argued as early as 1962 that an unfettered market in medical service would be much more open to group practice and prepaid medical plans, which were at that time strongly resisted by the American Medical Association and many hospitals (1962:154). In recent years group practice and prepaid plans have come to represent a much more substantial portion of health care delivery in the U.S., partly reflecting greater governmental encouragement. Such developments do not represent a deviation from free market economics, any more than the emergence of the modern corporation or economic cooperatives do. As a matter of fact, it is inter-

esting to observe the growth of for-profit corporate marketing of health care, with corporations like Humana aggressively invading the hospital field and with vast retail enterprises like Sears Roebuck experimenting in the specialized marketing of medical and dental care. If medicine is a business like other businesses, there is no reason in law or economic theory that it should not be organized for marketing on a large scale, with health care practitioners compensated on a salaried rather than a fee-for-service basis.

Absent effective resistance from the professional guilds, one might suppose that a great business opportunity lies waiting here for effective entrepreneurs. With the rapid increase in numbers of doctors, there appears to be a growing pool available for employment on this basis. And corporations developing in this field can frankly and explicitly compete against the inflated fees of private practitioners. The result could be a lowering of overall costs.

In fact, recent studies of doctor incomes in group prepaid health programs suggest cost-effectiveness at two points. First, physician income is substantially lower. A *Medical Economics* survey in 1986 concluded that "doctors with 60 to 100 percent HMO patients had a median gross income 40 percent *below* that of all surveyed M.D.s." This trend is confirmed by the fact that there were 595 HMOs in the United States by mid-1986 and that 48 percent of office-based M.D.'s now participate to some extent in such programs (Owens 1987:202). Owens suggests that "today only the most

The American medical system is an expression of traditions of selfless competence and caring; on the other hand, it is an expression of frank—even crude—economic self-interest.

starry-eyed advocates of fee-for-service believe prepaid care will go away." But second, use of surgery and hospital bed space is also substantially lower for HMOs (see Brown 1987:85–89 for a summary of U.S. as well as Canadian data). With the HMOs, apparently, we are beginning to see a breakdown of the system of private practice in which private, entrepreneurial physicians are in a position to set fees and determine demand more or less unilaterally. Eli Ginzberg (1985:182) predicts that "delivery systems such as HMOs, emergency centers, and hospitals that hire salaried physicians will have a much easier time," adding that "the reason HMOs have grown slowly was that they did not appeal to physicians. Now HMOs will be more attractive because an increasing number of young doctors will have difficulties getting established," and "we are going to see more corporate medicine of all sorts." The organizations, standing between patients and primary health care deliverers, are in a position to affect costs much more substantially.

Comments on the health care system would be incomplete without noting the confused state of health insurance and the role of government. The enactment of Medicare and Medicaid programs in the 1960s brought government into American medicine in a new way. These programs were not—and were not intended to be—"socialized medicine." They were insurance programs, funded by government, to reimburse the elderly and very poor for a large portion of their medical expenses. The essential system of health care delivery was

affected only marginally and indirectly. But since initial projections of the cost of these programs were grossly underestimated, government, in the 1970s and 1980s, has had to act to limit costs. This has been done partly by encouraging HMOs, by setting fee limits, by increasing co-insurance requirements, and by attempting to limit eligibility. Still, government's role has been that of providing funding for people purchasing a service in the medical economic market—not that of providing the service directly. The large majority of people who are neither poor nor elderly have relied upon private health insurance—most notably Blue Cross and Blue Shield—to protect them from unanticipated costs, often supplementing such programs with major medical insurance policies for protection against catastrophic expenses. These insurance programs similarly operate in the medical economic market, insulating most patients from many direct costs but requiring large insurance premium payments. The recently adopted DRG (diagnostic-related group) systems for reimbursing health institutions have already had significant effects upon such institutions, including more severe cost cutting and, in some cases, restrictions of service (Starr 1986: 122–23).

As we have noted already, efforts in the late 1970s to expand the role of government in health insurance foundered in the unfavorable economic climate of that period. No serious efforts have been mounted for many years to create in this country anything analogous to the British National Health Service.

Ethical Problems in U.S. Health Care Delivery

Does this complex, confused system present us with significant ethical problems?

It is well to remember that problems are defined both by facts and by values. Specifically they arise when we see conflicts between the facts in given situations and the values to which we are committed. What we perceive as problems will shift with our values, just as with the changing facts. Therefore, what is a problem to one person may not be to another—depending upon the values each holds. By the same token, ethical problems ultimately presuppose theological outlooks, because the particular values by which we measure problems gain their importance theologically. My own assessment of problems in the U.S. health care system is necessarily shaped by the theologically derived moral presumptions discussed above.

In light of those presumptions, one can record with appreciation the accomplishments of American medicine. The American medical system has participated in a sweeping improvement of health in the twentieth century. Human beings in this country have truly been helped to realize the values of God-intended physical existence on a much more impressive scale. One could hardly characterize the system as a disaster, whatever its problems may be.

Nevertheless, seen in a Christian theological per-

spective, there are indeed significant problems, among them these:

1. Substantial numbers of poor people currently receive little or no medical care. The enactment of Medicaid in 1965 distinctly improved health care delivery to poor people, but Medicaid does not cover all poor people, and the coverage provided is often inadequate. Moreover, the number of persons receiving Medicaid coverage has been declining in recent years, even when the number of poor people has increased. Medicaid coverage has declined from 91 percent of those below the poverty line in 1976 to 74 percent in 1980 and only 64 percent in 1984 (Harrington and Lempert 1988:7). Although states and localities can supplement Medicaid programs for the “medically needy,” as of 1982 twenty-one states did not do so (Harrington and Lempert 1988:6). Estimates of the number of people, poor and near-poor, who lack medical insurance vary, but it seems clear that the number has grown during the 1980s and now exceeds 30 million, or 15 percent of the population (Starr 1986:115–16). Such an increase appears to reflect both cutbacks in categorical assistance programs and a decrease in the number of persons employed in industries or businesses providing insurance coverage as a fringe benefit. Even coverage by Medicaid is no guarantee of adequate medical service, in view of the bureaucratic and transportation problems faced by poor people (Goetcheus 1980) and the refusal by many doctors to accept patients at Medicaid reimbursement levels perceived to be inadequate.

The gross inflation of physicians' incomes has created serious tensions between doctors and most other health care givers.

This failure to provide health care for tens of millions of Americans is a severe indictment of the U.S. health care system. In reference to our theological presumptions, it threatens the capacity of uncovered people to continue experiencing physical existence as a good gift from God, it damages their sense of personal self-worth, it undermines the unity of the American community, and it violates the principle of equality. In Larry Churchill's words, "A health care system which neglects the poor and disenfranchised impoverishes the social order of which we are constituted. . . . a health care system is no better than the least well-served of its members" (1987:103).

Can the burden of proof be met by current policy? Would provision for universal health care do more harm, overall, than good? Could U.S. society, confronting budget deficits and other economic problems, afford to make such provision?

Different routes might reach the same end of universal health care coverage. But the basic economic facts about the current U.S. system in comparison with those of other countries do not support the notion that the U.S. is doing all it could even with the resources it currently devotes to health care delivery. For instance, the United Kingdom, which devotes some 6 percent of its GNP to health care, somehow finds it possible to cover all of its people, while the U.S., which devotes around 12 percent of its (much higher) GNP, cannot. The number of doctors is rapidly increasing and the number of unused hospital beds hovers around 30 percent. Still,

15 percent of the people are unserved. Does basic economics provide an adequate rationale for our neglect?

Sociologist Paul Starr's comment may be more to the point:

Many observers are deeply convinced that the United States cannot afford or agree upon any plan for universal health insurance protection, such as that of most major Western nations. Our world groans under many intractable problems, but I am convinced that this ought not to be one of them. Decent health care for the poor is not a fiscal impossibility, nor a political impossibility, unless we become utterly resigned to a kind of national incompetence in public policy. (1986:132)

2. Even for the middle-income people who are not poor, the current system may represent a poor balancing of security with risk. Total security is not a possibility in this fragile world, and in the long run, as Keynes remarked, we shall all be dead. But substantial physical and financial security can help undergird the human spirit. So far as health care is concerned, the introduction of Medicare contributed greatly to the spiritual as well as the physical well-being of the nation's elderly. And the utilization of health insurance by a majority of the population makes a similar contribution at other age levels. Nevertheless, the insurance system is expensive and erratic. Because many procedures are inadequately covered or not covered at all, people are frequently left having to gamble on the relative necessity of an office

call or other uncovered medical service. The broad middle class is probably most vulnerable here. Many of the very poor and the elderly may be able to secure services relatively inexpensively. Middle-income people, whose budgets may be very tight, often face the difficult decision whether symptoms are serious enough to warrant professional attention. If the visit to the doctor is not really necessary, it will be money down the drain. But if the symptoms indicate serious or life-threatening conditions, then the money will be well spent. The probability may lie with the former, so the risk may be run. Would it not be better if the financial outlay for initial diagnostic services were low enough that people would not be tempted to risk what ought not be risked? Something can possibly be said for charging a modest fee for diagnostic services in order to minimize frivolous overloading of the system. Many HMOs, including the one to which I belong, charge a small fee (in the case of my HMO, a flat \$10 per visit for all services—including even complete physical checkups). But most medical practice in this country is not conducted on that basis.

The element of risk and uncertainty in medical care cannot be totally eliminated, as we have said. But would not our sense of security as accepted members of the human community be better supported if we did not have to make decisions pitting our economic well-being against our physical health and that of our loved ones? Our society long ago decided that no family should have to choose between ensuring its economic security and meeting the educational needs of its children. Sure-

ly that educational policy has helped greatly in maintaining the bonds of unity in this society—whatever the undoubted problems of the free public school system. Could we also devise a way of undergirding the basic security of everyone in having their health care needs met?

3. The inherited fee-for-service system, which exists now in a more aggressively competitive and materialistic cultural context, has contributed to grossly inflated professional income among doctors, compared to the general population, thereby possibly contributing to the first two problems and, additionally, to inordinate greed among doctors. The 1985 median net income of doctors was \$102,520 (Owens 1986:162); the 1985 median U.S. household net income was \$23,618, a figure including households with more than one income earner (*Statistical Abstract* 1987:463). Such a large income gap clearly conflicts with the presumption of equality. Can such a gap be proven necessary to preserve the high quality of American health care?

Noting that “the incomes of US doctors remain about 4–5 times those of the average employee [and] more than twice the corresponding ratio in the UK,” a British observer comments that the U.S. health care system may be less adequate than that of the United Kingdom (Binns 1987:54). It is difficult to arrive at objective criteria by which to measure the relative effectiveness of different health care systems in different countries. But it cannot be overlooked that U.S. indices for life expectancy and infant mortality are generally

***It is already too late to argue that the needs of poor people will be met
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average or below average for comparable Western industrialized countries. Among nineteen such countries, the U.S. ranked only tenth (tied with six others) in male life expectancy at birth. It was second (tied with eight) in female life expectancy. But among these nineteen countries, only Italy had a worse infant mortality rate (World Bank 1987). All the countries showed improvement in such indices between 1965 and 1985, and the differences among the countries were not great. What differences there are may owe as much or more to environmental factors and nutrition as to health care delivery. Still, American pride in U.S. medical accomplishments should be restrained.

More important, the available indices of effectiveness do not support the claim that the extraordinarily high median income of doctors in this country is necessary for the performance of the health care delivery system. And without such a rationale, how are we to justify such inequality of income in light of the presumption in favor of equality? Some inequality of income can be justified on the basis that unusual sacrifices are entailed in preparing for a medical career and that this career option must compete with other high-paying ones for the commitment of promising young people. But it is difficult to support so great a gulf between the median income of doctors and that of other people. Such a differential cannot be conducive to mutually respectful human relationships between doctors and patients, and it may contribute too much to an overall climate of competitiveness in American society. It may

also undercut the deeper professional motives of doctors themselves as care givers. Doctors have legitimate economic interests, and nobody should expect them to be absolutely altruistic. But the present system of health care delivery may lead too many of them into excessive materialism, thereby undercutting deeper commitments to service.

4. The fourth problem is related: The gross inflation of physicians' incomes has created serious tensions between doctors and most other health care givers. One might expect some hierarchical structuring of the health professions, given the differences in technical expertise. But health care in the United States has perhaps become inordinately hierarchical, with corresponding morale problems and institutional dysfunction. It may be too much to expect the health professions to rely upon St. Paul's metaphor of the "body of Christ," but surely that figure of speech has something to teach all human institutions about mutual respect and collegial pursuit of common goals with different people exercising different needed functions. We have all seen health care settings in which that vision approaches reality. A crisis of morale among nurses and other health care providers appears directly related to the too pronounced hierarchical structuring of medicine and the too great subordination of human caring to technical expertise (Moccia 1988).

5. A further structural problem in the economics of the dominant health care delivery system lies in the fact that patients represent not only persons in need but

also opportunities for enhanced income for health care professionals and institutions. There is thus a built-in conflict of interest. A surgeon, for example, has a professional interest in healing; but he or she also has a financial interest in performing surgery whether or not it is truly necessary. Such a conflict of interest is not necessarily resolved by responding to the financial interest rather than the professional one. But there is some evidence that surgeons operating on a fee-for-service basis prescribe surgery much more frequently than those paid by salary. Brown (1987:85) cites studies (Bunker 1970; Vayda 1973) showing that

the incidence of surgery in the United States and Canada during the late 1960s was about twice as high as it was in England and Wales, although the standard of health was not demonstrably different. While these researchers did not attempt to isolate the determinants of surgical practices, they did note a number of possibilities, of which the fact that North American doctors are paid through fees while British doctors receive salaries . . . was one.

Hospitals, committed to expensive payrolls and overhead and confronting increased competition and empty beds (particularly in light of the DRG policies), may similarly be tempted to encourage unnecessary utilization or to specialize in the more lucrative forms of care giving.

6. The sixth problem includes but also transcends the medical system per se. It can be argued that the system does not do enough for preventive health care and health maintenance. In visits to socialist countries and some welfare states (such as the United Kingdom) with more extensive welfare programs than our own, I have been impressed by the attention given to early infant care. Every infant is, from birth, provided with frequent regular checkups. Serious problems are caught early in life and, where possible, preventive measures are taken. The basis is laid for better health in later years, and infant mortality figures are minimized. The U.S. is not an unhealthy country, and its infant mortality rates, though not the best, are still rather good by overall world standards. Nevertheless, given the high quality of potential service in this country, it is sobering to remember that we are far from heading the list in health indices. Some inner-city situations, including some in my own city of Washington, D.C., are in fact rather poor.

But this also leads to the comment that most preventive medicine is not a matter of professional medical practice. The most important preventive health measures lie in the sphere of public health and adequate nutrition. U.S. standards for the former are quite good: sanitation services and regulations are in place, and serious attention is given to environmental health problems. Nutrition is also rather good in this country, but not equally so for all people. But adequate nutrition could virtually be guaranteed for all children, given the existence of a universal school system and over-

If health care is a basic human right, to which all are entitled as participants in community, the direction should be toward a less—not more—entrepreneurial structuring of the delivery system.

abundant food supplies. Why not make a free lunch (and in areas of need, a free breakfast) available to every school-age child in the land, dispensing with means-testing so that this would be defined as a universal right and not as a further stigma for the poor?

The Social Covenant

Each of these problems points to a more fundamental theological problem: What really is the character of human society? Faced with such problems, we cannot escape the haunting question posed by T. S. Eliot in *Choruses from "The Rock"*:

When the Stranger says: "What is the
meaning of this city?
Do you huddle close together because
you love each other?"
What will you answer? "We all
dwell together
To make money from each other"? or
"This is a community"?

The response of a Milton Friedman, although deeply critical of the U.S. economic system of health care delivery, is clearly more in keeping with a society structured on mutual economic exchange than with one based on deeper communal values. His response at least has the virtue of asking for consistency and insisting upon the cost-saving efficiencies that go with real economic competition.

But a Christian theological perspective must cut deeper. It envisions a community of mutual caring and common purpose and public dialogue. The full Christian theological interpretation of society is not likely to be shared by everybody—not even by all Christians. But Christians, as participants in the wider society, must press a point that has deep roots in their faith commitments: that the community as a whole has an obligation to support the participation of each of its members, a point recently underscored by the U.S. Catholic bishops' pastoral letter on the U.S. economic system (National Conference of Catholic Bishops 1986). Absent that shared commitment, the covenant underlying any civil society is reduced to utilitarian self-interest. At least from the time of St. Augustine, Christians have understood that when society is based on nothing deeper than mutual self-interest it has within itself the seeds of its own destruction. The more discriminating questions of social order have to do with the particular mix of private freedom and public responsibility that may be appropriate at any given time or place. We obviously cannot go into all of those questions, even in the more restricted sphere of medical economics, within the scope of this article. But it can be asserted here that under modern conditions society does have a responsibility to assure adequate access to basic health care. And further, that people should be relieved of undue economic anxiety and risk-taking to secure such care. And further, that the economic structure of the health care system should not place moral stress on communal

relationships, including those within health care institutions.

Some Implications

What implications might these assertions have for the present health care system?

Clearly, some form of universal health protection needs to be established, whether by insurance or by direct delivery systems. It is already too late to argue that the needs of poor people will be met by private charitable organizations and market economics if we only wait a while longer and appeal to human generosity. The relevant questions have to do with the form of public intervention, not with whether or not this is a public responsibility. I cannot venture deeply here into the debate over what form public intervention should take, but it would appear that an American solution is more likely to be structured as a universal program of insurance—possibly utilizing the existing system of private carriers—than as a direct system of health care delivery on the British model.

It seems to me that the fee-for-service system must, and will, increasingly give way to broader forms of financing and compensation. It is probably better for health professionals to receive most of their compensation by salary, for hospitals and other health care institutions to structure their accounts more broadly, and for patient-consumers to prepay most of their medical expenses through comprehensive health insurance or

taxes. In the present system, the HMOs represent a fruitful kind of experimentation for all concerned, and even without them, proprietary health care corporations have been growing by leaps and bounds (Wohl 1984).

I am among those who view the growth of the private health care corporations with some misgivings. They may well introduce new managerial efficiencies in medicine over the short run, and they will surely function to bring physicians' incomes into a more defensible relationship to those of other people. But at the same time they could lead to a deepening of the two-tiered health care system in which one's wealth severely affects the quality of care one receives. If health care is a basic human right, to which all are entitled as participants in community, the direction should be toward a less—not more—entrepreneurial structuring of the delivery system.

In the long run, much can be said for a health system that is in the public domain. Notwithstanding the negative press generally given the British National Health Service in the United States, I must record my own great appreciation for its services during a period of residence in England; furthermore, most of the British people with whom I discussed the system—including some economists and doctors—expressed similar appreciation. If their system were not so popular, we can be sure that the Thatcher government, with its deep biases in favor of unfettered free market capitalism, would long since have abandoned it. The British

health system, like the U.S. public school system, permits the existence of private practice for fees for those who prefer using it—and that kind of duality may well contribute to the efficiency and service of both the public and private sectors of practice.

An American system could not simply copy that of Great Britain or any other country; and, in any event, the U.S. clearly is not ready yet for a serious debate along such lines. Nevertheless, there is a deep under-

current of dissatisfaction with the present structuring of the American system. The real issue is not whether we will keep things just as they are, but whether an increasingly corporate form of medical practice will develop along private entrepreneurial lines or will involve a more substantial public sector. I favor the latter option because I believe it will be more responsive to the deeper social needs of our society. ☸

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“Am I Still My Brother’s Keeper?”

Theological Reflections on the Crisis in Health Care Management

IN THEIR RECENT pastoral letter, *Economic Justice for All: Catholic Social Teaching and the U.S. Economy*, the American Catholic bishops begin by posing three rhetorical questions: “What does the economy do *for* people? What does it do *to* people? And how do people *participate* in it?” Far more important than any specific answers that might be given, the questions indicate the bishops’ intention of articulating a “perspective on economic life that is human, moral and Christian” (National Conference of Catholic Bishops 1986:412). Reading through their pastoral letter, one realizes just how religiously and morally loaded these simple questions are. For the bishops’ own answers presuppose a normative view of what it means to be a person, in a community of people, that colors all

their expectations regarding the economy’s role in creating and sustaining the conditions under which we all might flourish.

The same cannot be said for what passes in many quarters as economic analysis. For contemporary economic perspectives, with few exceptions, pretend an indifference to human values, traditions, and the institutions in which these are embedded, and offer instead abstract quantitative models of rational choice that reduce every substantive commitment to a “preference” having equal standing with all other possible preferences. The result is that everything is valued only according to what rationally self-interested persons would pay to acquire or retain it. All other considerations

—for example, the inevitably substantive arguments concerning the nature of the public good or the just society—are dismissed as so much “theology.”

Such economic analysis is disturbing enough when the preferences at stake are merely those of individual consumers out to maximize the satisfactions that money can buy. But when institutional policy choices, under pervasive and increasing pressure from budgetary constraints, become justifiable ultimately on the basis of their cost effectiveness, one cannot help fearing a loss of integrity in those institutions. If not entirely ignored, the human purposes of economic activity expressed in the pastoral letter’s questions become clearly subordinate to the accountant’s preference for the bottom line.

Though one might expect to find this mentality among the managers of business corporations, the evidence suggests that not-for-profit institutions, both public and private, are increasingly managed according to similar assumptions. Hospitals and health care institutions are only one example. Private colleges and universities, including the one that I work for, have had to rationalize virtually every activity, including curriculum development, in terms of its economic impact. As a result, students make choices regarding their programs of study as if a university were merely a marketplace of ideas, while administrative decision making becomes ever more centralized and geared to the new science of enrollment management. Even when such economic rationalization succeeds in stabilizing

the costs of higher education, it usually fails to preserve any sense of the institution’s mission or distinctive values. Indeed, the usually subtle, but sometimes dramatic, erosion of these values seems to be one of the trade-offs involved in the triumph of economic analysis.

My purpose, however, is not to engage in another jeremiad denouncing the evils of contemporary institutional management. The parallel seen in academic administration suggests that health care management faces a common predicament that is hard to define and even harder to resolve. Here I hope to stimulate a new conversation about corporate values and economic exigency that might contribute to a renewed sense of mission among the managers of all such institutions, especially those health care systems whose foundations rest on explicitly religious commitments. I consider these remarks to be theological reflections because I believe that spirituality is the key to such renewal. In his *Health and Medicine in the Catholic Tradition*, Richard McCormick asserts the need for “a spirituality for health care personnel” (1984:42). But if such a spirituality is to be relevant to our predicament, it will have to emerge from a discernment of the Holy Spirit’s ongoing presence in the ethos of the institution itself. We must learn, then, to discover that brooding presence in our common travail over institutional values and economic exigency. When we do, we will gain not only a deeper appreciation of these values but also greater confidence in managing our institutions to serve them better.

I. What Crisis? Individualism and the Monetization of Health Care Policy

The existence of a spiritual purpose in health care institutions once could be taken for granted. It was assumed that the individuals working within the institution acted out of a sense of religious vocation, and the institution's own mission was clear and unproblematic. In Catholic health care institutions, for example, there was little need to speak about spirituality when the "personnel" were still primarily members of the founding religious orders, and when these orders themselves had no doubts about their roles within the Church. But these assumptions about a spiritual purpose no longer hold true. Obviously, the triumph of economic analysis is not what destroyed this latent spirituality, but it has helped us recognize the nature of our loss and the need for institutional renewal.

What moral peril is involved in the current pressures toward economic rationalization? One important set of clues is given in *Habits of the Heart: Individualism and Commitment in American Life*, written in 1985 by Robert Bellah and a team of social scientists. Their study, based on hundreds of interviews of ordinary, middle-class Americans, suggests that our private and public lives are now dominated by disturbing new forms of individualism. These new forms, apparently detached from the older American cultural traditions celebrated in Alexis de Tocque-

ville's *Democracy in America* (1835), Bellah identifies as "expressive" and "utilitarian" individualism. Though the roots of the one go back to Walt Whitman and of the other to Ben Franklin, in their current forms they converge in that peculiarly American expectation that private life will be totally spontaneous and unconstrained, while the exercise of any public responsibility is virtually determined by the remorseless logic of quantitative analysis.

Bellah and his associates speculate that, consistent with the emergence of expressive and utilitarian individualism, our public life is now governed by a pair of dominant character types, the "therapist" and the "manager." Though it would be useful at some point to consider Bellah's description of the therapist, here our focus will be restricted to its twin. *Habits of the Heart* understands the manager in the context of modern industrialism. More than just a new division of labor, modern industrialism is a "division of life into a number of separate functional sectors: home and the workplace, work and leisure, white collar and blue collar, public and private" (1985:43).

Within this industrial system of life, the manager ceases to be an entrepreneur and becomes virtually indistinguishable from the bureaucrat:

The essence of the manager's task is to organize the human and non-human resources available to the organization that employs him so as to improve its position in the marketplace. His role is to persuade, inspire, manipulate, cajole, and intimidate

those he manages so that his organization measures up to criteria of effectiveness shaped ultimately by the market but specifically by the expectations of those in control of his organization—finally, its owners. (1985:45)

Though the manager is motivated by market-oriented “criteria of effectiveness,” Bellah believes that in an integrated industrial system the imperatives of bureaucratic management tend to be unconstrained by values rooted in the other sectors of social life, both private and public. Nothing in an advanced industrial system, it seems, functions as an integrator of “generally shared codes of behavior” the way, for example, the family farm and the town may have in preindustrial America.

In the vacuum created by the dislocation of such private and public institutions, the triumph of economic criteria of effectiveness tends to be total and pervasive:

With the coming of managerial society, the organization of work, place of residence, and social status came to be decided by criteria of economic effectiveness. Those same economic criteria further facilitated the growth of national mass marketing and, with it, expanded consumer choice. The older social and moral standards became in many ways less relevant to the lives of those Americans most directly caught up in the new system. The manager could reorganize resources for greater effectiveness in economic life. Similarly, the relatively affluent twentieth-century American could reorganize habits and styles of life experimentally

to achieve a more gratifying private life. In this process, Americans learned to become more efficient in adapting to new sets of expectations and styles of consumption. (1985:46)

No doubt, most of us have personally experienced these trends as very positive and, indeed, for that reason would still prefer to live in a society that had achieved such a clear expansion in personal liberty. But consider also the new form of dependency that accompanied this successful revolution: “When economics is the main model for our common life, we are more and more tempted to put ourselves in the hands of the manager and the expert” (1985:271). How do Bellah and his associates propose to overcome this paradoxical outcome?

Habits of the Heart, among other things, reminds us of the significance of “moral ecologies.” We are to become aware of just how embedded in them our ordinary lives are, and to what extent the success of our ongoing struggle to achieve the public good depends upon them. Here, contrary to illusions generated by both forms of individualism, we confront the reality of institutions in our lives, not just the agencies of government, but that range of voluntary and not-so-voluntary associations, both public and private, that contain “the web of moral understandings and commitments that tie people together into community” (Bellah et al. 1985:335). Churches and synagogues would be the most obvious examples of indispensable moral ecologies in our society. But the same could also be said of the universities that educate

Genuine cost containment would involve more than a rigorous budgeting process; it would require personal, institutional, and systemic reform.

us, the corporations we work for, our trade unions and professional associations, and, just as important, our health care institutions.

The word *ecology*, though of only recent vintage, is quite provocative as applied to such institutions. On the one hand, it suggests something vital and organic: an interdependent set of flourishing species whose interaction with the larger social environment exhibits all the resilience and adaptability of living things. On the other hand, it suggests mortality, the possibility that certain species can be threatened with extinction because of paralyzing and intolerable changes in their environment. To conceive of social institutions as moral ecologies, then, not only illuminates the living sources of public moral consensus in our society but also raises questions concerning the extraordinary fragility of the cultural infrastructure sustaining this consensus.

Habits of the Heart makes a plea for the endangered moral ecologies upon which rest our society's capacity to recognize the public good. In several different ways, Bellah and his associates argue that "we will have to change our lives and begin to remember what we have been happier to forget" (1985:295). And the changes they have in mind are not so much personal as institutional. If our society is not to choke to death on its own pollution, we will have to reform our institutions in ways that are environmentally sound. They note as positive the current interest in business ethics but insist that this new blossoming of public moral concern will die on the vine unless corporations and business schools begin to struc-

ture themselves as *interdependent* moral ecologies (1985:290). Indeed, this new concern for business ethics may be the single most important point at which to challenge the dominant managerial style in our whole range of public and private institutions. For if the manager's expertise in economic analysis can somehow be made more responsive to the moral ecologies in which it is exercised, our society ought to achieve a simultaneous gain in personal integrity, institutional accountability, and social responsibility.

The message of *Habits of the Heart* is welcome news, of course, to people like me who teach business ethics for a living. But what does it have to do with the alleged crisis in health care management? Eli Ginzberg's *American Medicine: The Power Shift* is extremely useful in making this connection, for it documents the extent to which economic analysis now governs the strategies of health care management. Ginzberg uses the word *monetization* to dramatize "the rapid penetration since 1950 of the 'money economy' into all facets of the health care system" (1985:14). The biggest stimulus toward monetization, ironically enough, occurred with the federal government's commitment to the programs of Medicare and Medicaid. These not only increased the state's contribution to health care expenditure from 25 percent to 40 percent of the total but also helped by 1984 to triple the share of the gross national product that Americans devote to health care from 3.5 to 11 percent (Ginzberg 1985:xi). This dramatic growth in public expenditure has been matched by a marked decline in private funding for

health care institutions: in 1940 private philanthropy accounted for 24 percent of the operating budget of non-profit hospitals in New York City; by 1984 that portion had shrunk to barely 1 percent. As Ginzberg notes, “the charitable element in hospital operations dwindled as hospitals became more fully integrated into the money economy” (1985:15).

These economic trends might at first seem positive. After all, isn’t the expanded role of the government a sign that we have reached a new consensus regarding the public good, especially regarding our moral obligations to the elderly and the indigent? Wouldn’t the best of all possible worlds be one in which private philanthropy had become totally superfluous? This might be our conclusion if we were to ignore the impact of these trends on the moral ecology of our health care institutions. Having realigned themselves to serve a new health care market both stimulated and constrained by government’s partnership with private insurance companies, our health care institutions should ponder how this realignment will affect their distinctive institutional ethos, embedded as they are in the histories of particular communities. Won’t the new market orientation inevitably mean the triumph of the managerial style that Bellah and his associates find so problematic?

Unfortunately, as Ginzberg’s analysis indicates, this question did not remain speculative for long. Under the new market system, the health care preferences of the American people quickly sorted themselves out in two directions: on the one hand, we expected the govern-

ment to pick up the bill for a lavish expansion of health care services to all sectors of society, especially our own; on the other hand, we were appalled at the rapid inflation of health care costs and began to wonder whether we were getting our money’s worth. Continually whipsawed between these conflicting sentiments, health care administrators in both private and public institutions have been forced to experiment with a variety of “cost-containment” measures. Such pressure toward cost-containment strategies may well precipitate the triumph of the managerial style identified by Bellah.

There is a difference, however, between genuine cost containment and expenditure control. As Ginzberg points out, cost containment entails a “reduced inflow of real resources into the health care system without a diminution in useful output that would adversely affect the satisfaction of patients or their health status” (1985:27). What distinguishes it from expenditure control is its reference to the system as a whole and not just to the budgets of individual institutions within the system. Ginzberg fears that although expenditure control might enhance the bottom line for certain institutions, it could lead to an overall deterioration in the quality of health care in our society. Genuine cost containment, in short, would involve more than a rigorous budgeting process; it would require personal, institutional, and systemic reform. As Ginzberg observes, for example, “no innovation could make a greater contribution to cost containment over the long term than an investment by the American people in maintaining their own health

The public demands, as a matter of right, health care at the most sophisticated levels of medical technology, but it is either unwilling to pay for it or unwilling to guarantee equal access to these benefits.

through alterations in personal behavior” (1985:27).

Here, it seems, we can discern the ultimately paradoxical consequence of managing health care institutions on the basis of consumer preferences. At stage one, thanks to massive stimulus through government aid programs, American health care institutions come to accept the market oriented principle of consumer sovereignty. Major policy questions in health care management henceforth are to be decided on the basis of what the public demands. Stage two shows health managers being buffeted by conflicting consumer preferences. The public demands, as a matter of right, health care at the most sophisticated levels of medical technology, but it is either unwilling to pay for it or unwilling to guarantee equal access to these benefits. The paradox emerges at stage three, when health care managers, having concluded that cost containment is the only way to resolve this conflict, further insist that effective cost containment will happen only when the public is forced to make certain demands up itself, when it is led to modify its preferences through “long-term changes in education, reflected in new life-styles and behavioral patterns” (Ginzberg 1985:27). Consumer sovereignty is dead; long live consumer sovereignty!

Although Ginzberg argues in considerable detail against any quick-fix solutions, he remains unaware of this paradox. He therefore is unable to consider whether economic analysis itself, and the managerial style that it generates, may be as much part of the problem as part of the solution. In the end, though he describes the eco-

nomic consequences of the “monetarization” of health care, his piecemeal remedies seem to accept the triumph of economic analysis as irreversible and therefore not worth arguing about. As a result, its impact on management styles in health care institutions goes unnoticed, and fundamental questions—about, for instance, the appropriateness of market oriented thinking for such institutions—never get asked. Perhaps there is no alternative to the principle of consumer sovereignty. But before we concede that, let us explore the specific impact of cost-benefit analysis on the moral ecologies of health care institutions.

Cost-benefit analysis, the deceptively simple procedure by which inefficient options can be eliminated from managerial decision making, is a conundrum of welfare economics. As the term itself suggests, the focus is on issues of distributional equity or social justice. But welfare economics nonetheless rests on the concept of perfect market competition: that all other things being equal, transactions freely arrived at under competitive market conditions by definition represent the greatest achievable magnitude of both fairness and efficiency. Of course, as even neoclassical economists recognize, all other things are seldom, if ever, equal. Access to the market, for example, is determined by the resources one already possesses. What anyone is willing to pay in exchange for some product or service may be accounted as so many dollar votes in favor of one social preference or another, but never does the principle of political equality, which lends moral legitimacy to civil election procedures, govern these economic transactions. Welfare

economics, however, tries to devise strategies to compensate for the occasional market failures that inevitably occur under such circumstances.

Policies developed under the assumptions of welfare economics normally would be implemented by government, but in such a way as to expand and intensify market activity rather than undermine it. Cost-benefit analysis is a technique for deciding which policies, among the range of possibilities, are likely to result in the desired social improvements. In situations where society's preferences are mixed, and probably in conflict with one another, the analysis tries to determine the net aggregate benefit from a particular policy. If the net benefits are greater than the costs to society, then so long as those individuals who bear the costs are not worse off than they were before, the policy may be implemented (Phelps 1985:214).

Cost-benefit analysis thus seems to be merely a technical refinement on the axioms of utilitarian moral philosophy, which defines the good in terms of an action's social consequences. Indeed, it may be seen as an improvement over classical utilitarian theory to the extent that it allows for compensation to those individuals or groups whose preferences have to be set aside in order to achieve a net social benefit. Yet what is troubling about both forms of utilitarian calculation is that they recognize no higher standard of social value than aggregated individual preferences. Furthermore, they are wedded to a remarkably questionable presupposition, namely, that these preferences can be quantitatively measured and

manipulated, because they are not only comparable in terms of money prices but also exchangeable in an open market. In principle, at least, cost-benefit analysis would be impossible were either of these premises shown to be false.

Cost-benefit analysis, however, is not just a technique for public policy decision making. Thanks to the pervasive influence of government regulatory agencies and other programs on the whole range of public and private institutions, cost-benefit analysis has become a mainstay for institutional policy-making as well. Business ethics casebooks, for example, relate many examples of cost-benefit calculations for policies affecting environmental pollution, product safety, and other matters, most of which involve a trade-off between company profits and the economic value assigned to a human life. With the monetarization of health care, similar economic trade-offs may increasingly shape decisions regarding access to expensive medical technologies and procedures.

This expansion in the use of cost-benefit analysis beyond its original context in government social policy discussion makes our traditional institutional commitments most vulnerable to the new style of management. Even if cost-benefit analysis is appropriate for resolving political conflict over governmental policy, surely its use is questionable in institutions that claim to have some sense of themselves as moral ecologies. Health care managers, especially in religiously oriented institutions, ought to know more about the institution's founding

Health care managers ought to know that economic analysis cannot be allowed to override the character of an institution, if the institution has any character at all.

mission, not to mention the commitments of the community that nurtured and sustained it, than a government bureaucrat might be expected to know about society as a whole. Health care managers, in short, ought to know that economic analysis cannot be allowed to override the character of an institution, if the institution has any character at all.

I conclude that the crisis in health care management is real and systemic. The economic pressures and the managerial style ostensibly designed to cope with them are not unique to health care institutions but are symptoms of a pervasive erosion of traditional values in our nation's public institutions. Can anything be done to renew the sense of mission that animated these institutions and to make the dominant style of health care management more accountable to it? Or must we resign ourselves to the irreversible erosion of yet another fragile moral ecology, whose disappearance would still further deepen the nation's health care crisis. What is the alternative? In this context let us return to the question of spirituality in health care institutions. Only if we get the question of spirituality right do we stand a chance of resolving in a positive way the conflict between institutional values and economic exigency.

II. Health Care Institutions: A Place for Spirituality?

Richard McCormick's *Health and Medicine in the Catholic*

Tradition is a useful place to begin discussion of this question, for it seeks to make Catholic health care facilities "institutions of Christian priority" (1984:76). It takes the form of a commentary on "Ethical Guidelines for Catholic Health Care Institutions," a document written by a private group of Catholic theologians, ethicists, and health care personnel. The guidelines are worthy of serious attention because they consciously seek to integrate the whole area of health care into the same framework of Catholic social teaching that informs the recent pastoral letter *Economic Justice for All*. The result is evident in the guidelines' sensitivity both to the larger American cultural environment and to the organizational dynamics internal to Catholic health care facilities. Social justice in both areas thus becomes an explicit objective for such institutions.

Though McCormick does link this agenda with certain reflections on a "spirituality for health care personnel," his thinking about spirituality can be carried further by understanding health care institutions as moral ecologies. If institutions are moral ecologies, then spirituality is first of all a characteristic of institutions; it must not be regarded solely as something that spiritually sensitive persons bring to institutional life. Yet McCormick insists on a distinction between persons and their institutional roles that tends to undermine the ecological view of spirituality that I'm proposing.

Spirituality, as McCormick insists, refers to "a personal and corporate life-climate...[without which]...a gap will exist between personal belief and professional

life.” But everything depends on how one understands that gap. Is it merely one more reflection of the industrial organization of life into private and public spheres? Is it anything other than an expression of the occasional, but inevitable, conflict among the several institutions to which I have pledged my loyalty? McCormick’s answer, however, points in a different direction:

The results of such a gap can be both personally and professionally disintegrating. I refer to the distinction and eventual opposition that can arise between the role and the person (the “true self”). Roles, of course, are essential for social structure. They delimit behavior and make it predictable. We expect physicians and nurses to act in certain ways; when they play their roles in response to societal needs there is harmony in the system.

But such roles do not necessarily reflect the true self. If one constantly relates to others through a role, one can become alienated from one’s true self. The role may grow, but not the true self: that is, the qualities that nourish human exchange (patience, other-concern, communication, compassion, listening, caring) will be restricted to the role. They will become an “assumed manner,” an adopted etiquette that will not hold up very long. The true self will remain anemic, infantile, and immature. (1984:42)

Here, frankly, I am puzzled. What is the basis for this distinction between a person’s role and his or her “true self”? I suspect that McCormick’s “true self” is less a reflection

of Catholic theological anthropology, even at Vatican II, than it is further evidence of the pervasive hold of expressive individualism upon our imaginations. The assumption that my “true self” exists apart from my public roles and relations strikes me as a Kantian obfuscation of Catholic social teaching’s perennial emphasis on the social character of human personhood.

Modern individualism, in its philosophical expression, comes to a dead end in the kind of existentialism embodied in J. D. Salinger’s *Catcher in the Rye*. Though we may barely be able to recall our adolescent tussles with that classic, to what extent does it still define for us what is, and is not, authentically human? It is difficult, on these terms, to see how a personal identification with one’s public role could be anything other than “phoney.” Personal authenticity must be nurtured and sustained apart from one’s public role, which here appears as a very treacherous snare. McCormick clearly doesn’t intend to preach the gospel according to Holden Caulfield; but his distinction between “the true self” and one’s institutional roles and responsibilities, in my view, points in that direction.

There’s no denying, as McCormick insists, that health care personnel are susceptible to a greater amount of role conflict than most professionals. Some of these pressures could be discussed in terms of the ambiguous triumph of the therapeutic style, outlined in *Habits of the Heart*, which would suggest that primary care givers are just as much victims of the whipsaw effect of market expectations as are health care administrators. But unless

Spirituality remains the key to renewing our institutions as moral ecologies, but to think of this task primarily in terms of “a spirituality for health care personnel” would be mistaken.

we begin with a critical rethinking of these roles and their relationship to the institution's mission, the current pressures will tend to be accepted as given, and the role of spirituality will be reduced to some sort of safety valve for merely coping with these pressures.

Spirituality nevertheless remains the key to renewing our institutions as moral ecologies, but to think of this task primarily in terms of “a spirituality for health care personnel” in the current cultural milieu may leave us all too vulnerable to the siren songs of expressive individualism. More helpful, in my view, would be an effort to discover spirituality *in* the health care institution *itself*. Unless spirituality is recognized first as an essential condition of the institution's own ongoing life, the institution will hardly be powerful enough to understand, let alone resist, the opposite set of half-truths contained in utilitarian individualism. In short, unless spirituality is properly understood as a function of the institution as such, it can hardly be regarded as relevant to the crisis precipitated by the monetarization of health care policy.

There are two reasons for considering health care institutions as appropriate places for discovering spirituality. The first comes from a reading of Mary Douglas's anthropological perspective on social theory, *How Institutions Think*. Douglas shows that our metaphor of “moral ecology” is resonant with the structured processes by which any institution is formed, that while institutions can hardly be regarded as having “minds of their own,” they do confer personal and social identity on their members; create, preserve, and selectively forget various

institutional memories essential to their ongoing operation; classify and otherwise structure our thoughts and activities; and typically make most of the big decisions—life and death decisions—for us. She argues convincingly that institutions are first and foremost cognitive and transactional processes (1986:19), without which no group would hold together for any length of time to any degree of social complexity. Her perspective explains what we otherwise might know on an intuitive basis, namely, that just as institutions structure our thought processes generally, so do they also provide us with significant channels for spirituality. Indeed, the very structures by which institutions “think” are also operative in the formation of those moral ecologies in which, if anywhere, spirituality will surface institutionally.

Second, certain encouraging developments in the field of business ethics also tend to support this institutional view of spirituality. Over the past few years, for example, the focus of discussion has shifted from a concern for abstract systems of moral reasoning to a consideration of the ethos of modern corporations. This trend in organizational theory, most prominently exhibited by Thomas Peters and Robert Waterman's best-seller, *In Search of Excellence: Lessons from America's Best-Run Companies*, emphasizes the importance of “corporate culture,” that cluster of mission statements, moral commitments, institutional routines, and corporate codes of ethics that forms the moral ecology within any given business firm. Managerial success, so the theory goes, is rarely achievable apart from careful attention to the

corporate culture, which to some extent can itself be managed to promote the company's goals, or to respond to new challenges. Some theologians have developed perspectives on the corporation that parallel this shift in managerial theory, for example, Michael Novak's pioneering essay "Can a Christian Work for a Corporation?" and Max Stackhouse's recent *Public Theology and Political Economy*.

Both theologians speak with no hesitation about spirituality in the corporations. They assume that spirituality is a normal manifestation of any institution's ethos, and they call for a rethinking of much of modern theology in order to discern better what God has done, is doing, and may yet do in such environments. Both authors outline historical perspectives in which the "religious roots" of the modern corporation once again are evident. Here is one such summary statement from Stackhouse:

The ethos of the corporation, which still bears the marks of this history in its deepest fabric, continues to imbue all those working in the corporation with values rooted in this history: common economic action demands a work ethic, a set of values separate from familial and political control, a discipline guided by rational control, at least a sense of "profession," and a stewardship of wealth that is not one's own. Workers and managers in modern corporations continue to be drawn into an ethos wherein these moral and spiritual presuppositions are seen as "natural," although the overt theo-

logical foundations have largely been replaced by utilitarian and contractual understandings of human relationships, and mammon has become, for many, the reigning deity. (1987:127)

So Stackhouse, too, is concerned about the triumph of utilitarian individualism. Furthermore, he recognizes that "common economic action" in and of itself requires certain "moral and spiritual presuppositions," among which is "a discipline guided by rational control."

At this point, then, we can fruitfully reexamine the alleged trade-off between economic exigency and institutional values. Spirituality in the corporation cannot be conceived as compensation for the fact that the managerial role inevitably involves managers in cost-containment strategies and cost-benefit calculations. Spirituality must be discernible in the way managers achieve and maintain corporate discipline through the judicious exercise of such strategies and calculations. Either God is acting constructively through such administrative routines or God is absent entirely from business institutions. As Stackhouse suggests in his explicitly theological reflections, our God cannot be the God revealed in Scripture and tradition, as well as in reason and our own experience, if God isn't somehow present in such institutional forms. Needless to say, God's presence is not to be identified totally with such forms; to do so would be to make a god of "mammon." But instead of trying to be faithful to gospel values by systematically raising the suspicion of inauthenticity against our

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institutions, faithfulness might better be served by trying to discern whatever traces of the Holy Spirit's presence there are in the ordinary routines of these same institutions. There is more than one way in which facing economic exigency can be a test of faith.

In moving from spirituality in business corporations to spirituality in health care institutions, it is important to remember that although all institutions must have an economic dimension, not all institutions thereby qualify as economic institutions. The purpose of a business corporation is to maximize profits for its stockholders; this is not the case with private, especially religiously sponsored, health care institutions. Hence, the interplay between economic exigency and institutional values, if anything, allows managers more discretion in such institutions than they ordinarily would have in business. In principle, this is true, even in the current atmosphere of crisis. How, then, might spirituality in health care institutions help facilitate a more fruitful approach to economy exigency?

People who exercise responsibility in health care institutions must learn how to enter into dialogue with their institutions. The object of the dialogue, as I have learned from Thomas F. Duffy's "The Chronicle of an Old Chrono: The Charism of an Institution" (1986), would be to construct an interdependent set of narratives, in which the institution's own story gets told in light of the founding community's larger story, and in which the particular inquirer can place his or her own personal story. What might emerge from such a dialogue with one's own

institution cannot be programmed in advance. If it could, there would be no point in seeking a dialogue. Institutions, as Mary Douglas insisted, don't have minds of their own; but they do their thinking through us and are very successful at teaching us what and how to think for them.

Though the outcome of the dialogue cannot be predicted, some of the topics of the conversation are easy to imagine. In trying to work this out, I consulted the *New Catholic Encyclopedia's* articles on "The History of Hospitals" and "Modern Hospitals," and even one on "Hospitality." As I pored over an architectural diagram of the *xenodochium*, the all-purpose Christian hospice, dating to the time of the Emperor Constantine, which took in pilgrims and indigent travelers as well as the sick and the dying, I realized that the narrative may go back very far indeed. I was struck by the connections between the Church's mission and the ordinary life of the health care institution, including the practices of some medieval religious orders who treated their patients and guests as at least temporary members of their own community, and therefore as subject to its spiritual routines and disciplines. We would do well to consider how this precedent might help us understand the ecclesiological consequences of today's institutional mission statements.

This history can also yield a fresh perspective on economic exigency. What appears to us as a crisis may merely be a perennial problem. Cost containment, with sometimes happy and sometimes tragic results, has always been part of the health care administrator's

agenda. The rationing of expensive medical technologies and procedures is hardly anything new, any more than is the drive toward administrative centralization and institutional consolidation or the ongoing struggle to make the institution properly accountable to the appropriate secular standards and authorities. Recalling, for example, the atmosphere of crisis in which the Catholic Hospital Association was founded in 1915 could reassure us that just as the drive toward professionalization and standardization of services did not have to be regarded as a threat, neither should current efforts toward genuine cost containment be seen as incompatible with any institution's particular sense of mission. Instead, such pressures could be welcomed as challenges for spiritual renewal within the institution itself.

The construction of such interdependent narratives, as highly particularized as possible, might do more to assist health care professionals to rediscover a sense of institutional identity that they could live with than any generalized discussion of hospital guidelines, regardless

of how appropriate such guidelines may appear in the abstract. There will always exist a tension between economic exigency and institutional values. But this tension cannot be resolved by sharply denouncing or even subtly denigrating the position of those administrators whose role it is to deal with them responsibly. Rather than preach a religious solution from outside that role, I'm suggesting that health care administrators would be better served if they were helped by theologians to discover a religious solution within it. Such an approach will require health care institutions to seek new forms of dialogue that go well beyond the scope of the usual hospital ethics committees, however appropriate these may be for dealing with specific quandaries. These theological reflections result, then, not in a formula by which to resolve the tension between economic exigency and institutional values but something to go on in living out that tension responsibly, namely, a different approach to discovering and thinking out the spirituality already implicit in the organizational life of our health care institutions.

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“A consistent ethic of life does not equate the problem of taking life with the problem of promoting human dignity. But a consistent ethic identifies both the protection of life and its promotion as moral questions. It argues for a continuum of life which must be sustained in the face of diverse and distinct threats.”

—“A Consistent Ethic of Life:
Continuing the Dialogue,”
St. Louis University,
March 11, 1984

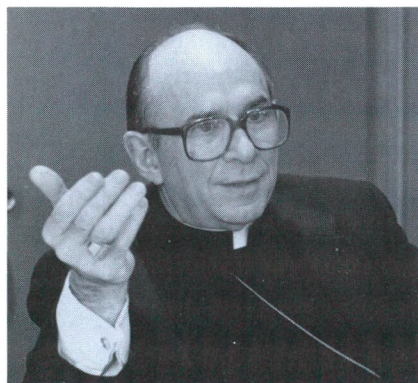


The Consistent Ethic

An Interview with Joseph Cardinal Bernardin

Since becoming bishop of the Archdiocese of Chicago in 1982, Joseph Cardinal Bernardin has emerged as both a mediator in his own troubled diocese and a leader within the National Conference of Catholic Bishops. In 1983 he chaired the committee of Catholic bishops whose study of the nuclear arms issue resulted in “The Challenge of Peace: God’s Promise and Our Response.” On December 6, 1983, during a lecture at Fordham University, Bernardin proposed a “consistent ethic of life” that could deal with some of our society’s most pressing moral problems: abortion, euthanasia, genetic engineering, nuclear war, poverty, pornography, and capital punishment. In his interview with *Second Opinion* on January 5, 1988, Bernardin discussed this consistent ethic, its relation to health care issues, and the mission of the Catholic church in caring for the ill.

“I have become very much aware that many people are inconsistent in facing issues. Some who strongly oppose nuclear warfare because it takes innocent life are not concerned about abortion. And some vice versa. I felt we should say, ‘If you really are a defender of life, then you must be concerned about all these issues.’”



Second Opinion: In 1983 you began talking about a “consistent ethic of life” in an effort to bring together some of the issues confronting the church and society. Why did you begin this emphasis?

Cardinal Bernardin: I had just been appointed chairman of the Catholic Bishops’ Committee for Pro-Life Activities and felt it important to provide the theological context or foundation for the committee’s work. Actually, the elements of the consistent ethic of life had been used as the basis for that committee’s work for some years. This is evident in the Respect Life Program begun in 1972, a program that considered a wide spectrum of issues. But I felt the need for a more precise and comprehensive articulation of the theological basis. To be very candid, I was quite surprised at the immediate positive reaction to it. The day after my Fordham speech it made the front page of the *New York Times*, and the presentation itself was carried by the Catholic documentary service, *Origins*.

Second Opinion: How do you account for this immediate positive reaction?

Cardinal Bernardin: The time had come for a closer look at the linkage among the life issues. And from that moment it has been very much discussed and is now part of the vocabulary of Catholic moral theology.

Second Opinion: What do you mean by a “consistent ethic of life,” and what are “life issues”?

Cardinal Bernardin: We believe that life is a gift from God and therefore must be protected and nourished at every stage of development. Furthermore, we believe not only that life is a sacred reality but also that it has social dimensions. People live in communities, which means not only that the *individual* has the obligation to protect life, but that it is also the obligation of *society* to protect life and provide the things needed to enhance that life. That is the theological basis and the starting point of the consistent ethic.

Now the next logical step in applying this principle is to say that everything that protects, enhances, and nourishes life is good, is necessary. Those things, though, that in some way either destroy or diminish life are not good. Using that criteri-

on, it soon becomes evident that all the issues are related. For example, abortion is the direct taking of innocent, unborn life. Nuclear war threatens to destroy life. There is also euthanasia, the direct taking of the life of a sick or elderly person. In this context, we can also speak of pornography, which is certainly life-diminishing because it's degrading. But it is also, at times, life-threatening and life-destroying because it leads some to violent actions. Then there is health care. People have an obligation to take care of their health, and society has an obligation to assist them in this responsibility. But if adequate health care is not available, the quality of life is diminished, and in some instances life itself is threatened. So any issue that in some way affects human life for better or for worse is a "life" issue.

Now it is very important to understand that even though all these issues are linked, nonetheless *each is distinct*; each requires its own moral analysis. And the solution for one may not be the solution for the other. Moreover, at any given point all may not be equally important. One issue might be more urgent or need greater attention at a par-

ticular moment than another one.

After the lecture at Fordham I used the metaphor of the "seamless garment" to help explain the consistent ethic. That term has since gained popular currency, but the "consistent ethic of life" is the proper way of describing my position.

Second Opinion: The consistent ethic of life contains positive theological elements—that life is sacred and that life is social—but is a negative principle also involved?

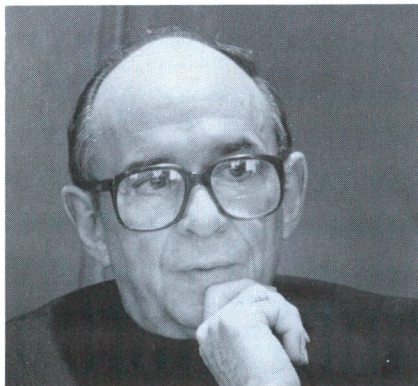
Cardinal Bernardin: The basic theological principle is positive: life is sacred and social and therefore must be protected and nourished. Flowing from this is the principle, which has always been part of Catholic moral theology, that the direct taking of innocent life is never permitted. Further, although the church teaches that the taking of life generally is not permitted, traditionally there have been exceptions in the case of self-defense, whether of an individual or a community.

The emphasis here is on innocence. The direct taking of the life of an innocent person is morally wrong. Abortion is wrong because

the unborn child is innocent and has a right to life, as we all do. He or she has not done anything to forfeit that life, so it must be protected. The principle also applies in issues relating to war and peace. One is permitted to use force under certain circumstances when every other means to resolve conflicts has been used, and when force is necessary to protect the life and integrity of the community. Force may be used in these instances, but it must be directed toward the aggressor and not toward innocent people. In other words, the intent of an action being undertaken to protect a nation must be against a military object and not against a civilian population. It is true that an attack with a military objective may indirectly harm innocent people. There the principle of proportionality must be taken into account: can a particular action be justified in terms of both its military advantages and the harms reasonably expected to follow from it?

Second Opinion: Is the consistent ethic of life something new to Catholic moral thinking? Have new issues called for its formulation?

“When a person has AIDS, then we are nonjudgmental. We treat AIDS as a human disease, and we reach out to the person with compassion. We do not ask how he or she contracted the disease.”



Cardinal Bernardin: The consistent ethic of life is not new in Catholic moral teaching. We have tried to bring this understanding into the public discussion of these life issues. The consistent ethic rests on basic moral principles that transcend denominational convictions or beliefs or teachings; I am very much convinced of that. It is true that the Catholic church articulates these principles within the context of its own teaching and its own denominational perspectives. But I maintain the validity of these basic principles for everyone. We are talking about basic human values, about fundamental principles that flow from human nature itself. When we speak to the broader community about this ethic, we do not rely on the authority of the Catholic church; we depend rather on the validity of the argumentation. Although for a Catholic audience I might use terminology that is part of our Catholic heritage, when I speak to the broader community I use an argumentation that transcends denominational perspectives.

The consistent ethic of life has always been part of the Catholic tradition, but a growing number of

new issues in modern society require serious study by the church. First, we face new concerns because of the advances made in technology—in medicine, in weaponry. The principles are the same, but we have new realities to confront. This is why it is important to articulate a consistent ethic of life and to apply it to all contemporary issues.

Second, I have become very much aware that many people are *inconsistent* in facing these issues. For example, some who strongly oppose nuclear warfare because it takes innocent life are not concerned about abortion. And sometimes vice versa. I saw an inconsistency there and felt we should say, “if you really are a defender of life, then you must be concerned about *all* these issues.”

Second Opinion: Do you think you have succeeded in articulating this position to those outside the Catholic faith?

Cardinal Bernardin: I think I have succeeded. Not completely, of course, but I believe I have witnessed some positive outcomes. About four years ago I gave a talk at the University of Illinois medical

school where I'm sure more than half of the audience was not Catholic. I stated quite candidly that I was a Catholic bishop and was speaking from my own religious perspective but that what I was articulating was not only a Catholic ethic. Afterward several people told me that they had never accepted the Catholic church's position on abortion, but in light of what I had said they would have to reflect further on the matter. I know of another instance in which the school newspaper of a public university was pro-abortion, and after my lecture on the consistent ethic the editors changed their position.

Even though people may not be totally convinced, the consistent ethic argument causes them to rethink their own position. Some people who espouse the right-to-life cause say that I have weakened the case against abortion, but I maintain that I have strengthened our position against it. I have made our position more credible and more persuasive not only for Catholics but for people generally, so I strongly reject that criticism.

Second Opinion: Other criticisms about the consistent ethic of life stem from perceptions that the Catholic church itself is inconsistent on a number of issues. Women's ordination is an often-cited example. What do you say to these criticisms?

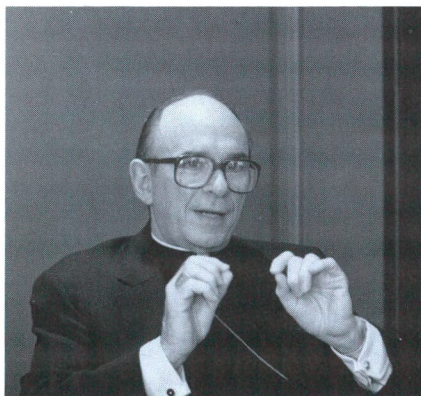
Cardinal Bernardin: I think that we are talking about apples and oranges in some of these cases. Let us consider the question of women's ordination. I do not see it as a justice issue. No one has the *right* to be ordained. Let me put it this way, if I may. The Catholic church, in its 2,000-year history, has never ordained women to the priesthood. So the question is not whether the tradition exists but what kind of tradition it is. Is it a tradition that developed because of social conditions in biblical times? Or is it a normative tradition, that is, somehow related to the will of Christ when he established the church? The Catholic church has taught the latter and believes it cannot change such a normative tradition. The 1976 declaration of the Congregation for the Doctrine of the Faith on this subject put it precisely that way, namely, that the Catholic church does not

consider itself authorized to make this change. That is why I see it as a different kind of issue, not a justice issue, and I do not see any inconsistency. I realize, of course, that many people do not agree with the Catholic church's understanding of this matter, and I know that frequently they maintain it is a justice issue. For the moment, we will simply have to disagree on that.

Second Opinion: Let's consider Catholic health care for a moment. What do you see as the primary, distinctive mission of Catholic hospitals today?

Cardinal Bernardin: I can put it very simply. Jesus showed a great compassion for people: he cured the sick, he comforted them, and he told his disciples that they should do the same. As a church, as a community of faith, we are expected to continue the mission of Jesus. So health care is part of the ministry that we are charged to carry on, and that has been true from the earliest days of the Church. I do not think it is the responsibility of the Church alone, of course, but the Church is one of many actors that have respon-

“Some people think God has written out in great detail everything we are supposed to do. People who are looking for immediate, definitive answers think that they do not have to do any thinking at all. They are looking for a kind of mental or emotional security that does not exist and is not humanly possible.”



sibility for providing health care.

The Catholic church does this first through its Catholic hospitals. In the Archdiocese of Chicago, which includes Cook and Lake counties, we have twenty-three hospitals (close to one-third of all the beds in this area) and more than twenty nursing homes. In addition, we sponsor clinics in certain areas of the city, especially the poor neighborhoods, and more recently we have been focusing attention on the prevention of illness and disease. Our job is not simply to take care of people when they are ill but to do what we can to teach and encourage them to maintain their health. We are now seeing the emergence of parish-based health programs in which nurses and pastoral workers offer health-related services. Moreover, most of our parishes have developed ministries of care for the elderly. Parish-based care is very important because most elderly people are at home. Our nursing homes are wonderful places, but the number of people that they can accommodate is very small in relation to the need.

Second Opinion: What are Catholic

parishes doing for the elderly in your diocese?

Cardinal Bernardin: Parishioners visit the elderly, make sure they have access to the sacraments because frequently they cannot leave their homes, and spend time with them. We have meals-on-wheels programs, and we make sure that the right people are notified if medical care is needed. Many of our elderly people can stay at home, but they need some support. This has become a very important ministry, especially in the city where some of our older parishes have large elderly populations.

Second Opinion: What do Catholic hospitals in Chicago do if people cannot pay or do not have adequate health coverage?

Cardinal Bernardin: This is a serious problem, and we are trying to face it realistically. Since coming to Chicago I have become instrumental in bringing the twenty-three hospitals together for regular meetings. These hospitals are all operated by religious communities; the archdiocese itself does not own any

hospitals. Although their operations are not under my immediate jurisdiction, I do have a responsibility to help guide their ministry as part of the church's mission in this area. And by church law, I have a certain responsibility to make sure they are operating within the bounds of Catholic teaching.

Health care, as everyone knows, has become a very competitive and costly business. Despite the mission statements of the religious congregations that sponsor these hospitals—statements that place a great emphasis on care for the poor—the financial reality of today's health care has presented great difficulties. Frequently these hospitals are not able to take in as many indigent patients as they would like. I understand the problems they are facing, for I am responsible for Catholic elementary schools, and I know how difficult it is financially to keep them going. Nevertheless, I wanted to challenge the hospitals on this issue. Without criticizing or blaming anyone, I wanted to ask what we could do together. I also knew that these hospitals were not equal in financial status: the suburban hospitals were doing much better

than the hospitals in the inner city. But in the inner city there are more poor people, and I did not want those hospitals to go bankrupt or to face a significantly greater burden. So I began talking with the hospital leaders, and they acknowledged that this was one of their great concerns. They felt they were not able to fulfill their obligation to indigent patients and remain financially viable.

As a result, we have begun something very creative. To my knowledge no other diocese in the United States has done exactly what we have done. We first began a study of what structure might make greater cooperation and collaboration possible. The twenty-three hospitals and the archdiocese cooperated in funding this study. The result of the study was a series of recommendations which would bring about the desired cooperation, make the hospitals more competitive generally, and also enable them to run their hospitals more effectively and efficiently so that they could fulfill their mission. I was told that we could get this cooperative venture started if at least half of the hospitals agreed to the basic concept. Well, we persuaded *all* of them to agree, and this led

to the development of a new organization, the Catholic Health Alliance for Metropolitan Chicago.

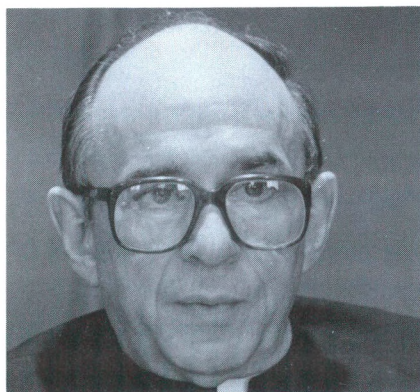
Second Opinion: Is this a financial cooperative?

Cardinal Bernardin: We are still in the process of working out a program, but the hope is that through collaboration each member will be strengthened, especially the weaker ones. Instead of having twenty-three totally separate entities, each fighting for its own life, the Alliance should enable the hospitals to use their available resources to the maximum so that they can take care of more people, including the indigent.

Second Opinion: Will these hospitals attempt in any way to cooperate with the parish programs you discussed earlier?

Cardinal Bernardin: This is one of the main goals—to establish a closer relationship between parishes and the hospitals. That relationship has not existed in the past. The hospitals had their own problems, their own challenges, and their own way of

“Hospital leaders felt they were not able to fulfill their obligation to indigent patients and remain financially viable.”



facing them. And the parishes had their own agendas. But we are beginning to see that a holistic approach to life is very important and that this kind of approach includes health care and spiritual ministry. One of the goals of the Alliance is to establish a supportive relationship whereby the parishes and the hospitals can respond creatively and productively to health care needs not only after people become ill but *before* any illness. I think we are going in the right direction.

Second Opinion: The health care community faces another tremendous challenge today, one that is raising significant questions within religious communities as well.

Cardinal Bernardin: You mean AIDS.

Second Opinion: What message most urgently needs to be said to people who are suffering from AIDS and related diseases and to those who are caring for them?

Cardinal Bernardin: We have a number of things to say. To people who have the disease, and to those

who care for them, we bring a message of compassion. We must show them that we care. We should not be judgmental when we approach them. Currently many of our Catholic hospitals are caring for AIDS patients, and we are also in the process of establishing an assisted living facility for people with AIDS. This facility is a joint venture between the Alexian Brothers and the archdiocese. We have provided the property, the building, and some funds, and the Alexian Brothers are providing the rest. When complete, it will be one of the largest facilities for persons with AIDS in this area. The care given will be holistic: not only physical and medical needs will be met but spiritual ones as well. We feel it is our obligation to reach out to these people and to their families just as Jesus reached out to the people of his day. People with AIDS are the modern lepers, in the sense that they are shunned by many who are afraid of even the slightest contact with the disease. We have to break through that fear.

The other approach we are taking is educational. We have embarked upon a comprehensive educational program to teach people what the

disease is, how it is transmitted, and how it can be avoided. This involves presenting both medical facts and moral values because we know that in most AIDS cases the disease was transmitted through sexual contacts, a large majority of which were homosexual, or through the use of intravenous drugs. We have to let people know that they should not engage in activities or behavior that puts them at risk. The reasons for such avoidance are both medical and moral.

Second Opinion: And the church has a responsibility to articulate those values that cohere with its moral teachings?

Cardinal Bernardin: Yes, we have a responsibility, though of course we are not the only ones. From a moral point of view, we do not approve of certain sexual activities through which AIDS can be transmitted, and we must be very clear about encouraging people to live in accordance with the church's moral code. We teach what is morally right and wrong. But when a person has AIDS, then we are nonjudgmental. The person may or may not have

contracted the disease through an immoral action or behavior. We treat AIDS as a human disease, and we reach out to the person with compassion. We do not ask how he or she contracted the disease.

Second Opinion: A major theme that runs through your work is responsibility. The U.S. Catholic bishops' letter on nuclear arms, written by a committee which you chaired, was called "The Challenge of Peace: God's Promise and Our Response," your own pastoral letter on AIDS was called "A Challenge and a Responsibility," and the most recent statement on AIDS from the U.S. Catholic Conference Administrative Board was entitled "The Many Faces of AIDS: A Gospel Response." How do you understand responsibility in light of faith?

Cardinal Bernardin: We believe in God. We believe that God created us and, in creating us, made us in his own image and likeness. He gave us a mind to think, and he gave us a free will so that we can choose what we want to do. We also believe that he has a plan for us. We believe that he challenges us to live in accord-

ance with the values that he has made known to us. But we have to do something to meet the challenge. So it is a partnership, a joint venture. It's not enough to say, "Well, we'll leave it up to God." Nor is it enough to say, "It's strictly a human endeavor; we don't need God." God has certain expectations of us, and it is our task to live up to those expectations. And we have to do it by using our minds and our wills.

Frequently, as the letter on war and peace pointed out, the principles are clear enough, but the de facto realities are often very complex. Well-intentioned people might agree on the principle but disagree on their analysis of a specific reality and therefore disagree on how that principle should be applied in that particular case. This is especially true in the social sphere. One of the difficulties today is that some people think God has written out in great detail everything we are supposed to do. They want a definitive answer for everything. But it has never been that way. It is not that way in the Scriptures either. People have always had to make decisions. They relied on God's help, but they also tried to live in accordance with

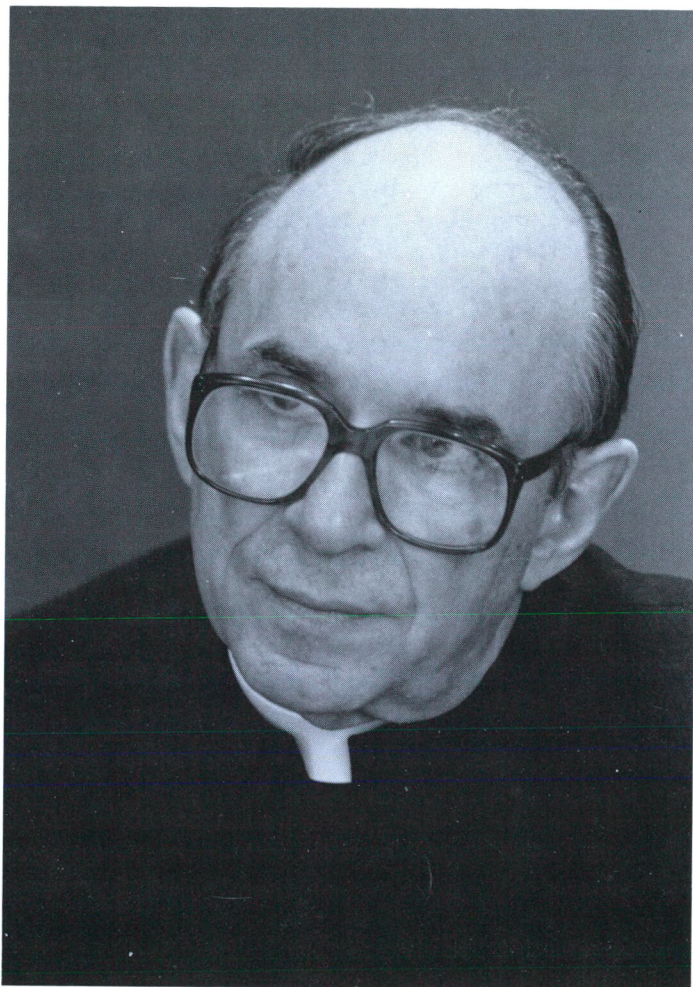
the teaching as they understood it. Read the Epistles of St. Paul, for example. He did not have everything laid out for him ahead of time. He had to make ad hoc decisions. People who are looking for immediate, definitive answers think that they do not have to do any thinking at all. They are looking for a kind of mental or emotional security that really does not exist and is not humanly possible.

Second Opinion: You seem an example of someone who doesn't see the issues as clearly black and white, who really struggles with them and understands that they're ambiguous and difficult. Where do you find the resources to explore these questions and to come to the very clear understandings that you have?

Cardinal Bernardin: Some issues, of course, are clearly all white or black. Some, however, are not. I think you have to be a person of faith, and I do believe with all my heart and soul in the Lord. I believe that, both in the Scriptures and in the teachings of the church, he has taught us how we should live, and I have spent my life reflecting on

them. At the same time, I know that I have to use my own intelligence to apply that teaching, that vision, to the circumstances in which I and those whom I serve find ourselves. It involves prayer and reflection; it means constantly staying in dialogue with people, keeping up-to-date on things, and being willing to change my mind. It is a constant challenge. If I were to say, "Well, I have it all figured out now, so I really do not have to get involved in this anymore," from that point on I would go downhill in terms of my own growth and development. This would also affect my ability to be an authentic pastor, to help people in their growth and development. But it *is* a challenge. There are many times when I am not absolutely sure whether I should do this or that, not because of ambiguity concerning the principles or the basic message of the gospel, but because of difficulty discerning what that message means today in a particular set of circumstances. How do you best go about it? And even if you know what the goal should be, you still have to decide how you are going to reach that goal. A person like me frequently finds himself in con-

troversy. When people do not agree, for example, on the AIDS statement or the letter on war and peace, it would be much easier for me to keep quiet and "let the world go by." When I retire, I might do that, but that would not be a responsible exercise of my current office. This does not mean that I like controversy or criticism. As a matter of fact, I am a very mild-mannered person and would rather avoid controversy. But I am very committed to my responsibilities, my work, my position. There simply is no way for me to avoid entering into the public forum, and I think most people understand that. ☸



"I believe that, both in the Scriptures and in the teachings of the church, Jesus has taught us how we should live, and I have spent my life reflecting on them. At the same time, I know that I have to use my own intelligence to apply that teaching to the circumstances in which I and those whom I serve find ourselves."



Fifteenth-century Italian artist Andrea Mantegna renders with special poignancy the strength and tenderness of the familial bond. (Engraving of the "Virgin and Child," c. 1470–90.)

Family Caretaking

Moral Commitments and the Burden of Care

ADVANCES IN modern medical technology have raised new questions concerning the nature and limits of caretaking obligations within the family. Despite the myth that technology relieves us of burdens and permits greater leisure, the reality in the area of health care is quite the opposite. Lives that in a previous age would not have survived illness now continue in ever increasing dependence, and the families of people with impairment or long-term illness are frequently called upon to serve as caretakers in situations demanding considerably more self-sacrifice than was required of earlier generations. Many of us know of lives that have been profoundly altered by care of elderly ill parents, children with serious impairments, or spouses with chronic illnesses who will never regain indepen-

dence. More and more, obligations arise which family members never seriously imagined as real possibilities. The modern nuclear family, now only several centuries old and consisting of parents and children living as an isolated unit, perhaps with grandparents in the home or nearby, faces a caretaking crisis. Single-parent families as well as “blended” families of husband and wife with children from previous marriages must grapple with the question of what seriously ill family members are due and why.

Although the extraordinary burdens of caretaking must be acknowledged, a case can be made for an ethic of stewardship in the family—an ethic of loyal self-giving that refuses to view others as mere means to our own ends. Several criticisms apply to the work of cur-

“Probably the least discussed and most badly treated matter in the literature of moral philosophy is the one that matters most in most people’s lives: familial relationships.”—Alasdair MacIntyre

rent revisionists who, in light of the considerable inconvenience that stewardship now can create, appear bent on dismantling the creative fidelities possible within families. Additionally, public policy must recognize that care givers themselves need to be cared for. All too often, public policy focuses only on those individuals in need after their families have found it necessary to relinquish care. Last, the technological expansion of care may well require a religiously based ethic that views caretaking as a praiseworthy and sacred vocation rather than as a hindrance to personal freedom. It is doubtful that contemporary moral philosophy, based on reason alone, contains the insight and resources to sustain family caretaking in its current expanded form. In this article these propositions and viewpoints will be developed in the contexts of filial, conjugal, and parental morality.

Filial Morality

As the proportion of elderly citizens in Western societies grows larger, adult children are increasingly bound by obligations to elderly ill parents. The human life span has been lengthened, leaving the elderly in a condition of relative dependence on their children. This transition inevitably focuses attention on an area which ethicists in our century have for the most part ignored, namely, filial morality.

The last philosophical thinker to address himself

systematically to filial morality was the British moralist Henry Sidgwick. According to Sidgwick, the obligation of children to parents is based on gratitude, that “truly universal intuition.” That children have a moral duty to requite benefits is so clearly agreed upon, argues Sidgwick, that it is open to no dispute “except of the sweeping and abstract kind” ([1907] 1981:259–60). He allows that filial obligation might be limited in the case of a parent who has been irresponsible in fulfilling parental duties, but even in such cases he believes that adult children should serve as caretakers.

The traditionalist perspective of Sidgwick is echoed, albeit less systematically, by C. S. Lewis. Writing in 1947, Lewis concerns himself with the tendency of “moderns” to displace the moral heritage. He refers to those who “claim to be cutting away the parasitic growth of emotion, religious sanction, and inherited taboos” in order to “debunk” the merely conventional (1947:41). At the end of *The Abolition of Man* Lewis lists some important moral traditions which he thinks should be preserved. Under the rubric of “Duties to Parents, Elders, Ancestors,” he refers to passages from most of the world religions and from many classical philosophers affirming that such duties do exist (1947:104). Here Lewis includes the Judeo-Christian precept “Honor thy father and thy mother.” He also lists a moral dictum from the ancient Stoic philosopher Epictetus, “To care for parents.”

Lewis’s worst fears have become reality, as have the “sweeping and abstract” arguments against which

Sidgwick warned. Writing in 1979, the philosopher Jane English questions the assumption that parents can be owed anything at all on the basis of gratitude. "What do grown children owe their parents? I will contend that the answer is 'nothing' " (1979:351). English grants that children may want to assist parents if a close bond of love and friendship exists, but this position places filial caretaking on the fragile basis of "spontaneous love." The biblical precept "Honor thy father and thy mother" grounds filial caretaking much more firmly, for "honor" is due even when "love" wanes, as it so often does. (See Callahan 1987:chap. 4.)

Another recent revisionist argument has been offered by philosopher Michael A. Slote. Slote argues that all sense of filial morality is based on the irrational cornerstone of religious piety. Children are placed under the yoke of obligation because they have been manipulated into the worship of a parental God. Do away with the illusion of divine authority, Slote maintains, and filial obligations will forever disappear, for surely such obligations cannot rest on reason (1979:321). But people by and large do feel obligated to assist their parents in need, and this common aspect of moral experience is not undermined by such philosophical sleight of hand. I am driven back to the ordinary person who attests to commitments in the sphere of filial morality. Everett Hall, the philosopher of "common sense realism," wrote that our knowledge of values must "find its test in the main forms of everyday thought about everyday matters in so far as these reveal commitment in some tacit way

to a view or perhaps several views about how the world is made up, about its basic 'dimensions' " (1961:6). Slote, I believe, has failed this test.

The tradition of Western morality affirms filial morality as an essential aspect of human experience. In addition to Old Testament precepts, there is a very influential New Testament passage: "But if a widow has children or grandchildren, then they should learn as their first duty to show loyalty to the family and to repay what they owe to their parents and grandparents; for this God approves" (1 Timothy 5:4, New English Bible). On a more general level, 1 Timothy 5:8 reads, "But if anyone does not make provision for his relations, and especially for members of his own household, he has denied the faith and is worse than an unbeliever." This latter passage is cited by Augustine in *The City of God*, where he argues that one is to care "primarily" for those in one's own household, because "the law of nature and of society gives him readier access to them" (1950:693). Thomas Aquinas repeats the Augustinian argument in his *Summa Theologica* (1950:549). Precisely how the Christian affirmation of filial morality should be interpreted is subject to considerable debate. It may well be that given the emphasis on human dignity characteristic of the early Christian movement, the elderly, like children, gained in status. As one prominent historian of Christian ethics notes, the earliest church fathers as a whole show a thorough commitment to the "duty of providing for a parent's needs in old age" (Cadoux 1925:194). Consistent with the patristic heritage, the

“Honor” is due even when “love” wanes, as it so often does.

contemporary Catholic moralist Bernard Häring maintains that one of the principal duties of children is “to assist their parents in every emergency, but *especially in their old age*” (1966, vol. 3:112).

By and large, then, the Western heritage of ethical ideas has underscored the importance of caring for the elderly parent, despite inconvenience. Both gratitude and respect for the aging parent as a fully dignified human being are deeply inscribed in the tradition; and it is this religious tradition that informs the strictly philosophical thinkers, however unconsciously, through Sidgwick. Between Sidgwick and the latter twentieth century, philosophers have had nothing to say about filial morality, though now the revisionism of English and others is available. Fortunately, not all of the philosophers are ready to jettison the concept of stewardship for the aging parent. Christina Hoff Sommers, most notably, has recently written on filial morality in a manner consistent with religious tradition. Sommers warns against the consequences of the modern hostility to the moral practices and institutions “that define the traditional ties binding the members of a family or community.” Before this century, she notes, “there was no question that a filial relationship defined a natural obligation” (1986:455, 439).

In an aging society, many adult children of elderly ill parents are faced with caretaking responsibilities of unprecedented magnitude. Feminists writing on the aging society caution against having too much of the caretaking burden fall on women, who are already in a

“superwoman squeeze” between job, children, and spouse. Certainly filial morality applies to men as well as women; it is clearly unfair to place too great a burden on women. Ethical egoists, emphasizing the usefulness to themselves of any and every human activity, note the obvious inconveniences of filial morality and thus refuse obligations which require considerable self-denial. Those who espouse the “principle of utility”—namely, that an action is good if it contributes to the greatest happiness of the greatest number of people—may determine that senicide should displace filial obligation. Given the proportions of the demographic transition to an aging society, we may well be at the crossroads between stewardship and the disregard of the aged that ethical egoism and utilitarianism might permit. Despite the serious pressures of technologically expanded care, the tradition of stewardship and filial morality needs to be sustained. Without this tradition, moral chaos will quickly emerge.

Conjugal Stewardship

Care for a chronically ill and utterly dependent husband or wife can rarely be sustained if it relies on spontaneity, mutual self-interest, or convenience. Care requires commitment and fidelity, virtues inconsistent with egocentric motives. Theologian James M. Gustafson shows little sympathy for the “egocentric, hedonistic interpretation of the ends of marriage and family” which centers

on the ethic of individual self-realization, making self-sacrifice a contradiction in terms. He prefers the image of marriage and family in which we are “stewards, deputies, or custodians of one another and of life itself.” For the steward, self-denial is a moral necessity for common life, entailing a “readiness to serve others at inconvenience to one’s own interests” (1984:157, 164, 170). The man or woman who quests ceaselessly for wider and more varied experiences, so that all relationships become mere experiments to be abandoned in favor of new explorations, can hardly grapple with the level of commitment modern medicine calls for (Lifton 1970).¹

In our technological age, it is imperative that the solemn vows of marriage be taken seriously. These promises encourage a spouse to achieve a form of self-fulfillment based on self-transcendence through caring for another person. In commitment one purposefully accepts the claim of another over oneself in both present and future.

Some, perhaps many, fear that the technological expansion of care locks them into a life of irrevocable self-denial. When a spouse who in a previous age would have died now lives on for years in a condition of total dependence, a husband or wife is confronted with tremendous challenges. It may be that a purely secular perspective is inadequate to sustain fidelity in such cases; perhaps the Judeo-Christian mystery of God’s own fidelity must serve as the prototype to be mirrored in our own lives. Stewardship implies a free act of self-giving which may require a religious framework. The

Jewish notion of *hesed*, or steadfast divine love in faithful covenant, the New Testament injunction “Love one another as I have loved you,” and the poetic images of marriage from the Book of Hosea reflecting the degree of fidelity hoped for between God and humanity—these motifs and metaphors may do more for the ideal of stewardship than strictly rational moral reflection.

The direction in which the Judeo-Christian notion of conjugal stewardship points is perhaps best illustrated by the French existentialist and Catholic philosopher of love Gabriel Marcel. Marcel reacted against Jean-Paul Sartre’s assumption that every human being is the enemy of the other, which interprets all human encounters as forms of conflict. For Sartre, freedom and fidelity are opposed: freedom of self demands an individualism unhampered by bonds of love and promise. Marcel prefers the ideals of mutual self-giving and faithfulness to others; he rejects self-enclosed individualism for an authentic existence of commitment to others (1956:74–75; see also Marcel 1982). “Creative fidelity,” argues Marcel, satisfies human longings for certainty and steadfast love; it liberates persons from chaos and unpredictability. A model of conjugal fidelity, Marcel cared for his fatally ill wife over a period of several years.

Yet the technological expansion of care threatens conjugal fidelity. Increasingly, to be a steward is to be penalized, for care requires ever more demanding acts of self-denial. But as Robert Bellah has pointed out, within American culture, many marry with such values

“What do grown children owe their parents?”

I will contend that the answer is ‘nothing.’ ”—Jane English

in mind as full communication and self-expression, both of which are essentially incompatible with self-denial (1985:chap. 4). Such values can never sustain the moral duties toward which modern medical technology is driving us. A religiously grounded image of marriage, however, insists on stewardship as a vocation to be supported and sustained in community. Given the technological developments that have altered the biological and moral balance of earlier times, this religious framework may be our only hope.

Parental Morality and Imperiled Newborns

The question of what parents owe newborns with serious impairments has recently been so thoroughly discussed that it requires little additional comment. Clearly the developments in neonatal medicine confront parents with dilemmas and pressures altogether unheard of just two decades ago. Social workers report “chronic sorrow” on the part of many parents unable to transcend their sense of helpless despair (see, for example, Kennedy 1970). Moreover, there is strong evidence that divorce rates are high in the families of these newborns because of “burnout,” loss of free time, and fatigue (Harris 1983). Helen Featherstone, herself the mother of a son with severe impairments, has written about parental response to caring in these circumstances. Normal children, she notes, exact heavy com-

mitment, but the demands taper off as the children grow independent. Impairment can disrupt this process, “extending a child’s dependence beyond a parent’s natural strength” (1980:19). “A disabled child,” she concludes, often “forces parents to think of their old age in ugly dismal terms.” Featherstone cites one mother’s response to the burden of care as an example: “And when I project, all I see is a sleepy life of never-ending diaper changing for all of us” (1980:35). Some parents resent the technological expansion of care and understandably long for a more natural style of medicine which is willing to let nature take its course.

Other commentators describe the ways in which families benefit from caring for a child with severe impairments. Rosalyn Darling (1979), for instance, focuses on the stages of parental adjustment to these children. At first, she observes, parents feel helpless and depressed in the midst of what appears to be an overwhelming tragedy. *With support* from family and friends, however, this first stage can be quite brief. Then parents can go on to accept their child, especially if support services are available. Finally, parents enter an “advocacy stage” in which they challenge the social prejudices that exist against the impaired. It is despite these prejudices that parents and families “in most cases” seem to adjust to the difficulties. For the most part, in the absence of serious personal or financial difficulties, the presence of the child “seems to draw family members closer together as an ingroup facing the hostilities of the outside world” (Darling 1979:172).

The significance of Darling's work is this: If families are given the emotional and community service support required, stewardship can be a fulfilling experience. Stewardship in the light of neonatal advances is always going to be challenging; it should not be overly idealized by those who extol the meaning and unity in acts of caring which some families discover. Nevertheless, the work of stewardship can be viewed as a creative vocation, and it is in this direction that Judeo-Christian thought must press. As Gustafson comments in his argument that parents should care for a child with Down's syndrome, "Finally, my view, grounded ultimately in religious convictions as well as moral beliefs, is that to be human is to have a vocation, a calling, and the calling of each of us is 'to be for others' at least as much as 'to be for ourselves.' " Such a calling does not solve all the complex problems of family caretaking, but "it shapes a bias, gives a weight, toward the well-being of the other against inconvenience or cost to oneself" (1981:154-55).

The Limits of Stewardship

Each of us knows persons who, when confronted with the responsibility of caring for a chronically ill child, spouse, or parent, have made tremendous sacrifices. Are there reasonable limits to the caretaking responsibilities in such cases? Of course there are power struggles within families which lead the elderly ill to choose

a life with persons other than family members—a choice some spouses and mature children might make as well. But is there any moral justification for a family's relinquishing care of a member who desires the love and commitment that a family, at least ideally, can offer? Does stewardship require radical self-denial, or does it require a balance between "being for others" and "being for ourselves"? Can a care giver make valid appeals to integrity of self and proper self-love? Feminists have rightly pointed out that a crucial problem for women has been selflessness and self-abnegation rather than an inordinate love of self. It is not unusual for women to express the fear that the technological expansion of care will mean for them more oppressive bondage to what has commonly been termed their "experience of nothingness"—the surrendering of their individual concerns in order to serve the immediate needs of others to the extent that they do not have the opportunity to develop as independent persons (see Saiving 1979).

These concerns are certainly valid. It is widely accepted that a concern for one's own well-being is a prerequisite for the self-giving which stewardship demands. Though selfless giving is often idealized, the reality is that those who care must themselves be cared for if depletion and the burnout of which the literature speaks is to be avoided. Some individuals may be able to thrive and prosper in the role of steward even if radical self-sacrifice is needed. Saints and heroes, however, are rare. Thus society must acknowledge that appeals made in the language of "obligation to self" have

Does stewardship require radical self-denial, or does it require a balance between “being for others” and “being for ourselves”?

moral validity and that stewards can justly call for public assistance in the form of respite, counseling, and group support.

This realistic assessment of stewardship inevitably leads us to public policy. One policy position seems to ignore the needs of family care givers: “If families would take care of the very young, the very old, the sick, the mentally ill, there would be less need for day care, hospitals, and Social Security and public resources and agencies” (Skolnick and Skolnick 1980:51). The good family, we are told, is essentially independent and self-sufficient. But in fact, the long-term care now required demands a policy of emotional and material support for families involved in the caretaking process. Too much public policy at present focuses on the needs of the individual whose family has relinquished care because of a lack of social and financial support. In fact, as Rosalyn Darling insists, society ought not to allow families to become exhausted in the first place.

Even with an adequate public policy, however, one wonders if the challenges of home care can be met without community-wide realization of the vocation of stewardship. At present, there are few areas in the United States where the family caretaker receives his or her due. Among social service professionals a wide consensus exists that the ill and disabled are more likely to achieve their potential in family, or familylike, settings; but the family itself must not be viewed as an isolated unit. Given the frequent absence of support, we must be tolerant of those who are unable to handle the stress

of stewardship and therefore must relinquish direct care. Some philosophers have argued that “ought implies can,” that no person is morally obligated to do anything he or she could not have succeeded in doing however strong the motivation. Accordingly, no person is morally reprehensible for having failed to do something that became virtually impossible, no matter how strong his or her character. Such language does not take us too far, however, because “can” is always a matter of degree. Clearly it is tragic that family members who want to care cannot do so because of the myth that the American family, like the American individual, must be utterly independent and self-reliant.²

The problem of care givers left uncared for is a major one, calling for a redirection in public policy. With scarce support services, families providing home care also face the difficult problem of “competing obligations.” The needs of one family member can, in conditions of scarcity, compete so seriously with those of another that the caretaker must relinquish some responsibility. Can there be a moral ordering of responsibilities? Would care for children take priority over care for the elderly because the young have had less opportunity to explore their potentials? If choices must be made, does one care first for one’s children, then one’s spouse, one’s parents, and finally one’s siblings? These questions are very difficult and even distasteful; moreover, I know of no moral theologian or philosopher who has attempted an ordering of family responsibilities. In an aging society, and in a technological culture which

can prolong the lives of infants and others who not long ago would have passed away according to a more “natural” science, stewardship becomes more complicated; choices may have to be made concerning who can be cared for. I make no attempt here to develop a moral calculus or ordering of family responsibilities, and it may not be a good idea for anyone to do so. The ordering issue must nevertheless, in light of the technological expansion of care, be considered by individual consciences.

Finally, caretaking in the family might be limited on the basis of “release by the promisee.” As theologian Margaret A. Farley (1986:75–76) has written, “Because the obligation to keep a commitment comes from yielding to someone a claim over me, it follows that if the claim is waived or relinquished by the recipient, my obligation ceases.” Adult family members might freely decide to forgo treatments that would seriously strain their families. In such a case, the obligation to a spouse or parent is not broken, but rather voluntarily dropped. Though some will disagree, my own interpretation of the distinction between ordinary and extraordinary care is that it allows for just these sorts of choices. As Gerald Kelly, S.J., defines it, *extraordinary means* are “all medicines, treatments, and operations which cannot be obtained or used without excessive expense, pain or other inconvenience for the patient or others, or which if used would not offer a reasonable hope of benefit to the patient” (1958:129, italics added). Presumably, then, a competent individual might decide that the burden of

caretaking for himself or herself placed upon other family members was excessive and therefore would choose to forgo the various technologies that have expanded stewardship.

Having established that there do exist valid moral reasons for limiting family caretaking responsibilities, I hasten to add that a proper public policy would enable persons to fulfill their roles as stewards in the spheres of filial, conjugal, and parental responsibility. To deal frankly with the realities of the current situation in many states is not to suggest that stewardship at even considerable inconvenience to self is no longer the appropriate norm.

The Limits of Philosophical and Theological Ethics

Although issues in family ethics have become increasingly important to many in our age of high-tech medicine, current ethicists have unfortunately devoted relatively little energy to this area. This essay concludes, then, with a critique of current ethics and a call for some redirection in the hope that the family will again become philosophically and theologically interesting.

With regard to philosophical ethics, most current thought ignores the fact that the self is a social animal with specific biological roles. Being a mother or a father, a sister or a brother, and so on, is socially and biologically descriptive of the self. Furthermore, these social-

Adult family members might freely decide to forgo treatments that would seriously strain their families.

biological roles define what for many is the primary sphere of moral reflection and concern in everyday experience. This area of reflection has been deemphasized in post-Enlightenment thought. Alasdair MacIntyre (1981:31) articulates a growing dissatisfaction with this deemphasis and offers the following criticism of a philosophy of the self that strips away the essential biological embeddedness of human existence: "The self thus conceived, utterly distinct on the one hand from its social embodiments and lacking on the other any rational history of its own, may seem to have a certain abstract and ghostly character." Stripped of "social embodiments," the self of the philosophers is indeed an abstraction. MacIntyre suggests an alternative:

I am brother, cousin and grandson, member of this household, that village, this tribe. These are not characteristics that belong to human beings accidentally, to be stripped away in order to discover the "real me." They are part of my substance, defining partially at least and sometimes wholly my obligations and my duties. (1981:32)

MacIntyre contends that philosophers ought to devote more time to the "special relations" of family and friendship which are so central to the moral domain. Roger Wertheimer offers a similar critique:

Probably the least discussed and most badly treated matter in the literature of moral philosophy is the one that matters most in most people's

lives: familial relationships. That's not surprising since that literature lacks a theory that could say much about those matters that would be both interesting and true. (Cited in Hauerwas 1981:277)

Perhaps the clearest summary of the current state of moral philosophy is that of theologian Stanley Hauerwas (1981:171), who finds that moralists take up the question of "what we owe one another as strangers rather than friends or kin. Indeed, all so-called 'special relations' such as husband-wife, father-daughter, brother-sister are seen as ethically anomalous." In general, the theoretical emphasis on "impartiality" in current moral thought as it has been handed down both from the followers of Immanuel Kant and from those upholding the principle of utility views special familial obligations as either irrational or relatively unimportant. Such sympathies are to be overcome in the name of universal reason. It appears that only Henry Sidgwick reacted strongly to the "secondary and derivative" status of familial morality in post-Enlightenment utilitarian philosophy. His recourse is to common moral experience: "Common Sense, however, seems rather to regard it as immediately certain without any such deduction that we owe special dues of kindness to those who stand in special relations to us" (1981:242). The final result of the general omission of family ethics from current philosophy is this: the conceptual framework to help people think through family caretaking is unavailable.³

In mainstream theological circles, the attention given to familial morality has also been found wanting. Gustafson (1984:155) maintains that marriage and family “have not received attention in moral philosophy, social ethics, and theology in recent years comparable to the attention given other issues of morality and human values.” His explanation of this inattention is insightful:

Even the casual reader of literature produced by Christian ethicists, for example, knows that far more attention has been given to homosexuality, abortion, and pre- and extra-marital sexual relationships than to marriage and families as communities and institutions. Perhaps because the order of magnitude of consequences is judged to be so much greater, writers have attended much more to issues of economic justice and world peace than they have to marriage and family. Among Christian writers perhaps there has been a reaction to the highly idealized portrayals of the “Christian family” that churches propagated in their family literature for several decades. (1984:155)

World peace and economic justice are of course important, but families facing increased burdens in an age of technologically prolonged caring demand attention as well. Certainly family ethics merits more attention than it has of late received.

If moralists can begin to focus attention on the family as it confronts the expanded demands of stewardship, it can be hoped that makers of public policy will move in a similar direction. The medicalization of modern life, the technological assault on death, the difficulty many in secular culture have in accepting human finitude and mortality, and the relative absence of an ethical framework that views self-denial positively—these aspects of modernity have burdened individual family care givers. A retrieval of stewardship, in consort with responsible public policy and a caution regarding the technological doctrine “Whatever can be done to prolong life must be done,” may free us from what has become for many a moral quagmire. ☸

NOTES

1. For another interesting account of egocentrism in American culture, see Bellah et al. 1985.
2. This myth is discussed in Keniston and Carnegie Council on Children 1977.
3. The beginnings of renewed interest in the ethics of the family can be seen in Blustein 1982 and O'Neill and Ruddick 1979.

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Third in a series

On Stanley Hauerwas



*Theology,
Medical Ethics,
and the Church*

“Medicine is but a gesture, but an extremely significant gesture of a society, that while we all suffer from a condition that cannot be cured, nonetheless neither will we be abandoned.”

Suffering Presence, p. 107

IN HIS RECENT article on the Methodist faith tradition, Harold Y. Vanderpool claims that the primary impetus of early Methodism lay in its determination to be a church like the early church (1986:317). The twentieth-century Methodist theologian Stanley Hauerwas continues as a faithful son of that tradition, calling the church today to be more like the early Christian community. He claims that if the modern church would be more like that community, it would not only be truer to itself but also be of some help to the larger world. Hauerwas goes on to argue that medicine needs to be surrounded by a community like the church so that medicine can be true to its commitments.

Giving the church a central place in his theology makes Hauerwas's theological enterprise distinctively

different from that of other theologians writing today. It obligates him to a thoroughgoing rethinking of Christian ethics. He is also among the younger of the thinkers being considered in this series, so his position is still developing, and Hauerwas himself admits to unexplained lacunae in his arguments (see 1983:“Introduction”). His recent systematic account of Christian ethics, *The Peaceable Kingdom*, forms the basis for Parts I and II of my exposition. His writings on medicine (primarily essays, many of which predate *The Peaceable Kingdom* and have been recently reissued in *Suffering Presence*) are the focus of Part III. In no sense do these works exhaust the Hauerwas corpus. He has written a number of essays on war, collected in *Against the Nations: War and Survival in a Liberal Society* (1985a), and on

Christian ethics—*Truthfulness and Tragedy* (1977) and *A Community of Character* (1981). His first book-length publication (1975) focused on the idea of character in theological ethics. He has also shown an interest in topics as diverse as story and theology, the Christian community, and retarded children.

I. Liberalism and Contemporary Theological Ethics

Hauerwas's approach demands that he pay attention to the historical circumstances in which he finds himself. We are, he claims, historical beings, bounded by the time and the place in which we live. The theologian must attend to the circumstances within which theology is done. We begin therefore with his account of Christian theological ethics in late twentieth-century American society, so that we can see what views Hauerwas is seeking to correct.

Hauerwas maintains that many theological ethicists often disguise the fact that what they do has any relation to theology. Like his teacher James Gustafson, Hauerwas criticizes those theologians who, in an effort to make arguments and reach conclusions accessible to anyone in this society, do theological ethics as if their Christian convictions were not important (1985c:12). Such an approach demands that religious particularities not hold the center of attention in ethical discourse (1986:142) and that ethicists downplay the distinctively

Christian features of their convictions. The language of the larger society that theologians then have to use in making their arguments is the language of liberalism. Hauerwas understands liberalism to be

that impulse deriving from the Enlightenment project to free all people from the chains of their historical particularity in the name of freedom. As an epistemological position liberalism is the attempt to defend a foundationalism in order to free reason from being determined by any particularistic tradition. Politically liberalism makes the individual the supreme unit of society, thus making the political task the securing of cooperation between arbitrary units of desire. (1985a:18)

A friendly critic might ask what difficulty lies in this practice. After all, as long as Christian convictions are not distorted, what is the harm of framing the arguments for a broader public? The theological ethicist would have a wider audience and perhaps a wider influence.

Hauerwas answers clearly: the language of liberalism, insofar as it presents a coherent alternative to Christian convictions, is a language foreign to the commitments of the Christian community.¹ He is concerned here both with the substance of liberalism and with the problems of using liberalism as an approach to morality. For Hauerwas, a commitment to community should be part of the substance of Christian belief. But liberalism does not teach persons how to live in trustful commu-

nity; rather, it encourages people to pursue their own interests without interfering with the rights of others (1986a:24).

Liberalism as an approach to morality is flawed because it presupposes a universal morality. For Hauerwas, there are moralities only of particular communities; a universal morality is an illusion. Not just liberalism comes under attack here but many Christian approaches to morality as well. Thus, for example, Hauerwas rejects the Roman Catholic understanding of morality based on natural law, which assumes that human beings can by reason alone come to an understanding of their central moral obligations. In this view, Christianity adds motivation for fulfilling these obligations but does not add any particular substantial obligations.

Hauerwas finds this claim that Christian commitments function only as motivations for doing what all human beings should be doing anyway to be misguided. He states that Christians have a particular morality because they have distinctive commitments. God has made a covenant with them and leads them on an adventure, and this God also makes particular moral demands upon them.

In his focus on the problems of liberalism, Hauerwas borrows from Alasdair MacIntyre's *After Virtue* (1981). MacIntyre holds that people today live in a morally fragmented world, that there is no coherent morality. MacIntyre points out, for example, that persons arguing against abortion use rights language and persons arguing for the option of an abortion use rights

*“We Christians must
rethink our relation
to modern medicine,
for we have been
taught that natural
death means when
doctors can no longer
do anything for us,
but it may be that
we must be willing
to die a good
deal earlier.”*

—Truthfulness and Tragedy, p. 109

language. The first group speaks of the rights of the fetus, and the second speaks of the rights of the pregnant woman. Even though both use the language of rights, they mean something different by that term.² MacIntyre suggests that we are using moral concepts that once had a home in larger cultural contexts but today exist apart from that context. With respect to abortion, the result is that many persons assume they have a coherent morality using rights language when in fact they have only fragments of what was once a more complete morality.

Another difficulty stems from the assumption that morality's task is to help people make choices. According to Hauerwas and MacIntyre, the purpose of morality is to instruct people about who they are and who they may become: morality should be focused not on decision making but upon character. Furthermore, given conflicting first principles, people still cannot decide what to do on the basis of a supposedly universalizable morality. Yet they continue to live with the illusion that a universal morality helps them decide.

Hauerwas appears to modify MacIntyre slightly. At times, he agrees with him that people today live in a morally fragmented world, a world that thinks it has a coherent morality but in fact does not (1986b:73). At other times, Hauerwas attacks this morality *as if it were a coherent one*. Then he goes on to maintain that it fails to do justice to the vision of the Christian community (1983:xxiii).

As fragmented, life in the context of liberalism has

deleterious consequences. People are much less certain of their convictions, and their convictions appear to them arbitrary, simply matters of choice. People know their own finitude and recognize that they are not the source of value. This uncertainty leads to admission of the ever-present possibility of violence because no way of settling moral arguments can be agreed upon. Eventually, people become cynical, even about their own projects, because nothing appears valuable enough to merit their commitment.

According to Hauerwas, people try to find a way out of this situation by calling for more freedom for the individual: individuals can decide for themselves how to live their own lives. Even this preoccupation with freedom, however, is for Hauerwas a form of self-deception. Society encourages people to seek freedom from all commitments and ties that in one way or another determine their being. Time after time, though, people discover that they are not as free as they imagine they should be. Still, committed as they are to freedom, they resolve again to enhance their possibilities of freedom. Eventually this very search is destructive: they find freedom only in disowning their past and working toward ever greater freedom from commitments in the future. Hauerwas proposes instead that people can begin to understand freedom only by owning their past, even or perhaps especially those parts of it over which they had no control.

Hauerwas finds problematic one other tendency of modern thinkers. In their attempt to create a universal

morality, they seek to ground morality not upon some contingent event, such as the history of the people of Israel, but in rationality itself. Such a foundation, they feel, would give them the confidence to make the decisions that human beings are required to make, decisions which involve their and others' suffering for their own moral projects. Only if they have a universal basis for morality do people think it can be legitimate to have others suffer for morality. Hauerwas rejects this position, believing such a universal basis to be illusory.

In such a world, religion, insofar as it is a particular religion, can be thought of only as a private affair, something that might help someone with personal problems, but not as something that might offer guidance about how a community should be shaped. In this country religion is useful only so long as it reinforces the belief that there is never any incompatibility between religious convictions and America. Most theological ethicists are unwilling to take a critical look at American society and to distinguish it clearly from the community of faith. The result is that one may never criticize the larger society from a religious perspective because doing so will mark one as a sectarian.

The consequences of these views lead to the ironic situation in which religion can never be publicly commended *as true and as having something to say about how public life ought to be conducted*. It has only to do with one's private life, appearing to everyone else as one opinion among others.

II. The Importance of Story and Community

Hauerwas wishes to begin elsewhere. He proposes a *Christian*, not a universal, ethic and believes that one must start by understanding what Christians mean by the claim that they are sinners (1983:21). They further understand themselves not simply as sinners but as adventurers who will be sustained by the moral resources given to them by God. These convictions "take the form of a story, or perhaps better, a set of stories that constitute a tradition which in turn creates and forms a community" (1983:21).

Probably no single feature of Hauerwas's work causes so much surprise as his emphasis upon stories or narratives. His intentions are quite straightforward. Contrary to those theologians who wish to start with doctrines, he insists that the narratives of God told first by the people of Israel and then by the church *are* the point, that doctrinal formulations are only secondary. Christians learn how to tell a story that includes them in God's life. To tell this story they must learn what it means to be creatures. Most important, they must come to understand their existence—indeed, all existence that we know—as a gift. They must learn to receive this gift, because no other response is appropriate (1983:27). Hauerwas identifies three claims here: first, we are contingent; second, we are historical; and third, we recognize God's story in the life of Israel and the church. That

“There is nothing wrong with paternalism or maternalism once we see that the development of autonomous beings is not the culmination of the moral life. Rather the goal of parenting is the creation of people who can enter into trustful relations because they have learned not to fear the other as a threat to their ‘autonomy.’ ”

—Suffering Presence, p. 132

story demands our transformation, and ethics, he proposes, is the study of that transformation.

In this book [*The Peaceable Kingdom*] I contend that Christian convictions do not poetically soothe the anxieties of the contemporary self. Rather, they transform the self to true faith by creating a community that lives faithful to the one true God of the universe. When self and nature are thus put in right relation we perceive the truth of our existence. But because truth is unattainable without a corresponding transformation of self, “ethics,” as the investigation of that transformation, does not follow after a prior systematic presentation of the Christian faith, but is *at the beginning* of Christian theological reflection. (1983:16)

Hauerwas thinks that a central failing of human beings is the refusal to see themselves as sinners. The primary reason for this is that they deny that they are contingent, that is, that they are creatures. They wish to maintain that they are the creators of themselves, indeed, that they are something only insofar as they are self-creators. Yet seeing themselves as sinners makes it clear that what they need is not self-creation but transformation.

Hauerwas then delineates what it means to be historical. He wants Christians to recognize first that they are products of history, that things were done to them over which they had no control, and second, that they can make that past their own by claiming it and putting

it into a narrative which gives them a sense of self. Hauerwas wishes to discuss history and freedom together: freedom is not to be discovered in constantly stepping back from our commitments, nor is freedom correlated with awareness. Freedom is not in making choices but in identifying with choices (1983:38).

But this is not all. Persons can be free only insofar as they are called out of preoccupation with themselves, and they gain this kind of freedom by telling God's story in a community. Because this community is central in rightly forming a person, it is essential that it be truthful. Among other things, this means that the community will have to live the story that their lives are not their own but God's. The Christian ethicist has the responsibility of assisting the community in the task of being truthful. That task is not an afterthought to theological reflection but a crucial part of it.

This responsibility of truthfulness constrains the Christian ethicist, because it requires that the ethicist attend first to the community and the story which it owns. Unlike a number of theologians, he refuses to speculate on the "truly human" without attention to the Christian story. Hauerwas fears that an ethic divorced from both the Christian community and the particulars of the Christian gospel will end by being a legitimization of the status quo.

The understanding of the particularity of Christian ethics is but one aspect of Hauerwas's claims about the relationship between the church and the world. One of his most persistent claims is that the church, when it is

truthful, is distinct from the culture in which it finds itself. Only when it is itself can the church be of service to the world: its being itself offers the world another vision of how things might be (1970:40).

Hauerwas wishes to avoid two temptations here. First, he resists the notion that the church is composed of persons who are better than their neighbors. Claims that the church is distinctive are not claims of superiority but claims about the radical nature of the gospel (1983:110). The gospel demands that we forgive the sinner, the sinner who is our enemy and the sinner who is our self. The church is the community that ought to teach us how to do that. Second, he opposes the temptation for Christians to see their morality as universal. If they do so, they will be tempted to use violence to enforce it. Hauerwas rejects both the claim to universality and the right to use violence, which he thinks is correlative to it. Christians rightly affirm that God intends God's life for all of creation; this claim certainly has "universal" implications. Yet they recognize that this intention has not yet fully manifested itself, so they must begin where they are, in the midst of history, giving witness to what they believe and hoping others will find the form of life attractive (1983:62).

Christians must give primary witness to the person of Jesus, Jesus as he is presented in the Gospels. Hauerwas does not reject church doctrines about Jesus, but he gives priority to the scriptural texts. Moreover, he recognizes that the Jesus presented there is not the "historical" Jesus but Jesus as he was understood by those

whose lives he had transformed. This, Hauerwas argues, is all that we have and all we can know.

In these texts one finds that Jesus does not call attention to himself but to the kingdom of God. Further, Jesus showed what was necessary to bring one's life into accord with the standards of that kingdom. Christians are called to be disciples, to orient their own lives according to Jesus' life. Discipleship will not be easy. At the very least, Christians will have to learn to forgive their enemies.

Hauerwas explains this imperative by placing Jesus against the background of the history of Israel, the background used by the writers of the Gospels. To the Israelites had been revealed God's prevenient and provident nature (1983:77), and the Israelites then had to learn to walk in the way of God. This meant not only going where God willed Israel to go but learning to love others as God loved them.

Against this background, for Hauerwas, what Jesus did becomes intelligible, especially his obedience to God's will. Christians too often focus on resurrection at this point and look past the cross. Hauerwas insists, however, that Christians should not have any illusions: they are asked to be ready to suffer for their convictions. They are called to take up a new form of life, which will bring them a new kind of power, the power of God that comes from responding to this invitation. In responding they free themselves of the powers that currently control their lives.

Jesus' announcement of the kingdom encompasses

all these demands. Hauerwas stresses the eschatological nature of this announcement, that is, Jesus' pronouncing that the world as we know it will end. To understand this, we must come to see the world as a storyteller might, with a beginning, middle, and end. For some, this might be reason for anxiety, because their familiar world will be no more. But Jesus also announces the good news that God has made it possible to live peaceably in the world, without violence.

Hauerwas argues that the life of Jesus is normative for Christians, especially his attitude toward the "outsider" and toward authority. Although Jesus' teaching was quite close to that of the Pharisees, his views of the outsider and authority differed radically. For the Pharisees, the outsider was unclean and could be rejected; Jesus, on the contrary, not only associated with outsiders but took opportunities to welcome them into the community by celebrating with them. In this way, Christians are to display their belief that God rules the world, not death or evil (1986b:132). Further, these celebrations can take place no matter who holds political power. God's rule has already begun and does not have to await a political revolution (1983:86).

What are the other manifestations of this community? How should it be known? According to Hauerwas, the Christian community manifests a readiness to accept the forgiveness already given by God. Hauerwas, in a twist on the usual Christian rhetoric, talks not about giving to and forgiving another, but about receiving from and accepting the other's forgiveness. He asks

Christians to forgo those kinds of control that they can exercise in giving, forgiving, receiving, and being forgiven. What they must accept is their loss of control. Then they will be able to live as a people able to accept themselves, their sins, and their past, without feeling that they have to tell lies to themselves and others about who they are and what they wish to become. But they can do this only because they accept Jesus' resurrection as the sign that they should use his life as a guide for their lives, rather than seeing his life in terms of their own world.

Hauerwas thus explicitly counters the individualistic understanding of the person that he finds in modern society. He counters with the church, which for him stands against not only this society but any political society. Unlike modern society, the church is formed by the conviction that God rules the world, and it bears witness to this fact. Part of this witness involves non-violence. For Hauerwas, violence is a sign that Christians do not in fact believe in the providence of God but wish to entrust themselves to their own powers. Instead, in this time between the times, Christians are called upon to witness to God's work in Jesus Christ.

Hauerwas is much misunderstood at this point. Some of his critics think he does not pay enough deference to the institutions of politics, that he has become a sectarian with no social ethic. His response is quite simple: the church is his social ethic (1986b:1-2).

It is now that we can begin to see how different is Hauerwas's approach—instead of decision, character;

*“When institutionalized
and regarded as morally
acceptable or at least
morally indifferent by
society, abortion is an
indication that a society
is afraid of itself and
its children.”*

—A Community of Character, p. 209

instead of universality, particularity; instead of liberal society, the Christian community.

III. The Distinctive Commitments of Medicine

It might be asked of Hauerwas why a theologian with his convictions would write about medicine.³ Although many theologians are interested in medicine because it presents opportunities to analyze individual difficult cases, Hauerwas wants to begin not with an individual case but with the character of the person. Thus his approach directs him away from what he calls “quandaries” that need resolution. Why, then, his interest?

There are a number of reasons. First, medicine is a practice not explicable solely upon liberal premises. For most people, physicians still have a kind of authority. Yet if people were consistent with their liberal premises, they would seek to deny that authority to the physician in the name of their autonomy. Thus it is possible to learn something from medicine about this larger issue of autonomy and interdependence.

Second, medicine is at the same time in danger of losing what makes it a distinctive practice. The language of liberalism has made great inroads into the self-understanding of medical practitioners (1986b:4). The language of autonomy has been made part of the physician’s claims, and now, in reaction to those claims, it has become part of the rhetoric of patients’ rights

movements, which criticize what is occurring in medicine.

Third, Hauerwas thinks that he is advancing a “natural theology” when he discusses medicine.⁴ He believes that simply having medicine involves significant moral commitments on the part of society. For these commitments to be sustained, a community of persons is needed to form the character of those who would enter the practice of medicine. To summarize: Hauerwas sees an opportunity now to say something to medicine, to ask it to live up to what is morally distinctive about it. In the process he takes the opportunity to deepen his critique of liberalism and its influence in this society.

Hauerwas has some reforming intentions in mind as well. Among other things, he wants to give another account of medicine than that offered currently. Hauerwas fears that medicine is coming to be seen as nothing more than a collection of skills that are morally neutral. When these skills are used badly, then the physician needs training in ethics—offered, of course, by more-than-willing ethicists. Instead, Hauerwas wants us to understand medicine as embodying certain commitments that are not morally neutral. These commitments are not seen by many in religious or philosophical ethics. The result is that the practitioners in these disciplines do not understand the delicacy of the situation in which medicine finds itself when they offer to help medicine with ethical instruction. Unfortunately, medicine appears to be taking up this offer of help, with fatal

results, Hauerwas believes, for the activities that medicine has embodied until now.

Hauerwas's method distinguishes him not only from his colleagues in philosophical and theological ethics but from those who argue that the knowledge of science stands at the basis of medicine and the physician's authority. When Hauerwas looks at our fragmented world anew to see which fragments from the past continue, he identifies as one the physician's commitment to treat the body (1974:175). This fragment comes to us as a remnant from our Christian past, a remnant displaying the Christian belief in the fundamental goodness of the body. Insofar as this belief has stood as a counter against those who would glorify the mind over the body, that remnant is relevant for our age. It reminds us that concern with the body is part of medicine's way of serving human beings.

But that is not how the task of medicine is understood today. Hauerwas believes that those in medicine who have accepted the language of liberalism mistakenly see their primary task as the enhancement of patient autonomy. It may be that autonomy is all a patient has in a fragmented world, but that conclusion is ultimately unsatisfying. Hauerwas demands instead that medicine should recall its moral imperative to be present to those who are suffering.

Hauerwas asks the community of persons found in medicine to reflect on the question of why we have a medicine at all. Persons cannot say that they practice medicine in order to avoid death, for this answer is in-

adequate. Not only is the avoidance of death foolish as a long-term goal, but it leads to those practices of a highly technological medicine in which patients are not permitted to die. Further, persons cannot, if they are Christians, say that they practice medicine in order to remove suffering, for that answer leads them to practices in which they have to destroy sufferers in order to remove suffering.

Hauerwas proposes instead that medicine is an example of a commitment that persons have to be present to one another when one is suffering in the body. Cure is not promised, nor the relief of suffering. Presence to the other is all that is and can be promised. In some cases, the fact that I am present is an aid to the other (1986b:63). Indeed, the reality of presence operates as a critique of the usual distinction between curing and caring. Presence sometimes cures. Hauerwas observes how remarkable it is that people are willing to be present to the sick because, as anyone who has spent time with a sick person knows well, the sick are not easy to be with. The sick are the "outsiders" to the human community; they demand a great deal from people and appear to give nothing in return. Yet in fact, the sick teach the health care practitioner. They teach what it means to be ill and how one may learn to live with illness.

The sick entrust themselves to healers even though medicine, along with the rest of human life, is marked by tragedy. Tragedy occurs because medicine is fallible and because, inevitably, medicine will involve conflicts in values (1986b:51). The physician may practice the

best medicine on behalf of the patient, but the best medicine may not be good for a particular patient. Surgery may be indicated for my ailment, but I am one of those people who unexpectedly react adversely to anesthesia. The best medicine has not been good for me. Second, physicians may simply be wrong about what is good for patients and, as a group, prescribe treatments that are deleterious. The history of medicine abounds with examples of once popular and now disproved therapies. Third, medicine will involve conflicts, sometimes of goods with goods and at other times evils with evils. The physician may have to choose between the good of the individual patient who needs treatment but will flee it if his or her disease becomes known and the good of society, which requires that this particular disease be reported to public health authorities.

We do not want to admit to ourselves that medicine involves tragedy. One of our responses is to try to maintain control by using lawsuits and other devices to eliminate or reduce uncertainty in our world. For Hauerwas, however, tragedies are unavoidable: persons will be harmed because of what health practitioners do. Those persons who would be patients must give up their illusions of control and prepare for a fallible medicine. However, a fallible medicine also presents complications to persons who would be health care practitioners.

Practices like medicine that involve not only difficulties but tragedies need people who have been

formed to carry on in the face of tragedy. Such people would be able to recognize even the suffering, difficult patient as someone who needed their presence; they would not see in every death defeat; they would be open to being taught by the patient. In the story Hauerwas wishes us to join, the patient is not simply an object of charity, a person to whom one turns in order to exercise one's Christian virtues. The outsider is essential; the outsider is valuable. What we find is that the outsider is God's good gift to us for our salvation. The patient is essential and not simply the object of the ministrations of nurses and physicians.

The difficulty, of course, is that professionals tend to see themselves as the initiators and powerful ones in these relationships, and in their power they wish to ground their authority. They must understand instead that their authority comes from the moral skills they possess, not from their scientific knowledge nor their willingness to serve the patient. Hauerwas insists that persons in medicine need to be constantly reminded that they receive as well as give in these relationships with patients. In order that this reminder be given, medicine needs an institution or community like the church (1985b:54). Hauerwas is not here calling upon us to return to religious communities in order to sustain an appropriate medicine. What he does maintain is that medicine, if it is to remain true to itself, needs a wider community to sustain itself, and such a community seems unavailable to it in our age.

IV. Welcoming the Outsider: Christian Responsibilities to the Retarded Person and to the Fetus

As Hauerwas sees it, nowhere are the differences between a truthful community and twentieth-century liberalism clearer than in the discussions of suffering, the retarded, and attitudes toward abortion.

Liberals, as Hauerwas understands them, see suffering as something which always should be overcome. For example, the suffering patient whose pain cannot be relieved provides the paradigm for the consideration of active euthanasia. In short, it is the reality of suffering that causes the most anguish for the person schooled in liberalism, whether a theologian or not. In saying this, Hauerwas does not wish to minimize the real and terrible sufferings which some people undergo. He objects, however, to those who, in their zeal to relieve the suffering, consider the possibility of removing the sufferer from the scene. Although “solving” the problem of suffering for the survivors, because suffering is no longer present, this practice is not one Hauerwas wishes to encourage. Instead, he asks, why do we assume that we have to relieve all suffering? Is that medicine’s distinctive task, or is there another?

Hauerwas maintains that, for Christians, suffering is a time to display their belief that God rules the world. Suffering and response to suffering can threaten that belief in at least two ways. First, if suffering has the last

“Patients have to learn that they cannot assume that the care of physicians can be without error. Indeed, patients must face the possibility that the best possible medicine of the day may be the wrong thing for them.”

—Suffering Presence, p. 51

word in human affairs, then it is true that God does not rule the world. Second, if Christians respond to suffering under the assumption that *they* must do everything to relieve suffering, then they do not witness to the fact that there are goods beyond those of this world, goods not in our control (1974:188).

What is it, then, that Christians must do with and for sufferers? They should alleviate the suffering, if that is possible. Beyond that, they should make themselves present to the sufferers so that sufferers know they are still within the human community, that suffering does not make them “other” and thus outcasts. Even if sufferers wish to believe that about themselves—and when persons suffer, they tend to—the presence of someone reminds them that they are still members of the human community.

Hauerwas’s experiences working with the parents of retarded children over a number of years has given him occasion to reflect upon how this society views the retarded and how it chooses to deal with parents who suffer because their children are retarded. Hauerwas finds that persons in this society tend to make two mistakes in discussing retardation. First, they assume that retardation is a terrible evil. Hauerwas objects to this assumption as a theological and moral mistake: retarded people may be different from others and may have different needs, but their retardation should not be characterized as a terrible evil. Second, many assume that most retardation has a genetic basis and that the appropriate course is to eliminate retardation. Hauerwas

makes the claim that in probably one half of all cases retardation is not caused by genetic factors (1986b:162).

Hauerwas does not regard in an entirely positive light these campaigns to eliminate retardation. They disguise, he feels, an underlying belief that being retarded is an unacceptable way of being human. They betray this society’s lack of the will and imagination to deal with persons who are classified as different from the rest of the society.

Those who wish to eliminate retardation may respond that in doing so, they would eliminate suffering. Hauerwas tries to show that the usual conceptions of suffering in this context are overly simple. He makes a distinction between suffering that simply happens to persons and suffering over which persons have some control, suffering endured because of some purpose that they have. Christians, he states in *Suffering Presence*, must learn how to be the “kind of people we ought to be so that certain forms of suffering are not denied, but accepted as part and parcel of our existence as moral agents” (1986b:167). This does not mean that Christians have to look for suffering; in fact, they should avoid unnecessary suffering. At the same time, they should acknowledge the inevitability of suffering.

In Hauerwas’s view, the campaign to eliminate retardation often disguises the unwillingness of people to have those unlike themselves among them, especially when the company of those persons causes difficulty. As long as the general society believes persons to be most themselves when they are free from all others, this

society will continue to be uncomfortable in the company of the retarded. Hauerwas finds in this attitude a false sense of self; he argues that identity comes not from independence but from needs as well. The retarded make people uncomfortable because the need of the retarded is obvious, reminding all members of society of their own need (1986b:169).

Concern for the retarded, worry that they may be discriminated against, fear that they will receive inadequate schooling can be either a goad to change the world or a motivation to eliminate the retarded person. The same might be said about approaches to a severely handicapped infant. Some justify nontreatment on the grounds that handicapped infants will suffer if they live. What is left unsaid is that persons often do not want to care for the handicapped and retarded.

It is most insidious that the very imagination which enables us to identify with others also leads us to see those others with *their* difficulties and *our* appreciation of those difficulties. It may well be that the retarded do not understand their condition as others do and thus their moral universe is different from that of others. Hauerwas encourages us to learn to accept that difference.

Hauerwas acknowledges that he has some theological claims to make here. The retarded are those persons in whom Christians recognize God. To understand this, Christians must give up their notions of a deity who is totally self-possessed and totally alone. To live that understanding out in the Christian community is a

challenge that will involve clarity about what Christians think makes a person retarded. They may learn that it is the retarded person's dependence, which turns out to be only one of the many forms of dependence that humans display and wish to deny. Hauerwas calls into question the very idea of being retarded, moving us to ask not "How do we care for the retarded?" but "What kind of a community ought we to be so that we can welcome the other?" (1986b:179).

The community is also important for Hauerwas's discussion of abortion. Hauerwas insists on exploring just what abortion means and does this by asking what it means for people in a particular community, not by asking what it means for all persons. He argued quite early, in *Vision and Virtue* (1974), that it was not clear that everyone understood what an abortion was. It was hardly a neutral term, and yet it was being treated as such.

In this early work Hauerwas argued against those who, depending upon some spiritual principle of personhood, held the fetus to be only "physical" and not a "person" (1974:150–51). Our being is first of all physical; I am who I am in and through the body. But our obligation to take the body seriously, even the body of the fetus, does not deny the existence of circumstances in which the fetus might be forcibly expelled from the pregnant woman. Hauerwas focused on the agent's perspective in the decision. In doing so, he avoided maintaining either that all abortions are immoral or that abortion is trivial, simply a matter of a woman's choice

*“Given the particular
demands put on
those who care for
the ill, something
very much like a
church is necessary to
sustain that care.”*

—*Vision and Virtue*, p. 215

in how she controls her body. Here Hauerwas wished to argue that abortion is a morally dubious practice within the Christian community, but that all actions which have the physical characteristics of abortions are not necessarily abortions in a moral sense (1974:148).

In *A Community of Character* Hauerwas clarifies his position. Here he more carefully argues the religious reasons to reject abortion. Consistent with his method, he focuses not on a decision whether one should have an abortion in a particular situation but on Christians' understanding of who they are and how they must be transformed. According to Hauerwas, Christians ought to see themselves as persons who welcome the other, and the other includes the child. Thus they have to ask themselves what persons they will have to become in order to welcome children into the world. The fetus is another form of the outcast that modern society is tempted to abandon. If Christians reject children and use abortion to carry out this rejection, then they join with that society. Again, this conclusion does not mean that all abortions are immoral. But it does establish a direction for persons, a direction that carries over from the question of abortion to a number of areas of contemporary concern (1981:225–28).

V. Evaluation and Response

Hauerwas has offered a powerful critique and the outlines of a serious alternative to the predominant approaches to medical ethics. In the process of doing that,

he has forced religious and secular thinkers alike to examine their own commitments.⁵

Hauerwas has pushed to the center of attention questions about the point and purpose of healing. Thinkers are forced to reflect not simply upon the very difficult problems that confront us in medicine today but upon the very assumptions that lead us to understand these problems as problems. In particular, Hauerwas asks the observer of Western technological medicine to reflect upon the significant moral commitments that sustain that medicine, the content of those commitments, and the means by which those commitments may be passed on in the future. Even if Hauerwas's approach is rejected, the character of the healer and of the community that sustains healers must be considered by any thinker who is serious about medicine.

Yet Hauerwas leaves us with a puzzle. As we have seen, his theological approach focuses upon the community—the particular community with its special commitments. This community is the Christian church in the rest of Hauerwas's work. When he turns to medicine, however, his perspective shifts. On the one hand, he discusses the significance of particular Christian commitments on such matters as abortion and technological medicine. He advises that the Christian community might have to practice an alternative kind of medicine if it is to be faithful to its commitments.

On the other hand, he argues that medicine needs a community very much like the church in order to sustain itself. If this is the case, then Hauerwas has, at least

implicitly, a set of criteria for good communities. It would be helpful for him to articulate these, and more important, to tell how he knows of them. In brief, assuming he is doing natural theology when he discusses medical ethics, and assuming that natural theology involves our knowledge of God apart from the revelation of God in Jesus Christ, it would be helpful for Hauerwas to articulate his own view of how such a theology is possible, given his claim that theology calls for particularity and Christian theology calls for the particularity of Jesus. Hauerwas might be very helpful to us in our understanding of medicine, but he does not appear to be consistent when he claims to be doing natural theology *and* a theology based upon the revelation of God in Jesus Christ.⁶

He should also come to terms with the possibility that such a natural theology would lead to an alternative understanding of liberalism and its stepchild, patient autonomy. Autonomy might be understood as the bare minimum necessary to protect patients from healers who do not understand the limitations of their role and who have at their disposal all the machinery and organization of modern technological medicine. Such a "minimal ethic," as it has been called by my colleague Allen Verhey, might be supported as just that, given that the possible alternatives in our world are not only Hauerwas's rightly formed community but the technological medicine he criticizes.

Thus far, churches seem to have ignored Hauerwas's call for an alternative to the medicine currently

being practiced (see Hauerwas 1974:181ff.). Just as the church could present a social ethic as an alternative to that of the larger society, such a medicine would be an alternative to the technological medicine offered to persons understood as medical consumers. Hauerwas wants care to be understood as presence. That, for him, is the appropriate alternative to the focus on technology in modern medicine. But at least two distinctive kinds of presence are found within healing today, and I suspect that both are necessary in healing rightly practiced. One is exemplified by the old-fashioned family physician who knew both who you were and who you wished to become. We are in danger of losing that presence in a highly specialized medicine where patient and physician meet as strangers. In my own view, it is the lack of such a presence that has led many to call for patient autonomy.

There is a second presence, however, when we are seriously ill—the continual bedside presence of a person such as the nurse. If there is a place where Hauerwas has lost an opportunity, it is in the use of language about medicine and nursing. He admits that much of what he has learned about medicine he has learned from nurses,⁷ that they carry out the activity of being present that is central to a medicine rightly practiced. Yet he persists in speaking of “medicine.” If he wishes to insist that both physicians and nurses share in being

present to patients, but that nurses do this better in the current circumstances of health care, he should make this clear. I am not maintaining (nor, certainly, is Hauerwas) that these commitments are found distributed either by gender or by profession. I am noticing that the profession of nursing appears to embody these commitments to caring and presence at least as often as does the practice of medicine. Of course, there are significant counterexamples: nurses can be as oriented to cure through technological means as the most invasive of physicians, and some physicians are as committed to care understood as presence as the most compassionate nurses. It is simply surprising that Hauerwas has not more explicitly attended to where he has learned what he has learned and then attended to his language. Perhaps the categories of medicine and nursing should be replaced by the category of healers.

I offer these comments not with any claim that they point to fatal flaws in Hauerwas’s project. They are offered in the hope that they will challenge Professor Hauerwas to think anew about the relationship between medicine and the church, between health and faith in this era of technological medicine. His contribution to that conversation has been both distinctive and distinguished, and one can only hope to hear more from him on these issues. ☸

NOTES

1. Hauerwas is not convinced that the current circumstances of the church are worse than those of the past because of liberalism. The situation of the modern church is neither better nor worse in his view (1985a:1).
2. MacIntyre argues, for example, that the one group gets its concepts of rights from Locke, while the other uses concepts from Kant and Aquinas (1982:7).
3. It is important to understand that when Hauerwas uses the term *medicine*, he means nursing as well as medicine. As I observe below, this usage causes him some difficulties, but I assume his intent is to avoid the health care bureaucracy's term *health care worker*.
4. Hauerwas made this comment during a discussion of his book *Suffering Presence* at the 1988 meeting of the Society of Christian Ethics (15–17 January, Durham, North Carolina). The point was also noticed by Vance (1986:12).
5. There has not been space to discuss a number of important areas in Hauerwas's work. The issue of narratives and stories is important for an understanding of Hauerwas's theological method. Those wishing to pursue this topic could begin with "A Story-Formed Community: Reflections on *Watership Down*" (1981:9–35) or "Aslan and the New Morality" (1974:93–110).
6. On this point, see Vance 1986:12.
7. Hauerwas reported this in a conversation at the meeting of the Society of Christian Ethics, 15–17 January 1988, in Durham, North Carolina.

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SECOND OPINION GUIDELINES FOR AUTHORS

1. The manuscript should be typed on one side only, on standard white paper, with margins of at least 1¼ inches. All material, including extracts and references, should be double-spaced. Manuscript length should not exceed 25 double-spaced pages.
2. Style and spelling in the journal are governed by *The Chicago Manual of Style* (13th edition) and *Webster's New International Dictionary*. If you have any questions on style, please consult these sources.
3. Authors are urged to use nonsexist language.
4. Figures, diagrams, tables, and charts, if appropriate, should be submitted on separate pages and keyed to their position in the text. In addition, a list of legends or captions should be typed separately.
5. We welcome suggestions for illustrations. Our criteria for selecting illustrations are relevance to the article and visual interest.
6. Articles should be aimed at a diverse but educated public. Do not write for the six specialists in your field, but rather for the general reader.
7. Notes, citations. Notes are to be reserved for substantive observations, and their use is discouraged. They should be numbered consecutively and placed in a separate section following the text. All notes that consist merely of supporting citations should be placed in parentheses in the text, listing (in order): last name of author, year of publication, and page numbers where appropriate, e.g., (Tillich 1967:353). Subsequent citations of the same source should also follow this model.
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Examples

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