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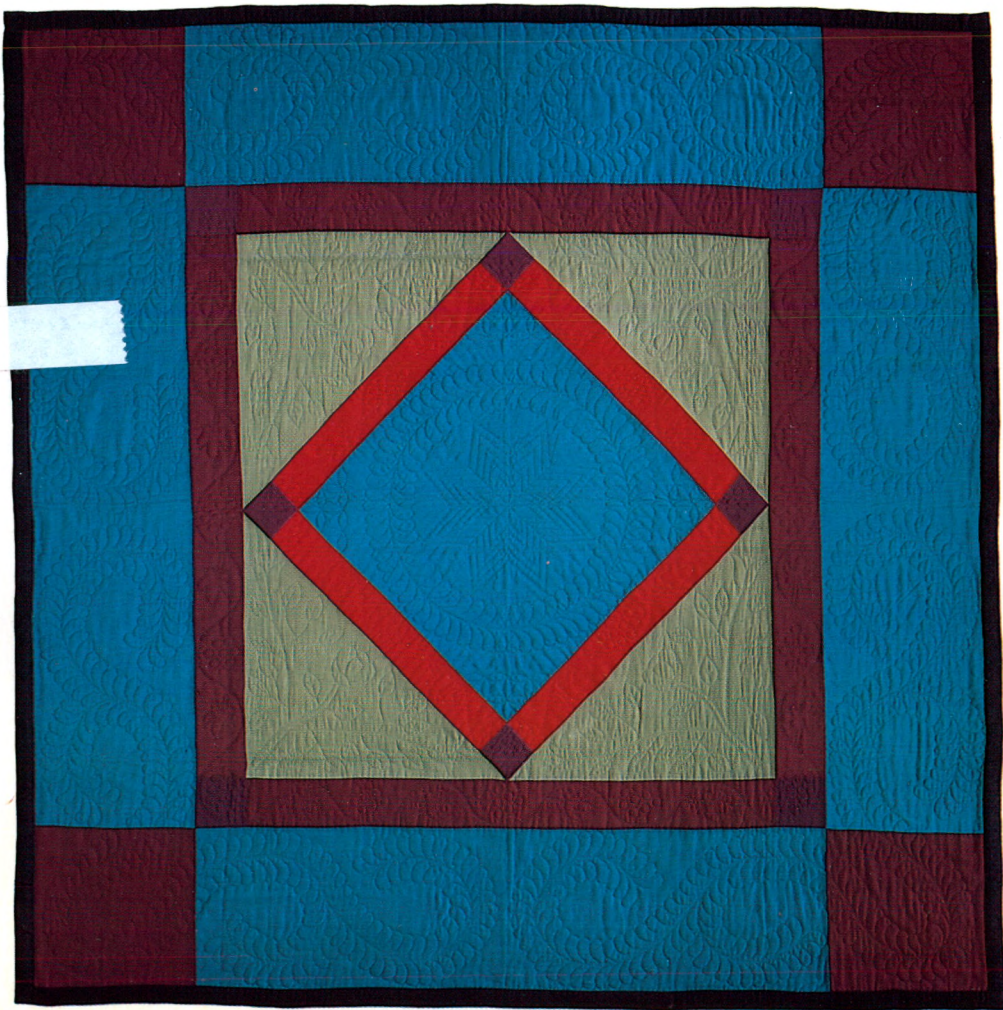
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S E C O N D O P I N I O N

HEALTH • FAITH • ETHICS



Alternative Healing Therapies • Justice in Insurance • Substance Abuse • AIDS and Spirituality

COVER

Diamond in the Square. Pieced wools by unknown Amish quiltmaker, c. 1920–30.
Lancaster County, Pennsylvania.

Collection of Esprit de Corp, San Francisco. Photo by Sharon Risedorph and Lynn Kellner.
From *Amish: The Art of the Quilt*, published by Alfred A. Knopf/Callaway, New York, 1990.

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HEALTH • FAITH • ETHICS



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The Park Ridge Center exists to explore the relationships among health, faith, and ethics. In its programs of research, publishing, and education, the Center gives special attention to the bearing of religious beliefs on questions that confront people as they search for health and encounter illness. It also seeks to contribute to ethical reflection on a wide range of health-related issues. In this work the Center collaborates with representatives from diverse cultures, religious communities, health care fields, and academic disciplines and disseminates its findings to professionals and others interested in health, religion, and ethics.

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

Volume 18, number 1* • July 1992

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INITIAL COMMENT

Homespun

homespun *fig.* Of domestic origin or quality; simple, unsophisticated, unvarnished; . . .

The Amish quilt on the cover of *Second Opinion*, like the subjects of all our covers, signals something about the contents of one or more of the articles within. In this case the proper word is “more”: most of the pieces accent the voices or enterprises of ordinary people trying to make sense of their illness or health, of people seeking simple solutions or attempting to speak unvarnished truths about their condition.

Whoever studies the whole collection of quilts in *Amish: The Art of the Quilt* will discern the aesthetic value of these artifacts, which are not technically homespun because they are not spun but which are still “of domestic origin.” They represent American expression at its most simple—and yet are quite complex. (We are reminded of Alfred North Whitehead’s famous dictum: “Seek simplicity—and distrust it.”) The quilters would never have found their way around complex Chantilly laceworks. They were confined to a narrow repertory of patterns and designs. Yet they were always bursting the bounds of the merely simple, as the stunning cover suggests.

Robert C. Fuller very deliberately takes us back to the roots of “alternative medicine” in America, where experimenters, most of them not well equipped technically, gave expression to their own homegrown therapies, some of which survive into our own time. Fuller is not interested in having readers become devoted to these sometimes forgotten, often obsolete,

and frequently discredited approaches to healing. He does help occasion a fresh look at the interest people have in finding their own address to their problems.

Stephen G. Post follows with seven conclusions or proposals for those who would connect health, faith, and ethics in dealing with problems of substance abuse. Who better can provide testimony, unsophisticated though it be, than the abusers who are abused by their own practices? In Post’s article, the professionals stay at home, as it were, and the people speak up in voices that can help the professionals understand.

For many Americans, the Mennonites are located not too far from the side of the quilt-making Amish, their historical kin. The Mennonite religious movement seeks “simple, unsophisticated, unvarnished” approaches. But unlike their Amish cousins, the Mennonites have moved more and more into the crossroads of complex, sophisticated, and “varnished” American culture, a world of health insurance plans and organ transplants. So a Mennonite company that seeks to provide insurance for its members while doing justice to both the authentic character of Mennonite life and the high-tech world of medicine has to struggle with ethical and practical issues, and does so, we learn, in ways that can benefit others. Scot D. Yoder tells the story.

Govindappa Venkataswamy, the subject of Missy Daniel’s interview, takes us geographically far from American homespun, but this devotee of Sri Aurobindo is clearly in search of the “simple.” Some readers of *Second Opinion* will find the voice of this distinguished

eye surgeon—and the “higher consciousness” he invokes—to be alien. But representing this voice on these pages helps us fulfil the mandate of the Park Ridge Center to range widely in the worlds of comparative religion. Archbishop William Temple once said that there is no such thing as comparative religion; there are only comparatively religious people. Dr. Venkataswamy is not being “comparatively religious” or “interreligious”; he exemplifies and exegetes a single and particular tradition remote from the West with an eye on helping those who would see, also in the West.

Joel E. Frader brings us to a setting where ordinary people take their ordinary understandings of faith and put them to work. These understandings, homespun and “of domestic origin,” may not actually represent the catholic scope of the faith tradition from which they come. Homespunners often narrow the range of dogma, belief, and confession and create problems for those who would help them. The physicians, ethicists, chaplains, and family members who stand by in the face of unsophisticated faith expression may wish they could bring the ampler understandings of faith to bear on situations. But sometimes they have to leave encounters with emotions that mingle frustration and hope. Here is not catholic but domestic realism in full force.

When new diseases, especially life-threatening ones, push those who contract them to the boundaries of ordinary medicine or care, they have to reach rather desperately for meaning and support. Frank G. Sabatino speaks for himself, but he provides eloquent,

unvarnished expression to the homespun addresses—no, not yet solutions—to the AIDS crises most close to home.

Second Opinion, in turning this time from the laboratories and universities, the research centers and technological forums in order to observe and listen to homespun approaches, is not turning away from the mainstream alternatives to alternative medicines. But the authors of these articles help remind us that no one cares more, and few need more to be heard, than the subjects and victims of illness, the patients and sufferers and seekers. Like the quiltmakers, they are seeking simplicity and distrusting it. But then they go on seeking it further, as most of us do and will and must.



Martin E. Marty



Establishing the mesmeric trance state.

Courtesy of the Wellcome Institute for the History of Medicine, London.

The Turn to Alternative Medicine

Robert C. Fuller

IN LATE 1991 *TIME* MAGAZINE'S COVER STORY focused on the growing interest in alternative medicine among Americans. "New Age medicine is catching on," readers were told. "Fed up with surgery, drugs and quick fixes from their doctors, Americans are turning to an array of alternative therapies ranging from the believable to the bizarre" (Wallis 1991:68). The article went on to explain that this "turn" away from mainstream medical practice is usually motivated by the sheer desperation that comes either when our pains (for example, back pain) do not fall under the purview of conventional medicine or when we have a terminal illness and all conventional treatment options have been exhausted. In such moments Americans are willing to experiment with healing systems that run the gamut from those that have had some acceptance by medical science (osteopathy, chiropractic, acupuncture) to the "frankly bizarre" (reflexology, crystal healing, color healing). The implication is that when Americans turn to unconventional medicine, they

are quite consciously turning away from the cultural mainstream and turning, at least temporarily, toward the cultural fringe. And the further implication is that although a few of these alternative medical systems may be close enough to conventional medicine to have some healing value, the others work—if at all—purely by the power of suggestion.

This assessment is correct in many respects, but it misses the important fact that this turn is a turn that happens *within* mainstream, middle-class American culture rather than being a turn *away* from it. Beginning with mesmerism, hydropathy, homeopathy, and mind-cure in the nineteenth century, interest in alternative medical systems surprisingly has been centered in the educated middle class. Moreover, a principal reason that middle-class Americans have been so fascinated is that many of these healing systems offer religiously edifying interpretations of body-mind-spirit interaction. The beliefs and practices of alternative medical systems perpetuate a form of religious or metaphysical thinking that has had a wide acceptance among the educated middle class since at least the time of Emerson.¹ The turn to alternative medicines is thus in large part a turn to alternative metaphysics. If we wish to understand their healing successes or their

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continuing appeal, we must be sensitive to an enduring style of unchurched American religiosity.

The Nineteenth-Century Background

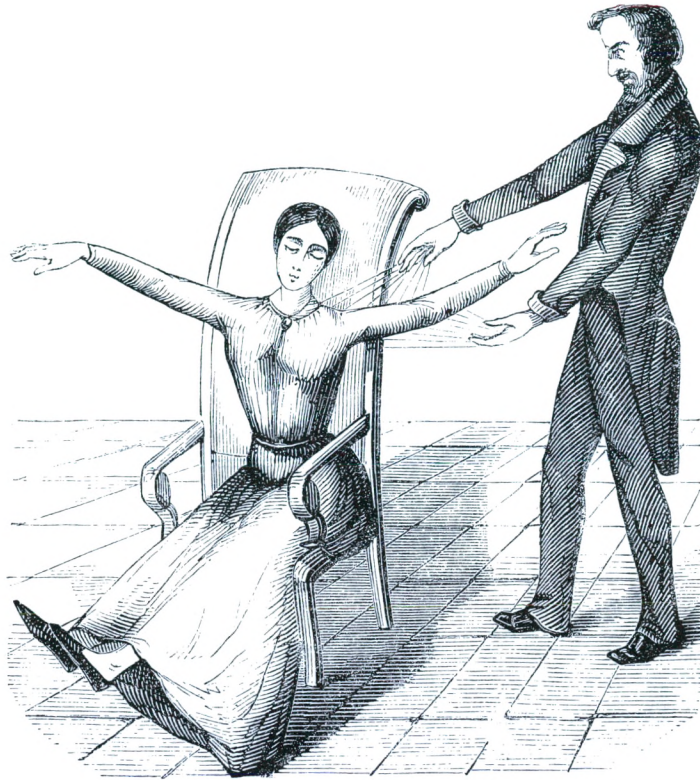
WHEN IN 1836 RALPH WALDO EMERSON proclaimed that "Nature is the symbol of spirit," he represented a nonbiblical and unchurched strand of American religious life. For Emerson, nature is itself "the organ through which the universal spirit speaks to the individual, and strives to lead back the individual to it" (Emerson 1968, 1:62). Emerson and his fellow Transcendentalists made institutionalized religion irrelevant to the individual's quest for an intimate relationship with the universe. Emerson could speak of such things as "instreaming divine spirit," and "an influx of Divine Mind into our mind" without using the biblical language of supernatural intervention. Instead he asked us to look into the ineffable depths of our own individual spirit or psyche to find an inner point of contact with the "currents of Universal Being." His suggestion that our own biological and psychological natures possess an inner correspondence to Universal Being hit such a responsive chord in popular American thought that historian Sydney Ahlstrom refers to him as the "theologian of something we may almost term 'the American religion'" (Ahlstrom 1972, 1:605). Among other things, this American religion has endured in the form of healing systems that explore the point of inner correspondence between the physical and spiritual realms.

Emerson is, of course, a recognized and esteemed highbrow intellectual. We must be prepared for the fact that a good many of the spokespersons for alternative medical traditions are more middlebrow in their educational and literary backgrounds. But their attunement to unchurched American spirituality is for this reason all the more instructive. Thus, for example, during the 1840s and 1850s a number of individuals traveled New England giving

lecture-demonstrations of what was variously called mesmerism or the science of animal magnetism. In the act of popularizing this European-born medical theory, the American mesmerists gradually modified their beliefs and practices to meet their audiences' metaphysical needs or interests. And in so doing they fashioned a system of medical beliefs that became the template from which a good many alternative healing systems were eventually fashioned.

Franz Anton Mesmer (1734–1815), a Viennese physician, claimed to have detected the existence of a superfine substance or fluid that had until then eluded scientific notice. Mesmer referred to this invisible fluid as animal magnetism and postulated that it permeated the physical universe. He explained that animal magnetism constituted the etheric medium through which forces of every kind—light, heat, magnetism, electricity—passed as they traveled from one physical object to another. Mesmer believed that animal magnetism was evenly distributed throughout the healthy human body. If for any reason an individual's supply of animal magnetism was thrown out of equilibrium, one or more bodily organs would consequently be deprived of sufficient amounts of this vital force and eventually begin to falter. "There is," Mesmer reasoned, "only one illness and one healing." Therefore, because any and all illness can ultimately be traced to a disturbance in the body's supply of animal magnetism, medical science could be reduced to a set of simple procedures aimed at supercharging a patient's nervous system with this mysterious life-giving energy.

In his earliest practice Mesmer passed a magnet over his patients' bodies as a means of inducing an inflow of animal magnetism. His followers, however, were far more enthused over the hypnotic-like trance that many "mesmerized" patients entered. Indeed, a good many patients fell into a peaceful trance and, upon awakening, pronounced cure. An American mesmerist by the name of George Bush informed his readers that "the state into which a subject is brought by the mesmerizing process is a state in which the spirit predominates for the time



Woodcut showing a mesmeric session, c. 1840.

Courtesy of the Wellcome Institute for the History of Medicine, London.

being over the body” (Bush 1847:160). The possibility of achieving such an intimate correspondence of the physical and spiritual realms struck the metaphysical imaginations of a good many progressive thinkers. Physicians, Universalist ministers, clockmakers, politicians, publishers, and wealthy dilettantes alike were fascinated by mesmerism’s potential for disclosing the metaphysical dimensions of the human condition.

Reports of mesmerism’s cures abounded. Among the conditions for which cure was claimed were rheumatism, loss of voice, stammering, nervousness, digestive disorders, epilepsy, blindness, insomnia, St. Vitus’s dance (chorea), and the abuse of coffee, tea, and alcohol. Even more interesting is the fact that the many books, journals, and pamphlets issued to the reading public dwelt com-

paratively little on the healings themselves. They instead extolled mesmerism’s potentials for expanding the scope of science to include the empirical documentation of humanity’s higher spiritual nature. More than its actual healing powers, it was mesmerism’s capacity to synthesize science and theology that attracted thousands of middle-class seekers. Mesmerism offered its adherents a new approach to understanding how the miracles of the Bible had actually been performed and promised to put them in possession of the lawful means whereby they might consciously draw upon a powerful spiritual force to use in their daily lives.

One American mesmerist, Phineas P. Quimby (1802–1866), reasoned that our thoughts function something like shunting valves that either connect us with—or close us off from—animal magnetism

(which he referred to as “vital force”). “Disease,” he insisted, “is the effect of a wrong direction given to the mind” (Quimby 1921:319). If we think spiritually, optimistically, and positively, we remain inwardly receptive to the spiritual world and thereby maintain physical vigor. If, however, we become embroiled in pessimism, materialism, or fear, we fall out of harmony with higher spiritual influences and fall victim to physical disease. Quimby taught thousands of patients that by making appropriate adjustments in their own thoughts they could establish rapport with the very spiritual power that makes for health and prosperity. One such patient, Mary Baker Eddy (1821–1910), transformed Quimby’s teachings into Christian Science. Others, including Warren Felt Evans (1817–1889), expanded Quimby’s teachings into what became known as the mind-cure or New Thought movement.

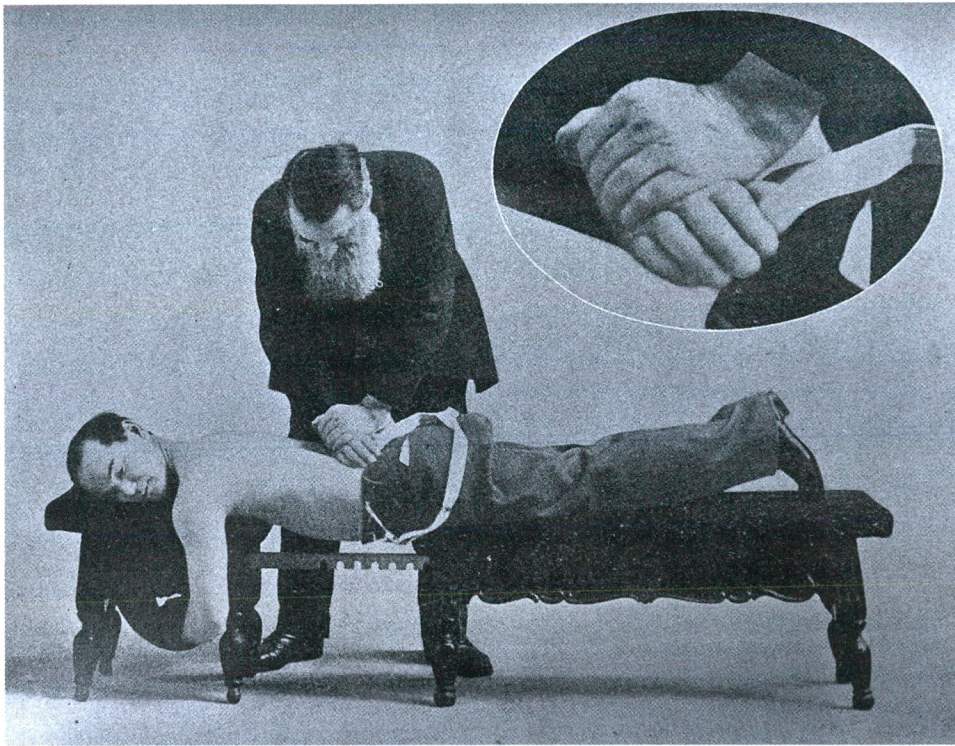
The mind-cure gospel of learning to “become one with the Infinite” gained tremendous popularity near the turn of the century. William James, who devoted a chapter to the study of mind-cure in *The Varieties of Religious Experience* and who himself benefited greatly from the writings of those propounding mind-cure, observed that their approach to mental healing “must now be reckoned with as a genuine religious power.” He believed that the entire movement with which mind-cure was associated spoke to “those for whom the conception of salvation has lost its ancient theological meaning.” He predicted that because mind-cure “gives to some of us serenity, moral poise, and happiness, and prevents certain forms of disease as well as science does, or even better in a certain class of persons,” it was destined to play a great role in the evolution of twentieth-century popular religion (James 1961:90, 100, 110).

From its initial introduction, mesmerism mingled with other currents of the American metaphysical milieu. Many were quick to note the parallels between Mesmer’s science of animal magnetism and the teachings of the Swedish mystic Emanuel Swedenborg (1688–1771). Swedenborg’s writings provided a more embellished cosmology

and ontology for explaining mesmeric healings. According to Swedenborg, the universe is composed of several interpenetrating dimensions—physical, spiritual, and angelic, among others. Each of these dimensions is in some imperceptible way connected with every other. And, under the right conditions of rapport or correspondence, energies from higher realms can flow into and produce positive effects within lower realms. Mesmerism had simply stumbled upon a technique for establishing this rapport or correspondence and made possible the “psychic influx” that can promote health and harmony in the human realm.

By the end of the century, both spiritualism and Theosophy were to integrate fully into the mesmerism-Swedenborgianism mix. As early as 1843, a mesmerist placed a young cobbler by the name of Andrew Jackson Davis into an entranced state of consciousness only to have Davis begin receiving messages from departed spirits. Thus was born American spiritualism, or trance channeling, and to this day it has connections with the vocabulary and techniques found in metaphysical healing systems. The founder of Theosophy, Madame Blavatsky, was herself a healer and trance channeler and was responsible for introducing into American popular culture a host of new terms derived haphazardly from Hinduism, Buddhism, and the Western occult tradition. References to auras and humanity’s simultaneous existence in physical, astral, and etheric bodies dovetailed nicely with Swedenborgian and mesmerist notions.

It is important to understand that from the start these metaphysical healing systems mingled together so completely that it is almost impossible to make firm distinctions between them. Their adherents approached them with common intellectual agendas and had no real interest in preserving any sharp differences in their backgrounds or theoretical orientations. Americans read unsystematically from these movements’ writings and so mingled their terminologies that these originally distinct philosophies became fused in popular understanding. Even in the 1990s, alternative medicine



D. D. Palmer demonstrating chiropractic technique.

Courtesy of David D. Palmer Health Sciences Library, Palmer College of Chiropractic.

continues to be its own subculture within middle-class America. The otherwise disparate practitioners of these systems typically know one another and feel comfortable using the terminology of other systems. They frequent the same bookstores and attend the same seminars. And most important, they all seek a metaphysic that elucidates the ways in which humanity might find a point of inner connection with a higher spiritual reality.

Chiropractic and Osteopathy: The Metaphysical Connection

BY THE TURN OF THE CENTURY the American Medical Association (AMA) had gradually risen

above the various state and local societies to become the dominant professional organization for orthodox physicians. For the first time in American history there was a medical system with sufficient lobbying power, control of access to hospitals, and monopoly over the accrediting of medical schools to claim unrivaled status as medical *orthodoxy*. Henceforth, all other contenders for a share of the nation's medical market would find their "alternative" status clearly and repeatedly defined for them by an organized medical establishment. Yet as the twentieth century dawned, the AMA was to find at its fringes two worthy opponents—chiropractic and osteopathic medicine.

Both of these "alternative" systems were rooted in the metaphysical theories popularized by mes-



From *Principles of Osteopathy*, by Dain L. Tasker, 1913.

merism and spiritualism. Chiropractic and osteopathic medicine are for this reason paradigmatic examples of the paths that metaphysical healing systems would have to take in the twentieth century if they insisted upon openly competing with the AMA for access to the nation's medical marketplace. Although remarkably similar in their founding ideologies, chiropractic and osteopathic medicine have subsequently steered quite different paths in their quests for professional recognition and broad-based public support. We might note that today there are over 40,000 chiropractic physicians in the United States, treating at least 9 million patients annually. Osteopathic physicians number more than 24,000 and treat 20 million persons per year. And thus although these medical systems were founded on healing philosophies that differ greatly from those of medical science, they have fully established themselves in the wider institutional context of American health care.

Daniel David Palmer (1845–1913) began his

career as a grocer and fish peddler in What Cheer, Iowa. Without formal education, Palmer nonetheless read widely and seemed particularly drawn to novel philosophical ideas. One of these novel ideas was spiritualism, from which he picked up a number of metaphysical terms for describing humanity's connection with spiritual forces and energies. The young Palmer also came across a mesmeric healer who tutored him in magnetic healing. Palmer procured several books on mesmeric healing that were to remain central texts in his personal library for the rest of his life. He soon opened his own magnetic healing practice in Burlington, Iowa, and later moved it to Davenport. Steeped in a wide variety of late-nineteenth-century American metaphysical philosophies, Palmer was well on his way to developing his own theory of illness when a janitor by the name of Harvey Lillard stopped by his office. Lillard, who was deaf, told Palmer that his deafness had begun when he had injured his back 17 years before. Palmer placed Lillard face down on a

couch and moved his hands up and down Lillard's spine. He felt an unusual lump at one vertebra and applied pressure with his hands. Palmer felt the vertebra move back into place, and lo and behold, Lillard could hear perfectly.

Similar healing successes followed. Palmer reasoned that the vital energy flowing from the brain to the various organs of the body is occasionally blocked by misaligned spinal vertebrae, and he concluded that this blockage was the direct cause of disease. Healing therefore required that misplaced vertebrae be manually forced back into position. He called his new medical philosophy *chiropractic* from the Greek words *cheiro* (hand) and *praktos* (done or performed). Palmer explicitly maintained that the fundamental principle of chiropractic was the insight that all physical life is an expression of a divine or metaphysical reality: "An intelligent force which I saw fit to name *Innate*, usually known as Spirit, creates and continues life when vital organs are in a condition to be acted upon by it. That intelligent life-force uses the material of the universe just in proportion as it is in condition to be utilized" (Palmer 1910:35).

Palmer's background in spiritualism and mesmerism assisted him in reasoning that Innate, as it exists within the individual human being, is in fact "a segment of that Intelligence which fills the universe." According to Palmer, "Innate is a part of the Creator. Innate spirit is a part of Universal Intelligence, individualized and personified" (1910:491). This metaphysical principle became the foundation of chiropractic healing. As the cover of the Palmer School of Chiropractic Medicine's official publication, *The Chiropractor*, put it, "We are all well when Innate Intelligence has unhindered freedom to act thru the physical brain, nerves and tissues. . . .

Diseases are caused by a LACK OF CURRENT OF INNATE MENTAL IMPULSES." The manipulative therapy that Palmer designed to free vertebral dislocations was thus his equivalent of the mesmerists' magnets and hand gestures—a physical technique intended to align the person in such a way as to make him or her more receptive to the working of a higher spiritual power.

Osteopathic medicine's origins are strikingly similar (there is indeed a strong possibility that D.

D. Palmer borrowed freely from the writings of the founder of osteopathy). Andrew Taylor Still (1828–1917) was the son of a Methodist minister who eventually set up a magnetic healing practice in Kirksville, Missouri. Conversant in both the spiritualist and mesmerist literature of the day, Still developed a technique for manipulating the spine in such a way as to bring about

remarkable healings. Osteopathy—from the Greek words *osteon* (bone) and *pathos* (suffering)—was declared by Still to be "God's law." He proclaimed that it was the only healing science that "analyzes man and finds that he partakes of Divine intelligence. . . . [since] God manifests Himself in matter, motion, and mind" (Still 1908:275). While Still did not envision an influx as most American mesmerists did, he asserted that God grants life to creation by imparting to us a nonmaterial agency, or electricity. The task of the osteopath is to remove any obstruction to this "highest known order of force (electricity)" and thereby restore people to health.

Osteopathy was swift to mute its metaphysical voice. The instructors Still hired at his American School of Osteopathy were intent on grounding osteopathy on physiology and medical science. In the eagerness of its practitioners to find a peaceful rapprochement with the AMA during the 1950s,

**Chiropractic's public
acceptance, professional
recognition, and access to
government-sponsored
programs have come in direct
proportion to its abandonment
of its metaphysical origins.**

osteopathy left behind once and for all any philosophically distinctive marks, and its identity as "alternative" quietly disappeared. The situation with chiropractic medicine is more complex.

D. D. Palmer's son, B. J. Palmer (1881–1961), was adamant that chiropractic medicine not stray from its philosophical roots. For more than 50 years he reiterated his conviction in Innate Intelligence's pivotal role in the control of physical health. Not all of chiropractic's growing legion of physicians and instructors listened, however. The movement's detractors repeatedly singled out the concept of Innate as an untestable, and hence unscientific, theory. Chiropractic physicians have consequently tended to relegate the writings of the Palmers to dusty archives and have instead concentrated on research into the physical causes of musculoskeletal dis-

tress. It is hard to escape the conclusion that chiropractic's public acceptance, professional recognition, and access to government-sponsored programs have come in direct proportion to its abandonment of its metaphysical origins.

Up to 30 percent of Americans visit a chiroprac-

tic physician during their lives. In the earlier part of the twentieth century chiropractors drew their clientele heavily from the lower economic classes. Laborers, farmers, and salespeople are more prone to

the musculoskeletal problems for which chiropractic techniques appear best suited. And, too, the comparatively lower fees charged by chiropractors make them an attractive alternative to M.D.'s. With the extension of insurance benefits to chiropractic treatment, this socioeconomic factor in determining the appeal of chiropractic treatment has become even less significant. More significant at present is the fact that patients who utilize chiropractic services believe themselves to be at the margins of the concern and interest of M.D.'s. Medical doctors are notoriously untrained for, and consequently unsympathetic to, ailments of musculoskeletal origin. They



An artist's illustration of Therapeutic Touch.

Reprinted from Janet Macrae, *The Therapeutic Touch* (New York: Alfred A. Knopf, 1987), with permission of Michael Sellon, artist.

often make light of their patients' pain and simply attempt to reassure them by telling them that "nothing is wrong" or that it is "just their nerves." Patients experiencing real pain understandably feel disenfranchised in a medical community whose underlying conceptual framework is blind to the reality of

their situation. Medical scholars Gregory Firman and Michael Goldstein observe that

the chiropractor, in such situations, fills the patient's needs by validating the patient's beliefs that some definable organic pathosis exists, by empathizing with the patient's idea of how serious, painful, or disabling the condition is, and by impressing upon the patient that the chiropractor will cure the disease by direct intervention. (1975:640)

What needs to be underscored, however, is that the aura of metaphysical discovery continues to draw at least some of the more than 9 million persons who visit chiropractic physicians each year. As Eugene Linden wrote in *Time's* feature on alternative medicine, the chiropractic physician he visited for lower-back pain considered giving him "a line of Eastern philosophy" to be just as important as making a spinal adjustment. Linden recounts that "at first I found Christoph's messianic zeal as off-putting as the detached manner of the doctor at my H.M.O. Then Christoph checked my 'energy centers.' . . . Deficiencies in my sixth (or was it fifth?) 'chakra' notwithstanding, once Christoph had finished his Procrustean pullings, crackings and pushings, the pain was gone and I felt 20 lbs. lighter" (1991:76). A sizable number of chiropractic physicians know that not all Americans are so quick to lampoon this kind of offbeat spirituality. In fact, a good many continue to specialize in it. In the 1960s a popular tract entitled *Your Health and Chiropractic* impressed upon readers and potential patients the higher power energized by chiropractic technique: "The smartest man in the world is the Man Inside. By the Man Inside I mean that Other Man within each of us that does most of the things we give ourselves credit for doing. You may refer to him as Nature or the Subconscious Self, or think of him as merely a Force of a Natural Law or, if you are religiously inclined, you may use the term God" (McClusky 1962:48). In the 1970s chiropractic physician and former dean of philosophy of Sherman College of Chiropractic G. F. Riekman summarized

the conviction of many chiropractors that they practice a "New Age philosophy, science, and art":

The chiropractic philosophy is based on the deductive principle that the Universe is perfectly organized, and that we are all extensions of this principle, designed to express life (health) and the universal laws. Since vertebral subluxations (spinal-nerve interference) are the grossest interference with the expression of life, the practice of chiropractic is designed to analyze and correct these subluxations, so that the organism will be free to evolve and express life to its fullest natural potential. (1978:174)

Contemporary Interest in Holistic Health

THE HOLISTIC HEALING MOVEMENT that gathered momentum throughout the late 1970s is rife with symbols evoking an explicitly religious interpretation of the healing process. The basic premise of holistic healing is relatively straightforward and at first glance appears to be little more than the rhetoric of a generation of Americans eager to rehumanize their technological society: "Every human being is a unique, wholistic, interdependent relationship of body, mind, emotions, and spirit" (Belknap, Blau, and Grossman 1975:18). This is, however, far from a bland truism. The introduction of the term *spirit* alongside *body*, *mind*, and *emotions* carries with it a bold metaphysical interpretation of reality. It entails committing oneself to a belief in the interpenetration of physical and nonphysical spheres of causality to a degree that makes holistic healing not only an alternative approach to medicine but an alternative worldview.

Among the best-known spokespersons for holistic healing have been Norman Cousins and Bernard Siegel. Cousins, former editor of the *Saturday Review*, confronted a serious illness for which medical physicians gave him a rather bleak prognosis. His best-selling book *Anatomy of an Illness* (1979) has become a classic indictment of the medical profes-

sion and its needlessly materialistic vision of the human person. Cousins recounts his own decision to will himself back to health through a deliberate regimen of optimistic and cheerful thinking. His lengthy remission brought a great deal of popular attention to the role of attitudinal factors in both creating and curing physical disease. Yet lurking in Cousins's description of the mind's curative powers are highly suggestive references to the little-understood "life-force" that drives the mind and body toward perfectibility. In a later text entitled *Human Options*, Cousins elaborated: "the human brain is a mirror to infinity. . . . No one knows what great leaps of achievement may be within the reach of the species once the full potentiality of the mind is developed. As we create an ever-higher sense of our cosmic consciousness, we become aware of our ever-higher possibilities and challenges" (1981:167). The well-known physician Bernard Siegel has been even more explicit about the holistic healing movement's faith in the sanative power of extraphysical and extrapsychological powers. Siegel has cancer patients read books on meditation and psychic phenomena so that they can learn practical techniques for tapping into higher healing energies. Describing the "theophysics" he believes will emerge in the scientific world in the near future, Siegel writes, "If you consider God, and you can use this label scientifically as an intelligent, loving light, then that energy is available to all of us. We are part of it, we have a collective unconscious. . . . If you get people to open to this energy, anything can be healed" (1984:92).

Another example of Americans' involvement with holistically oriented healing movements can be seen in the 5,000 nurses who have studied Dolores Krieger's technique of Therapeutic Touch. Krieger, a nursing instructor at New York University and student of theosophical teachings, developed a healing technique predicated upon the existence of a universal energy underlying all life processes. She believes that Western science does not understand energy in the same context as do the Eastern religious traditions, and she therefore identifies this

subtle energy permeating the universe with the Hindu term *prana*. Krieger states that *prana* is the metaphysical agent responsible for all life processes and is thus the ultimate power behind every form of healing regardless of the particular rationale or technique a physician might employ. Every living organism is an open system and has continuous access to *prana*. So long as an individual retains contact with this vital energy he or she remains healthy; illness ensues when some area of the body develops a deficit of *prana*. The act of healing, then, entails the "channeling of this energy flow by the healer for the well-being of the sick individual" (Krieger 1979:13).

Recapitulating Mesmer's science of animal magnetism in nearly every detail, Krieger has devised a system of practices for nurses to use in their efforts to "channel" *prana* into patients. She explains that before we can transmit *prana* to a patient, we must first become inwardly receptive to the flow of this spiritual energy into our own system. Healers must learn to purify and open up their own internal *chakras*, or spiritual energy centers, through which *prana* enters into the human nervous system. To do this we must acquire a whole new way of life that will facilitate our entry into spiritually receptive states of consciousness. Instruction in Therapeutic Touch, she says, is an "archetypal journey" that will initiate newcomers into the symbolic realms of human consciousness. It is an "experience in interiority . . . [that] presents you with a rich lode of circumstances through which you can explore and grapple with the farther reaches of the psyche" (Krieger 1979:77).

Nor are nurses involved in Therapeutic Touch alone in their archetypal journeys. Participants in perhaps the most successful example of holistic medicine—Alcoholics Anonymous—are similarly guided to acquire "an overwhelming 'God-consciousness' followed at once by a vast change in feeling and outlook" (*Alcoholics Anonymous* 1955:569). Alcoholics Anonymous has emerged as one of the most powerful mediators of wholeness in our day precisely by warning against the attempt to

rely on self-sufficiency. Its “Twelve Steps” program encourages persons to turn their individual will over to a higher power as the necessary first step not only toward physical improvement but toward a “spiritual awakening” as well. This touting of the spiritual benefits to be gained from holistic approaches to healing in Alcoholics Anonymous is subdued in comparison to the wider expanse of the movement. Numerous volumes with titles like *The Holistic Health Handbook*, *A Visual Encyclopedia of Unconventional Medicine*, and *Wholistic Dimensions in Healing* appeared in the late 1970s to acquaint readers with “a variety of representative systems for healing the whole person and awakening the spirit within” (*Holistic Health Handbook* 1978; Hill 1978; Kaslof 1978). Included in these encyclopedic volumes are descriptions of osteopathy, chiropractic, acupuncture, homeopathy, iridology, reflexology, tai chi, yoga, Ayurvedic medicine, Shiatsu, rolfing, Kirlian photography, Philippine psychic surgery, and Therapeutic Touch.² The introductory essay in *The Holistic Health Handbook* (1978:174) aptly summarized the central teaching of all these groups by instructing readers that “we are all affected by the universal Life Energy.”

New Age Crystal Healing

THE REVIVAL OF UNCHURCHED supernaturalism during the 1970s and 1980s has generally been called the New Age movement. What is common to New Agers is that they prefer to view God as a “pure white light” or “divine spirit” rather than in the traditional biblical categories of father or king (though many New Agers believe that the Bible is intended to be read metaphysically, and they retain nominal ties with Judeo-Christian institutions). New Agers believe in what might be called an *emanationist cosmology*. That is, they believe that this pure white light continuously infuses varying degrees of vitality into each plane of reality—mineral, vegetable, animal, human or mental, and astral. This divine spirit is understood to enter each

individual’s consciousness through the aura from which it is then diffused into the seven interior centers or *chakras* that supply the body with power and vitality. New Age medicine is based upon these metaphysical laws:

When white light flows harmoniously into the interior centers (the *chakras*), our condition becomes healthy and more harmonious. When there is some obstruction in the *chakra*, blocks are formed, and these blocks prevent energy from flowing freely, and the body is unable to heal itself. (Chocron 1983:4)

New Age color healing and crystal healing are examples of medical techniques that would seem appropriate to this metaphysical vision of the universe. It is thought that divine white light is refracted into its seven constituent colors as it permeates the human aura. Each *chakra* receives one of the seven color rays and in turn transmits this vital force throughout the body. Red, orange, yellow, green, blue, indigo, and violet thus correspond to the seven *chakras* located along the spinal column. Any technique that can aid us in activating the proper flow of divine light through our various *chakras* can thereby be of medical value. Placing colored gems over appropriate *chakras*, deep massage, and meditation are all thought to promote such healing activity.

The most touted of New Age healing devices, however, has been the use of crystals. Enthusiasts claim that because rock crystal is almost entirely devoid of color, it is an almost perfect capacitor of divine white light. Explanations of exactly how crystals wield their healing powers vary from practitioner to practitioner. Some maintain that the unique properties of crystals make them excellent receivers or receptors of metaphysical energies. Others suggest that crystals work by amplifying the person’s own energies. This confusion about whether crystals harness the power of personal or extrapersonal energies is possibly due only to semantic difficulties in the New Age lexicon. The vocabulary employed by New Age healers—largely of



An Indianapolis crystal practitioner demonstrating the Vogel-cut crystal techniques.

Courtesy of Cynthia Rumbaugh, photographer, and Linda Laing.

theosophical and mesmerist parentage—describes humans as existing simultaneously in the physical, etheric, and astral planes. Crystals apparently have the ability to harmonize the physical body with the etheric fields from which healing energies ultimately emanate. Crystal healer Korra Deaver explains:

Crystals act as transformers and harmonizers of energy. Illness in the physical body is a reflec-

tion of disruption or disharmony of energies in the etheric bodies, and healing takes place when harmony is restored to the subtler bodies. The crystal acts as a focus of healing energy and healing intent, and thereby produces the appropriate energy. (1985:40)

The training to become a crystal healer is undertaken with all the reverence and mystery of a shamanic ritual. Meticulous attention is given to the

selection of the particular crystal that will most enhance one's own personal "vibrations." After an appropriate stone has been selected, healers must learn to center themselves inwardly and to purify their psyches of nonspiritual desires and emotions. Breathing exercises, relaxation techniques, meditation, and the repetition of spiritual affirmations are all recommended as techniques for properly centering oneself. Many hold and meditate upon their crystals in a manner similar to the ancient art of using crystal balls for divination. "Crystal gazing," as Deaver describes it, is "the science of inhibiting normal outward consciousness by intense concentration on a polished sphere. When the five senses are thus drastically subdued, the psychic receptors can function without interference" (1985:16). To aid in this process of inner transformation, crystal healers often repeat such affirmations as "I am the Light of God," "I am filled with the Light of the Christ," and "I am a radiant Being of Light temporarily using a physical body."

As crystal healer Katrina Raphael writes, "Crystal healings are designed to allow the recipient to consciously access depths of being previously unavailable, and draw upon personal resources to answer all questions and heal any wound. . . . The person who is receiving the crystal healing has the unique opportunity to contact the very essence of being" (1987:20–21). Crystal healers caution us to put our ordinary ego aside in order to become a purer channel of divine energy. We must open ourselves fully and suspend our human will so that we can follow the Higher Guidance that flows directly from the Supreme Soul. Crystal healing, then, is a spiritual path and spiritual discipline in its own right. Hence Korra Deaver downplays the narrow focus upon physical healings and counsels that "even if the breakthrough is only in your own understanding of yourself-as-a-soul, as a Cosmic Being, your efforts will not have been in vain" (1985:7).

Healing as a Rite of Initiation

IT WOULD BE FOOLISH TO SUGGEST THAT Americans' only interest in alternative medical systems is religious. Most of those who "turn" to chiropractic physicians seek relief of persistent pain, not unsolicited doses of metaphysical abstractions. Acupuncture, too, has moved closer to medical orthodoxy in this country by demonstrating its effectiveness in blocking pain. Now licensed in 21 states and covered by many insurance companies, acupuncture has earned at least a marginal status in the American medical delivery system. Much of this legitimation is due, however, to a tendency among practitioners to downplay the theoretical system underlying acupuncture (which postulates the existence of a vital energy system, *qi* or *ch'i*, that flows throughout the body along ultrafine meridians and is itself rooted in the ontological ground of all being, the Great Ultimate). Acupuncturists have instead largely been content to stress its physiological results. Many herbal and dietary regimens likewise make little recourse to an explicit metaphysic but rather herald the natural wisdom of a drug-free, noninvasive approach to health.

It would be equally foolish, however, to ignore the fact that tens of thousands of middle-class Americans have turned to alternative healing systems less out of medical desperation than out of spiritual hunger. I would even suggest that most of these groups (the majority of chiropractic physicians excluded) attract popular followings not so much for their ability to heal as for their ability to communicate a sense of participating in some ultimate reality. Their therapeutic doctrines (belief or myth) and practices (ritual) are proving extraordinarily effective at enabling individuals to achieve what William James called a "firsthand" religious faith. That is, they make belief in the presence and power of supranatural forces a vivid reality for individuals to whom religion had formerly consisted of nothing more than dull habits and lifeless doctrines handed to them by others.

The affinity of these groups with enduring strains in Americans' unchurched spirituality helps account for the fact that the literature produced by metaphysical healing groups is more widespread and more avidly consumed than their actual healing practices. The ideas they promulgate are apparently perceived to be equally as wholeness-producing as their physical techniques. As the introductory section of *The Holistic Health Handbook* suggests, "Perhaps more important than the techniques is the expansion of consciousness they foster" (1978:13). We are told that the principles of the various holistic health systems covered in the book (acupressure, Shiatsu, reflexology, chiropractic, meditation) open up a "relationship to inner worlds" and thereby "awaken the spirit within." Dolores Krieger promises students of Therapeutic Touch that they will commence an archetypal journey. Her students—individuals trained in nursing science—soon become avid readers of books on yoga meditation, Tibetan mysticism, and the relationship between the "new physics" and Eastern religious traditions.

Initiation into alternative healing systems tends to transform a person's sense of identity and awareness of the wider environments they believe themselves to be inhabiting. For example, an early student of chiropractic was moved by her direct communion with Innate to alter her previous belief that she *has* a soul to a more existentially vivid belief that she *is* a soul: it is "not that I have an Innate Intelligence, but that I am Innate Intelligence in this physical shell" (Lubove 1909:74). Shirley MacLaine is another example of such religious transformation. Television hosts Johnny Carson and Jay Leno have had a field day with such revelations as that she bathes daily with four crystals at the corners of her bathtub. Nonetheless, her use of crystals and

related meditational practices led her to the conviction that "a healthy state of spirit controlled my mind and body. I realized I was essentially a spiritual being, not a mind-body being" (MacLaine 1985:110). And in such convictions rest the vitality of religion in human life.

Perhaps the clearest illustration of alternative medicine's capacity to turn persons toward alternative metaphysics can be found in the case of professional nurses introduced to Therapeutic Touch. No

longer agents of a pharmaceutical technology, these nurses come to understand themselves instead as "channels." One of Krieger's students describes her new healer's role as "a channel, definitely, for the universal power of wholeness. I am certain it is not 'I' who does it." Another now sees herself "as a vehicle through which energy can go to the patient

in whatever way he or she can use it" (Krieger 1979:108). As yet another student expressed it, "using Therapeutic Touch has changed and continues to change me. . . . [It] requires a certain philosophy, and this philosophy permeates one's total existence" (Quinn 1981:62). The benefits these persons attribute to their newly acquired philosophy read like a page from Abraham Maslow's studies of peak experiences: increased independence from the approval of others; increased self-reliance; the ability to view things in their totality; a more caring attitude toward others; the sense of being an integral part of the universe; and the abandonment of the "scientific method" as the sole approach to the nature of reality.

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The Role of Suggestion

THE QUESTION REMAINS WHETHER ANY OF THESE metaphysically charged medical systems can actually heal. Most interpretations of these groups dismiss their alleged successes either as being utterly coincidental or as being caused by some other factor like suggestion. For example, almost all illnesses go through a series of ups and downs before the body's natural recuperative powers restore health. Assuming that the alternative healer's methods do no serious harm, this natural variability in the disease would alone prompt patients to credit improvement to the healer's "powers." If the patient begins to improve, this will be attributed to the alternative healing method (as it would have been attributed to an "orthodox" physician's treatment). If the condition merely stabilizes, this too proves the effectiveness of the treatment in arresting the ailment. Even if the patient's illness gets worse, he or she will be told that this is because the treatments started too late or that they need to be stepped up—further contributing to the plausibility of the treatment method. Thus the variability of disease is itself a sufficient factor to enable "healings" by coincidence.

It is also common to assume that the power of suggestion (for example, aroused hope, confidence in the healer, increased adrenaline flow) accounts for nonmedical healings. The implication here is that alternative healing systems inadvertently function as psychotherapies. Alternative healers are able to name a patient's illness in a way that evokes patients' confidence in the healer's understanding of the nature and meaning of their illness. The healer's seeming expertise concerning the origins of the illness helps elicit the patient's hope of recovery. As psychiatrist Jerome Frank explains in his *Persuasion and Healing*, "The ideology and ritual supply the patient with a conceptual framework for organizing his chaotic, mysterious and vague distress and give him a plan of action, helping him to regain a sense of direction and mastery and to resolve his inner conflicts. . . . Methods of religious healing also have

aspects that heighten the patient's sense of self-worth" (1963:63).

Meredith McGuire is one of the few scholars to have applied this kind of social-scientific analysis to American metaphysical healing groups. McGuire rightly focuses upon what she calls the sense of "personal empowerment" that adherents of these movements claim to have received through their treatments. She concludes that these healing systems employ a "ritual language" that represents and objectifies a higher power believed to be capable of augmenting the individual's internal resources. The ritual language that nonmedical healers use to describe their practices is therapeutic in and of itself. It transforms "hope in hope itself" to hope in the efficacy of a strong transcendent power. McGuire reasons:

Increasing evidence in Western medical terms suggests that illnesses previously thought to be biogenic are related to social and psychological states such as stress, conflict, sense of "threat," rapid social change, and sense of powerlessness. . . . If this is the case, it is plausible that non-"scientific" healing methods, such as we are studying, may be able to address problems as well as, if not better than, the dominant scientific medical system. *Believing oneself to be in touch with a greater power* may very well *literally empower* the individual believer to be more effective in daily life or at least to cope more adequately. (1983:327)

McGuire strikes me as being on the right track. What still needs to be explained, however, is how alternative healers "literally empower" their patients. As it stands, McGuire's reasoning is still dismissive. She alludes to a distinction between simple belief *in* a greater power and belief that one has *experienced* this power. But because she doesn't follow up on this distinction, she seems to imply that these groups are therapeutic not because of anything unique to their methods but rather because of the power of suggestion or sheer credulity. In other words, the view is still that insofar as a given illness is psychosomatic in origin—and studies reveal that

up to 80 percent of all illnesses are—metaphysical healers stand as good a chance of helping their patients as M.D.'s.

Religion and Healing: The Experience of a Higher Power

I THINK THAT MORE IS GOING ON HERE. I believe, in fact, that alternative healers frequently provide their patients with experiences that have a demonstrable effect upon psychological and physical well-being. The felt experience of encountering a sacred reality can be shown to have a wholeness-generating quality that can “literally empower” persons to health. In other words, I contend that the explicitly religious aspects of alternative healing groups have a therapeutic value distinct from the factors (like coincidence and suggestion) that one would find in healing methods lacking these metaphysical elements.

My argument concerning a uniquely and distinctively religious factor responsible for the healing of many persons has three steps: (1) we must review contemporary literature on psychosomatic illness to identify certain psychological conditions that affect physical health; (2) we will then examine psychological theories that show how the experience of relationship with a higher power is able to influence the psychological conditions underlying health; and (3) we can then demonstrate how alternative healing groups make this relationship with a higher power available to modern Americans in a way that effectively “heals” the psychological conditions that otherwise make us prone to illness. My concern with demonstrating the therapeutic efficacy of certain types of religious experience should not be misinterpreted as an attempt to establish whether or not these beliefs are true. I am, however, trying to lend credence to the notion that these metaphysical healing groups do in fact mobilize therapeutic resources that are unlikely to be tapped in any other way.

We know with some certainty that stress is a

factor in the onset of disease. Stress has been implicated in the etiology of gastrointestinal disorders, respiratory disease, cardiovascular disease, hypertension, duodenal ulcer, and even cancer. We know, furthermore, that a variety of psychological conditions connected with stress are particularly associated with the psychosomatic interaction leading to disease. Among those most relevant to us are the experience of meaninglessness, major sociocultural change, poorly channeled aggression, loss of hope, and the emotional poverty that comes from the lack of reciprocity or depth in interpersonal relationships. To be sure, we do not fully understand all that is entailed with the concept of stress; nor do we understand the neurophysiological mechanisms that translate social and psychological factors into physical disorders. It is not always clear, for example, why a particular event is “stressful” for one person but not another. It is thus important that when discussing psychosomatic illness we look not at outer events themselves so much as at the personality factors that affect how individuals respond to such events. We must therefore pay attention to the psychological processes that cause individuals to lose vigorous relationships with their environment and instead fall prey to the meaninglessness, emotional impoverishment, aggression, and overall sense of futility that medical literature recognizes as being associated with the origins of psychosomatic illness.

I wish to show that alternative healing groups are particularly effective at healing (or preventing) the kinds of psychological processes that make us vulnerable to psychosomatic illness. To explain this I use a form of psychoanalytic thought known as object relations theory and its cousin movement, self psychology. According to both theories, psychological well-being requires that we have a coherent sense of self; a sense of self, moreover, that feels prized, valued, and intrinsically worthy of love. The work of theorists such as Melanie Klein, Henry Guntrip, Otto Kernberg, D. W. Winnicott, and Heinz Kohut examines the growth of such a healthy self in the medium of personal relationships. They point out that optimal psychological development requires a

responsive social environment in which individuals have continuous access to a nurturing parent who mirrors back to them a felt sense of personal worth. As Guntrip puts it, "For good or ill, the universe has begotten us with an absolute need to be able to relate in fully personal terms to an environment that we feel beneficially relates to us" (1969:327). The newborn finds such an environment supplied by the nurturing parent. In the world of the infant there is no clear-cut demarcation between the I and the you. The self is merged with the "higher" being of the parent and finds its worth mirrored in his or her affirming presence. This mirrored sense of worth gives rise to a healthy narcissism—the ability to maintain a sense of being a prized, cohesive self. As the child grows up, she can establish intimate personal relationships and feel a sense of connectedness to valued cultural ideals, thus sustaining this feeling of being related to a "higher," intrinsically meaningful reality.

It is inevitable that the child's need for recognition and admiration will eventually be disappointed by the valued and esteemed parent upon whom she has placed unrealistic demands. The blow to self-esteem produced by the unmet need for recognition and admiration creates frustration and internalized rage and aggression. This blow also distorts the individual's narcissistic structures. In stark contrast to popular misconceptions of narcissism as a condition marked by excessive self-love, it is now understood to be the psychological consequence of an individual's inability to form relationships that will provide recognition and a sense of self-worth. (In other words, narcissism is characterized by too little, not too much, self-esteem.)

Insofar as an alternative healing group can meet a person's need for empathic interpersonal relationships or for a sense of relationship to a "higher being," it would be able to remove destructive emotions and effect a healing process.

The damage to our natural and "healthy" narcissistic tendencies causes us to form psychological barriers to protect ourselves from further emotional hurt. The individual becomes increasingly incapable of genuine reciprocity, intimacy, or openness in his relationships with others. Such pathological narcissism is thus characterized by a shallow emotional life and almost total lack of empathy. The person becomes closed off from the give-and-take of relationships and consequently becomes unable to recognize the needs of others, identify with any consistent set of moral values, or have a realistic sense of his own finitude. Importantly, the precarious self-image associated with unhealthy narcissism creates continuous frustration, rage, and aggression that is ordinarily internalized and directed against the self.

These are, as we have seen, precisely the psychological conditions related to the etiology of psychosomatic illness.

As psychoanalyst Heinz Kohut (1978) and cultural theorist Christopher Lasch (1970) have pointed out, a fairly large percentage of those living in modern Western societies suffer from some degree of narcissistic disorder. It is important to remember that "unhealthy" narcissism is a reflection of the precariousness of sustaining wholesome self-esteem and is thus to some extent characteristic of the human condition. Kohut has repeatedly emphasized that the narcissistic need to see ourselves mirrored and esteemed by the nurturing parent is potentially the core of a strong, cohesive self. Because the narcissistic structures are what make it possible to view the world in relation to ourselves, they contain the seeds of the highest developmental achievements of adult life. Creativity, humor, empathy, genuine

love, and wisdom all require a sense of continuity with the world. If our narcissistic needs are adequately met and channeled, they provide the foundation for a mature engagement with life based upon what Kohut describes as a felt “sense of supra-individual participation in the world.”

We are finally in a position to understand how so many alternative healing groups can *empower* their adherents. It would seem that the success and continued popularity of these alternative healing systems come from their ability to engage and transform the self's narcissistic needs. Let us consider three ways in which they bring the resources of religion to bear upon their patients' health: First, by helping to heal the psychological conditions that cause many psychosomatic ailments and thereby foster recovery; second, by alleviating the blow to self-esteem that accompanies nearly all forms of illness regardless of cause; and third, by addressing the need for wholesome self-esteem even in those who are not ill at all.

First, it is reasonable to infer that the rage, frustration, and internally directed aggression created by our unmet narcissistic needs are prime causal factors in the etiology of psychosomatic illness. It follows that insofar as an alternative healing group can meet a person's need for empathic interpersonal relationships or for a sense of relationship to a “higher being,” it would be able to remove these destructive emotions and effect a healing process. I need not dwell on the sensitivity and empathy that alternative healers typically have for their patients. But I should underscore that the literature—written both by healers and by their patients—fully supports the hypothesis that alternative healing systems permit the warm interpersonal environment in which individuals can let down their self-imposed defense mechanisms and come to feel themselves as

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prized and cared for. Perhaps more important, the beliefs and practices in these alternative healing systems are designed to foster experiential awareness of our intimate relationship with a higher spiritual power. The language of *prana*, animal magnetism, Innate, and the like make God immanent enough to permit relatedness or merger yet still sufficiently metaphysical to constitute the idealized object capable of bestowing meaning and value upon the self. These healing systems provide ritualized experiences whereby people temporarily separate themselves from mundane sensations and gain access to a metaphysical reality. Their adherents find themselves enveloped by a spiritual power to which they inherently have permanent access. This helps them not only to ground their self-esteem in a sacred reality but also to feel themselves safely and positively connected to the world around them. For

some individuals, initiation into these metaphysical healing systems makes God accessible in ways that institutional religion never could and in this way releases inherent tendencies toward healthy and creative living.

Second, the onset of illness itself provokes narcissistic rage that subsequently serves as an impediment to recovery. Illness presents people with a severe challenge to their ability to affirm their own significance within the cosmos. Patients often consult a doctor for more than the remission of their symptoms; they often also seek relief from the fears that have been aroused by their illness, and they seek ways of interpreting the reasons for their having fallen out of favor with the cosmos. By giving patients confidence that they have inwardly reconciled themselves to the ultimate powers upon which life depends, alternative healing groups make possible the restoration of a coherent sense of self. An excellent example of alternative medicine's ability

to regenerate patients' self-esteem was the actress Jill Ireland's much-publicized struggle with breast cancer. Ireland was severely traumatized when she first learned of her condition: she found her life increasingly chaotic, senseless, and terrifying. She was introduced to a holistic health practitioner who taught her to meditate, and she also learned to make use of what she described as the "healing properties of quartz crystals for focusing and energizing my mind and body." Her discovery of previously unknown potentials for connecting herself with a wider spiritual reality enabled her to regenerate herself psychologically and to overcome the damaged self-image, the sense of meaninglessness and vulnerability, and the internalized aggression born of her illness. Speaking of the "gifts" she had received from her temporary victory over cancer, Ireland (1987) mentioned having more confidence and being "more at ease" with herself. The experience, she said, "brought meditation to my life" and "has enriched my relationships with my children and the people close to me."

Third, the unique capacity of these movements to bring the resources of religion to meet our narcissistic needs makes them highly attractive and, indeed, empowering, even for those who are not physically ill at all. Peter Homans, a psychologist of religion, has drawn attention to the fact that the Protestant denominations that have so influenced American religious life have prospered in Western culture precisely because of their ability to meet this fundamental prerequisite of physical and psychological vitality. His comments bear directly upon the reasons that alternative healing groups function as a kind of cultural successor to classical Protestantism for many middle-class Americans.

[Classical Protestantism] created a unique and highly effective solution to the universal psychological needs for idealization and merger. Protestantism synthesized these needs with viable and appropriate cultural objects through its doctrine of the transcendent existence of God, which met the need of the self for idealization, and through the evangelical

doctrine of the believer's oneness with Christ—I am in Christ and Christ in me—which nurtured the believer's associated need for merger with a supreme cultural object. In this way Protestant Christianity articulated with the narcissistic needs of its followers. (1979:194)

As Homans observes, the capacity to merge psychologically with "a supreme cultural object" is necessary if adults are to meet universal psychological needs. Yet many persons in modern Western culture find it increasingly difficult to "idealize" the God of institutional religion sufficiently to make this a viable option. This is especially true of the educated reading public whose exposure to secularizing influences makes them somewhat immune to the wholeness-generating powers of traditional religious symbols. And herein, I believe, lies the therapeutic value of alternative medicine for so many modern Americans. They have made conceptions and even experiences of God accessible to those who, for whatever reason, were not being reached by institutional religion. We should note the suggestion of another psychologist of religion, Donald Capps, about the forms of religion that may be expected to foster well-being in our age: "If religion exerts less influence on the social order but retains its influence on personal life, as various secularization theories suggest, this 'privatization' of religion provides a favorable context for an increasingly close association of religion and narcissism. . . . A transformed narcissism may provide the foundation not only for psychological well-being but also for such spiritual well-being as can realistically be expected in a secular world" (1985:242).

If my interpretation is correct, the turn to alternative medicine is not prompted exclusively by medical desperation. Nor is it either a turn toward sheer superstition or a turn away from the traditional values of the American middle class. It is, however, a turn away from the metaphysics of either scientific medicine or church religion. But historical perspective shows this to be a turn toward a metaphysical tradition long-standing in Americans'

unchurched spirituality. And insofar as it is attentive to humanity's psychological needs, it may well be, as Capps suggests, a turn both to psychological

well-being and to as vital a form of spirituality as can be realistically expected in our secular age. ☉

NOTES

1. I do not mean to imply that all alternative medical systems exhibit the metaphysical belief structure that I deal with in this article. Nutritional and exercise therapies, for example, seek to strengthen and regulate basic metabolic processes through diet and sundry fitness regimens. Likewise, many massage and breathing systems make no claims concerning the presence or activity of extrasomatic energies. It should be noted, however, that unorthodox systems of the nonmetaphysical kind tend to emphasize preventive rather than curative practices. And even when some adherents emphasize an alternative medical system's known physiological properties, Eastern notions of subtle body energies such as *ch'i* or *prana* have a way of adjoining themselves to these explanations and thereby invoke reference to ultimate metaphysical realities such as Brahman, the Tao, the Cosmic Body of the Buddha, and so on.
2. Several of the medical systems listed here are not covered in this article. Reflexology postulates that the energy pathways for the body all converge in the foot and, consequently, massaging the foot can promote healing virtually anywhere in the body. Iridology is a diagnostic procedure based on the assumption that different parts of the iris reflect changes in corresponding areas of the body. Ayurvedic medicine is based on ancient Hindu texts describing health as a function of the three humors (fire, mucus, and wind). Shiatsu is a form of Japanese finger-pressure massage that stimulates and soothes key points along acupuncture meridians. Rolfing is a form of deep massage used to bring the body into vertical alignment. Kirlian photography is a diagnostic technique using a special form of photography that can ostensibly record and detect weaknesses in the human aura. Psychic surgery, such as the form that was practiced in the Philippines and received a great deal of attention during the 1970s, utilizes the healer's psychic powers for treating the patient's nonphysical energy systems.

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The Drunkards. Oil on canvas by James Ensor, 1883.

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Grass-Roots Reflections on Substance Abuse

A Community Dialogue Approach

Stephen G. Post

I know no safe depository of the ultimate powers of society but the people themselves; and if we think them not enlightened enough to exercise their control with a wholesome discretion, the remedy is not to take it from them, but to inform their discretion by education.

—Thomas Jefferson

THERE HAS BEEN CONSIDERABLE DISCUSSION over the last several years about moving health care ethics in the direction of community dialogues or, as some prefer, “town meetings.” In Oregon, Vermont, Colorado, and a dozen or more other states, such dialogues have focused on questions of health care access and rationing. In a budding national organization, American Health Decisions, a coalition of citizen groups is identifying community priorities to make the delivery of health care more humane, appropriate, affordable, and universal.

Bioethicist Daniel Callahan, in recommending that Americans think about health care access and rights in terms of the common good rather than limitless individual desires, suggests that legislative decisions about priorities should be “preceded and accompanied by public forums, hearings, and educa-

tion programs” (1990:207). He cites the “system of grass-roots discussion and debate for the general public pioneered in the Oregon Health Decisions program” as a useful example of what should occur more widely (1990:207). In this article I describe the process of one regional community dialogue, the Greater Cleveland Community Dialogue on Values and Health Care, for which I serve as associate director. I then present the value affirmations that emerged from the Dialogue-sponsored town meetings on the specific topic of substance abuse.

Dialogue Structure, Participation, and Process

THE GREATER CLEVELAND DIALOGUE is an independent entity facilitated and staffed by the Center for Biomedical Ethics of the School of Medicine, Case Western Reserve University.¹ The Dialogue is committed to the idea that too much of health care

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ethics has been spun deductively by professional thinkers, many of whom have not listened carefully to the voices of the people. The Dialogue therefore refrains from basing its work on formal empirical studies of public opinion. Instead it uses an inductive, nontheoretical approach to health care ethics, one that takes into account the narratives of sufferers.

The Dialogue, a core group of 30 community leaders from various advocacy groups and professions, selects the broad topics for these narratives. Then, for each topic, it schedules a series of three-hour town meetings, extending over a period of six months. As topics shift every six months, new members with relevant expertise are asked to join the core group.

Members of the core group attend the town meetings, held in the neighborhoods of Greater Cleveland at churches or synagogues, neighborhood centers, nursing homes, drug treatment centers, and elsewhere. At these meetings, which are widely advertised by the local media, the people of Cleveland present powerful testimony regarding their personal experiences with the pitfalls of our health care system. Some speakers are prescheduled, but many are not. A panel from the core group may ask questions of each speaker.

Of course, town meetings have their problems. For instance, as in the Quaker meeting, one never knows if an individual will be moved to speak endlessly. Each testimony is therefore limited to five minutes, though in reality the stories are so gripping that they often go on for twice the allotted time.

The chief job of the core group is to deliberate bimonthly on the materials gathered from public testimony. In addition, the core group meets with local, state, and national policymakers from Greater Cleveland to gain practical knowledge of current policy initiatives that raise basic value questions. The core group benefits from its internal dialogue as well as from its dialogue with policymakers and with the public.

At the end of each six-month period, the Dialogue submits a report on the basic values that should guide regional policymakers. The official

report on each Dialogue topic is mailed to over 5,000 community leaders in Cleveland, in the state capital, and across the nation. The reports are used in public and private schools as educational tools.

As associate director of the Dialogue, I acknowledge the debate about the extent to which such dialogues can achieve consensus (see Fox and Leichter 1991). However, I believe that the values identified thus far in the Cleveland Dialogue present a reasoned consensus. In our highly pluralistic culture, when consensus is not possible on a given point, disparities of opinion must be acknowledged. But a remarkable degree of consensus is possible when the people of a community are listened to and when subsequent deliberations about values and public policy are a response to what has been said. In Cleveland this consensus could occur despite the fact that the Dialogue's core group members shared no single ethical theory or theological principle.

From January to June of 1991, the Dialogue's core group selected substance abuse as the topic for a series of community meetings in Greater Cleveland. Other community dialogues, which commenced in February 1990, covered the topics of the medically underserved, long-term care, mental health, and rationing. For the substance abuse topic, the core group included a leader from the Islamic community; a judge from the county juvenile court; the vice president of Blue Cross and Blue Shield of Ohio; executive directors of the Federation of Catholic Community Services, the Commission on Health Concerns for the Greater Cleveland Federation for Community Planning, the Center for Substance Abuse at Case Western Reserve University, Alcoholism Services of Cleveland, the Children's Defense Fund Greater Cleveland Project, the Interchurch Council of Greater Cleveland, the Cleveland Neighborhood Centers Association, and the Women's Alliance for Recovery Services; as well as regional coordinators from the American Association of Retired Persons, the Association for Retarded Citizens, and many other groups. Ethicists, theologians, lawyers, political philosophers, Cleveland's leading talk-show host, nurses,

physicians, and social workers also served on the Dialogue core group.

The body of this article deals with the seven key values that surfaced in public testimony during the town meetings on substance abuse. They were not framed in advance by the Dialogue staff or the core group.

Testimonies and Affirmations

THE TESTIMONIES ESTABLISH SEVEN KEY VALUES in response to substance abuse: (1) *freedom from intoxication*, whether through legal or illegal substances, because intoxication harms individuals, families, and society; (2) *consistency* in all areas of society in discouraging intoxication; (3) *social justice*, because hopeless environments encourage the escape into substance abuse; (4) *responsibility*, both personal and community, for deterring substance abuse; (5) *fair access to treatment*; (6) *equality for women* in treatment; and (7) *prevention*.

As an introduction to the discussion of each of these values, I have included some testimony from the town meetings. While the words that follow the testimonies are my own, they are reflective of the core group deliberations. The core group will publish its final report by mid-1992.

1. Freedom from Intoxication

Testimony

"My drug of choice was cocaine, which caused me to lose a lot in my life. You know, it's easy for me to dwell on the material things I lost, but today I see the material things were not that important. It's that I lost myself, and that's when I became willing to change. I lost a job I had worked at for 17 years, I lost a home I bought, a wife and son now living in another state. Like I say, all that doesn't matter because today I have myself back. It's not the outside things, it's the inside

things. All my life I dwelled on what was on the outside. Today it comes from the inside. I don't need the material things that I thought were so important, that I thought made me myself. Today I find out that just being joyous and happy is what's most important to me." (*former cocaine addict*)



"I had absolutely no idea how to live sober on the streets. How would I live out there? Just as a small example, when I was living in a halfway house, we had times to do our laundry, and if I went downstairs and someone's laundry was already in the washer, I would just be frantic over this because I literally had drank my way through everything—getting dressed, driving, doing my laundry. Every functionable thing I was doing at the end of my addiction, I was doing with alcohol and drugs available at all times.

"I changed my whole life-style, and I have changed my way of thinking about everything on a daily basis. I choose not to pick up the drink or the drug today. And it isn't that I haven't had the opportunity, and it isn't that there isn't a bar on every corner and I couldn't just walk in. But I tend not to put myself in situations where I think I might lose my sobriety. My sobriety is the most important thing in my life today. I stay real active doing things that encourage sobriety." (*a recovering alcoholic and addict*)



"One of the first things that I can recall in my life is being taken out of bed in the middle of night by my mother, with blood on her face, and taken with my two brothers across town to my grandmother's house, and while there, having my alcoholic uncle saying he was going to kill the SOB, who was pounding on the door because he wanted to take us home. . . . My mother, on the other hand, was a very loving, very religious person, and she kept us all together, my brothers and myself. . . . However, she was a martyr, and I don't think she knew it, but I think she really enjoyed her martyrdom. She didn't understand what was happening in her life any more than we children understood what was happening to us. This was the type of atmosphere I lived in, so the two main emotions I had growing up were fear—that was probably the most dominant—and the love I got from

my mother. My religious faith came from my mother.”
(*son of an alcoholic father*)



“In my years directing the free clinic; I am amazed by the horrid problems. You know, road maps of surgical scars because of the life-style of drugs and alcohol. Gunshot wounds, knife wounds, accidents, and even a 24-year-old with evidence of an old heart attack on her EKG because of cocaine use.” (*physician who has provided substance abuse care at the Free Clinic in Cleveland*)

Discussion

INTOXICATION IS FOR MANY A RITE OF PASSAGE into adulthood and maturity. In the late 1960s, drug and alcohol abuse increased among young people to an unprecedented level. By the 1970s news stories described children age “ten or eleven using marijuana, drinking heavily, and even moving on to cocaine. Children whose bodies and minds had not even moved into puberty were already poisoning their bodies” (Engel 1989:x). Substance abuse has declined somewhat among young people since the mid-1980s, but this trend has been less noticeable among disadvantaged youth. In 1986, high school students in the United States continued to use illicit drugs and abuse alcohol to an extent far greater than in any other industrialized nation in the world (Halloran 1986).

One hundred and fifty Ohio adolescents gathered in 1990 with the governor of the state in a summit meeting, “Youth Expressing Solutions for a Better World.” A report on substance abuse published after the summit included this passage: “Some of the young people concluded after attending the event that ‘straight people are not boring’” (Governor’s Office 1990:10). The adolescents’ assumption that sobriety is boring reveals how deeply ingrained the appeal of intoxication is. We manipulate our minds and behavior to “get high.” The human mind, capable of endless creativity in countless fields, should be held inviolable and precious,

but we do not hold it so. In our families and schools, we must provide opportunities for young people to discover the power of their well-functioning minds and the value of this functioning as a form of freedom.

Timothy M. Rivinus, a leading psychiatrist dealing with alcoholism and substance abuse among college students, emphasizes that these self-abuses cannot be deterred until they become socially unacceptable (1988). We are all responsible for defeating the assumption that alcohol and drug intoxication are “all right.” They are *not* all right. Addiction can spawn death of self and innocent others, insanity, family abuse and neglect, fetal alcohol syndrome, huge medical costs, lost talents and productivity, and countless other serious harms. Thus it is troubling that sobriety is a value sometimes so casually rejected. Trendsetters, who often define what is chic, have sometimes contributed to this rejection.

Those in our society who have special opportunities to inculcate the value of freedom from intoxication have an obligation to do so, and many today are doing so. For example, there are those who propose, on the basis of both spiritual and ethical values, abstinence from alcohol and drugs. The Nation of Islam is one such group, and one of its Cleveland leaders, Omar Ali-Bey, has been an important voice in the substance abuse dialogue. In addition, leaders from the Jewish and Christian communities serving with the core group have asked that the Dialogue call on all community religious bodies to denounce intoxication and to emulate the temperance movements of the last century.

2. Consistency

Testimony

“I’m a firm believer that there is an overall conspiracy to keep drugs in the black community. I think that it serves two purposes. It serves to keep black people in check, and it serves to continue to finance America.

“I can remember when Bush had said in a state of

emergency address, or the state of the union, that he could identify two spots along the border where over 90 percent of all the cocaine was coming into the country, and then he cut the border patrol by 36 percent. If we can do things like stop tiny microchips from coming into this country under the auspices of national security acts, then I'm sure that we can stop these large quantities, shiploads, airplanes of dope from coming into this country." (*unidentified speaker*)

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"DARE is an acronym for Drug Abuse Resistance Education. It's taught mainly in the elementary schools, but it is also taught in the junior highs and high schools. In Cleveland, this is our second year. . . . We talk about four types of peer pressure and eight ways to say no to drugs. We hone in on alcohol and cigarettes, the drugs of choice for elementary kids.

"We talk to them about their families, support groups, risks, consequences, decision-making skills. In these lessons we use a workbook and at the end of the lessons the students have to make a statement about how they are going to stay off drugs. They have to do this publicly in front of their peers, and then the best statements are presented on a stage before the parents.

"We bring in role models for the students. The role models we choose are high school students. . . . We talk to them about the YMCAs and churches. . . . We also talk heavy about how the media encourage drugs in America, about the techniques that are used in advertisements and commercials. We spend a lot of time on that.

"We have a box where the children can write us notes and messages. A lot of times they'll tell us about things going on in their families. And they don't sign their names. We tell them to remain anonymous. But the messages they write raise an important question: Where are the children learning right or wrong?" (*Cleveland police officer, Drug Abuse Resistance Education*)

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"Much of what has been said already is part of my life. I came from an alcoholic home, so I am an adult child of an alcoholic. I am an only child, so the entire brunt of my Dad's alcoholism I felt." (*pastoral counselor at a local hospital*)

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"They found 50 billion dollars to kill a lot of people in the Middle East, but they can't find one billion dollars to support drug treatment here. It's a damn shame!" (*unidentified speaker*)

Discussion

OUR SOCIETY CONVEYS THE MESSAGE that altering the mind and behavior with chemical substances for nonmedical reasons is desirable. While our society is able to say, with respect to alcohol, that it is unacceptable to endanger others through drunk driving, it does not say that intoxication is undesirable or even shameful. There is a need to attach more value and prestige to moderation and sobriety, and in the case of the chemically dependent, to abstinence. No society that glamorizes intoxication can easily eradicate alcohol and drug abuse.

Consistency means the avoidance of such contradiction and hypocrisy by families, business, and society. Children and adolescents should be consistently guided to value freedom from intoxication. Instead, they receive mixed messages from parents who set bad examples or from media, advertisements, and other means. If we are consistent, we can convey the message that substance abuse is not sociable, not attractive, and not grown up.

As we have seen over the past several decades, consistency has played an impressive role in changing public attitudes toward smoking. A degree of consistency has been achieved because of the efforts of business, government, and the public. A powerful example of a push for consistency is the antismoking campaign launched in 1984 by the British Medical Association (BMA), intended to end tobacco advertising and promotion in Great Britain. Although TV ads had been banned, the BMA was concerned with the promotion of sporting events by tobacco companies. In a special report, the BMA made the following statement: "Tobacco advertising promotes the idea that smoking is normal, good and

glamorous. Tobacco advertising continually tells people that smoking is desirable" (British Medical Association 1986:81). The report emphasizes the contradiction between knowing the hazards of smoking and allowing advertisements.

The value of freedom from intoxication should be emphasized in this society with a fervor equal to or greater than the fervor we exercise in stressing the value of freedom from smoking. The testimonies we have heard in this dialogue drive home the effects of substance abuse—15 percent of all annual deaths, spouse and child abuse, AIDS, loss of careers, cirrhosis of the liver, diminished cognitive function and memory, the severe withdrawal of *delirium tremens*, relational difficulties, car accidents, date rape, and unintended pregnancies, among many others.

In the interest of social responsibility, American corporations can make freedom from intoxication a central concern. Ultimately, the business community will gain from a concerted effort on that front: its foreign competitiveness is compromised by increasing health care costs that are in part the result of unhealthful employee behaviors (Califano 1986). But more broadly, an effective work force cannot emerge from a society in which 60 percent of the world's illegal drugs are consumed (Berger 1988). A National Institute on Drug Abuse study shows that the cost to businesses in terms of lost productivity, property crime, absenteeism, and accidents is about \$100 billion annually (National Institute on Drug Abuse 1986).

Drug prevention programs sponsored by the schools are a necessary step in the right direction. The schools have a major role to play in establishing consistency, but they cannot succeed if the business community does not work toward consistency as well. Nor can the schools succeed when young people go home to parents who are themselves substance abusers. Schools can disparage substance abuse when role models in the home encourage it, but not as successfully. It is especially tragic when parents instruct children on the harms of substance abuse but do not set the proper example. Children

and adolescents need good role models; they also need the courage to tell their peers that intoxication harms both individual and society.

3. Social Justice

Testimony

"We must understand first that, ain't nobody gonna pay to get you off drugs because they want us on drugs and especially black men today. . . . Our values are so distorted to where we think that Air Jordans is what make Michael fly through the air like that, and that's what I will kill you for because I got on a pair of Jocks and I want them Jordans.

"We must understand love. How we are taught to hate ourselves. That we are actually ugly men. We look in the mirror and see these big noses, man, and this nappy hair. . . . See what I'm saying. And treatment centers don't mean nothin' brother. Don't mean nothin'. That's just another place to make us stupid, to put us in so we be locked down and they know where we at—you know what I'm saying—the same thing as jail because drugs are something that are crazy, 'cause, you see, I did drugs." (*unidentified former addict and gang member, convert to the Nation of Islam, member of Islamic antidrug organization*)

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"We talk to the kids about self-esteem. How can a child have self-esteem? I've been into homes where some of the children don't have beds to sleep on at all. How does a child like that gain self-esteem, starting out that way?" (*police officer*)

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"To get rid of the drugs in the community, we need to replace them with something. Jobs, we need more jobs. If we had something for these people to do with their energy, to bring pride back into their lives, they could see that there is another direction." (*unidentified speaker*)

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"I always considered drug addiction as symptomatic of a bigger problem. It doesn't make sense to look at drugs as an isolated problem. Yes, this person has moved into an addiction cycle, usually because of a multiplicity of reasons that have to do with economics, socialization, religion, family, and everything. If you just take the problem of addiction in isolation, you're never going to solve the problem." (*executive director, Community Action Against Addiction*)

Discussion

THE VALUES OF FREEDOM AND CONSISTENCY lead to the issue of social justice. Social justice refers to the deep structures of society that foster genuine equality of opportunity for all citizens. People who lack jobs, education, and social status confront oppression at every turning. Freedom from intoxication is not easy for people who lack hope for the future, who live in ghettos, who are impoverished, who lack appropriate role models, and who reside in environments that seem to be special targets for heavy cigarette and alcohol advertisements.

Substance abuse can be correlated with lack of self-esteem, which in turn arises from lack of love, poor schools, and many other poverty-related environmental factors. Drug abuse can in part be understood as self-enhancement, making up for a lack of genuine self-esteem. The popular admonitions to those who lack self-esteem—"Be the person you want to be," "Offer more to yourself and the world," "Accept challenges," "Enrich your life"—sound hollow when the cycle of despair and hopelessness is so deep that a T-shirt reads "Go ahead, shoot, I'm already dead!"

As one community member observed, "To get rid of drugs in the community, we need something to replace them, namely, jobs." Others at the forums stressed that if young people in the community could turn their energies toward useful well-paying activities, such as construction or some other trade, "pride might be returned to their lives." Some who spoke from the audience testified to making thousands of dollars from drug dealing as an alter-

native to working at McDonald's: "I can go buy those gold chains I always wanted, I can buy them starter jackets, I might take Momma out for Mother's Day. I couldn't do this before, because I was at McDonald's."

Ultimately, each individual must take personal responsibility for substance abuse. Nevertheless, injustice remains a significant factor that must be addressed. Indeed, the response to substance abuse must not be compartmentalized but *integrated* with the wider social problems from poor education to poverty itself. But the more drug abuse becomes a problem for the poor alone, the greater the risk that we will forget the problem altogether.

4. Personal and Community Responsibility

Testimony

"I am in my tenth year of sobriety, and as everyone else has said before me, it's a new life, it's the only life that I want to lead today. My higher power is a God who is loving and kind and a God who I believe also is very strong in my recovery. I think I reached him only by becoming powerless myself. Why did I take so long? I think because of being very proud and very closed in and not able to say 'I'm powerless.' I think I found God when I finally could say that I needed him. I didn't need him before, even though I was a clergyman. I think the externals of my profession meant a lot to me. They still do. But the internal never really hit home, I don't think, until I was finally down and out and said I need a higher power. I found that in AA." (*pastoral counselor*)



"I'm not going to sit here and tell you no bunch of lies about this America who love black people and all that kind of stuff. What I'm saying is that, ultimately, we are going to have to start our own programs. What we ultimately had to do, we had to just start a program. . . . So I would just say that we have to begin to encourage community. Again, when we talk about community

empowerment, community responsibility, it's important that the community begin to do whatever it can to be responsible for itself." (*friend of a substance abuser*)

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"Some social systems have gone haywire in the African community—you know, how we learn and teach our children. The family structure, the belief, and certain philosophies have gone by the wayside. We don't know who we are. You ask children, 'Who is your father? Who is your grandfather? Who is your great-grandfather?' They can't tell you. They have no place in history. They lose context. They lose their place in the world. And when we understand what it is to be an African, and we start understanding what we have to do and then impart this to children, we start understanding some of this problem." (*unidentified speaker*)

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"We have 583 young black men who are signed up with what we call the Black Watch Movement, here in the city of Cleveland. And at any time, we can call upon them to mobilize to move drugs out of the community. . . . We have to stand together, and we have to be prepared to die if need be to save our women and our children, and nobody has to give you that type of authority. You have to just have that type of commitment, just by being God's creation." (*unidentified speaker*)

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"I've been in three or four treatment programs. I lasted for a certain length of time, and I know good and well that no program really does anybody any good unless they really want it to. And if we don't give individuals something that they can look down the line for—something so that once they do clean themselves up and come back out here they do have a new direction that they can go in—then we're not doing nothing.

"I don't think that you can throw anybody in a treatment program to solve the problem of an addiction. I never would believe that. What we try to do is take people who have made a decision about an addiction, and try to enable them to go through that

process. We don't work miracles in drug treatment programs. Are you asking if the solution is drug treatment? I say for some people, a part of our community, that might be an answer." (*unidentified speaker*)

Discussion

DURING THE TOWN MEETINGS on substance abuse, the participants spoke often about the importance of personal and community responsibility. They expressed a general suspicion of "looking for the wrong people to solve our problems." A number of people from the black community, for instance, were troubled by a "slave-master way of thinking" that looks to "white folks" for salvation from drugs. Clearly, one very powerful force in the black community is the Islamic faith, which forbids the ingestion of alcohol and nonmedicinal drugs. As one person from the Nation of Islam stated, "I agree with what some of the brothers said earlier: we have to start finding some solutions to these problems within our own communities."

The Dialogue sees a very significant role for organized religion in teaching the values of restraint and sobriety, and it encourages leaders of all faiths to reaffirm these values, especially in neighborhoods troubled by substance abuse. This affirmation is every bit as important as the call for social and economic justice, or for a more peaceful world. As one Islamic leader said, "We need the justice of Martin Luther King, Jr., but we also need just as desperately the discipline of Malcolm X."

Impoverishment of environment precludes a fair start in life. Nevertheless, one thought was expressed often at the town meetings: it is every individual's personal responsibility to resist the lure of substance abuse, and it is every community's responsibility to establish its own voluntary organizations, both religious and secular, to struggle against drugs.

5. Fair Access to Treatment

Testimony

“Everybody talks about how you go into drug treatment and it doesn’t work. Well, I use an analogy. It’s like if I had a house to paint and somebody gave me one gallon of paint and they said paint this house. I looked at the paint and I looked at the house. I took my brush and I painted it maybe, sketchy, the front of the house. The guy comes back in three days and says, ‘That’s the worst paint job I’ve seen in all my life. It looks terrible.’ That’s a little bit of what happens in substance abuse treatment.

“Take cocaine addiction. Anybody in the treatment field knows that one of the earliest things you have to do with cocaine addicts is get them involved in the detoxification program, which should last anywhere from three to five months. No one is going to pay for that, people. It is incredibly expensive to detoxify a person from the drug of cocaine. If anybody knows the addiction cycle and the relapse and all the involvement, you know that it’s an incredible investment to simply detoxify a person thoroughly from the cycle of abusing cocaine. Once the person is detoxified, then you can certainly start infusing some of the other things that are necessary to make sure that the person does not relapse and stays involved in a positive way with the environment. Who pays for that? If you have Blue Cross/Blue Shield and you are a very middle-class person, and you have a job, you might get 29 days. You get 30 days at Kaiser [an HMO], maybe, if you’re lucky. You’re not going to get what you need. That’s if you’ve got money! My God! What if you’re a little strawberry on the street and you’re out there and you get busted and you say ‘I need some drug treatment’ to detoxify? What are we paying in the county now? Two days?”
(*unidentified speaker*)

“Someone said to me, ‘Too bad you didn’t go into your last program first,’ and I said, ‘No, the others got me ready. They broke me down, step by step.’ I was apparently not ready enough yet when I went into the other treatment programs. I had a tremendous

emotional block that I was not going to be treated. So we can’t give up on the person who is trying. If, for instance, my bishop had given up on me, I’d be dead. I didn’t get sober until I was 51 years old. He could have just said, ‘That’s enough, we can’t spend any more money on you,’ but he didn’t, he’s kept it up. And he’s also instituted for us—I’m a member of it—a health board for the clergy of our diocese, whereby we monitor our own clergy and we go out two by two to talk to them and bring them into treatment. All of us are in the program.” (*pastoral counselor*)

“Some people go to jail. I just heard a story recently about a guy who went and robbed a bank. The following morning he went to the police and told them exactly what was in the note and gave them the money, and said, ‘I’m the one who did it.’ He just wanted to go to jail to be able to deal with his addiction. It’s very sad, but it’s true.” (*unidentified speaker*)

“It is tough. You spend hours and days on the phones for each client if they don’t have insurance, and most of them don’t. Yes, there are county beds. They are always full. Sometimes you get lucky. It’s not hard if the client has already had a seizure or is shaking in front of your very eyes, because you can send them to the emergency room, where they have to be taken in.” (*physician*)

“So much is spent to prosecute people, incarcerate people, interdict drugs. Yet there are limited dollars for treatment and rehabilitation.” (*unidentified speaker*)

Discussion

CHEMICALLY DEPENDENT PEOPLE CANNOT BE social users, and often they can change their behavior only with extensive assistance. Treatment for substance abuse is very difficult for the uninsured to acquire (Institute of Medicine 1990). Data show that



The Day After. Drypoint and aquatint by Edvard Munch, 1895.

currently in the U.S. about 5.5 million people depend on or abuse drugs and that these people need treatment and counseling; but in 1990, only 850,000 people received this necessary care (Gerstein and Lewin 1990).

Both private and public sectors have a role in providing access to treatment. The Institute of Medicine of the National Academy of Sciences affirmed society's obligation to give "adequate support for appropriate and timely admission and the completion (or maintenance) of good quality treatment for people who cannot pay (fully or partly) for it, whenever such people need treatment according to the best professional judgment and seek treatment or can be induced through acceptable means to seek it, assuming there is some probability of positive response" (Institute of Medicine 1990:98).

Perhaps the appeal for better treatment must be

made to the enlightened self-interest of our entire population, since inadequate treatment affects everyone. The blunt fact is that alcohol and other drugs are associated with up to 50 percent of spouse abuse, 20–35 percent of suicides, 62 percent of assaults, 52 percent of rapes, 38 percent of child abuse, 68 percent of manslaughter charges, 49 percent of murders, and 50 percent of traffic fatalities (Institute of Medicine 1990). Thus an argument for access to treatment need not rest on an appeal to individual rights, which are legally controversial and unwelcomed by some policymakers. But if everyone can understand that treatment access benefits all people, because no one is immune from the above threats, then a consensus about universal access could emerge.

At present, federal and state funds for dealing with substance abuse are severely limited. For 1991,

the proposed allocation for the “war against drugs” was only \$10.6 billion (White House 1990). The majority of these funds—70 percent—was directed at interdiction measures, leaving only \$2 billion for treatment efforts. Overall, only 30 percent is devoted to reducing demand through education and treatment. This asymmetry in part explains the significant number of testimonies by people whose friends had either feigned insanity or committed a felony in order to gain access to treatment. The Dialogue core group was particularly struck by this revelation.

6. Equality for Women

Testimony

“If you are a pregnant woman who is in the late stages of pregnancy and suffering from any drug, chances are you will never get help in this state and in this county. There are very few programs that will help a woman who is in late second term or early third term, no matter what.” (*director, adult division of the county probation department*)

“This experience that I am going to tell you about is true. I have spent nights in the snow and the sleet and the rain, going back and forth to different hospitals with a friend of mine. Me and her are crying out ‘Help, help, help!’ They say, ‘We don’t have any room, you have to come back in six months.’ . . . So I said, ‘Isn’t there someplace? Isn’t there something that can be done for this person?’ They said, ‘Well, call us back and we’ll see, because we are full. We don’t have any beds.’

“So we came up with this idea. We went to this hospital and said there were voices talking to her and that the voices had a gun and wanted to kill someone. They took her right in. Right in. But they put her in a place where there were people that really were listening to voices and seeing things, which did not really help. She went through extensive psych therapy, and they finally got her in treatment for drugs. . . .

Can anyone give me any ideas, truthful solutions, honest ways to get in?” (*friend of a substance abuser*)

“See, for us Hispanics, women aren’t supposed to be known as addicts or drunks, only as mamas.” (*unidentified speaker*)

“Hitchcock House [a halfway house for women] was the most important thing in my recovery, because I really did not know how to live daily without drinking and drugging.” (*unidentified speaker*)

Discussion

THE DIRECTOR OF CLEVELAND’S WOMEN’S Alliance for Recovery Services—a screening, referral, and prevention program funded by the Ohio Department of Alcohol and Drug Addiction Services—reported to the Dialogue that medically indigent women must often wait a month or more for admission into a hospital detoxification program. With some notable exceptions, hospitals generally have very few beds for indigent addicts because such beds are not profitable. Hospitals generally limit stays to two or three days because of financial constraints. Inpatient treatment opportunities specifically for indigent women are rare, and most are limited by Medicaid to a weekly outpatient counseling session. Returned to the environment where substance abuse occurs, these women commonly relapse, resulting in both feelings of failure for the women and a waste of the funds spent during the initial detoxification stage. Moreover, women frequently face the problem of being responsible for children, so that many are simply unable to avail themselves of treatment at all.

The Women’s Alliance for Recovery Services asserts these facts in its literature: “Medical treatment for alcoholism and other chemical dependencies is less accessible to women,” and “Women have fewer support systems which enable them to

remain in an ongoing recovery program" (Women's Alliance 1990). The Alliance also points out the following: because of social stigma, particularly among Hispanics, family members are less likely to identify alcoholism and drug abuse in women; the treatment course is very complicated for women who have children; specific biological factors lead to rapid progression of addiction symptoms in women; and other forms of oppression against women like domestic violence are related to their addictions and must be addressed during recovery.

Because the number of treatment centers for women is inadequate, filling the gaps in the continuum of treatment is exceedingly difficult. Thus, for women, the problem of lack of access to treatment, already monumental for all indigent people, is further compounded.

Against this tragic background, then, we can begin to consider the plight of pregnant women who have alcohol or drug addictions. It is wrong to scapegoat addicted women who are pregnant, particularly indigent ones, because they have so little access to treatment before pregnancy. However much society is appalled by fetal alcohol syndrome and cocaine-addicted infants, this tragedy has its beginnings in injustices that our society does not adequately address. The brutal fact is that medically indigent pregnant women are immersed in inequities.

A pregnant indigent woman who abuses drugs has almost no programs open to her once she enters the second trimester. With their few beds for indigent people, hospitals do not want the liability that might arise from a miscarriage or from the birth of a damaged infant. The few treatment centers that will help a pregnant woman lack medical expertise and physicians.

Pregnant women who use illegal drugs should not be subject to special criminal prosecution based on alleged harm to fetuses (Packard Foundation 1991). Current laws prohibiting the use, possession, or sale of drugs and delivery to minors are sufficient. Extending such laws to women based on their physiological connection with the fetus is inap-

propriate for three principal reasons: (1) we have no evidence that this additional threat will deter substance abuse; (2) pregnant women, fearful of legal action, may avoid treatment altogether; and (3) prosecution for delivering harmful substances to the fetus currently focuses on women using illicit drugs, the harmful effects of which are not as firmly established as are the effects of fetal alcohol syndrome (FAS), a leading cause of birth defects and mental retardation. In summary, the "get tough" approach is a poor substitute for treatment.

The Dialogue is concerned with the deplorable impact of substance abuse on the fetus. Tens of thousands of children are born each year suffering from the permanent effects of FAS. FAS children suffer from small size, facial abnormalities, and central nervous system damage. Even when the syndrome is not fully present, children suffer from fetal alcohol effects (FAE). Maternal use of illegal substances such as cocaine may also have long-term, harmful effects on children. We all respond emotionally to this tragic harm inflicted on innocent victims at the beginning of life, and our society suffers the economic costs of neonatal intensive care and long-term support.

We can respond to this problem in a nonpunitive and productive manner if we (1) educate women about the dangers of both licit and illicit substance use during pregnancy; (2) develop drug treatment programs that meet the specific needs of pregnant women by providing, for example, prenatal care and child day care; and (3) dramatically improve treatment opportunities for indigent women so that they can recover from addiction before they become pregnant.

7. Prevention

Testimony

"If you talk to people about when they started dabbling in drugs, it's younger and younger. I know at Safe Space, which is a runaway station associated with

the Free Clinic, you get these youngsters in at age 13. . . . And it's not uncommon that they've had their first drink, or tried their first joint, or done their first bit of cocaine at age 8 or 9. Maybe not regularly, but they've at least tasted it. So the younger we educate, the better." (*physician*)

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"You can go into a treatment center and you stay for three years, but when you come back out and the same thing is going on in the streets, you right back with Joe around the corner in the garbage cans, smokin' them rocks again. Don't denounce your friends because you found a new life. Once you see that what you doin' is right and truly right, go back to your friends, tell them. That's what makes us, being the brothers of blacks, so successful in Cleveland, because they know us." (*unidentified convert to Islam*)

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"I think education is very important, and I see more of that today than I ever have. But all the knowledge in the world doesn't necessarily mean that you're going to get help. It didn't help me right away. It wasn't until I hit bottom, so to speak. I think if we can reach the children early, if we can identify the problems in our lives, that would be a big help." (*unidentified substance abuser*)

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"I would say that we should not depend solely upon people who we identify as leaders, but we must become leaders ourselves. I think we have enough common sense to know what needs to be done and then we just need to go ahead and do it because when God created us, he made us his representatives on earth. So that authority has already been given." (*unidentified speaker*)

Discussion

PREVENTION IS CLOSELY RELATED TO CONSISTENCY. Prevention efforts can reach at-risk populations and fortify their psychological, social, and spiritual functioning. A large part of prevention has to do with creating a conscientious media and a socially

responsible business community. Primary prevention programs attempt to deter substance abuse from beginning among youths and adolescents. To be successful, such programs must teach refusal skills, train parents, target multiple systems within the community, teach advertising analysis and resistance, provide role models, begin early, and combine mass media with school curricula and parental responsibility (Ohio Department of Mental Health 1990). One effective primary prevention program is DARE, described in the foregoing testimony on consistency.

Secondary prevention focuses on people at the early stages of abuse. As the American Medical Association (AMA) suggests, "Programs at this level should incorporate components for identifying individuals who need medical treatment or counseling and for making appropriate referrals to community resources" (American Medical Association 1991). High-level prevention includes long-term attention to recovering addicts in order to prevent relapse. As the AMA states, "Persons dependent on alcohol or other drugs can be regularly monitored for relapse in addition to being assisted with health care, job placement, and counseling" (1991:2106).

Summarizing Grass-Roots Affirmations

THE GREATER CLEVELAND DIALOGUE brings together people from all walks of life to express their sufferings and opinions. Professional ethicists have a role to play in this process, but chiefly as listeners and interpreters rather than as theoreticians. The ethics that arises from this process is at least as useful as the conclusions that descend deductively from the many rival "first principles" of a more theory-driven approach.

If community dialogues provide a partial answer to questions of ethics and health care, they do so because they include the public. Policies related to health care affect the public and must be in tune

with public sentiment if they are to be effective. Moreover, a different style of health care ethics emerges from the dialogue process. My view is that a truly public bioethics is ultimately necessary, since the policies our society develops in the area of health care can be meaningful only if they are grounded in

the general will. We need to work harder at widening the umbrella of bioethics to include the public, for the sake of the community and for our own education as professionals. Certainly major questions for the future surround the nature of consensus and the process of achieving it. ☉

NOTE

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Corporate Decision. Egg tempera on gesso panel by George Tooker, 1983.

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Transplants, Justice, and Health Care Reform

What Can Health Insurers Contribute?

Scot D. Yoder

"HOW CAN HEALTH INSURANCE COMPANIES PUT ethics into practice? Can they be advocates for justice and reform in health care?" I asked myself these questions when Mennonite Mutual Aid decided not to limit coverage on organ and tissue transplants in its new health insurance plans. Though not surprising, the decision was contrary to the recommendation of the Organ Transplant Task Force which MMA had chartered and which I had chaired. My initial disappointment gave way to cynicism when I learned that the recommendation had been overturned by a market survey. The product design had incorporated a \$100,000 cap on organ transplant coverage, until a telephone survey revealed that a majority of clients were unwilling to forgo this coverage to achieve a basic benefit plan. Bowing under the pressure of the market, MMA had decided to disregard the recommendation.

As an employee of MMA I certainly understood the importance of manufacturing marketable

products. In the last few years membership had sharply declined as premiums had risen dramatically. It was essential that the new product be given every chance to succeed. At the same time, I was disappointed that an organization accountable to the church, and one that prides itself on being "more than just insurance," would let market demand eclipse ethical principles. Were my hopes and expectations unreasonable? Should an insurer be expected to put ethics ahead of the market? How or to what extent can health insurance companies put ethics into practice?

The aim of this article is to explore these questions in some depth, using the experience of MMA and its Organ Transplant Task Force as an illustration. The question is not so much whether insurers are able to act ethically—I do not mean to imply that they are inherently immoral or that they generally practice unethical behavior. The question is how and what can health insurers contribute to discussions about health care ethics and policy, and can they bring the resulting insights to bear on their practices and policies? What can be expected of insurers?

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MMA and the Organ Transplant Task Force

MENNONITE MUTUAL AID (MMA), Goshen, Indiana, is not a typical health insurance company. It is a nonprofit organization whose stated mission is to lead

Mennonites and related groups toward greater practice of the biblical principles of stewardship and mutual aid. As an inter-Mennonite church organization, we offer members the opportunity to help each other by sharing financial risks and resources. To achieve this, MMA provides insurance products, financial services, charitable programs, and educational resources.

Founded in the late 1940s to provide loans to volunteer service workers after the Second World War, it has since grown to offer a variety of insurance products and financial services. Though it offers auto coverage, life insurance, annuities, retirement plans, and estate planning services, the backbone of MMA's business is health insurance. It currently serves between 30,000 and 35,000 adults through group and individual health policies.

MMA continually lives with the uneasy tension between church and business. As a church organization it is formally accountable to a board of directors elected by Mennonite and related Anabaptist churches. Its religious focus is on promoting the Christian principles of stewardship and mutual aid, that is, sharing resources to help others in need. These principles are an important, and to a certain extent, a defining part of the Mennonite tradition. However, as a business it also faces the relentless pressure of an increasingly competitive market for insurance products and financial services. The financial crisis facing our health care system creates a tremendously stressful and unstable business environment for health insurers. It is out of this daily experience as a church organization and business that MMA confronts ethical issues.

The Organ Transplant Task Force was not MMA's first foray into the field of ethics. The organization has always operated under a clearly defined set of ethical investment guidelines. MMA also fosters education on ethical issues in the field of health care as part of its fraternal program.¹ In 1985 it established a Health Ethics Review Committee from the health and legal professions to help "it [MMA] and its constituents consider appropriate responses to the ever rising river of ethical dilemmas we are facing in relation to medical care" (Rogers 1988:15). The work of the committee led to the 1988 publication of *Medical Ethics, Human Choices*, a medical ethics study guide for use in congregations, Sunday school classes, and small groups.

The Organ Transplant Task Force

WITH THIS HISTORY OF INVOLVEMENT IN ETHICS, it was not surprising that MMA should establish a task force to review the area of organ transplantation. The task force charter identifies three specific objectives:

1. To arrive at a better and more complete understanding of the practical and normative impact of organ transplants and organ transplant technology.
2. To provide Mennonites and other Anabaptists with an overview of the issues and suggest an outline for an Anabaptist position on organ transplantation.
3. *To develop a recommendation regarding MMA's organ transplant payment policy* to submit to MMA's management and board of directors. (Organ Transplant Task Force Charter 1990, emphasis added)

While the first two objectives include elements of an educational endeavor, the third objective is explicitly intended to bring ethics to bear on the business practices of the organization.

The Organ Transplant Task Force, composed of nine people representing different professions, perspectives, and areas of expertise, was established in January 1990. Our team included a physician, a nurse practitioner, a seminary student, a pastor, a lawyer, a writer, a member of MMA's management team, a health actuary, and a philosopher.² Three of the nine members were employees of MMA, and all had health insurance, a majority through MMA. (In retrospect, given the direction that the group's thinking later took, an uninsured person would have been a valuable addition.)

The diversity of the task force added richness and vitality to our work. Our professional training and experience generated not only a variety of perspectives and expertise but also an assortment of styles or methodologies for doing ethics. As a group we learned to blend the analytic with the intuitive, the conceptual with the experiential. Our resources included not only ethical theories and medical statistics but also interviews with a nurse who was part of a transplant team and with people who had undergone transplants. One member shared with us the ongoing plight of a close friend who was waiting for a lung transplant. This reminder that real lives were at stake kept the group grounded in reality.

The task force met monthly over a period of six months, and our work culminated in a four-part summary report, actually a position paper.

The initial segment paints the moral landscape for the report. First, the task force acknowledged that we had concentrated on the financial dimension of organ transplants, possibly to the exclusion of other issues. While ethical questions concerning procurement, the nature and effectiveness of the procedures, and methods of allocation were worthy of consideration, MMA's role as a third-party payor

and the task force's objective of developing a payment policy led to a natural focus on financial issues. Second, the task force identified justice in the allocation of basic health care resources, not organ and tissue transplants per se, as its principal ethical concern.

The theme of justice crept into our discussions so persistently and to such an extent that we became frustrated by the narrowness of our assignment. We were convinced that the issue of organ and tissue transplantation could not be adequately addressed without looking at the broader picture of justice in the allocation of basic health care resources. Organ transplantation retreated to a secondary role, functioning more as a case study. It became clear to us that the ethics of transplantation should be evaluated in the context of their impact on access to basic health care.

The concepts of *justice* and *basic health care* turned out to be as elusive as they were powerful. The task force spent much time discussing the concepts and even offered some clarifying statements, but in the end we shied away from proposing specific definitions. In retrospect there were at least two reasons for this reluctance. First, there was the problem of focus and scope. The task force had been asked to consider organ and tissue transplants, and spending the time required to define the concepts of justice and basic care more clearly would have detracted too much from that focus. Second, I believe there was an unspoken fear that analytical dissection might diminish the moral power of the concepts themselves. We wanted to appeal to people's hearts as well as their minds.

Nevertheless, because justice was to serve as the primary criterion for evaluating transplants, it was essential that the task force at least outline the notion of justice in health care that was operative for the group.

I was disappointed that an organization accountable to the church, and one that prides itself on being "more than just insurance," would let market demand eclipse ethical principles.

All people are entitled to a certain basic level of health care. This entitlement arises not only from a theory of natural or political rights, but from the concept of respect for people as beings created in God's image and God's desire that people be whole. Injustice is created by societal practices or institutions which directly or indirectly deny people the basic health care required for wholeness. (Alderfer et al. 1990:1-2)

This view explicitly links justice to basic health care, grounds the connection in a theology of health and wholeness, and establishes justice in access to basic care as a criterion by which to evaluate health care policies.

The task force did not reach consensus on what constituted a basic level of care though we agreed that preventive care, wellness, and universal access would be emphasized. Moreover, we unanimously agreed that however basic care was defined, most organ and tissue transplants should not be included. With their high cost and limited availability, transplants were viewed as symbolic of the excess and individualism in health care which thwarts every attempt to provide basic care and equality in the health care system.

Though we recognized that justice in health care was the more fundamental question, the task force felt compelled to address its assigned topic. The following three statements summarize our views on the ethics of organ and tissue transplantation:

1. The most serious ethical problems associated with transplants do not arise from the nature of the procedures themselves but from the fact that they tend to be expensive, resource intensive, end-of-life procedures. While it is true that transplants are not unique in this sense, they have become symbolic of our cultural acceptance of and fascination with high-tech medicine.
2. Justice requires that transplants not be considered a health care priority. Despite our

reluctance to put an apparent monetary value on human life, we must recognize that resources available for health care are not unlimited and that it is essential to set priorities. These priorities should emphasize prevention, wellness, and basic care for all over against exotic and expensive end-of-life treatments for a few.

3. Considerable judgment must be exercised in making decisions about organ or tissue transplants. While transplant technology and procedures are improving, there are still numerous risks and side effects involved including, but not limited to, severe emotional and financial stress, altered lifestyle, extensive drug therapy, and continual threat of rejection. Often the patient merely trades one set of problems for another. This dark side to transplants is very real but not well publicized. (Alderfer et al. 1990:2)

If the first section of the report paints the moral landscape, the second attempts to locate MMA within it. It begins by recognizing that the variety of the MMA's roles at times imposes conflicting obligations on the organization. MMA's mission to lead its constituency "toward greater practice of the biblical principles of stewardship and mutual aid" creates for it a prophetic role—one that entails not only leadership but leadership with moral convictions. The task force challenged MMA to step beyond the narrow realm of products and services to be an agent for change in the broader health care system, to promote a system that would guarantee basic health care for all people.

But MMA is also constrained by pragmatic boundaries within which it must operate as a health insurer. Contractual obligations prohibit MMA from significantly altering payment practices for transplants on policies already in force, and regulatory agencies in each state require that certain mandated benefits be included in all policies sold in that state. Financial viability and market need compel MMA to offer products that will be actuarially sound and competitive in the marketplace.

The tension between the prophetic and pragmatic is keenly felt in the development of new health insurance products. In designing new products, MMA has the opportunity to assert its prophetic role and push for features that promote a more just distribution of health care resources. But here is also its best opportunity to implement features that are more sensitive to the ever-changing market. And for MMA, sensitivity to market need not only ensures financial stability but also promotes its constituents' participation in mutual aid. The task force recognized this tension and stopped short of exhorting MMA to assert the prophetic above and beyond the pragmatic: "MMA must balance the desire to be prophetic with the desire for broad participation in mutual aid" (Alderfer et al. 1990:3).

So as not to be frozen by this tension, however, the task force noted that MMA's leadership is not limited to the development of insurance products and that in fact, "experience would indicate that product features alone are a relatively ineffective way of changing attitudes and beliefs about the proper use of health care resources" (Alderfer et al. 1990:3). It urged MMA to find other ways, such as the development of the medical ethics study guide, to raise concerns about ethical issues in health care.

THE THIRD SECTION OF THE REPORT POSITIONS the church in the moral landscape alongside of MMA, examining the church's role in addressing the broad problem of justice in health care as well as the specific issue of organ transplantation. The task force suggested that the church should provide "education, admonition, and emotional and spiritual support for its members on these subjects." More important, it drew attention to the fact that many of the assumptions affecting our attitudes and decisions regarding health care are essentially religious. We must recognize the "foundational religious beliefs about life, death, and our bodies which underlie many of our health care decisions" (Alderfer et al. 1990:4). Inasmuch as these are religious beliefs, the church has a vital role in shap-

ing the values that form the foundation of a just health care system.

The final section of the report includes the six recommendations made by the Organ Transplant Task Force. Three of the six pertain specifically to transplants; the remaining proposals address the issues of justice, basic care, and mutual aid.

The first two recommendations suggest specific cost-containment controls but do not impose limits on transplant coverage.

1. MMA should develop a list of transplant centers which provide quality care at a "reasonable" cost. If possible, MMA should pursue an arrangement with its reinsurer³ which is developing a special agreement with selected transplant centers to provide quality services for an agreed upon price.
2. MMA should work with members covered by its current products to control transplant cost through aggressive use of managed care options. These options include precertification and large claims management.⁴ Members should be encouraged to use one of the transplant centers selected by MMA or its reinsurer.

The types of controls mentioned in these proposals are already widely used in the insurance industry in an attempt to both improve the quality of treatment and reduce the cost of transplants. Falling generally under the rubric of *managed care*, they reflect the increasing tendency of insurers to negotiate directly with providers for preferential rates.

The third recommendation contains distinct guidelines for new product development.

3. New products developed by MMA should provide reduced coverage for organ transplants along the following guidelines:
 - a. Procedures should be limited to those which are not considered experimental treatment for the condition in question.

- b. Members should be encouraged, through precertification and large claims management, to use transplant centers selected by MMA or its reinsurer.
- c. Full coverage should be provided for kidney and cornea transplants due to the high success rates, good quality of life, and financial payback associated with these procedures.⁵ Periodic evaluation should be done to determine if other transplant procedures meet these standards.
- d. MMA's payment for all other approved procedures should be limited to 60–80 percent of the actual cost.

Items 3a and 3b reaffirm the standard restriction of payment for experimental procedures and the need to manage care, respectively. These recommendations are admittedly noncontroversial.

Item 3c counsels full coverage for certain transplants. Its inclusion is an implicit acknowledgment that vast differences in both effectiveness and cost make generalizations regarding transplants dangerously inadequate. While stopping short of providing precise measures for evaluating transplants, the recommendation does identify success rates, quality of life, and financial payback as general criteria for evaluation. Thus coverage could be legitimately provided for select transplants (like kidney and cornea transplants) with relatively low costs and high success rates. The proposal is intentionally open-ended to allow for the possibility that other transplant procedures may, as they become further refined, also become acceptable for coverage.

Item 3d, which imposes the most stringent restrictions on transplant coverage, was the result of a compromise: we wanted to define a limit that would balance the strength of our message, fairness, effectiveness in reducing utilization and cost, and marketability. We struggled deeply with questions of justice. On the one hand, severe restrictions would send a powerful message about health care priorities and draw attention to the issue of justice in health care. Ideally, they would also keep costs down. On

the other hand, they would also favor the wealthy—those who could afford to pay the portion of expenses that insurance did not cover. Would the imposition of limits actually widen the gap between the “haves” and “have-nots” and undermine our goal of working toward a more equitable health care system?

Although I found the compromise rather disappointing, it was both necessary and acceptable. The murky ethical water in which we swam, honest differences of opinion, and the difficulty of translating ideals into policy made compromise necessary. The belief that product features alone are an incomplete, if not ineffective, way of influencing ethical decisions made compromise acceptable. We were much more interested in drawing attention to the ethical imperative of setting health care priorities than in limiting any individual's access to a potentially lifesaving procedure.

The fourth recommendation challenges MMA to explore the possibility of providing a basic health care plan.

- 4. MMA should further research the feasibility and implications of offering a low-cost/low-benefit health plan. The plan should specifically address the issues of affordability and justice, providing basic care while limiting a variety of benefits.

The wording is significant. Recognizing the complexities involved and unable to reach consensus on what constituted basic care, the task force stopped short of specifying the details of such a plan or even recommending its development. We were not retreating from our belief that people are entitled to basic health care but merely conceding that the vehicle of commercial insurance may not be the proper medium for providing this care.

The fifth recommendation counsels MMA to reach out to church leadership for help in dealing with the complex issue of justice in health care.

- 5. MMA should make a formal request to Mennonite church boards to make the issue of

justice in health care, and in particular access to health care, a central issue for Mennonites.

This recommendation implicitly recognizes that MMA, as an insurer, has a limited influence on the attitudes and beliefs of its constituency. Furthermore, the proposal reflects the conviction that in order to understand the health care crisis and confront it effectively, we must examine the fundamental values and assumptions that drive and sustain the health care system.

In certain respects the sixth and final recommendation is the most significant, though I am not sure the task force understood it that way at the time.

6. The church along with MMA should reconsider the nature and forms of mutual aid participation. We need to find creative ways to practice mutual aid in its New Testament sense. New ideas could include alternatives to traditional insurance models.

In our discussion of transplants, justice, basic care, and mutual aid we constantly found ourselves pushing against the boundaries of what is possible using the tool of commercial insurance. The boundaries imposed by regulatory, underwriting, rating, and marketing constraints narrowed the field of possibilities and stymied attempts to devise creative solutions. This final recommendation suggests that the insurance model traditionally used by MMA to facilitate mutual aid may be an inappropriate tool for addressing the concerns of justice and basic care. Even more, it insinuates that under the present circumstances the insurance model may cease to serve as an effective instrument for promoting mutual aid.

MMA's Response

WHEN THE REPORT WAS PRESENTED to the board of directors in August 1990, the Mutual Aid Services Committee, sponsor of the task force, expressed

appreciation for the work and general support for the report's content.

There was clear affirmation of the cost-containment measures included in recommendations 1 and 2. Recommendation 3 calling for reductions in coverage for transplants received the most discussion but the least agreement. Questions were raised about how the task force arrived at the decisions regarding the degree of coverage limitation and what procedures should be covered. What was the rationale for setting coverage at 60–80 percent? Was there adequate justification for providing full coverage only to kidney and cornea transplants? Recommendation 4 received little discussion; it was noted that MMA was already planning to look into providing a basic plan in 1991. Recommendations 5 and 6 also received a clear vote of confidence, though no specific action was taken. In short, despite strong affirmation for the work of the task force, the board committee took no formal action to implement the recommendations.

I was both confused and disappointed by this response. We had worked hard to formulate a strong, coherent position, and while we knew that we were primarily consultants, we had undertaken our work with the expectation that our recommendations would be approved. It was particularly painful for me, as chair of the task force, to inform the other members that our work, though appreciated, had not led to any action. The report seemed to die that day, and it was unclear what, if anything, would result from our work.

Upon reflection, I should not have been so surprised by this response. First, there was not sufficient continuity between the original request of the board and the eventual report. Two years had elapsed between the committee's approval to initiate the task force (August 1988) and the final report (August 1990)—time enough for the committee personnel to change and other issues to take prominence. Second, it is not obvious what action would have been appropriate. For instance, recommendations 1 and 2 were consistent with other more aggressive managed-care measures that MMA had

implemented over the past few years. They were directed more appropriately toward management than to the board. Existing plans to develop a new low-cost health plan made formal action on recommendation 4 unnecessary.

The committee's lack of action on the third recommendation was the most disappointing. Strong board support for limiting coverage for organ and tissue transplants might have had a powerful impact on any future health insurance product development for MMA. However, not all committee members agreed that sufficient rationale had been presented to justify items 3c and 3d, which singled out certain procedures for full coverage and reduced payment for all remaining procedures. Moreover, the committee was reluctant to make policy or become involved in detailed product development. The board did not have a history of involvement in that level of specificity and was unwilling to set a new precedent, particularly in a time of turmoil in MMA's health insurance line of business.

Finally, the work of the Organ Transplant Task Force was overshadowed by other very significant agenda at the board meeting. During the late 1980s MMA, like many other health insurers, had been laboring under the weight of rising health care costs and increased competition. Loss of membership resulting from rising premiums had made the wisdom and feasibility of staying in the health insurance business uncertain. However, at this August 1990 meeting the board of directors drafted the following strong statement:

We as an MMA board reaffirm our commitment to provide health care products; and we will support staff in aggressively seeking in-

novative ways to strengthen health care offerings. We recognize the risks and support management in the use of resources to meet this end. (Brunk et al. 1991:1)

Though this pivotal statement eclipsed the work of the Organ Transplant Task Force at the time, it put MMA on a course that would ultimately force it to confront the very issues the task force had highlighted.

In response to the board's statement, the Individual Health Alternatives Task Force was formed in the fall of 1990. The primary objectives of this group were to "make health care financing options available to our constituency who do not have employer coverage" and to "influence our constituency through education to become better stewards of health care resources and enable them to support mutual aid"

(Brunk et al. 1991:1). After several months of study this task force produced a six-point strategy related to MMA's individual health insurance business. Three of the six proposals closely resemble elements of the report prepared by the Organ Transplant Task Force. (It should be noted that members of the Individual Health Alternatives Task Force were provided with the Organ Transplant Task Force report but because of the board's lack of action were under no obligation to follow its recommendations.)

A significant component of the strategy is the objective of "educating members to use resources wisely and justly in an effort to control cost, provid[ing] information on injustices in the health care system, and encourag[ing] them to become advocates for more positive government involvement" (Brunk et al. 1991:1). Further details called for MMA to develop a corporate statement "reflect-

"All people are entitled to a certain basic level of health care. This entitlement arises from the concept of respect for people as beings created in God's image and God's desire that people be whole."

—Task Force Report

ing our values and beliefs about health care" that would discuss the need for "access to a basic level of health care for all people" (Brunk et al. 1991:6). These ideas, and especially the reference to justice in the use of health care resources, clearly echo the sentiments of the Organ Transplant Task Force.

A second goal included developing a program that "shares medical expenses across participants without the features of insurance" (Brunk et al. 1991:14). Designed to emphasize the concept of sharing and mutual accountability, this would be a nonregulated postassessment plan in which money to pay a claim would be collected only after the claim had been incurred. Ideally, it would be administered largely at the local level. This idea of a congregational sharing plan to serve as an alternative to traditional insurance resonates closely with recommendation 6 of the Organ Transplant Task Force which called for MMA to reconsider the nature and form of mutual aid and to explore alternatives to the insurance model. As of March 1992 (the time of the writing of this article), MMA had not developed this plan.

A third component of the strategy called for the development of a limited-benefit/low-cost health plan: "To improve access to basic health care by providing a financially viable plan with reduced premiums, some catastrophic coverage, a preventive care benefit, and some aspect of the fraternal programs" (Brunk et al. 1991:8). This product was subsequently developed and offered in September 1991. It includes coverage for inpatient hospital expenses, outpatient surgical and catastrophic expenses, an annual \$75 preventive care benefit (for routine physical examinations and tests), and limited first-dollar benefits (no deductible) for accidents. It also features a per-occurrence deductible (choices of \$250, \$500, \$1,000), 80/20 coinsurance, and a \$1 million lifetime maximum benefit. Maternity coverage is not included in the standard package, but a rider offering a set maternity benefit may be purchased. The plan does not include coverage for normal pregnancy and elective Caesarean sections; marriage, family, or individual counseling; treat-

ment for mental or nervous disorders; treatment for substance abuse; outpatient diagnostic X rays or laboratory tests not performed as part of preadmission testing, or outpatient prescription drugs (Brunk et al. 1991:8-9).

Inasmuch as the goal of reducing benefits was to improve affordability in order to allow more people access to the coverage (the basic benefit plan is 40 percent less expensive than the MMA comprehensive health plan), the Individual Health Alternatives strategy follows the Organ Transplant Task Force recommendation calling for research into the feasibility of a limited-benefit health plan. However, a closer look at the benefit structure of the plan indicates that the two groups used very different concepts of *basic health care*. Most notably, the plan includes full coverage for organ transplants, health care which the Organ Transplant Task Force clearly defined as not basic. Furthermore, although the plan does provide a minimal preventive-care benefit, it incorporates a variety of features, like per-occurrence deductibles and no coverage for prescription drugs, that discourage utilization of basic medical treatment. In short, the plan is more effective at providing catastrophic coverage than access to basic care. What can account for these differences?

In order to determine what people wanted and could afford in a health insurance product, MMA retained a marketing consulting firm to survey current MMA members and prospects who did not have employer coverage. Among other things, the survey was designed to test the market demand for a basic benefit plan and determine what features such a plan would include. Support for developing a basic benefit plan was confirmed, with 58 percent of the respondents preferring a basic insurance policy and only 37 percent preferring a comprehensive policy (Midwest Marketing Research 1991:35). Respondents were also asked what types of coverage they would be willing to give up in order to reduce premiums. The following table shows responses to the question (Midwest Marketing Research 1991:34):

Maternity Coverage	63%
Psychiatric Coverage	40%
Outpatient Prescription Drug Coverage	38%
Routine Office Visits	36%
Major Organ Transplants	20%
Outpatient Surgery Coverage	8%
None	18%

The results of this telephone survey became important in the product design of the limited-benefit plan. At the risk of oversimplification, the approach was to begin with a standard comprehensive health policy and eliminate benefits in the order of client preference until the premiums could be reduced by 40 percent. As a result, the basic benefit plan will pay for a major organ transplant but will not pay for the penicillin to cure a routine ear infection.

This curious outcome points to the important distinction between defining or providing basic health care and financing it. Survey respondents were not asked to define basic care, nor were they asked to comment on the issue of justice and access to health care. They were asked questions about what they wanted in a health insurance product. The responses indicated they were willing to personally finance regular and less expensive health care that could be planned and budgeted for, but they wanted insurance to cover more catastrophic accidents or illnesses that posed a severe financial threat.

It is this distinction that explains the difference between the Organ Transplant Task Force and Individual Health Alternatives Task Force understandings of basic care. The common use of the term *basic care* masked fundamentally different concepts or questions. The Organ Transplant Task Force operated from within a normative framework, relying heavily on the language of entitlement and distributive justice. The principal questions concerned what level of care people are entitled to and how resources are to be distributed. In contrast, the Individual Health Alternatives Task Force addressed the pragmatic concern of health care financing, specifically through the medium of insurance.

Its goal was to offer an affordable, marketable health insurance product. To state it another way, the Organ Transplant Task Force started with the question "What *health care* should people have?" whereas the Individual Health Alternatives Task Force began with "What type of *insurance coverage* is it that people want and can afford?"

The Insurance Industry and Health Care Reform

WHAT CAN OR SHOULD INSURANCE COMPANIES contribute to the discussions on ethical issues related to health care and health care delivery? As the vehicle through which the vast majority of Americans finance their health care, private health insurance is an integral part of our present health care system and the crisis it faces. Thus insurance companies will undoubtedly be affected by any changes or reforms to the system. Moreover, as an enormous enterprise with a formidable political lobby, the insurance industry will quite likely participate in designing and implementing reforms. If insurance companies are indeed central players in the reform process, we must very consciously consider what to expect from these powerful financiers of health care.

The health insurance industry is inextricably linked to the health care crisis through the problem of access, the issue at the core of most discussions about the health care crisis and reform. We are accustomed to equating insurance coverage, whether it be private or through a government entitlement program such as Medicaid and Medicare, with access to health care. If a person has insurance coverage, we assume they have at least some access to health care. Evidence of how thoroughly we accept this premise can be seen in a special issue of the *Journal of the American Medical Association* (May 15, 1991) devoted to the topics of health care access and reform and appropriately titled "Caring for the Uninsured and the Underinsured."

Even the grim statistics employed to depict the magnitude of the access problem are typically given in terms of the number of persons uninsured. Estimates of the number of uninsured in the U.S. range from 33 million (Bailey 1991:104) to 40 million (Callahan 1990:73). According to physician Byron Bailey, 6 million of the uninsured have incomes below the national poverty level but are not covered by Medicaid, 3 million are medically uninsurable, and 24 million are employed but cannot afford the high cost of health insurance (Bailey 1991:104). The rate at which the number is increasing is as alarming as the number itself. The total number of uninsured has risen 24 percent over the last decade while the number of uninsured children has increased 40 percent (Blendon and Edwards 1991:2563).

This growing crisis has incited an outcry for health care reform, a process that will inevitably and profoundly affect the insurance industry. At one extreme are proposals that would virtually eliminate private health insurance, replacing it with a public single-payor system. At the other are several proposals that would rely heavily on the private health insurance industry. Reforms proposed by the American Medical Association (Todd et al. 1991:2504), the Pepper Commission (Rockefeller 1991:2508), Physicians Who Care (Bronow et al. 1991:2512), and a myriad of individuals call for mandated (or highly encouraged) employer coverage to be supplied largely by the private sector. Others, such as the Heritage Foundation, argue for mandated individual private insurance for catastrophic coverage, at least partially funded through tax credits (Butler 1991:2542). Even some proponents of government-sponsored insurance to provide universal access allow for some involvement of the

private insurance industry (Roybal 1991:2456; Fein 1991:2557).

If they are to be involved in reforming the health care system, what can or should private insurers contribute? The question is not how will they use the industry's significant political lobby, but rather

how can they contribute toward designing and implementing a health care system that is both effective and just? To look more closely at this question, I will assume a scenario in which health care reform takes the form of a public-private partnership in which private insurance covers the majority of citizens through mandated employer or individual coverage.

Though I am not suggesting that this type of

reform will be the most effective or just, there are at least three reasons to make use of this scenario. First, because it has the backing of several influential groups including the American Medical Association, the Health Insurance Association of America, and the Heritage Foundation, the likelihood of such reform is considerable. Second, reforms of this sort create a prominent role for private insurance. Finally, it can be argued that utilizing private insurance to achieve universal access changes the nature of relationships and obligations within the health care system.

This last point is too often neglected in discussions of health care reform. The traditional obligations in the insurance industry are the legal (contractual) obligations owed to clients and the fiduciary obligations owed to stakeholders (stockholders, shareholders, members, and so on). Reform that alters the market system and creates a reliance on the private insurance industry to provide an entitlement widens this range of obligations. As a result of such reform insurance companies will ac-

With their high cost and limited availability, transplants were viewed as symbolic of the excess and individualism in health care which thwarts every attempt to provide basic care and equality in the health care system.

quire the obligation to sustain a system in which all people have access to health care. Furthermore, inasmuch as employers or individuals would be legally (if not morally) obliged to purchase insurance, one could argue for a corresponding obligation on the part of insurers to make the fulfillment of this obligation possible.

Assuming the reform scenario described above, I would like to submit three propositions in response to the question of what contributions we should expect from private insurers. First, we should not look to insurers to help us define the basic (minimum, adequate) level of health care, a concept crucial to most reform proposals. Second, we should insist that insurers help improve or sustain access to health care by making insurance more affordable. Finally, we should challenge insurers to play a role in shaping the values that will lead to a more just health care system.

Insurance and Basic Care

UNDERLYING THE PUSH FOR REFORM is the conviction that we have a moral obligation to provide everyone with access to basic health care—that there is a minimum or adequate level of health care to which all people are entitled. Unfortunately, advocates for reform generally find it much easier to assert or accept this obligation than to define the concept of basic care itself. Nevertheless, nearly all propose that access to basic care should be guaranteed through some sort of insurance mechanism.

Why, then, if insurance is to be the vehicle, should we not look to insurers to help us define this basic level of health care? First, commercial insurance is a market-driven industry and thus is not designed to dispense entitlements. Second, in-

surance is a vehicle for financing, not for providing health care.

Physician Steven Miles's distinction between the implicit and explicit meanings of basic care helps to clarify how a market orientation limits the insurance industry's ability to define basic care. According to Miles, the implicit meaning of basic care is manifest as a normative conviction that health care is a basic or fundamental human right. The implicit

meaning establishes or defines the community. "Here we draw the line not between services but inclusively around our community" (Miles 1990:1). In short, it implies universal access.

Though insurance companies strive to expand their markets and increase the number of people they insure, they do so exclusively,

using both health status and income to define the community. The management of a risk pool is a highly selective process with tremendous competition for individuals or groups that present a good health risk. In contrast, persons who are unhealthy are charged higher rates, refused coverage for preexisting conditions, or denied coverage altogether. As Dr. Timothy Johnson, medical consultant to ABC News, stated in a February 1992 "Nightline" program, health insurance has become a "risk avoidance industry." In addition, income has increasingly invaded the selection process as rapidly rising premiums make quality insurance unavailable to a growing portion of the population. The private insurance industry is best equipped to provide not universal coverage but coverage for that segment of the population that is healthy or affluent.

The explicit meaning of basic care is descriptive, focusing attention on what is to be provided, not who is to receive it. It involves "developing a rational system of healthcare priorities to define a core set of medical benefits which are distinguished from non-

**"Often the [transplant] patient
merely trades one set of
problems for another. This
dark side to transplants is very
real but not well publicized."**

—Task Force Report

core benefits" (Miles 1990:1). This definition implies that the value of treatments can be ranked relative to one another and that the level of basic care is relative to the resources available. In fact, the very concern with basic care arises only within the context of limited resources. If we had the means to provide everyone with all the care they would need or want, there would be no need to distinguish between basic and nonbasic health care.

Several systematic approaches to defining this set of core benefits or services have been proposed. Most include a cost-benefit analysis of treatments, the results of which are further refined through some process of value judgment (Klevit et al. 1991:14; Eddy 1991:786). In most cases the final outcome is used to develop a prioritized list from which treatments to be provided can be selected based on the number of people to be served and the resources available. An example of such an approach can be found in Oregon where the Oregon Health Services Commission has been working since 1988 to produce a prioritized list of health services to be used to define the level of care which will be provided to all persons under the federal poverty level (Klevit et al. 1991:141).

In contrast, insurance companies are more apt to define basic care in terms of a limited benefit package, the contents of which are determined by market demand. The question for insurers is not "What health care are people entitled to, and what can society afford to provide?" but "What benefits do people want, and which ones are they able to purchase?" Instead of the highly rationalized and systematic cost-benefit studies, insurance companies are more likely to employ market surveys. These surveys are designed to test consumer preferences, not to elicit views on entitlement or justice in health care.

The equation of insurance with access to care masks a second factor that limits the insurance industry's ability to define basic care: traditional health insurance is not designed to provide health care but to finance it. More precisely, it is designed to protect individuals from financial loss resulting

from sudden or unexpected accident or illness. Characteristics of risk like uncertainty and significant potential loss are fundamental. There is little to be gained, for either the insurer or the client, by insuring health care that is not uncertain (for example, preventive care) or that does not pose a significant financial threat. In these cases either there is insufficient risk to spread or the risk cannot be spread effectively across the population.

This problem is illustrated in the debate over insurance coverage for childhood immunizations. Health care professionals are frustrated with insurers' reluctance to cover these clearly cost-effective treatments.⁶ According to Donald A. Henderson, M.D., former dean of the School of Hygiene and Public Health at Johns Hopkins University, it is paradoxical that "insurance companies, which are endeavoring to minimize health care costs, are not willing to pay for one of the most cost-effective procedures in the entire medical armamentarium" (Skolnick 1991:2454). The insurance industry's response is not to deny the cost-effective nature of the immunizations but to assert that it is not appropriate for insurance to finance routine, predictable needs. Providing coverage for immunizations has the net effect of merely "trading dollars." That is, clients would be able to provide immunizations for their children for about the same amount of money as they would pay for insurance coverage for the services.

The Insurance Industry and Cost Containment

THE INTERDEPENDENCE OF HEALTH CARE COSTS and access is undeniable. The number of uninsured has significantly increased during the past decade, despite the fact that the amount of money we spend on health care has risen dramatically. Again, the statistics are shocking. Between 1980 and 1987 total U.S. expenditures on health doubled, per capita expenditures rose 87 percent, and the expenditures as a percentage of gross national product (GNP) rose

from 9.1 percent to 11.2 percent (Callahan 1990:269). Projections are that the cost of health care will reach \$1.5 trillion or 15 percent of our GNP by the year 2000 (Callahan 1990:265). Despite our best intentions, we simply will not be able to sustain a system that guarantees universal access if we cannot contain this runaway medical inflation.

Under the current system, the relationships among health care costs, insurance, and access are extremely complicated. The commonsense notion is that cost containment improves access through insurance. That is, if insurers can keep costs down, premiums can be maintained at lower levels, and more people will be able gain access through affordable insurance. To this end a number of cost-containment measures have been implemented, including prospective payments (preestablished payment schedules based on condition) and various managed-care programs such as preadmission certification, large-claims management, and capitation arrangements. In this last arrangement, providers are paid a fixed amount per person instead of being reimbursed on a fee-for-service basis. However, the continued rapid rise in health care expenditures would suggest that these programs have been only marginally successful, if at all. Furthermore, there is some indication that instead of reducing the actual cost of care, these measures have primarily curtailed the cost shifting that allows providers to render care to the uninsured. Thus to a degree they have aggravated, not alleviated, the problem of access (Carson 1991:94).

Effective cost containment will be necessary for the success of any reform intended to provide and sustain universal access. Failure to manage our limited resources will mean that we can provide less to people or that we can provide for fewer people. In either case, we face the tragic choices associated with rationing. Even though limited resources will eventually force us to ration health care regardless of our management techniques, effective cost containment that improves efficiency in the system can help us to avoid or at least to delay some of the tragic rationing

decisions. As ethicists Reinhard Priester and Arthur Caplan argue, this makes cost containment ethically imperative:

The stakes are [so] high—life and death, permanent disability or the restoration of function—that every effort must be made to resist or at least delay the implementation of rationing policies. (Priester and Caplan 1989:922)

As mentioned, cost-containment strategies are not new to the insurance industry. Companies employ managed-care programs like preadmission certification, utilization review, preferred provider arrangements, and health maintenance organizations in order to develop a competitive edge in the marketplace. Nevertheless, under a scenario of universal access achieved largely through mandated private coverage, cost containment is spurred on by the two new obligations noted earlier—to sustain a system in which all people have access to health care and to make the fulfillment of the employer's or individual's obligation to provide coverage attainable.

The Insurance Industry and Health Care Values

DESPITE OUR BEST EFFORTS at cost containment, health care reform will not be successful unless we can modify the misguided values or assumptions that support our current health care system and fuel the crisis it now faces. If we fail to alter these values, then our most creative reforms will not blossom into long-term solutions.

Bioethicist Daniel Callahan has articulated this position clearly and convincingly in his book *What Kind of Life: The Limits of Medical Progress*. In that important work he identifies and challenges two ideals that drive our current health care system:

One of them is that it is a plausible and worthy goal to attempt to meet all individual health needs, to seek a cure for all disease. The other

is that the quest for this goal is an economically feasible one if only sufficient efficiency is brought to bear, an efficiency that can be enhanced by basic biomedical research and ways of providing healthcare that are more cost effective. (Callahan 1990:29)

Callahan goes on to argue that a health care system based on these ideals is flawed, not only because it is inefficient and poorly designed but because it seeks the wrong ends (Callahan 1990:29–30). I want to build on the two themes he identifies, taking a special look at how they relate to the insurance industry.

Individualism pervades our health care system, affecting not only the ends we seek but also the means we choose to pursue them. It is certainly evident in our choices for financing health care. One need only observe its advertisements to understand that the insurance industry believes customers purchase insurance predominantly out of self-interest. That is, they purchase policies not to enhance the community good but to assure their own access to health care and protect their personal financial assets. Even MMA's advertisements reveal this bias: "You get the care *you* need most," "*You* get excellent protection . . . a good value for *your* dollar," "Save money—and get protection *you* can count on" (emphasis added).

How can the insurance industry help to shape this value into a more community-oriented approach? It can begin by reshaping its appeal to the market. Insurance companies will continue to be primarily market-driven, but we should not underestimate the power of advertisement to shape the marketplace. Insurance can be promoted as a means for expressing social concern—a way of helping others as well as protecting yourself. Insurance, particularly if it is the vehicle through which we provide universal access, is a method of spreading risk

across the entire community. If the value of community can be cultivated in consumers, then insurers will not be afraid of saying the obvious: "Some of your premiums went to help your neighbor who needed care."

In addition to reshaping the market, insurers could rediscover and develop underwriting practices that are more consistent with community values. A return to community-based rating, in which the

composite risk characteristics of the community are considered (instead of those of particular individuals or groups), or restrictions on the extensive use of preexisting conditions clauses are changes that would demonstrate a community orientation. More extensive and creative use of reinsurance could be used to spread risk further and stimulate experimenta-

tion with self-insurance, where local groups could assume the functions, responsibilities, and liabilities of an insurer.

The assumption here is not that private insurers will willingly make these changes but that they will be morally obligated to do so if they advocate reform which changes market systems to their benefit and places them in the position of providing access to health care deemed an entitlement. In the Netherlands, where public, not private, insurance pools are part of a system of providing universal access, the obligation of individuals and employers to provide coverage creates a corresponding obligation on the part of the insurers to provide that coverage.

In practice, the obligation to accept all moderate and low-income persons means that medical underwriting,⁷ exclusion of preexisting conditions, exclusion of small employers, and exclusion of employers in certain industries are considered unethical. . . . The

**If the value of community can
be cultivated in consumers,
then insurers will not be afraid
of saying the obvious:
"Some of your premiums went
to help your neighbor who
needed care."**

result is community rating, based on income, with the premium shared between the employer and employee on an equal basis. (Kirkman-Liff 1991:2497)

If the private insurance industry is called on to fulfill this same role in the U.S., companies will have similar obligations.

Callahan's second point draws attention to our virtually unquestioned faith in the progress of science and the power of management. We believe that science has the ability to solve almost any technical problem and that management skills allow us effectively to control economic contingencies. Thus we are led to deny the reality of limits and the ultimate need to ration health care resources. Callahan argues that sustaining a guaranteed level of health care is feasible only if we set a limit on the quest for cure as well as establish a decent minimum level of health care.

The insurance industry may find it difficult to challenge these deeply held beliefs. Setting limits on consumer demand will be an arduous task for companies that are intensely market-driven. We cannot take lightly the argument that saying no to customers could be risky. In a competitive marketplace there will always be some company ready to fill the demand. It may also be difficult for insurance companies to strike a balance between their drive (and obligation) to manage and contain costs, and the need to accept the reality of rationing. Insurers must find a way to pursue managed care and other cost-containment programs vigorously without being seduced by the hope that they will keep us from ultimately having to make difficult decisions. Despite these obstacles, the insurance industry can

Market surveys that ask clients about desired benefits but fail to include clear information regarding cost of the benefits only perpetuate the idea that there are no limits and that it is possible for people to have whatever health care they are willing or able to pay for.

work at helping to reshape this ideal in at least three areas: education, regulation, and product development.

First, in the area of education individual insurance companies and industry associations like the Health Insurance Association of America should

endeavor to provide people with information about the impact of their decisions. Insurance removes individuals one step from having direct responsibility for their health care decisions. Insurance companies are a rich source of information regarding the cost of health care and specific treatments. They should make this information readily available to clients and find ways to disseminate it. Market surveys that ask clients about desired benefits but fail to include clear information

regarding cost of the benefits only perpetuate the idea that there are no limits and that it is possible for people to have whatever health care they are willing or able to pay for.

Second, the insurance industry should work with legislators and regulatory agencies to develop laws that reflect the changing nature of the health care system and the insurance industry's new role in it. Specifically, state-mandated benefits should be set at a level determined not by consumerism alone but by a recognition of resource limitations and health care needs. Insurers should support reform proposals that connect the level of benefits with a determination of what constitutes a basic level of health care. Only in this way will we be able to bridge the gap between defining basic health care and financing it.

Finally, insurers should address the concerns of justice in the allocation of health care resources and

offer products that are more community-oriented and cost- and resource-sensitive. These products would feature extensive use of cost-containment programs and limited benefits selected on the basis of efforts to define ethically a basic level of care. Product offerings not only should respond to changes in values reflected in the market but should be used to help change the market itself. The processes of reshaping foundational health care values and developing products should support and complement one another.

Conclusion

WE STARTED WITH TWO QUESTIONS: (1) How can health insurance companies put ethics into practice? and (2) Can they be advocates for justice and reform in health care?

The experience of Mennonite Mutual Aid and its Organ Transplant Task Force suggests it is possible for insurance companies to address these issues through educational activities and, to a more limited extent, through product development. At the same time, the experience also draws our attention to regulatory, fiscal, and marketing concerns that limit the ability of insurance companies to implement substantial changes. At MMA this is felt as a tension between the church and business, between the prophetic and the pragmatic. Though other terminology may be used, a similar tension exists for secular commercial insurers.

The high costs of health care and the limited access of many Americans to even basic care are charting a course toward the inevitable reform of our health care system. As a powerful constituent in the current system, the private health insurance industry will unquestionably be involved in shaping this reform and will probably retain a role in the restructured system. Though somewhat limited by the forces mentioned above, specifically its free-market orientation, the industry can contribute to the reform and stabilization of the health care system through a concentrated effort to control cost and reshape the foundational values of the health care system.

Most important, we must recognize that reform which secures a position for private insurance in a restructured health care system will create new obligations for the industry. The explicit moral tenet behind reform is that people are entitled to a basic or adequate level of health care, that society is obliged to provide at least that much. If the insurance industry accepts and benefits from a central role in providing universal access to that care, then it must accede to this assumption and the obligations it entails. These obligations are to sustain a system in which all people have access to health care and to assure that those groups or individuals who are required to provide insurance for themselves or others are able to do so. If insurance companies pay serious attention to these obligations, they will be taking a significant step toward putting ethics into practice. ☸

NOTES

1. Because of its tax-exempt status, MMA is able to channel money that would normally go to pay taxes back to its members as part of the fraternal program: aid is given in the form of financial assistance (for medical bills, health insurance premiums, or adoption expenses) and educational programs.
2. Task force members were Willard Krabill, Beth Landis, Michael Boge, John Yoder-Schrock, Carol Suter, Helen Alderfer, Jerry Troyer, Sid Richard, and Scot Yoder.
3. A *reinsurer* is an insurer that accepts a portion of the risk underwritten by the primary insurer. For example, on a \$1,000,000 lifetime maximum policy MMA may retain the first \$250,000 of the risk but reinsure the remaining \$750,000. The insured, however, is only aware of the contract with MMA.

4. These programs allow insurers to make sure that the insured is receiving appropriate cost-effective medical care. Precertification (preadmission certification) is a process in which an insurer certifies the appropriateness of the medical treatment and the expected length of hospitalization for the condition in question prior to the hospitalization. If there is potential for a large claim, the insurer may become even more involved in managing the care.
5. According to the actuarial firm Milliman and Robertson, Inc., the cost of a kidney transplant is significantly less than the cost of chronic hemodialysis and peritoneal dialysis treatments (Brink 1990:25). As a rule, however, transplants are much more expensive than other treatment modalities.
6. According to the National Vaccine Advisory Committee, a 1989 Health Insurance Association of America survey revealed that 45 percent of employer-based health insurance plans and 62 percent of preferred provider plans covered basic childhood immunizations (Skolnick 1991:2453).
7. Medical underwriting is the process through which an insurer determines whether or not and on what basis it will accept an application for insurance. It usually involves a review of the insured's medical history and current health status, and can result in denial of coverage, limitations on coverage, or increased premiums.

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“I don’t think an ordinary doctor thinks of transforming the body. He can make the body more perfect, he can make the body cleaner, he can make the body free from disease. But he’s not trying to develop the power and perfection of the spirit. This is a new concept.”



Photography by
John Nordell

Spiritual Consciousness and Healing

An Interview with Govindappa Venkataswamy

For much of his life Govindappa Venkataswamy has been a pioneering eye surgeon. In 1976 he founded the Aravind Eye Hospital in Madurai, deep in south India, where today more than 50,000 major eye operations are performed each year, most of them for free. The hospital, the largest and most productive eye-care facility in the world, is also recognized for its resident training program and its mobile eye camps in rural villages.

Venkataswamy is a disciple of Sri Aurobindo and the Mother of Pondicherry. Sri Aurobindo, an Indian nationalist from the Pondicherry Territory in southern India, was a seer and a poet. He was also founder of the philosophy of cosmic salvation through spiritual evolution. According to Venkataswamy, the teachings of Sri Aurobindo and his close associate the Mother of Pondicherry are in continuity with those of the ancient sages of India: they rest on the belief that behind the appearances of the universe lies the Reality of a Being and Consciousness, a Self of all things, one and eternal. All beings, in this view, are united in that One Self and Spirit but divided by a certain separateness of consciousness, an ignorance of their true Self and Reality in the mind, life, and body. It is possible through psychological discipline to remove this veil and become aware of the true Self, the Divinity within us and all things. It is these spiritual teachings about the higher consciousness that Venkataswamy has tried to instill in the daily practice of medicine at Aravind, and visitors to the hospital often remark upon the sanctity of its operating rooms. "Modern technology combined with spiritual consciousness is the need of the day," says Venkataswamy.

Venkataswamy has suffered from severe psoriasis, and acute rheumatoid arthritis has crippled his fingers badly, yet he trained himself to hold a surgical knife and use the operating microscope so that eventually he was able to perform a hundred or more operations at a stretch. He headed the eye department at Madurai Medical College for 20 years and has received the Helen Keller International Award and the Padma Sri Award, one of the highest honors given by the government of India in recognition of an outstanding contribution to the country or its people in any field. He is also a director of the Seva Foundation, which is devoted primarily to service projects, many concerned with the prevention and cure of blindness.

In the spring of 1991, Venkataswamy visited Harvard Divinity School to deliver the Harold M. Wit Lectures, which were established to bring to the university "unusual individuals who radiate in their thought, work, and being . . . spiritual qualities and values" and to examine the question of living a spiritual life in the contemporary age. Free-lance journalist Missy Daniel interviewed Dr. Venkataswamy for Second Opinion.

Second Opinion: I'd like to begin where you began your lecture the other day, talking about your father. Can you explain the influence he had on you, as a doctor and as a human being?

Venkataswamy: My father was a farmer in a small village in the southern part of India. He had very little schooling, only two or three years. He was a deeply religious man. Some of the sects of Hinduism have various caste marks, and he used to have a Vaisnava mark on his forehead every day. The Vaisnava mark indicated that he was a member of the Hindu sect devoted to the cult of Vishnu, a god of the Hindu triad. Once a month, traditionally, he walked to the temple of our family deity, about 30 miles each way. People used to take a pot of melted butter to be offered to the gods. They would light all the temple lights with this melted butter.

My father was a strong follower of Gandiji [Gandhi]. He was a hard disciplinarian. He wouldn't allow people to tell lies, and people were not capable of telling lies in front of him. He was straightforward, and he had a vision of educating his children, which other people usually just did not think of doing. He built a house that was far more advanced in planning and execution than what a villager would normally build. He was the trustee of a

“I go to the
meditation room
and ask—
not in words,
but in a silent talk
with God—
that I be
a better tool,
a receptacle for
the divine force.”



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temple. The temples, built hundreds of years ago, are now usually taken over and managed by the government. The state appoints somebody as a trustee—a religious man, acceptable to the community—to take care of the property. As trustee, my father built a nice hall with granite at the temple near our village. He also knew about new techniques in farming and agriculture. That was the character of my father.

Second Opinion: Was he a spiritual man?

Venkataswamy: No, you can't call him that. He was a religious man.

Second Opinion: What is the difference?

Venkataswamy: You see, the religious man adopts the normal dogmas and codes. He goes to church regularly. If today is the Sabbath day, he knows what sort of food to eat, what not to eat—that is the religious man. A spiritual man is more in touch with the experience of the soul or the experience of higher consciousness. You can have a spiritual man who does not follow any of these ethics or codes, like some of the mystics.

Second Opinion: Would you be a very different person were it not for your father?

Venkataswamy: Certainly, certainly. I think he brought me a

strong sense of discipline. For instance, he was a very small farmer, with very little money, but he kept a clear account of everything he did. It was the duty of the children to maintain the accounts. Everybody knew how much debt we had, how much money we were making from the farm, how much the bullocks cost, how much produce we had. This became a very common practice in our family. That was the strong training that he gave us.

I was 32 when he died. I was the eldest in the family, and in a family system like ours, I was responsible for educating my two younger brothers and two younger sisters, for organizing and fixing their marriages—that is the usual custom we have—for finding suitable partners for them. I looked after all of them. I was the head of the family.

I was not married, because of my arthritis and skin trouble. Now my brother takes care of me, and I stay with him all the time. His children are as much attached to me as they are to him. Everybody feels that I am one of them. That sort of joint family system works wonderfully, but it is breaking down in India now. People are finding jobs and moving out of the traditional village life. But it is still very important for me. My brothers and sisters still usually ask my advice—Can this girl marry this boy? and things like that.

Second Opinion: And what about your family guru?

Venkataswamy: This is our usual tradition, that each family has a guru. The guru comes and visits once a year, and you go to see him whenever you go to the temple. The guru looks after you, advises you about worldly life—whether you can purchase this, whether you can marry this girl. The guru is also supposed to advise you about the life beyond, heaven or hell. So a guru is like a traditional pastor or priest, you could say. Normally a guru has 50 or 60 families who live in 15 or 20 places. Once a year, the guru and his family come with a bullock cart, and the disciples provide the bullocks. My family would provide the bullocks to take the cart to the next village, where the guru's other disciples are. Like that, the guru makes a tour, and it may take two or three months. It is very nice to see. Some of them were good scholars. They stayed in the disciples' houses, and they cooked for themselves. They didn't eat with us. Whatever they cooked, they gave a portion as an offering to the deity and to the disciples also.

Second Opinion: And is the son of your father's guru now your guru?

Venkataswamy: My father's guru didn't have a son. In those cases the son-in-law may become a guru, but that system is also breaking down now. The traditional systems of guru and disciples are slowly disappearing with the modern movement of people from the villages, with the

coming of industry, and so on. We have no family guru right now, so I adopted Sri Aurobindo and Mother [the Mother of Pondicherry] as my gurus, but it's a different tradition now. I "adopted" them. It is not hereditary.

Second Opinion: You said you met Gandhi several times. Would you talk more about those meetings and about his influence on you?

Venkataswamy: At the end of 1944 I joined the army and went for training as a doctor, a medical officer. Gandhi was in prison at that time. When he was released from the prison, he came to stay with one of his disciples in Poona, where he had once been imprisoned in the Aga Khan's palace. A friend and I knew he was staying there, so we went to see him. I asked him if there was any message for us—and we were working in the British Army at that time! He was fighting the British! He said, "Is that good for you, to get advice from me now?" He was a very nice man. He gave his autograph, which he used to charge money for—five or ten rupees. That money went to help the untouchables, the backward classes in society at that time. He collected a lot of money. I don't have the autograph anymore. I'm afraid I lost it somewhere.

I also saw Gandhi in Delhi subsequently, when I was in the army. He would stay in Birla's house. Birla was a big industrialist, like Henry Ford.

That's where Gandhi was shot and killed, in Birla's house. But then he would also stay with the municipal janitors, and every evening and morning he would offer prayers. There was an open space, and they put up a platform. He went there at a regular time and started his prayers, and people used to go and listen. He did that all his life. I went to one of those prayer meetings in Delhi. And once when I was still a schoolboy, he passed through my small town. It was a big thing for us to see Gandhi. That must have been about 1931 or 1932. I also used to see him in trains, traveling from place to place.

Second Opinion: How did he influence your medical practice?

Venkataswamy: One thing was his stress on moral values: speaking truth all the time, leading a simple life, practicing celibacy, not coveting others' property, and more than anything else, having the courage and confidence to fight injustice without violence. That was a very big thing for us, because the British were ruling at that time, and they had created terror in the minds of the people, that we couldn't live without British support. Gandhi was able to wipe out that feeling of dependency on the British, and all with love and kindness, not by threatening people, like Saddam Hussein. His whole approach to the traditional Indian culture was love. He wanted British people to live well. He didn't want them to

suffer. He said that all people have to live well. That doesn't mean somebody can dominate and exploit other people.

Second Opinion: Is it true that he would have nothing to do with the modern practice of medicine?

Venkataswamy: He was educated in England, you know, and he was scientific in outlook. He did a lot of research on food and nutrition. He said that the body had its own capacity of resistance, and in order not to break it, he adopted nature cures. But that was very rational. It was not some dogma. Very rational, Gandhi was. At one time he wrote that he would not take cow's milk. But then he found out that his body would not be able to survive, and he took to goat's milk. He did a lot of research, and his conception of disease did change. When somebody demonstrated that malaria is transmitted by mosquitoes, for example, he appreciated that, and he treated it.

Second Opinion: It's also been written that Gandhi's own nursing skills were extraordinary.

Venkataswamy: Wonderful, yes, they were wonderful. I didn't live with him, but some of my friends did. We were called Gandhiites; that is, we were wearing these hand-spun clothes all the time, and we were not supposed to be violent, not tell lies, not smoke, not drink—a certain code of conduct, like what you

expect of a priest. We observed celibacy in life before marriage. No sex at all. Some of these virtues were indoctrinated in us.

Gandhi had, apart from his political struggle to fight the British, several constructive programs. One was care of people with leprosy, and he started leprosy colonies. One of his disciples had terrible leprosy. So he put him in his own ashram [the secluded dwelling of a Hindu sage], in a separate hut, and nursed him morning and evening. That was a tremendous job for a man who was supposed to take care of the whole country. He was loving and kind, and he often took care of people in the ashram.

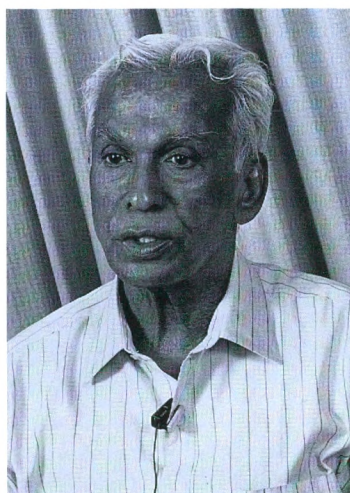
Second Opinion: Was he a religious man or a spiritual man?

Venkataswamy: I think you can say he was more of an ethical-religious man, in the sense that he had his strong ideas about virtue and vice. He used to read *Gita*, quote *Gita*, every day. [The *Bhagavad Gita* is the first-century Sanskrit philosophical dialogue that expounds the duties and customs basic to Hinduism.] He had codes of conduct, but he was always quite open. It's clear in his autobiography that he was searching for truth all the time. In that way, he was a wonderful man. He could meet a person like Jinnah, the founder of Pakistan, and if Jinnah wanted to eat beef, Gandhi said, "yes, go ahead." But Gandhi would not eat meat. He was very friendly and very loving to lots of

people, people who were opponents, like Britishers. That was his nature. There were people who were very greatly opposed to some of his ideas—some of his Communist friends, for example, had gone to Russia and come back with ideas about making India a Communist country. He was loving and kind to them—he loved them in extraordinary ways—yet he strongly opposed them also, without creating hatred or ill will. That was the strength of Gandhi.

Almost every day you would read what Gandhi had said about this, what Gandhi had said about that. We were dreaming of a country, of Gandhi's nonviolent nation. He said that the government should be nonviolent and that everybody's basic needs should be met: there must be proper nutrition, every child must be taken care of, good health must be provided. Gandhi was very clean about his habits, very hygienic. He always was careful about the water he drank, and he wanted to have simple toilets for everybody. He stressed sanitation. Scientific nutritionists used to consult him. He said that meat is not necessary for the body, but milk is essential for the body, some sort of animal matter. He was very open all the time. You could always discuss with him, and he enjoyed it. His codes of conduct blended well with the basic discipline of my father—always being truthful and hard-working, leading a simple life.

“You are not thinking of the patients’ social status or the money they are going to pay or what benefits you can get out of them. This relationship is much more at the soul level.”



Second Opinion: Do you read the *Bhagavad Gita* every day?

Venkataswamy: I used to, in those days. Now I read Sri Aurobindo every day.

Second Opinion: What are your own daily spiritual practices?

Venkataswamy: We have a meditation room in the hospital, and I go there at 6:30 in the morning. I ask—not in words, but in a silent talk with God—that I be a better tool, a receptacle for the divine force. Something like, “Let me be a better instrument for your will to be done. Let me not lose my consciousness to some of the instincts—anger, jealousy, egoism.” And I ask how exactly we can have love and compassion for the patients who come to us.

The important thing in Aravind Hospital work is the deep communion we want to make with the ordinary patient, whether it is a villager or a town man or a person who comes from upper-class society. Not intellectual understanding, but a deeper understanding—just like a mother with her child. There is a deep inner communication between a baby and a mother. You want to get to the core of the person so you can tell that this one is anxious, that one is worried, that one is depressed. How exactly can you get into the patients completely? You make them at ease physically and mentally. Then you make them feel that you un-

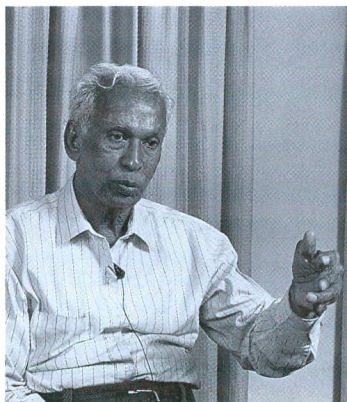
derstand they're uncomfortable and that you are capable of giving relief, whether it is the relief of sight or freedom from the pain. You want to have some sort of inner communication with the patients. You are not thinking of their social status or the money they are going to pay or what benefits you can get out of them. This relationship is much more at the soul level.

Second Opinion: Can you do this, even when you are treating hundreds of people a day?

Venkataswamy: You see, we pray that we have love and goodwill for everybody. It is easily said, but to practice it constantly? You pray for it, but then sometimes you get irritated. Some patient says, "You know who I am? I can do a lot of good things for you," or "I can do a lot of bad things to you if you don't oblige me." I say I will do my best, but the best must come from the heart, not by a command or force or authority. I resent it, but I don't show it. Some would like to say, "I can give much money to this hospital. Take care of me, and forget about all those other people." But what about all the other people? We don't want to slight anybody, and we respect them all. Even this experience helps me to grow spiritually in the sense that I am not tied to the man because he has got a lot of money and power and I want to have it, but I'd like to have some contact with his inner being. And that works wonderfully.

"The mind is only groping now. When you get to the higher consciousness, it is like having daylight.

In the dark, you don't know if there is a wall in front of you or a pit. But once it is daylight, you know."



Second Opinion: How do you understand death and dying?

Venkataswamy: The last time I was with Ram Dass (one of the American founders of the Seva Foundation), somebody asked him to write about what happens after death. Sri Aurobindo and Mother have written a lot about what happens after death. You think that when you die, you will go to heaven or to hell. But Sri Aurobindo and Mother have done such a lot of work on death and life. They divide your being. You have got a physical body, we all know that, and that matter is going to decompose where you bury it. Then you have got your mind. Mind is a different world, the mental world. Then we talk about something called *vital*—every living being has got it. Every being has got desires, love, hatred, compassion—all these things are "vital" values. Your vital being goes to the vital world, like the mental being goes to the mental world. And then the core of you, the soul, the psychic being, goes to the psychic world.

Rebirth is a must. If the soul is to reach the highest consciousness, you must use opportunities given to you for this world, and then succeeding worlds, until the soul evolves higher and higher. The psychic being goes to the psychic or the spiritual world, and before it is born, it decides what to experience. Suppose you don't experience physical power in this birth. In the next birth perhaps you want to have mental ex-

perience, you want to become a scholar. You desire that. And then the psychic being, the true spiritual part of the soul, “assembles” the parts necessary to be born again in a particular, chosen human form.

There are lots of very highly evolved souls waiting to be born on this earth. The earth is the only place where the souls can make their evolution, can progress. In other realms, like angelic realms, there is no evolution. Such beings are happy, but static. So the souls all want to get into human beings, because then the soul has an opportunity for evolution. Mother used to say constantly, “This child has got a wonderful soul. Let us take him and see how we can grow it.” She was not talking about physical appearance, or mental appearance, but something she was able to see from the depth of the soul.

Second Opinion: Are you afraid, then, of dying?

Venkataswamy: You see, I’ve not come to the stage of someone like Sri Aurobindo, or Ramana Maharishi, a contemporary saint. I’m still a modern being, and so I am afraid of dying, of leaving all this. Not long ago my uncle died, my mother’s brother, the last of that generation in the family. Even at 82 or 83, he suffered a lot, but he still wanted to live. But it’s said about Sri Aurobindo that he decided to die so that the supramental power, the supermind, could come down into him.

He sacrificed his body. Now it’s said that he exists in the earth’s consciousness as a power to heal and do the divine will.

Second Opinion: You’ve often been a patient as well as a doctor. You’ve struggled with severe arthritis, psoriasis, and not long ago with a serious case of hepatitis. What have those experiences done to you?

Venkataswamy: My mother was ill for a long time, and it was difficult for me to leave her. But I had a meeting in Geneva at the World Health Organization, and then I had to come to the United States for meetings of the Seva Foundation. Earlier I had gone to Nepal with Ram Dass to see some of the Seva work there. I think I must have contracted a hepatitis infection there and didn’t realize it. In Geneva I learned that my mother had died, and I went back to India. At that time I was not feeling well. Then, after the Seva board meeting, I suddenly became ill with jaundice. It was so bad that people were afraid I might die, but I had no feeling like that. Something in me felt that I was going to survive. Can you call it a premonition? It was something like that, the feeling that I have got to go through some more experience, perhaps, of growth.

Mother talks about the supramental consciousness, that it is here on the earth now, like a power, like a light, like knowledge, and you are asked or

persuaded to grow up in consciousness, or at least to be aware of it. I have been interested, especially in these last few months and weeks, in how I can get closer to the supramental consciousness. It’s not easy—like walking up Mount Everest, so difficult it is. And to see whether I can change my own body—my skin trouble, the arthritis. I’m just trying it, and I don’t know how long it will take. Nothing has happened so far, but sometimes, you see, you have a feeling that you’re going to get some virus flu. I have had feelings like that. You think, I don’t want to have it, and then you don’t get it. You find that something is going to attack you, and you try to resist it. That is an experience that I have had. But with other troubles, like the arthritis and the skin trouble, I have to learn to work on it and see what I can do.

Some of the spiritual beings could transform their bodies. With the spiritual consciousness can come radiant light. Sri Aurobindo himself was dark-skinned like me, but when he came to higher consciousness, his body was golden and shining. Higher consciousness changes the physical appearance of people. This is one of the things that is really exciting for people: how to perfect the body—and not in the sense that an athlete can do it, though that is also perfection. Some people want to have muscles, dexterity, gymnastic skills. Others want to have endurance. If you read the diaries of

Sri Aurobindo in his early days, you see that he put a lot of emphasis on changing his physical endurance and his body. He fasted for nearly three weeks at a time without losing any energy for his work—he worked in the same way physically and mentally. He could absorb energy from the environment around him. But his body was wasting away because matter was not getting to the body. In the same way, he was trying to exercise his body to be free from gravitation's force—not exactly levitation, but something similar to it. He said, "I tried today and I failed. I'm going to try again tomorrow." He had been experimenting like that. That's really an exciting game, or exercise—like gliding—to see how you can grow up to higher consciousness and see what that consciousness can do.

Second Opinion: You've said that this higher consciousness can affect even our cells. How?

Venkataswamy: We try with our minds and our emotional will to mend our bodies, like a soldier who puts his cells to severe work in a battle. But the cells themselves don't fight. The cells are inanimate. You use your will on the cells to do something. You say, I want to turn a somersault, or two, or three, and you try and they do it. As you grow into the higher consciousness, it is aware that you need a good body. The spiritual force is able to work on the body, and now the cells are

going to respond to that. In life, before humans came, there was a place where the human mind was evolved. It came out as mental consciousness. From ape or from another animal, humans came, and then they began standing on their two feet. They developed necessary changes in their bodies. The mind produced changes in the body, and you had a difference between animal and human, not only in the human's mind, but in the physical posture, the brain, and the capacity to think about it. All these produced changes in the basic body.

Now the same thing is true when the higher consciousness comes. It has to alter the body, not only to perfect it. You see divine appearance, perhaps already in the figure of Christ. From the appearance of a person you are able to make out whether that person is a physical laborer or an intellectual or a spiritual person. The cells in the body respond to the consciousness. They have their own aspirations, and they now have agreed on this higher consciousness. This is the dramatic experiment Sri Aurobindo and the Mother have done. There have been various people, hundreds of saints and seers—whether Buddha, or Christ, or the disciples of Christ—who have realized the divine, but they were not thinking of transforming the body or transforming the mind. Still, that came as a definite step in the process.

All the efforts of Gandhi to lift people up to higher consciousness

could not be sustained. In the same country where there is so much truthfulness, so much non-violence, we still see so much corruption. People could be changed. But unless you are able to lift people up and bring a new being—call it the supermind, or something like that—this change will not become permanent. People will go up, and come down. But once we are changed, we will remain changed. We are able to crawl, then to stand, then to walk. We are not going to crawl again. The higher consciousness, the supramental consciousness, comes, and then a new being has to come. That being will not go down again. That being's mind, his vital, and his body will be spiritualized. But not everyone is going to be spiritualized.

Sri Aurobindo's teaching states that the One Being and Consciousness is involved here in Matter. Evolution is the method by which it liberates itself; consciousness appears in what seems to be unconscious, and once having appeared it is self-impelled to grow higher and higher and at the same time to enlarge and develop toward a greater and greater perfection. Life is the first step of this release of consciousness; mind is the second; but the evolution does not finish with mind. It awaits a release into something greater, a consciousness which is spiritual and supramental. The next step of the evolution must be toward the development of Supermind and Spirit as the dominant power in

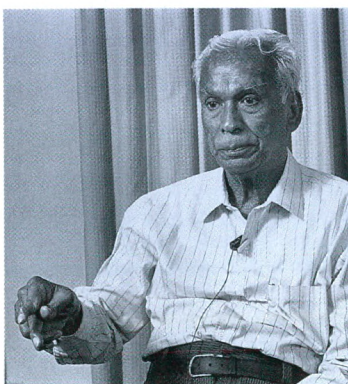
the conscious being. For only then will the divinity in things release itself entirely and it become possible for life to manifest perfection.

Second Opinion: Not everyone is capable of accomplishing this?

Venkataswamy: With human beings, not everyone can be the runner of a four-minute mile. Not everyone can be a scientist. But at least you'll find a new creation of beings coming up. It's just like when we say we have trained a man to go to the moon. That means a lot of physical endurance. In the same way, a being will come that will be able to work on the supramental consciousness, to see the truth about it. That being's body will be changed and will adapt to that consciousness. The mind is only groping now. When you get to the higher consciousness, it is like having daylight. In the dark, you don't know if there is a wall in front of you or a pit. But once it is daylight, you know. When you go to the true consciousness, you have a vision of things much clearer than what you have now.

Second Opinion: "The sufferer is part of you," you've written. The cells in your retina are similar to the cells in mine. Our organs can be transplanted, our platelets are the same, there is little difference in our matter, you've explained. How does someone achieve that identification with the sufferer?

"We want people who have the capacity for all the technical skills. But we also want people to grow in the spiritual consciousness, so that they can go to the spiritual consciousness and also handle an electron microscope—both."



Venkataswamy: That is a wonderful experience. Normally we limit ourselves—I am me, you are so-and-so. But when I grow into higher consciousness, I seek the stage of universal consciousness, where I find that I can feel *your* impulses, as though they were coming in me. That is how to use the spiritual force. Suppose I want to change your ideas or your impulses. You say, I don't know how to get rid of my habit of drinking. But gradually the spiritual person is able to alter something in you, from inside you, without your knowledge. A person really has to grow in the higher consciousness, slowly, slowly.

This is what we want to have in our center at Aravind. In the center we are thinking of establishing, we want people who have the capacity for all the technical skills. But we also want people to grow in the spiritual consciousness, so that they can go to the spiritual consciousness and also handle an electron microscope—both. That would be a wonderful thing, because then you would know and see things from a different perspective. Right now we are using space technologies in modern medicine; in the same way, when higher consciousness comes into medicine, we will find that it can cure illness. It knows exactly where illnesses come from and cures them. It can see that the body is able to resist diseases; it can prolong your life or make your life, your body, and your mind more capable of increasing their forces and capacities.

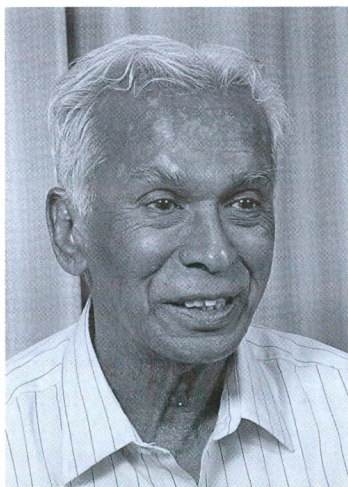
Second Opinion: How can Western doctors acquire that attitude about the sufferer and experience that sort of compassionate relationship? So often they are trained to put distance between themselves and patients, to be objective, not subjective.

Venkataswamy: There are lots of people here in the U.S.—Western doctors or people working in hospices—who understand. But there is a fear in the doctors that they are going to contract the disease or that they also are going to become victims of pain. When you are able to grow above that conscious level—like a mother who knows her child's needs—you can deal with a patient without being afraid that it is going to affect you. Everybody has a fear of suffering. Innately, we don't want to get sick, we don't want to suffer. But if you can just understand suffering, that it is a part of the game . . .

Second Opinion: Well, then, what is suffering? What is pain?

Venkataswamy: Pain is a vibration that the nerve cells interpret as opposite to pleasure. Some scratching means pleasure. The same touch with a pin gives pain. But the nerve endings are the same. The impressions are carried to the brain, and then you interpret the one as pain and suffering, the other as pleasure. Ramana Maharishi was able to get de-

“We have to work in the ordinary life and slowly grow in the higher consciousness. It is wrong to think that unless you are a mendicant or a martyr you can't be a spiritual person.”



tached from pain. The detachment is like self-hypnosis.

Doctors can't interpret everything by mechanical means, but that is how they have been trained—with electrocardiogram, with oscillograph, with this or that machine. But I don't think any machine can measure love.

Second Opinion: Do you yourself still perform operations?

Venkataswamy: I have given up doing operations over the last four years. Occasionally I still see patients. My idea was to train the next generation, not just to operate, but to grow, to take responsibility. Gradually they must order their vision to see these things also. So I just go into the background and allow them to come forward.

Second Opinion: You spoke at Harvard about our need for spiritual laboratories just like scientific laboratories. Will you say more about that idea?

Venkataswamy: You have here people in meditation centers, where they are trying to work on the inner consciousness. You have the same thing in traditional monasteries and in some other disciplines as well. In such centers, people seek a way of progressing higher so that they can see some sort of a spiritual consciousness—whatever religion they follow, whether Christianity, Sufism, or Buddhism—and grow into that higher consciousness.

You could have hundreds of these centers, or laboratories, just as you have hundreds of laboratories where someone's working on an AIDS vaccine, or something for arthritis, or prevention of cataracts, or a cure for cancer, in Boston, Berkeley, Stanford.

Second Opinion: It's possible to have the same system for spiritual research?

Venkataswamy: Well, yes, it's just a thought. And that higher consciousness may help you to do your scientific tasks much more precisely, because then you have got a better tool. The higher consciousness is going to improve your mental capacity as well as the capacity of the body.

Second Opinion: You emphasize that yours is a spirituality interested not in renunciation (*sannyasa*), but in work and action and discipline (*sadhana*). And you speak often about making the body a better instrument, a better creation.

Venkataswamy: The traditional seekers of God often see an evil world, with the body always trying to pull them down to its pleasures. They think, don't listen to the body. Get into meditation instead. But people who during meditation go into higher consciousness lose all that consciousness when they come down to earthly life. So, even traditionally, in the Indian yoga system, there is the practice called *karma yoga*—

work and action. Suppose you've got a wonderful idea for a gadget that can make you fly without a plane. Unless you act on the idea, it is of no use. The whole of modern communications or modern transportation may depend on this. It has to come into use by ordinary people. We have to work in the ordinary life and slowly grow in the higher consciousness. It is wrong to think that unless you are a mendicant or a martyr you can't be a spiritual person. You can even be a spiritual person making money in a business, but you cannot be possessed by the money.

Second Opinion: India has such a visual culture. A person's glance can speak volumes. And images are so important there. You can talk about blindness and sight, light and dark, seeing the divine—*darsan* in Sanskrit—on many levels, both physical and spiritual.

Venkataswamy: Yes, yes, yes. Normally what we call vision, physical sight, has to do with the ray of the light waves, how it impinges on the cells of your retina. But people who achieve higher spiritual consciousness, whoever they may be, have true vision. They can see things much more clearly, without using physical eyesight. They could be blind. So there is in nature a perception that doesn't need the organ of the eye and light and all those things.

Second Opinion: In India you have spoken of the need for a "social marketing system" for health care. Can you explain what that means?

Venkataswamy: America has strong for-profit marketing systems. The system is a good one, just as the management system or industrial system is good. Who uses it is the important part. In this country you have a system that the Russians have not succeeded in: you are able to produce all that an ordinary person needs—a house, a car, a telephone, a television, all those things. You are also able to change people's habits, like smoking. A strong marketing system was used to say that smoking causes cancer. People do very powerful marketing in a country like India to make money, selling soap or detergent or cosmetics, and people buy these things. I would like to use the same marketing system. The system is good for creating awareness. You make a product available at a cost people can afford, and they want to buy it. I am trying to give them good eyesight. I would like to give them good health, but I want to do it as powerfully as the person who is selling Coca-Cola or hamburgers.

You see, I can set up hospitals—not difficult. But now we are spending nearly 40 percent of our money to create an awareness, to motivate people to come to us. Once a man loses his sight he can't work, and at that time it is dif-

difficult for us to get him to come. He has no money and is no longer able to support himself. But suppose we educate him and motivate him to come yearly for an examination—before he has developed a serious disease or lost his sight. Then he will still have money, and it is easier for him to come to be operated upon. You have a powerful system to do that in the U.S. You are at least able to tell people about the chances of getting a certain disease.

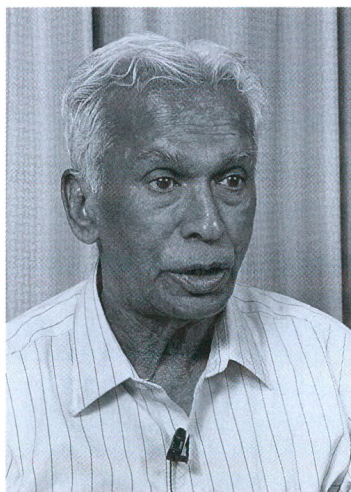
Second Opinion: You mean preventive medicine?

Venkataswamy: Yes. And you also put a lot of emphasis these days on positive health—jogging, keeping your weight down, not losing your temper, avoiding things that can cause high blood pressure. All these things are entering the culture now. People are in better health now, and not just free from disease; ordinary life expectancy has gone up. People are healthier at the age of 80. I am 72, and I would like to see if I can make this body even a little better. They say this is possible, if you go into higher consciousness.

Second Opinion: I've been told that Aravind Hospital is as much an ashram as your ashram in Pondicherry is.

Venkataswamy: I would like to have that. I mean, that is the effort. *Ashram* traditionally means a simple place. People have to be able to sleep on the floor, have

"Normally in hospitals in developing countries patients feel a lot of intimidation. The ordinary people, the villagers, feel that this is not a place for them. We want to make all sorts of people feel at ease, mentally and physically."



simple food, no luxuries. But that is not essential. If you are accustomed to your morning breakfast with orange juice, certainly have orange juice. Deprivation of your physical habits doesn't make an ashram. Simply becoming an ascetic doesn't make you an ashramite.

At the hospital we would like to focus on the work that has to be done, on how we can handle ourselves most efficiently, on how we can best use our total time and energy. The average number of operations for a doctor in my hospital is 2,000 a year. For doctors in other hospitals, it's about 120. That is what has made us self-supporting, and we are charging much less than what patients would pay another private doctor. We are doing a lot of work for free, but we are trying to make optimum use of the staff.

Second Opinion: How do you do that without sacrificing quality and sensitivity to the individual patient?

Venkataswamy: You develop the optimum, as in a factory . . .

Second Opinion: But here a factory is thought of as being very impersonal.

Venkataswamy: Well, take an airport. It is able to transport so many people, 100,000 people a day. A plane lands every minute. It is a matter of organization, just as with our own bodies. So many things are happening. The cir-

culatory system, the respiratory system, the immune system are all doing their jobs, and you have a system that is more powerful and useful. We are trying to do it like that in Aravind Hospital. It is a question of how to handle more people efficiently, and with a kind spirit.

Second Opinion: There is also something you have called “the Aravind culture.”

Venkataswamy: Normally in hospitals in developing countries patients feel a lot of intimidation. The ordinary people, the villagers, feel that this is not a place for them. We want to make all sorts of people feel at ease, mentally and physically. Suppose someone is more comfortable on the floor than in a chair. We’ll give people what they are accustomed to. We don’t deprive anybody. The whole point is to make that person feel at ease, comfortable with himself, and not awed by things.

Second Opinion: Can you teach a health care professional to seek the higher consciousness and to understand that compassion means the sufferer is part of you?

Venkataswamy: One needs material that can be moldable. We have to find the right people. If they are already corrupted, it is very difficult to undo those things. If you want to train somebody, you get them young.

Second Opinion: What would you tell American doctors about practicing medicine?

Venkataswamy: I think American doctors are doing wonderful work in the sense that they are always trying to pioneer, find new things. But it is not good to have a large number of people whose health care is not covered. Someone is trying to organize a national program on blindness so that everyone who is not insured can be taken care of, but there will always be somebody else who is avaricious or greedy. Human nature is what it is. But that is a characteristic of the whole society, not only doctors. Doctors are part of their society.

Second Opinion: Do you read Indian poetry?

Venkataswamy: I used to, but now I read only Sri Aurobindo

and medical books. There is a new concept from Sri Aurobindo in the most recent annual report of Aravind. He talks about evolution and about “a divine life in a divine body.” He says the body, the cells, will become spiritualized, and that is “the ideal that we envisage.” Now I don’t think an ordinary doctor thinks of changing or transforming the body. He can make the body more perfect, he can make the body cleaner, he can make the body free from disease. But he’s not trying to spiritualize the body, “to develop the power and perfection of the spirit.” This is a new concept.

Second Opinion: And how do you do that?

Venkataswamy: You try to bring the higher consciousness. Just as you try to perfect the body to go to the moon. You build higher consciousness to move the body, so that the body gets divinized.

Second Opinion: Can you practice medicine to that end?

Venkataswamy: That is what I would like to do. ☸



To Childhood Illnesses. Lithograph by Ben Shahn, 1968.

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*Seventh in a series edited by Steven H. Miles
and Kathryn Montgomery Hunter*

The Case Hoses and Hope

Joel E. Frader

AT FIVE MINUTES AFTER MIDNIGHT on December 31, I found myself standing in an amazingly busy pediatric intensive care unit. I'd just examined Deanna, a patient in desperate straits who had been sent to us from a community hospital. Despite our technological expertise, our efforts weren't providing her with enough oxygen or removing enough carbon dioxide from her body. We faced a difficult road.

Deanna was 14, though she could have been 25—she was tall and substantially overweight and looked much older than her years. All I knew at that point was that she had had a fever and cough a month before, taken some antibiotics, and been somewhat better for a time. She and her parents had then come to our area from their home in the South to visit their extended family. Two days before Christmas, her symptoms had recurred. After four days of getting worse, she'd been taken to a hospital emergency department at a community facility and admitted for pneumonia. Diagnostic tests had not helped define the cause. Several antibiotics had produced no

improvement. In fact, Deanna's condition had deteriorated dramatically; she needed more and more supplemental oxygen. Eventually she needed to have a tube placed in her windpipe so that a mechanical ventilator could breathe for her, and our hospital team had gone to bring her to us for pediatric intensive care. We hoped to work some magic that the community facility could not.

When Deanna's parents arrived (the patient had come by helicopter), they made an immediate and troubling impression on me. Deanna's mother explained that she had opposed the transfer to our tertiary care center. She said she'd had a premonition while sitting with her daughter at the community hospital. Accordingly, she believed that God had already decided to "take" her daughter and that nothing the previous doctors or we could do would make any difference. She said that she had recently been through a similar experience with her mother: she had "known" her mother would die despite the predictions of the doctors to the contrary. Her mother *had* died, confirming the untrustworthiness of doctors and the reliability of her own intuition. She was thus reluctant to agree to further diagnostic or therapeutic interventions. Neither Deanna's father nor her grandmother (the father's mother) shared this pessimism, however. They helped persuade Deanna's mother to agree to an invasive test

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to sample material from the girl's lungs to help us understand the nature of her disorder.

Despite my concern about triggering a battle with the mother over her daughter's care, I also broached another subject. I told the family that our respirators and other "conventional" treatment might not be able to keep Deanna alive (Deanna was so sick that we virtually had to anesthetize her to treat her—she couldn't participate in any of this talk). In addition, we were worried that the effect of the ventilator itself could make her lungs worse. I told the family members we had another treatment that only a few hospitals in the country could offer to older children: extracorporeal membrane oxygenation, or ECMO.

I explained that ECMO uses technology developed to help surgeons operate on the heart, and I described its components: tubes to divert blood around the heart and lungs, pumps to take over the heart's job of circulating blood, and thin membranes that allow oxygen to flow into the blood and carbon dioxide waste to escape. I added that ECMO could replace an ailing heart or lungs for days or weeks until the organs healed. After giving a brief explanation of the general process, I let the matter rest.

The lung sampling revealed nothing useful. Over the next few days our therapy produced no improvement, and we worried that the level of support was in fact harming as much as helping. During this time, Deanna's mother said she had not given up, but she consistently referred to her daughter in the past tense. In addition, she would not discuss Deanna's current treatment; she wanted to talk only about her daughter's last few months. She also began to talk about developing symptoms of her own. She attributed her facial numbness and diarrhea to "nerves."

By Deanna's fourth day in the hospital, we had no definitive diagnosis and some deterioration. I again discussed ECMO with the family. When I mentioned that ECMO would require us to use banked blood, the mother objected that her daughter might become infected with the AIDS virus, and my attempts to reassure her about the adequacy of HIV testing of blood had little impact. Besides, many of us thought, concern about blood-borne infection missed the point. Deanna would probably die without ECMO and blood.

When Deanna developed a rash, her mother expressed certainty that our treatments were poisoning her daughter and that it was time to back off. The house staff responded reflexively to the mother's anxiety and changed most of Deanna's medications. The rash came and went nevertheless.

Early in the morning of the seventh day, disaster struck. The "cuff," a little balloon that keeps air from leaking around the tube in the trachea, broke. Without it, the back-pressure from Deanna's sick lungs forced the oxygen from the respirator back around the endotracheal tube. The needed oxygen couldn't get into Deanna's lungs and hence into her blood. Her oxygen levels plummeted; her heart rate and blood pressure fell. She had to receive chest compressions. Even after a new tracheal tube with an intact cuff had been placed, Deanna's condition was much worse. We had no idea whether her brain had received sufficient oxygen while the doctors and nurses were performing cardiopulmonary resuscitation and inserting the new endotracheal tube. We knew Deanna had little hope at that point. After a prolonged discussion among the involved physicians, we decided to recommend ECMO.

I spoke with the family at great length. I included a detailed description of ECMO, complete

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with drawings of the machinery and tubes that would be used. Deanna's mother opposed the treatment, sure that our previous therapy had already made her daughter worse than she'd been when she arrived and that none of it mattered anyway. Again, the grandmother and father convinced Deanna's mother to agree, mostly because we doctors felt Deanna would die within a day if we didn't try ECMO. We also agreed that if Deanna deteriorated further while on ECMO, we would withdraw support.

An essential aside: ECMO is a big deal—the bigger the patient, the bigger the deal. In many situations, the extracorporeal circulation requires the insertion of transparent tubing into or near the heart. The machinery sucks dark venous blood returning to the heart from the body and squirts it off to the membrane oxygenator (much like the bypass device used for “open heart” surgery). From there, a pump pushes bright red oxygenated blood to the aorta, with the tubing often entering the bloodstream via an incision in a carotid artery in the neck. In adult-sized patients, the tubing approaches the diameter of a small garden hose. With a large patient on ECMO, one sees tubes like mutant spaghetti everywhere; industrial machines are attached, as it were, by the patient's blood in a network that calls up frightening visions from television science fiction. It isn't pretty.

With the institution of ECMO, Deanna's blood gases improved. It was not that Deanna improved, of course—the machinery simply did what her lungs could not. We could only hope that the equipment would buy time while Deanna's body got better. In order to assess the damage from the night's catastrophe, we stopped all medication that would interfere with evaluating Deanna's mental function. We could always restart sedation, pain medication, or drugs to “relax” her muscles.

In the next 24 hours, several findings led us to believe the worst. When we started ECMO, Deanna's eyes had reacted to light; by the next morning they no longer did. Her blood had a persistent chemical abnormality which led us to infer that serious injury

had occurred at the time the endotracheal tube cuff had failed. Her kidney function deteriorated. Electronic monitoring of her brain activity indicated widespread damage, again probably from oxygen deprivation.

While we watched these grim signs, Deanna's mother became agitated and enraged. When she first saw her daughter after the beginning of ECMO, she burst into tears and accused me of deliberately misleading her. She insisted that she would never have agreed to ECMO had she known how big the tubes were. She had imagined tubing the size we use for intravenous fluids, and it had not occurred to me to specify anything different. None of the doctors or nurses could help Deanna's mother say how the size of the tubing mattered, but clearly she felt it did. After that initial outburst, she never spoke to me again. She would not respond to direct questions, would not look at me. She conversed with others as if I were not present. I felt lost.

After 18 hours of ECMO, we completed a full electroencephalogram (EEG). It showed no evidence of cerebral brain function. Several of us did clinical examinations and found no clinical evidence that Deanna's brain worked. We administered drugs to unmask any residual effect of the muscle relaxants and used an electronic device to assure ourselves that her nerve-muscle connections worked. We concluded that Deanna was clinically brain dead. We chose not to confirm our diagnosis with more tests. We all agreed to recommend withdrawal of life-supporting treatment.

I went to face the family. I delivered the news, and Deanna's mother proceeded to tell her husband and mother-in-law that she'd known in the first hospital that her daughter was “gone.” She raged that they never should have allowed Deanna to come to our hospital where we had made her death so much harder with our rash-inducing drugs and our oversized tubing. The father agreed to our stopping the machines sustaining the daughter's body. The parents and grandmother wouldn't even talk about an autopsy. Deanna's father told me that his wife had miscarried another baby, and the doctors had per-



To Parents One Had to Hurt. Lithograph by Ben Shahn, 1968.

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sueded them to agree to an autopsy. When the procedure had not identified the reason for the loss of the baby, the family felt let down. They couldn't let that happen again.

The surgeons stopped the pumps and removed the tubing. We disconnected the ventilator. Within seconds, Deanna had no measurable blood pressure. In just a few minutes, the electrical activity of her heart stopped. Standing by, the family members sobbed. The family turned to embrace the nurses, pointedly spurning the doctors. Neither my touch nor verbal condolences led even to eye contact with me.

I want never to have a similar experience. I had tried so hard to be the exemplary attending

physician, physically and psychologically available, working to seem as if I had nothing on my mind besides Deanna's care. In fact, I had had little else on my mind for that week. But nothing I did had worked. With respect to Deanna, I could rationalize that my technically expert colleagues in critical care, cardiothoracic surgery, infectious disease, pulmonary medicine, and so on, had been no more successful than I. But my failure to connect with Deanna's mother and ultimately her father and grandmother left me sad and sickened. It seemed the mother's premonition and our hoses had spelled defeat from the outset. ☹

Commentary

Listening for the Healing Story

Steven H. Miles

BY CONVENTION, MEDICAL ETHICS WOULD FOCUS on the treatment decision for the child-patient in this case. Who should decide about the care of this dying child—the caring doctor or the loving family? Is the best decision an all-out effort, a temporary trial of aggressive support, or hospice? This approach has several steps. First, define the ethical decision. Then extract the elements that form the crux and context for decision making, including the poor odds for “successfully” treating the child. In this scenario, however, the mother’s point of view comes into focus too late, delivering a crushing final verdict on the case.

Dr. Frader, a skilled physician and ethicist, knows all this. Clearly, he feels that child-focused ethical decision making in this case failed. It failed not because the child died—death is ever present in medicine, good and bad. It failed because the decisions made both before and after she came to Dr. Frader alienated the mother from the doctors and from her child, and finally even the doctor from his

own work. *Alienation* is the salient feature of this case; it is the reason that Dr. Frader tells this story. Can we make a new inquiry into the ethos of this case, to understand why this alienation occurred?

This new inquiry notes the great difficulty that the mother and doctor had in talking about the child’s last days. This difficulty is interesting because of what it was not. It was not the mother’s absence or the doctor’s inaccessibility: the mother was present, and the doctor was accessible. There were no insurmountable cultural differences. There were many occasions for discussion. The clinical course was not so brief as to prevent the parties from reflecting on the facts or events. There was no lack of empathy or lack of recognition of the gravity or emotional intensity of the events. The physician and the mother had each had important previous experiences with death. All the elements for shared decision making were present. Even so, the doctor and mother seemed unable to speak to each other.

When an impasse develops with a principle-based framework for ethics decision making, we may ask if the parties knew how to use the tools of ethical analysis: beneficence, respect for autonomy, respect for family proxies, law, analogy to paradigm cases, and so on. But the area of difficulty in this case is not logic but moral communication.

My hypothesis about the moral communication

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here is this: the doctor and the mother were unable to develop a common story-language to use in speaking about this child's care. Without this framework, decisions could be neither jointly posed nor jointly labored over. Analytic moral reflection could not begin. To understand how a story might have "worked" in this case, we must look more carefully at how time "passes" in analytic ethics and in the lives of people.

Focusing on ethical decisions directs us to points in time—when the tubes of the extracorporeal membrane oxygenator are inserted or removed, for example. These ethical opportunities occur at discrete instants on a diagnostic-therapeutic clock. Tick, a profoundly ill patient is hospitalized. *Should he be in a hospital?* Tock, information is imparted. *What should we tell?* Tick, a decision is made. *What should we do?* Tock, an outcome occurs. *Should we now revise our plan?* Tick, . . . The tick-tocks denote the nameable events. The demarking of medical-ethics time is so taken for granted that we can forget that most of the real action takes place in the passage between these instants. A mother's heart sinks at the sight of big red tubes and the sense that a sucking machine has kinship with her dying flesh and blood. These moments between decisions are the seeds of stories. The newly germinating stories, which will grow to bear the fruit of ethical decisions, are at first heard only as trite phrases and insights in hospital hallways:

The doctors did all they could.

He lived a complete life.

She is a fighter.

She was a fighter.

He did not react, but he knew I was there.

Well, we know he was unaware and did not suffer.

God is taking her home.

These trite phrases can be read as *plot proposals*. They propose and reveal ways by which people make sense of difficult times.

I heard one of these plot proposals for what it

was only after my residency. A man with severe heart disease was admitted to my care with kidney failure after dialysis had been newly started. The grief-stricken wife demanded all possible treatment for her husband. Two weeks later, it was evident that he would neither be lucid nor live at home again. After many conversations with the wife and her son, we agreed to discontinue dialysis. Several weeks after he died of kidney failure, the widow called me and said, "Doctor Miles, I just want to thank you for doing everything you could do." At the time, this struck me as an ironic epigram on a hospitalization in which the decision had been made to stop a life-sustaining treatment. Some months later, a psychiatrist colleague, Joe Schwartz, helped me recognize how this remark signified the healing germ of a story to close a difficult hospitalization.

These plot proposals are fragile in the medical world. "She's a fighter" is often heard in the neonatal intensive care unit. It has often struck me as an absurd projection to describe a two-pound, prematurely born, life-support-dependent child as someone as robust or intentioned as a fighter. We who control the machines are struck by the utter fragility, dependence, and passivity of such infants. Yet "she's a fighter" is a heartbreaking statement by which parents acknowledge the dire struggle, the possibility of defeat, the violence of disease and technology, and their need to impute an assenting will to the child who is so aggressively invaded to be saved. The attentive physician senses the tide as this innocent verbal flotsam goes by. A shrug can be an annihilating rebuke.

What kind of story could have helped Dr. Frader and the mother find common ground? I can only hazard a guess. The mother offered several plot ideas: God was "taking" her daughter, for example. As the doctors and mother failed to arrive at a common story to justify the effort, the proposed plots became more ominous, and the mother saw as "poison" what the doctor was calling a "disaster" and "catastrophe" with "little hope." Let me suggest that a useful proposal to float out and try to build a moral story on might have been "I'm sorry, it looks as though

there is not much more we can do to save your daughter's life. We can make sure that she feels no pain." This proposal to speak not of decisions but of the limits of what medicine can do provides a rationalization (plot) within which a precious life, an inevitable death, and medical duty can be reconciled and where the mother's grief can be met by the physician's sorrow at the limits of our skill. Trying out this plot about medical futility can relieve the doctor and mother of the impossible burden of deciding to refuse to go on trying to save this beloved and dying child.

Ethicists have recently analyzed *futility* (see Schneiderman et al. 1990; Lantos et al. 1989). They point out that probabilities of benefit are usually low, but rarely zero, and that survival, however brief, can be meaningful to some. The burden of such close reasoning can and sometimes should be shared, but it can be more correct than helpful. Complex calculations do not expiate a tragic choice.

We need a richer way of listening to the proffered moral insights and suggested healing stories

in trite phrases like "premonitions of death" and "God is taking her" that are often heard in hospitals and were heard in this case. Perhaps we could follow Rudolf Bultmann's somewhat paradoxical term and endeavor to "demythologize" these conventions (1958). This demythologizing would look past what strikes us as too trite or too simplistic to be true in

a modern hospital or modern medical ethic. We would seek to understand the moral experience that supports the survival of these truisms, the insights that made them memorable when they were new.

Perhaps in these phrases, rather than in the argot of medical ethics, lie the elements of a common language to bridge the depressing alienation in this case. These phrases can reveal a lay view of the

relationship of medicine to dying, of the task of being faithful to a life even as it is allowed to die. If so, more attention to these phrases could help doctors and families creatively work in the in-between times where stories are nurtured to heal unbearable and mysterious pain. ☉

**The decisions made both
before and after she came to
Dr. Frader alienated the
mother from the doctors and
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Commentary

Stories That Heal, Wheel within a Wheel

Earl Schwartz

God is Builder of Jerusalem,
 Gathering the scattered of Israel into it;
 Healer of the brokenhearted,
 Binding up their wounds;
 The One who sums the number of stars,
 Calling each by name.

(Psalm 147)

THE PSALMIST PLACES THE METAPHOR of “brokenheartedness” between two corresponding images: first, the “scattered” community, whose return to Jerusalem signals the “healing” of the brokenhearted; second, the stars of heaven, which, though numerous beyond human reckoning, are not only reckoned but recognized in God’s sight. The psalmist testifies to the sense of crushing anonymity that brokenheartedness conjures up, but the God who calls each star by name knows each of the brokenhearted by name as well.

Similarly, the biblical metaphor for a personal identity that extends beyond death is *yad v’shem*—“a hand and a name.” A person with a name is not

forgotten. In biblical Israel, to die was to be “gathered to one’s people.” One’s “name” was one’s place in the people’s story. The individual bears the unique and exalted *dignity* of human personhood, but “we discover the self through a community’s narrative tradition” (Hauerwas 1983:28).

In classical Jewish sources, narratives of this sort are termed *aggadah*. The great body of accumulated *aggadah*, beginning with the Bible and weaving its way through the length of Jewish history, is studied as a sacred source because it provides many examples of how an individual’s story can be linked with the story of a people’s encounters with transcendence.

In the story of Deanna and her family there is the trace of an aggadic subtext. Deanna’s mother’s expression of her premonitions concerning God’s will suggests that the family may be Christian. Christianity, like each of the enduring faith traditions, includes an aggadic dimension. Theologian and developmental theorist James Fowler, among others, has termed this element of Christian life its “core story.”

A religious core story enables us to see and comprehend our lives in relation to the life, history and intentions of God. It provides a context of ultimate meaning for the events and

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relations of our lives; it gives us decisive images by which to interpret what we suffer and to sustain and guide us in what we hope. (1984:116)

How may an individual's story serve an aggadic purpose in extending moral vision, strengthening hope, and healing brokenheartedness? Under some circumstances, the link can be established through no more than a gesture. A young rabbi, prepped for surgery, lay on a gurney in a hospital corridor. Through the haze of sedation he heard a terrible clamor nearby. Unable to concentrate fully on the uproar, but also unable to ignore it, he drifted in and out of the disturbance, slowly realizing that one side of the dispute was being argued in Hebrew. Eventually the rabbi understood that the problem had to do with a child whose Hebrew-speaking mother could not understand and did not trust the English-speaking physician who was asking the terrified mother to allow him to treat the child's ear infection. The rabbi roused himself sufficiently to call the mother to his side. The woman, clutching her child, quickly came to him. The rabbi explained in Hebrew that he was about to undergo surgery and that in preparation for the surgery he had shaved his beard and removed the kippah he normally wore on his head but that he was indeed a rabbi. Then he told the woman that he would like to bless the sick child and that after the blessing the child should be entrusted to the doctor. The rabbi concluded with the assurance that the child would recover. The child was blessed and then turned over to the physician. Peace and quiet once again having been restored, the young rabbi drifted off to sleep, also to be turned over to a physician for successful treatment.

It would be reasonable to attribute the rabbi's success simply to his use of Hebrew or to the mother's confidence in the efficacy of his blessing. But more is at work here. It is the woman's recognition of the rabbi as a member of her story, inasmuch as they were both unmistakably linked to the story of the Jewish people, that allowed the woman to trust his presence and listen to his advice. The

physician, in contrast, was an alien presence whose life intersected with the lives of the woman and her child at the onset of illness. The rabbi, on the other hand, though he had never met the woman, was understood as present and committed to her before and beyond the particulars of misfortune and professional expertise. The woman heard the rabbi "call her by name," and thus he prescribed treatment for wounds the physician could not touch.

EACH OF US IS, LIKE DEANNA'S MOTHER, subject to the flicker of "premonitions" and "intuitions." During a crisis, such premonitory apprehension may become overwhelming. The experience of such apprehension is universal, but its content is radically idiosyncratic. It is in the nature of medical practice that the people physicians continuously come into contact with are often beset by premonitory apprehension. The evocation of a common story (*aggadah*) may help some to see beyond their particular fears.

The climax of Deanna's narrative is the physician's painful observation that following Deanna's death "neither my touch nor verbal condolences led even to eye contact with me." Inasmuch as Deanna's family did welcome the support of nurses standing nearby, one may suspect that the pointed rejection of the doctors was due to their failure to succeed instrumentally by healing Deanna. This failure, however, was not attributed to the nurses, who were perceived as having been largely successful at *their* task of caring for a sick child. If the relationship between physician and patient is perceived as essentially instrumental, even when the physician extends him- or herself in personal kindness, it is not surprising that instrumental "failure" leads to a rejection of the relationship as a whole.

However, when doctors, patients, and family members see one another only in instrumental terms, equating "medicine" with "medical procedure," the possibility of finding aggadic common ground is lost. The myth of the "good country doctor" does not rest simply on a sentimental recollection of greater personal accessibility but on a

vision of doctor and patient sharing a communal *aggadah* that transcends the particular stories of physician, patient, and family.

Was there a potential *aggadah* that exceeded the idiosyncratic self-absorption of Deanna's mother's "story," on the one hand, and the physicians' instrumental focus, on the other? It is the physician's challenge to search for such commonality, despite the corrosive effects of modernity on genuine *aggadah* and an incongruence of class, geography, language, or faith. We should be clear that what we are speaking of here is not a vague, generic "spirituality." The sustaining power of *aggadah* is to be found, in large measure, in its *particularity*. Genuine *aggadah* is never purely theological. At its heart is an evocation of the encompassing story of one's own particular "people." In searching for a line of communication at this stratum of human identity, the key questions are these: Where do you come from? Who are your "people"? What is *their* story? What have you learned from them about the vicissitudes of life? The necessarily nonreciprocal dimension of the physician-patient relationship may be complemented by an aggadic symmetry. It is an act of trust on the part of physicians to acknowledge this symmetry, but through this trust they may more successfully convey the message that physicians, patient, and family will face ultimate questions together rather than in single file, "patient and family first." Patients or families without aggadic resources lack a potentially powerful tool in the struggle against meaninglessness and despair, but this holds true for physicians lacking aggadic resources as well.

Deanna's illness extended over the Christmas-New Year season, but there is no reference to the themes of the season in exchanges between

physicians and family. The absence of these themes is all the more striking in light of Deanna's mother's conviction that "God had already decided to 'take' her daughter." Assuming that Deanna and her family were Christians, we are left to wonder what effect evoking the larger Christmas *aggadah* of hope and renewal may have had on the quality of exchanges between the attending physicians and Deanna's

family. In the midst of Deanna's travail, a word from a physician who could genuinely reflect on Matthew's description of the near hopeless circumstances of Jesus' childhood may have helped to open a line of efficacious communication with her parents. This opening could, in turn, have been joined to a question concerning what they themselves had learned from their

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work and "folk" concerning perseverance in the face of desperate circumstances. The conjunction of these two strains of reflection may have helped to galvanize the parents' and physicians' sense of common commitment and purpose. Deanna's mother's beliefs appear to have confounded the best efforts of the physicians to enlist her support in their struggle to diagnose and treat Deanna's illness. But the aggadic traditions of Christianity, far from inevitably interfering with sound medical practice, can help to steady the step of the brokenhearted, when they are called by name.

A physician who sensitively evokes a link between the story of the physician, patient, family member or friend, and an operative *aggadah* that encompasses it, may well find a potent antidote to the debilitating self-absorption that crises often precipitate. As theological ethicist Stanley Hauerwas points out, it is the finding of one's story in God's story, wheel within a wheel, that enables a person "to see life as more than a succession of

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events” and “gives us the skills to go on” (1983:68). It is at this intersection that one finds the language of solidarity against despair, the language that calls one by name—the word or gesture, anecdote or allusion, song or prayer that is a shared token of ultimacy faced together. One cannot create *aggadah* for oneself. Its power comes precisely from the fact that it is *received*. It is the narrative evidence of genuine community, and of a community’s power to strengthen and inform.

This solidarity cannot substitute for personal awareness and kindness, but it can extend its significance beyond the realm of the purely personal.

Some physicians may shrink from such contact. Cultural or moral differences may make contact on these terms seem impossibly alien, or unbearably revealing, for, in a sense, the affirmation of a shared *aggadah* is indeed confessional. Then again, we must admit that there are times when the distance is simply too great and hopes too far spent for contact to be made. An aggadic fabric cannot be stretched indefinitely. But if there is power in *story* to extend the reach of moral vision and the touch of concern, it is to be found in an aggadic weave where patient, family, and physician can stand together. ☸

NOTE

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AIDS as a Spiritual Journey

Frank G. Sabatino

WHEN I WAS A SENIOR IN HIGH SCHOOL, I decided to enter the Christian Brothers, a Catholic religious order dedicated mainly to teaching. In retrospect, I guess it would be more appropriate to say that I was recruited to the order. I don't recall any active fantasy about a *vocation* until that term was used by a Brother Cyprian, a recruiter based in my high school.

At 17, life goals or vocations seemed quite remote to my reality. If I had to choose one, then a fairly noble cause, education, appealed to my spirit. And so, lacking any solid evidence to the contrary, I supposed I might have a vocation, and I joined the order.

My stay was brief, in no short measure because I realized I had chosen a life-style I really didn't embrace. Yet while in a religion class there, I had a truly remarkable experience that sensitized me to language and forced me to make a decision. The concept of predestination, which had arisen in a lecture on Calvinism, was a puzzling one for me. I asked, in class, how one reconciles God's omni-

science, which I could only conceive of in linear terms, with human free will. The answer I got was a quote from St. Paul: "For Christ's sake, I am a fool." A fool. A fool? It was the first repudiation of rationality that I remember hearing in my entire life. "Think" had become a credo for me by that time. Perhaps it was the dominant influence of IBM's motto in the mid-1960s, but rationality, thinking, was supposed to save you from the problems (lack of direction? trouble?) that befell those who acted without thinking. Now, to assert my faith, I was being asked to be a fool. Talk about a test of faith!

I failed. I left the communal bedlam of Glencoe, Missouri, the site of my novitiate year in the Christian Brothers, for the haven of the intellect, the University of Chicago. The year was 1966.

I WAS DIAGNOSED WITH KAPOSI'S SARCOMA, an AIDS-related cancer, in December 1988. At the time my life, I thought, was a testament to planning. I had wished to be a vice president of a publishing company before I was 40, and I had accomplished that goal. I had wished to end an unsatisfying long-term relationship, and I had. I desired to become active in a community organization, and I was asked to join the board of the major gay and lesbian health clinic in my community.

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There were, to be sure, problems in my life. I did not believe in the mission of the organization I was working for. I had entered into another relationship with someone whose values I did not share. But these seemed like minor matters to me. I was successful by outward accounts: I had a decent income and a nice home, and I enjoyed a circle of bright, caring friends. Those successes that I had enjoyed I ascribed to hard work. I did not think my talent was so large that it warranted recognition, but I did believe that perseverance and a basic faith in honesty, hard work, and application were being rewarded. Things were as they ought to be.

Immediately after my diagnosis, nothing was as it should be. Frightened by the diagnosis of an “always fatal” disease, I scrambled to assemble second and third opinions just three weeks before Christmas. Not wishing to spoil my family’s holiday, I shared my diagnosis with only two very close friends.

Then, just two weeks after my diagnosis, at a business breakfast with two architects, I heard a seemingly casual question: “What do you think of the AIDS situation? It has devastated the architectural community in Los Angeles.”

I attempted to reply as the health care editor I was. I described the problem as an epidemiological nightmare. I said the problem was a serious one for hospitals, because the intensive treatment that patients needed was often unreimbursed. I said the problem was particularly bad in San Francisco and New York. I espoused the opinion that education of the public and of practitioners was desperately needed.

While I responded, I remember having the strange sensation that part of me had left my body. That other part hovered about six feet above the table where we were seated. That other part looked on while a capable editor had a rational conversation with two other people. That other part was both amused and horrified by the spectacle it witnessed.

MY INABILITY TO INTEGRATE MY DIAGNOSIS with my day-to-day life was most noticeable in the evenings. I simply was unable to sleep for more than three or four hours a night. After about eight weeks, I was near exhaustion.

I remember very little about the day I had my nervous breakdown. I do recall asking a co-worker to sit with me on the floor of the men’s room. I felt faint, and I wanted to allow whatever disturbed me to “blow through” my body. My co-worker agreed to sit with me, and after about five minutes, I began to feel better. I thanked him for the time he spent with me.

Later that morning, I took a phone call at my secretary’s desk, in an open corridor outside my office. For whatever reason—it may have been the recollection of a conversation I’d heard about a particularly strong wind that had buffeted the offices of our Washington office that day—I had the strong presentiment that the windows were going to crash in. I could feel the pressure building, so I stopped the conversation I was having. I asked several editors to leave their offices and gather around the desk where I was, hoping to spare them from the flying shards of glass I imagined would soon be flooding their offices. They complied with my request. In a few moments, the danger seemed to pass, and I suggested that they return to their offices.

I later left for lunch with a freelancer who worked for us, a young woman for whom I had both professional and personal admiration. Walking with Jane to a restaurant, I was struck by the eyes of passersby. It appeared to me that a number of people—more than half of those I saw on Michigan Avenue—were zombies, walking bodies with large black circles about their eyes. The eyes were vacant and lifeless.

I remember a pleasant lunch during which Jane recounted her experiences on a recent trip to Europe and I reminisced about a similar trip I had made nearly 20 years earlier. After lunch, the head of personnel services asked that I step into her office. A friend, she closed the door and asked what was happening. Several of my staff had apparently

mentioned that I was exhibiting strange behavior.

I had confided my diagnosis to her some weeks earlier, aware of my need for extra time to see doctors and also aware that I needed to explain why my office door, which was generally always open unless I was in a meeting, was now closed most days. My friend suggested that I had been under a lot of pressure lately and that perhaps I needed a rest. She informed me that my doctor had been called (although I don't know how she knew who he was) and that a friend would soon be arriving to escort me to a local hospital, where my physician would be waiting. Later that day I was admitted to a hospital with the diagnosis of stress disorder.

WHILE RECOVERING AT HOME FOR A MONTH and struggling to cope with the effects of Haldol, which had been prescribed for depression, I also began a clinical trial sponsored by the National Institutes of Health to assess a combination of drugs in the treatment of HIV infection. My thinking during that time was extremely disordered. I tried to focus on remembering my doctors' appointments. It seemed that all I did was sleep and go to doctors.

When I returned to work, I'd read copy and wonder what it meant. Meaning eluded me. I was going to die, and I stared at garbled reports of lobbying efforts to secure more money from the government for health care funding. I supposed that if a sentence had a subject and a verb, it must have some meaning to someone, even if the meaning eluded me at the moment. Similarly, at home I noticed that an inordinate amount of my time was occupied with maintenance activities. I wondered why I cleaned. Wouldn't the house only get dirty once it was clean? I had to remind myself to eat; eating maintained energy, allowing me to get

through the day. Existence was the only meaning I could muster.

I began reading books, not to see what they said, or to enjoy the experiences they relayed, but to provide a focus for my mind. Books, I came to realize, are amazing things: pages follow pages and they have an ending. They reinforce the concept of order at the same time that they testify to the uniqueness of any ordering system. When I completed a book, I felt that I had completed a task and shared an experience. I fancied that the discipline of reading would focus my mind in a direction.

It would stop the errant wandering of my mind, which seemed obsessed with the absence of meaning in my life, with the viability of suicide as an alternative to a life without meaning.

LARGELY IGNORED IN THIS RECOUNTING OF MY experience thus far is the support that I received from other people during this time. My parents, who were unaware of my homosexuality until I informed them of my diagnosis shortly before my breakdown, began calling daily to see how I was doing. Dear friends called, told me they were praying for me, or visited. Others suggested that I spend a weekend with them. At work, my boss inquired if there was anything he could do. An old friend listened as I shared my fears about the future, about the non-meaning in my life, about the aimlessness of my activities. Friends dropped off books. Two that were especially helpful, once I permitted myself to pick them up, were *Love, Medicine and Miracles* by Bernard Siegel and *The Road Less Traveled* by M. Scott Peck. The first book suggested to me that hope was an undervalued adjunct to medical treatment. The second book discussed the concept of pain as indispensable for growth. I recall one especially powerful image: that the beauty of a flower we witness open-

I believed that I could pray for strength to accept my illness, but I thought my goal should be to attain peace with myself by the time I died. A goal of not dying always seemed vain, not worthy of prayer.

ing is only our appreciation of beauty; it ignores the growth pains the flower must experience as it pushes forth.

Slowly, I began to explore my own self, my beliefs. Although several people had encouraged me to consider keeping a journal, when my own brother brought it up, I considered it seriously. The book I bought to start my journal had a unicorn on the cover. Later I read that the unicorn was a Christian symbol for Christ, raising a horn of salvation for humankind. I also read that in Chinese mythology, the unicorn was a harbinger of offspring. Whether a tool for salvation or a portent of fertility, my journal came to be an outlet that allowed me to see myself in relation to my world—my family, my friends, my career.

AFTER I WAS DIAGNOSED, I LEARNED I WAS eligible for an NIH-sponsored drug trial to evaluate an approach to the management of AIDS. The trial involved a combination of two agents, AZT (zidovudine) and DDC (dideoxycytosine). Each drug was taken for a month at a time in alternating sequences. The idea was to lessen the specific toxicity to either drug taken alone for long periods of time. The trial I was in was also attempting to determine the most efficacious dosage of one of the agents, DDC. Those in the trial were on different doses of the drug during the months it was taken.

After 10 months I began having problems with my legs. A numbness in the soles of my feet progressed to pain in my calves. Walking became extremely painful. Although I was taken off the drugs I had been taking, my legs continued to deteriorate. To steady my gait, I began using a cane. Then I needed two canes. When I began falling more frequently, I was given a walker.

I was sent for magnetic resonance imaging to determine if these problems were virus-related or drug-related. Seeing no evidence of virus-related damage, my physician concluded that the damage was drug-related. There was no indication whether the nerve damage would be temporary. It was I who inquired whether physical therapy might help.

Reasoning that it certainly wouldn't hurt, my physician arranged for outpatient therapy.

I remember how painful the exercises were. I also remember how frightened I was at the prospect of not being able to walk again. At one of my lowest points, I remember lying on my bedroom floor trying to do leg lifts. I began crying and saying aloud, "I give up. If I'm not going to walk again, I accept that. I'll accept what I have to accept. But please, God, let me know if I'll walk again. I just can't take the uncertainty anymore. Please, help me to accept this, if that's what my life will be." It was the first time in many, many years that I remember praying.

For whatever reason, I never believed I could or should pray for a cure for my disease or for me personally. I believed that I could pray for strength to accept my illness, but I thought my goal should be to attain peace with myself by the time I died. A goal of not dying always seemed vain, not worthy of prayer. About three days after this experience, at a dinner at a friend's house, I had feeling in the bottoms of my feet for the first time in several months. At first the feeling was so strange that I didn't know what it was. I couldn't remember if I had shoes on or not, and I didn't know if I was feeling the vibrations of shoes tapping on the floor or actual sensations in my feet. I looked down to see that I had removed my shoes (it had been snowing outside when I entered my host's house) and that the sensation I was feeling was coming from the soles of my feet. Slowly, after two more months of physical therapy, I regained the ability to walk.

My experience of praying was incredibly significant to me. It represented to me an admission of the limits of both my rational and physical dimensions. I was totally helpless. I had to admit my lack of control. For the first time in my adult life, I admitted that I was a creature and that there indeed must be a God, someone who created life. I was not the sum total of planning and hard work; I was one more individual in the world who confronted his humanity, his frailty. My mind had gone, and now I had witnessed my ability to control my body slipping away. I believe that my final ability to

admit my lack of control opened me to the possibility of prayer, of receiving spiritual energy and strength. Miracles don't exist for those who are uncomfortable with the spiritual dimension; they're only reversals, unexplained phenomena, aberrations.

At this point in my life, I began to attempt to meditate each day. A friend had encouraged me to try to summon the image of a white rose while my eyes were closed. Sometimes it was very difficult to do. On my own, I tried to envision the sun radiating its rays. I attempted to relax and permit my body to receive the sun's warmth and energy.

ABOUT 10 MONTHS AFTER I REGAINED THE ability to walk, I was asked to address an interfaith task force in the city of Chicago composed of individuals engaged in pastoral care. An organization was trying to determine what, if anything, it might pursue as a suitable response to the AIDS epidemic. As a patient, one who was not a practicing member of an organized religion but one for whom spiritual practices had been meaningful, I was asked to relate my experience. After I told my story, an observer said, "So what are you saying? That we should sponsor a series of personal witnessings?" I was devastated. I felt that my very personal story, one that was painful to recount, was being relegated to exhibitionism and emotionalism. I left the meeting completely upset.

In time, my attitude changed. I thought about what the man had said. I began to believe that, indeed, lives are little else than personal witnessings of the values that inspire them. Afterward, I began to try to spend more time with people who had been recently diagnosed with AIDS. I believed it was important for them to see that several years after diagnosis I was still working, still loving other people, still living.

TO MY MIND, WRITING ABOUT SPIRITUALITY is an enormously embarrassing task. It is presumptuous. Am I living a spiritual life? Do I have the foggiest notion of what spirituality is? I often fear that my notions of spirituality are nothing more than the compulsions of an ex-Catholic raised to value mean-

ing yet confronted with an absence of it in his own life. And yet, having said that, I'd like to reflect on the types of inquiry AIDS has led me to.

In trying to discover the meaning of this disease for me, I've been forced to reflect on the nature of my life. I've been forced to admit that forces other than rational and physical ones appear to be operative in my life. I've come to believe that it's not only permissible for me to admit that my sense of order has been arbitrary, it is necessary for me to admit that if I'm to be truthful.

Because AIDS pushed me to the limits of both my mind and my body, it forced me to explore another dimension to find strength. My own religious training, unfortunately, did not help me. In fact, it was a block to my spiritual development. My religion's discomfort with discussing sexuality, coupled with my own homosexuality, led me, inaccurately, to believe that I was not a spiritual person.

I believe that a very great challenge to contemporary religion is to confront both sexuality and spirituality and to speak to their integration. If, indeed, the role of religion is to provide a person with a way to find self-fulfillment and to define his or her relationship to society, I cannot understand how the topics of sexuality and spirituality can be ignored.

I fear that religion's discomfort with sexuality may lead many people, like me, to suppose that spirituality—which is vague, which is largely intangible—does not exist. I sometimes wonder why I was in the generation that saw *Time* magazine emblazon on its cover the shocking question, "Is God Dead?" I cannot help wondering if the irrelevance of religion to many in my generation (although I do not see myself as a spokesperson for a generation) cannot be directly traced to its unwillingness or its inability to speak frankly about sexuality and spirituality. In contemporary health care, it now appears that the problem of AIDS transmission is growing among intravenous drug abusers. I find this ironic, because I view that social problem as further evidence of society's failure to provide people with spiritual strength. Why are

people so dispirited—look at the word—so hopeless, that drugs provide them with their only refuge from a cold, heartless world?

I would like to suggest that drug abuse—like promiscuity—is a response of individuals to the spiritual pain that comes from isolation, a pain that is too little discussed in contemporary society, a pain that needs to be ministered to. Isn't it ironic that the medical world that provides us with models for pharmaceutical approaches to pain appears to have suggested to an entire generation, incorrectly I believe, that drugs can calm spiritual pain? I don't believe they can.

What do we learn from drug abuse? What do we learn from promiscuity?

Both are ways, generally unsatisfying, for people to ease the pain, often perceived to be unique, that they experience living with the overwhelming disconnectness of modern society. I fear that a world incapable of providing incentives for altruism or love or other "spiritual values," simply because they offer no economic reward, is one doomed to die. I find it sad that the word *incentive*, something that "makes

us sing," has become a synonym for *bribe*. If actions aren't linked to economic rewards, we seem to have little reason to undertake them. This mind-set now extends to a health care delivery system that awaits government incentives before it tackles the shocking lack of access of millions of Americans to basic health

care services. This is why I've come to believe that AIDS, which cultural critic Susan Sontag likes to believe is a metaphor, is something much stronger. I believe it may well be the world's cry for spiritual help.

At this point in my life, my faith, such as it is, is a trust in myself. It is a faith that my own life, and this disease as a part of it, is an opportunity for me to connect with other individuals, both those with AIDS and

those concerned with other evidence of the erosion of spiritual values, to help each other. The trust I have in myself, which daily wavers considerably, comes from three very important sources: my family, my friends, and my work environment.

I wonder if the most spiritual part of my life hasn't been my realization that my connection to other people sustains me. ☸

**Drug abuse—like
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REFLECTION

When Nurses Take Risks

Emilie Beck

"DID SOMEBODY SPILL SOMETHING?" was my first thought as I watched a Filipino colleague do a 180-degree turn and then peer back into room 423, our four-bed room at the end of the hall. But the hallway of a telemetry unit is normally a little chaotic anyway, so I started back to my own patient, who, despite knowing that I was getting him a pain pill, had put his call light back on again. "Maybe it's his roommate," I thought, an elderly man in the next bed who was constantly getting tangled in his oxygen line.

"Oh, my God! He's dead! He's dead! Do something!" An obese woman in a black coat ran from room 423 with her hands halfway above her head, as if she were being robbed. It was loud and it was powerful. The Filipino nurse started up the hall quickly. "Call a code," she said remarkably quietly. "Oh, God! Oh, God!" the screams continued, turning into a piercing wail. A male nurse who was also in the hall at the same time walked into the room. By this time, several visitors at the nurses' station and in nearby rooms extended their heads to look. This was probably the real thing, although there was still the possibility that another cardiac patient had merely had a choking spell and panicked a family member. It didn't matter; the adrenalin hit like a ton of bricks.

I was halfway between room 423 and the nurses' station, so I turned and yelled to the ward secretary,

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"Call a code! Extension 5555—room 423." The ward secretary just looked. "Call a code," I barked. "Room 423." She did it.

"Get that cart down here," I said to another nurse who had run out of the nurses' station. She also blinked momentarily, and I repeated briskly, "The crash cart . . . 423." I ran down the hall prepared for the worst, silently praying that it was an overreaction on somebody's part.

The screaming woman blocked my entrance to the room. "Oh please, God. Do something!" I wanted to flatten her, I was so desperate to get beyond her into the room. Simultaneously and mercifully another nurse moved her gently to the side. At the same time I heard on the overhead paging system, "Code Blue, Code Blue, Room 423 . . . Code Blue, Code Blue, Room 423," in the flat tone of a routine announcement. One knows, however, that every single nurse and every health care worker is wondering who's on duty in the cardiology unit, who's arresting, and, if they're really honest with themselves, saying silently, "I'm glad it's not my patient," meaning, "I'm glad it isn't me." The first thing I saw was Ray doing cardiopulmonary resuscitation on the chest of a remarkably handsome, unconscious African-American male. Ray's rhythmic pumping seemed oddly out of place, as the young man's eyes were wide open staring vacantly at the ceiling.

"What happened, Ray?"

"Cardiac arrest."

"Are you sure?" I asked, scanning the beautiful body in front of me; he was too young to arrest, too healthy—it didn't make sense. "Stop the compressions a second."

Ray stopped abruptly. I pressed my stethoscope hard onto the guy's sternum. "Nothing." Quickly to the carotids for a palpable pulse . . . again, nothing, then to the groin pulse. "Nothing," I said, as Ray glided expertly into a beautifully done rhythm.

"What have we got here, Ray?" I asked.

"I don't know," he replied. "I just came in."

"How old? 32? 34?"

Ray shrugged. "I think he's a new admission from ER; he just got up on the unit."

"Do you know the diagnosis?" Ray shook his head no as he kept pumping. I turned to the crowd of RNs entering the room. "Whose patient is this?" Two or three people said, "Marta's?"

"Get her!" I snapped.

"Color's good, Ray," I said. "Can we have some more light in here?" Someone immediately turned the overhead lights on. "I'm opening up the line," I said, noting that the intravenous did not contain potassium and, thank God, was running very well. "Where's that cart?" I demanded. "Coming," a voice replied, and indeed the ensuing rumble comforted my ears. "Do you need a board, Ray?" The cardiac arrest board was thrust up toward the patient's chest.

"No," he said, "I used the headboard."

"Hey, Ray," I said, "not bad for a guy." Pretty quick thinking for any nurse, for that matter. I swung the bedside light onto the patient's face. I could hear drawers opening all over the cart as a flurry of mild confusion and activity began in earnest. Behind me, preparations were being made for the insertion of another intravenous line.

"Pupils are fixed, but your compressions are good," I said to Ray. Then, "Are you OK? Getting tired yet?"

"I'm all right." A voice intruded: "Marta doesn't know why he was admitted. He came through ER."

"Find out if there are any allergies. Where is that anesthesia team?"

"Someone said they had an arrest in ICU, but they're on the way."

Suddenly, subtly, but perceptibly, the young man's color changed. Since he was African-American, the average cyanotic change wouldn't show . . . especially on the evening shift, but clearly, his lips were darkening; I inserted my ungloved finger into his mouth and was chilled to note the buccal mucosa becoming darker.

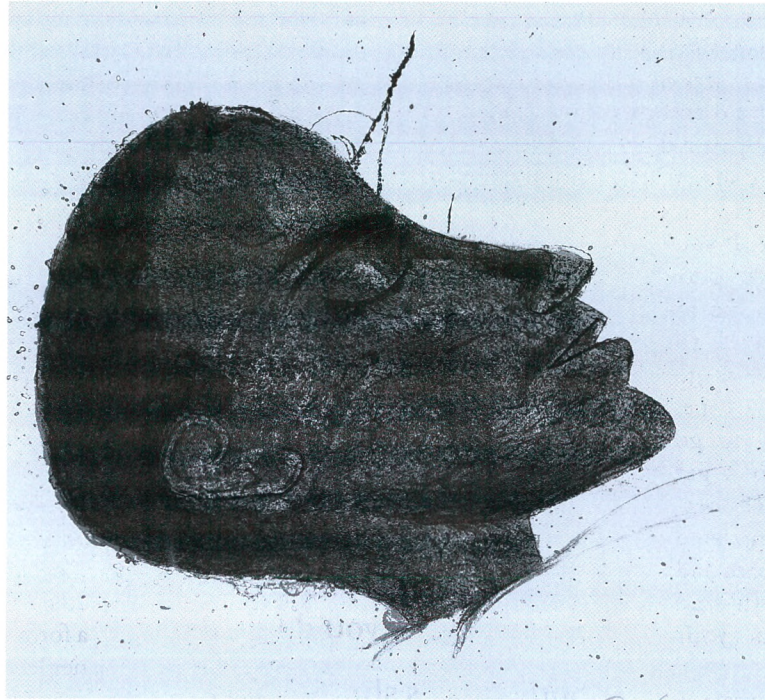
"He's not exchanging," I proclaimed, hoping somehow for help. "We're losing time," I remarked to no one in particular. Staff were fumbling with the cart.

Within the deepest part of my being an enormous sense of anxiety and urgency arose, even though we had a fairly controlled situation. I thought for a fleeting moment—our patient was probably a cocaine addict in sudden cardiac arrest, not unusual in our inner-city hospital. But if he were an addict . . . I glanced quickly at both arms, looking for hard evidence of intravenous drug use and, seeing none, glanced at the doorway again. No anesthesia team. Beyond the bustle I could not hear the sound of pounding footsteps indicating that the team was arriving. A tiny little warning voice said inside my own brain, "You know you always break a blood vessel in your lower lip every time you do this . . ."

"Get me suction," I said loudly and went down, pinching the young man's nostrils, waiting to blow as hard as I could between Ray's poundings.

"Two and three and four and . . ." At the count of five I could sense Ray easing his stroke perceptibly as he resumed an audible count. I exhaled everything I had of my own life's breath into the man, half-expecting blockage but feeling the gurgle of large amounts of mucus trying to impede my efforts. Up I came tasting wet slime with a horrible foul-smelling odor, hyperextending the head even more, thanking an unseen God that he was not obstructed. Down again, this time mashing my own teeth onto the patient's . . . something was wrong. He was exchanging, but he felt "loose" somehow, like calves' liver, only worse. Geez, this guy hadn't brushed his teeth in days. Between puffs, I glanced again at the buccal mucosa and the tongue. Ominously, he was not pinkening up. The tongue was darker now as my personal desperation deepened. "And four and . . ." Again, Ray and I had merged into a rhythm literally pouring everything we had into this stranger. Twice I had to wipe my own mouth because the saliva was causing me to lose the seal I had established over the man's mouth. I had to be careful not to come down too hard, and I could hear the audible click of my own enamel scraping the man's.

"Suction!" I demanded fiercely, coming up from several breaths now as I tried to concentrate on the rhythm; professional staff were beginning to descend on the body in droves.



Beside the Dying. Lithograph by Ben Shahn, 1968.

Collection of the New Jersey State Museum. Museum Purchase, FA1968. 192v.

"Here's the team," said an encouraging voice from behind the crash cart. "Thank God!" I thought. "Finally."

"Where were you guys?" I asked the resident.

"We just had an arrest in the ICU right before this."

"Oh. We thought you were on vacation or something."

We shocked the patient multiple times, poured in the drugs, maintained a beautiful rhythm: everything was nearly perfect. I shone the flashlight that announced massively dilated, permanently fixed pupils. Our patient simply would not come around. We stopped. I was surprised.

The following day, the usual broken blood vessel appeared in my lower left lip, making my mouth painful and sore. I had also contracted my worst case of cold sores—herpes simplex—doubtlessly from the CPR. I looked ugly; I felt bad. About two weeks later, there was a message from the health service stating

that I had been "inadvertently exposed to tuberculosis," and wouldn't I please go to the health service for mandatory skin testing. "Hmmm, coroner's case. TB, inner-city African-American male, about 32." Then it hit: AIDS. I had probably done mouth-to-mouth resuscitation on an undiagnosed AIDS patient, possibly an intravenous drug user. It really wasn't so terribly long ago that I had had my first needle stick during a home blood transfusion on another dying AIDS patient.

My colleagues screamed at me. "How," they wanted to know, "could you DO that!" We all knew what this meant, and we all feared for each other; absolutely nobody approved of stupid "heroics."

THIS WASN'T HEROIC. THE HESITATION WAS THERE: I thought—should I or shouldn't I? But when a patient starts to slip, either you act or you don't. Somebody's slipping away. And that's all you see, that's all you care about. That sense of urgency is very,

very intense when somebody arrests acutely in front of you. It's softer, it's less intense, and it's far more poignant when somebody slips away little bit by little bit. Both experiences are serious losses and they have to be dealt with afterward and they have to be dealt with reflectively, usually in sudden, unexpected little "outbursts" of privately shed tears.

Nurses sometimes take "mental health days" after a really bad experience. If you don't do it—don't give yourself some space and time to "get it together" and to reflect—then you have to go into a kind of burnout to cope. Those emotions have to go somewhere. If you don't get your own act together, personally get your life regulated and healthy and organized and let go, you are of no earthly use to yourself, let alone your patients.

After many discussions and ample time for reflection, given the circumstances, would I do it again? You bet! But why? What is the "force" that impels you to do what you really don't want to do or would prefer not to have to do? What is the difference between people who sit in an office and talk about medical ethics and the people who are out there in the trenches doing it? You could look at this case devoid of emotion and say, "Well, the poor sucker is dying. If I touch him I may die too; therefore I probably should not do it. Why should two of us die when one can be saved?" Now, that's very logical. But when you're standing next to a bedside and somebody's dying, a tremendous surge of adrenalin comes up, and emotion, and deep urgency. You move beyond this objective, logical stuff. You can't *not* have an impulse to save.

The practice of nursing forces one to confront issues of life and death very early on, at the ages of 18, 19, 20, 21. We get to the nitty-gritty of what's important in issues of life and death much earlier than most people, who start losing their parents maybe in their mid-thirties or early forties. We see it quite early on. It's a very intense period.

For me, it isn't the fact that it's a patient. It's the fact that it is the life of somebody outside myself. In an emergency, that life assumes a much higher degree of importance to me than my own. About 10 years ago, I started to develop a personal philosophy about what was important to me within a religious framework. I tried to put it down on paper. It really came down to "The Other." The focus of God's love

was not to be directed toward oneself; love was to be focused outwardly on somebody else, toward another. For practical purposes, there are only two major commandments: love God and love your neighbor. Of the Ten Commandments, number 6 is "Thou shalt not kill." Not to save a life when you could, might be, minimally, a form of indifference, and by neglect, a way of killing.

These beliefs are tremendously reinforced in nursing, because you have the opportunity

to act upon them. The system is geared to provide expression for a deep sense of caring. And your colleagues, who share similar values, provide an avenue of expression for these beliefs. This is as true for male nurses as for female nurses. Having seen so many people—hundreds and hundreds of people dying, possibly thousands—I think that human life is very, very important.

One consideration in this case was that this was a younger person, 32, 34 years old, *young*. He should have been in a robust state of health, should have been in his prime. He could have had a life. And the irony was that he couldn't be saved. That happens, sadly.

You don't know what's possible until you try, but you can be absolutely sure that if you don't try, the person is going to die. I am reminded of an Old Testament verse (Deuteronomy 30:19): "I have set before you life and death, blessings and curses: therefore choose life, so that you and your descendants may live."

**This wasn't heroic. The
hesitation was there:
I thought—should I or
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patient starts to slip, either
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Somebody's slipping away.**

ISSUES & CURRENTS

Abusive "Lifesaving"? Another Look at CPR

Ron Hamel

IT WAS ONLY 28 YEARS AGO that the American Heart Association issued guidelines for the use of cardiopulmonary resuscitation (CPR). This potentially lifesaving procedure was intended to be employed in cases of *unexpected* cardiopulmonary arrest. More specifically, it was meant for the treatment of cardiac or respiratory arrest due to acute myocardial infarction, drowning, drug sensitivity, intoxication, anesthesia induction, electrocution, hypoxia from airway obstruction or suffocation, and cardiac catheterization.

Today, however, CPR is typically initiated for any patient who suffers a cardiopulmonary arrest, unless a do-not-resuscitate (DNR) order has been written. Such an order usually requires the consent of the patient or the patient's surrogate. But consent is not required to initiate CPR because it is viewed as an emergency measure. Presumed consent is operative, rather than consent prior to use as with other treatments. This routine use of CPR has resulted in patients and their families coming to expect it. In fact it has become what one author calls "society's standing order against death." In some ways it is the ultimate technological feat—snatching human beings from the grip of death.

Presumed consent and routine resuscitation make sense in cases of sudden, unexpected cardiopulmonary arrest. But do they make sense with patients whose death is expected from a terminal condition or who are in a persistent vegetative state? Is every death an "emergency event"? Answering yes suggests rather interesting views about death and the human condition! If the answer is no, then could it be that presumed consent to resuscitation is inappropriate in

some situations? Perhaps CPR, outside of emergency contexts, should be considered like any other life-sustaining procedure, thereby requiring prior consent. The assumption would be that CPR is *not* performed unless it is judged to be of likely benefit to the patient, and unless an order is written for it on the basis of patient or surrogate consent. The appropriateness of CPR for a particular patient would be determined in conjunction with the appropriateness of other lifesaving and life-sustaining measures. It would be part of the deliberations about the goals for this patient's care and the overall treatment plan. It only makes sense to specify goals before deciding upon therapies.

Why even entertain such a change in practice and policy? The first and most important reason is patient well-being. The medical and moral justification for any treatment is that it will be of some benefit to the patient. And generally there should be some proportion between the benefits hoped for or obtained and the burdens of the treatment itself or the quality of life to which it contributes. We have increasing evidence that CPR is frequently not "successful," particularly with certain categories of patients.

One fairly recent review of 19 studies of patient outcomes (Moss 1989) found that the mean percentage of patients successfully resuscitated was 41 percent. A "successful" resuscitation was described as the restoration of cardiac rhythm for more than one hour after cardiac arrest. A mean of 27 percent survived for some time but died before discharge. Fourteen percent (or 33 percent of those successfully resuscitated) survived to be discharged from the hospital. And a mean of 12 percent of patients were alive six months after discharge. The survival rate is even lower for certain types of patients. Patients with malignancies, neurologic disease, renal failure, respiratory disease,

and sepsis had a less than 10 percent survival rate overall; frequently there were no survivors. (The survival rate of patients with malignancy was 0–3.5 percent, neurologic disease 0–6.7 percent, renal failure 0–10 percent, respiratory disease 0–7 percent, and sepsis 0–7 percent.) Patients who had asystole as the cause of their arrest, multiple organ failure, or more than one prior arrest also had very low survival rates. Patients who were homebound or in a nursing home prior to the arrest had a survival rate of less than 5 percent.

On the other hand, the survival rates for patients for whom CPR was originally intended were higher: 26–46 percent for individuals having ventricular fibrillation after myocardial infarction, 22–28 percent for those with drug reaction or overdose, and 19–50 percent for individuals with ventricular arrhythmias (Moss 1989:351). Ironically, the largest number of resuscitations is probably performed on individuals who have the lowest success and survival rates.

Successful resuscitation and survival, of course, are not the only considerations in assessing the benefits of CPR to patients. Quality of life after resuscitation is also of critical if not primary importance; serious consideration must therefore be given to the effects of CPR upon patients. Moss reports on the basis of his survey that the resuscitated patient can be predicted to endure one or more of the following complications: “temporary survival, often with prolonged mechanical ventilation in an intensive care unit; pain from rib or sternum fractures; pneumonia; pulmonary edema; permanent neurologic damage; and depression, a reduction in functional status, and fear of another cardiac arrest” (1989:353–54). Patients for whom survival rates are the lowest experience a much greater than 50 percent chance of multiple complications from CPR. Moss’s findings would suggest that, in assessing the appropriateness of CPR for a given patient, it is essential to weigh not only the potential benefits to the patient but also the likely harms. To expose patients to the harms of resuscitation when they have little chance of experiencing its benefits would seem to be abusive.

Undoubtedly, CPR benefits some patients. But does it provide sufficient benefit to sufficiently large numbers of patients to justify its routine use on the basis of presumed consent? Given the survival rates and complications associated with CPR, it would

make more sense to assess the appropriateness of CPR for each patient as with any other lifesaving or life-sustaining treatment. If the physician judges that CPR is likely to be of proportionate benefit (and such judgments, we recognize, are difficult), then it can be offered to the patient or surrogate. CPR is clearly not a magic bullet (though in the popular mind, it may be perceived to be), so why treat it as such? What justifies a bias in favor of its use for patients for whom death is not sudden and unexpected? Not only might its inappropriate use be abusive to some patients, it might also offer the patient and family false hopes, hinder them from facing the realities of the patient’s situation, and delay realistic and fitting responses.

There is a second reason for rethinking the practice and policy of CPR. In very many cases, death is not an “emergency” event; it is not sudden and unexpected. Rather it results from an irreversible condition—a disease process or aging. There is a time to live and a time to die, as the biblical writer so wisely observes. Death can be delayed in some instances, and good reasons for doing so at times exist, but this should not be done without considering to what benefit and at what price. Routine use of CPR may well foster the illusion that death can be cheated; it is the ace-in-the-hole against death. But might this not delay coming to terms with the most certain of life’s realities for both patient and family? Might this use of CPR to pull the patient back from the grip of death cheat both the patient and the family of a “good” death? And what does such a practice say about our attitudes toward death, medical technology, the human condition, and, for those who are believers, life beyond death?

The final issue is the prudent and just use of medical resources. Americans have largely been operating under the assumption that they can have whatever medical care money can buy. While this may be close to being true in many cases, such an attitude does not contribute to good stewardship of resources and may well lead to squandering. When 35 million Americans are without health insurance and an almost equal number are without adequate health coverage, a policy of presumed consent and routine CPR may be not only imprudent but also unjust. If there is ever going to be meaningful reform of the health care system, Americans will need to begin thinking about health care as a common resource for which all are

responsible (and to which all may be entitled). They will need to consider their obligations to other members of society when they think about how they use health care resources and how much they use. Using and demanding physiologically futile or marginally beneficial procedures—and at considerable cost—constitutes a failure in good stewardship and the just use of resources. The responsibility here lies not only with health care professionals but also with patients and their families.

The idea of reversing CPR practice and policy surely goes against the stream. It is certainly not without its own problems and complexities, and perhaps it is ultimately a bad idea. But for the reasons mentioned (and there are undoubtedly others), it bears discussion. In the meantime, suggestions for modifying current policy as it applies to some patients have been made.

In concluding the review cited above, Moss articulates a position that seems to be gaining acceptance.

In these patients [those with a less than 5 percent chance of survival and a greater than 50 percent chance of multiple complications], the performance of CPR is futile and can be predicted to cause much greater harm than benefit. In general, when a treatment has a very high probability of causing harm, the physician is not obligated to propose or provide treatment. Thus, patients with chronic, progressive conditions whose deaths are anticipated pose an exception to the usual practice of providing CPR to all hospitalized patients, and the physician serves no useful purpose by offering the choice of CPR or no CPR to them. In such cases, it is the responsibility of the physician to inform the patient that the risks of CPR outweigh the benefits and to present a realistic treatment plan, including DNR status, that will maximize the patient's comfort, peace, and dignity in his/her final days and minimize pain and suffering. (1989:354)

A similar position is taken in a position paper published by the American Thoracic Society.

The purpose of a life-sustaining intervention should be to restore or maintain a patient's well-being; and it should not have as its *sole* goal the unqualified prolongation of a patient's biological life. On this basis, a life-sustaining intervention may be withheld or withdrawn from a patient

without the consent of the patient or surrogate if the intervention is judged to be futile. . . . A physician has no ethical obligation to provide a life-sustaining intervention that is judged futile . . . even if the intervention is requested by the patient or surrogate decision maker. (1991:481)

Ambiguity surrounds the term *futile*, of course, and there has actually been considerable debate recently about its meaning. Futility can be interpreted *physiologically*, in which case CPR would be futile if it did not reestablish cardiopulmonary function. But, as physician Stuart Youngner (1988) points out, futility can also be interpreted as the inability to *postpone death* (even though CPR has its immediate physiological effect), or *lengthen life for some period*, or maintain a certain *quality of life*. It may even refer to the very low *probability* of achieving these goals.

These distinctions are important and have significant implications. Physiological futility and the inability to postpone death are medical judgments that can and should be made by the physician. But deciding that a treatment is futile because it would preserve a life of insufficient length or quality or because the probability of success was too low to justify the burdens or costs is a judgment involving benefits to the patient, values, personality, and goals. Such judgments should involve the patient or surrogate.

What does this mean concretely for approaching patients or their surrogates about CPR? First, in those cases where CPR would be physiologically futile or could not postpone death, the medical or moral justification for using it recedes. There is no obligation to do what is futile. In fact, as noted above, there are moral reasons for *not* providing it, patient well-being and justice among them. In these instances, patients or their surrogates should not expect it, nor should physicians offer it. And there is no need for consent to a DNR order. Offering futile CPR in such cases, even with a strong recommendation that it be forgone, could well confuse patients or their surrogates. They might think that because CPR is being offered, it must be of some benefit. Patients or, worse yet, their surrogates are then put in the position of making a very difficult decision that really should not have to be made. In addition to creating a good deal of stress, an offer of CPR may create guilt, internal conflict for the surrogate, or even conflict among family members (Hackler and Hiller 1990).

Not offering CPR as a treatment option, however, does not mean not informing the patient or surrogate of a decision about the patient's care and the reasons for it. Not providing CPR, after all, has an irreversible consequence, one that patient and family should know looms on the horizon. This discussion would, in fact, provide an opportunity for the physician to broach with the patient and family or surrogate the patient's medical condition, appropriate measures in response, and the likelihood of death. It would also provide an opportunity for both patient and family to begin preparing for the death. The American Thoracic Society position paper takes a similar stand: "If a physician decides to withhold such an intervention, he or she has a responsibility to inform the patient or surrogate decision maker of that decision and to explain the decision's rationale. The physician should also offer reassurances that the patient will continue to receive all other care that is medically indicated within the context of an overall treatment plan agreed upon for the patient" (1991:481).

More difficult surely are those situations in which CPR might offer some benefit to the patient. They involve not only probabilities, but more important, patient values and other patient-related factors. In these cases, patients should be involved in decision making. "Even if the physician feels strongly that resuscitation is not advisable because the burdens outweigh the benefits, the patient or surrogate should have the opportunity to assess the chances of success and the desirability of any extension of life, and their wishes should almost always be followed. Resuscitation obviously should be undertaken if a patient with decision-making capacity requests it" (Hackler and Hiller 1990:1283). Crucial here is what information the patient is given and how that has been presented. The patient must be given a realistic assessment of his or her condition and adequate information about the nature of CPR and its likely risks and benefits. Since a decision about CPR can be so final, discussions preceding it should not be rushed and should allow for questions to be raised, understanding to be tested, misunderstandings to be clarified, and reassurances to be given.

What if a request for CPR comes from the surrogate? Surrogacy implies that the surrogate chooses what he or she believes the patient would choose if capable. This requires some knowledge of the patient's

preferences, beliefs, and values. As knowledge of these diminishes, the surrogate must decide on the basis of the patient's best interests. This involves discerning what a reasonable person would choose in the circumstances, "taking into account such things as relief of suffering, restoration of functioning, and quality and extent of life sustained" (Hackler and Hiller 1990:1283). Needless to say, the surrogate also needs a realistic picture of the patient's condition and of what CPR can or cannot do for the patient.

Disagreements will sometimes arise between the physician and surrogates about the patient's best interests. If the surrogate's judgments are reasonable, the physician should probably acquiesce, unless he or she believes doing so would bring significant harm to the patient. There may even be legitimate occasions when the physician follows the surrogate's decision in order to be responsive to family needs. However, as Hackler and Hiller point out, "family needs should be clear and compelling to justify additional suffering by the patient" (1990:1283), and there comes a point in time when respect for the family must give way to the well-being of the patient.

While most surrogates operate in a responsible manner and truly seek the patient's well-being, not all do. When a surrogate fails to meet the requirements of surrogacy—capacity to make decisions, and representation of patient preferences or pursuit of the patient's best interests—physicians should not be bound by their decisions. As Hackler and Hiller put it: "When the family does not and will not deliberate in an appropriate manner, or when their views about suffering and quality of life differ substantially from those of most reasonable people (and there is no indication that the patient shared such views), then physicians should not be forced by hospital policy to adhere to family preferences" (1990:1283). Under such circumstances, it would be appropriate for the physician to seek the assistance of a mediator. If differences are not resolved, a hospital ethics committee (or some other appropriate body) could review the surrogate's decision.

In the end Hackler and Hiller recommend that

even if CPR would not be clearly futile, physicians should be able to write a DNR order without family consent if (1) the patient is unable to consent, (2) the burdens of the procedure would clearly outweigh the benefits, (3) the surrogate does not

provide an adequate reason for refusing consent, and (4) the physician has made appropriate attempts at mediation (as established by hospital policy). (1990:1283)

They believe that physicians proceeding in this manner are unlikely to have serious legal difficulties if a review has supported the physician's judgment about the surrogate's reasoning and decision and that the best interests of the patient would not be served by CPR.

Although suggestions to modify current CPR policy or to modify it in the ways outlined here have not met unanimous approval, there appears to be momentum in this direction. These changes, however, may not go far enough. They still operate under the assumption that CPR should normally be provided and that DNR orders should be written.

For some patients at least, it might be worth considering CPR as we do any other lifesaving and life-sustaining treatment: the assumption would be that in nonemergency situations, when death was expected as the result of aging or a disease process, CPR would not be routinely performed. An order would have to be written *for* CPR if it were judged an appropriate procedure for a particular patient. It will

undoubtedly be difficult to overcome the technological imperative, but for the sake of patients and of those who have to administer CPR, it seems worthwhile to take a hard look at the current practice and policy of CPR and its underlying assumptions and values. The marvels of technology can continue routinely to wrest the dying from the shadows of death, but to whose benefit and at what cost?

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Scientists and religious leaders met in Washington, D.C., in May to address together the growing environmental crisis. To organize the meeting, scientists sent an appeal, "Preserving and Cherishing the Earth: An Appeal for Joint Commitment in Science and Religion," to religious leaders all over the world. An excerpt:

We are now threatened by self-inflicted, swiftly moving environmental alterations about whose long-term biological and ecological consequences we are still painfully ignorant—depletion of the protective ozone layer; a global warming unprecedented in the last 150 millennia; the obliteration of an acre of forest every second; the rapid-fire extinction of species; and the prospect of a global nuclear war that would put at risk most of the population of the Earth. There may well be other such dangers of which, in our ignorance, we are still unaware. Individually and cumulatively they represent a trap being set for the human species, a trap we are setting for ourselves. . . . We are close to committing—many would argue we are already committing—what in religious language is sometimes called Crimes against Creation.

And, as religious leaders and scientists learned at a previous meeting, the effects of environmental



degradation are borne disproportionately by the poor. Participants heard a secular parable illustrating that point:

Imagine humanity as a village of 100 families. Then, 65 families in our village are illiterate, and 90 do not speak English, 70 have no drinking water at home, 80 have no members who have ever flown in an airplane. Seven families own 60 percent of the land and consume 80 percent of all the available energy. They have all the luxuries. Sixty families are crowded onto 10 percent of the land. Only one family has a university education. And the air and the water, the climate and the blistering sunlight, are all getting worse.

(*Parade Magazine*, 1 March 1992)

During 1991, the average percentage of a state's annual budget going to welfare was 3.4 percent. The percentage of all federal domestic spending going to the elderly was 46 percent, while the percentage devoted to children was 11 percent.

(*Harper's*, March 1992)

A nationwide study of Medicare patients found that in 1986 blacks received coronary artery bypass grafting (CABG) less often than whites. The CABG rate was 27.1 per 10,000 for whites (40.4 for white men and 16.2 for white women), but only 7.6 for blacks (9.3 for black men and 6.4 for black women). The difference was greatest in southeastern states, particularly in rural areas.

The investigators compared the rates of CABG with the rates of hospitalization for myocardial infarctions, a measure indicating the need for CABG. Although hospitalization rates for myocardial infarctions were slightly higher for whites, this did not account

for the much larger difference in CABG rates. The CABG rate for whites, but not for blacks, increased in areas with more thoracic surgeons, presumably due to physician-induced demand. The investigators, having analyzed data from 86,463 Medicare patients, conclude that "the discrepancy in the CABG rates between blacks and whites . . . suggests that social and cultural factors may interfere with access to care even though a national health insurance policy is implemented."

(*Journal of the American Medical Association*,
18 March 1992)



Percentage increase, during 1991, in the number of people seeking emergency food aid in U.S. cities: 26.

(*Harper's*, March 1992)



Over the past 30 years people in the U.S. have increasingly come to understand that smoking leads to illness and death. Cigarette smoking nationally is on the decline. In 1965, 40 percent of U.S. adults smoked; in 1988, only 28 percent did. The number of smoking-related illnesses and deaths nationally has leveled off



for men—although for women it continues to rise. Communities have passed more than 400 local ordinances placing controls on tobacco. Smoke-filled restaurants, offices, and stores are, in many places, a thing of the past.

However, other statistics are less encouraging. Worldwide, smoking is responsible for an estimated 2.5 million deaths each year. More than 49 million adults in the U.S. continue to smoke. During 1988 smoking caused over 434,000 deaths in this country. More than 3,000 U.S. teenagers become regular smokers every day. Lung cancer is now the leading

cause of cancer deaths among women in the U.S. Most troublesome of all, cigarette consumption in developing countries has increased dramatically, with serious health consequences already evident.

(Evangelicals for Social Action's *Advocate*,
March 1992)



Results from a survey of 1,150 high school seniors listed in *Who's Who Among American High School Students* suggest that students are still not convinced by arguments to be more careful sexually, even after Magic Johnson's disclosure that he has the AIDS virus. The survey, taken by Educational Communications, Inc., indicates that 21 percent of the students said they were "worried" or "very worried" about contracting the virus. Before Magic's announcement the figure was 12 percent.

About 28 percent of the teens said they were sexually active. Of those, 45 percent said they don't engage in sex without a condom, but 42 percent said they would have intercourse even if a condom were not available. "These alarming findings confirm our worst fears—high school students see themselves as invincible," said Paul Krouse, publisher of *Who's Who*. "Unfortunately, it seems the message of the danger of AIDS will spread only with the number of young people who succumb to it."

The organization said 70 percent of the students who responded were girls.

(*American Medical News*, 9 March 1992)



Prostitution receives due attention in Edwina Gateley's *I Hear a Seed Growing* (Source Books, \$12.50), a book featured by Demethria Martinez in a recent issue of the *National Catholic Reporter*. British-born Gateley studied at Chicago's Catholic Theological Union. After a period of prayer and reflection—in the Sahara and in a forest near Chicago—Gateley entered the city wilderness, there to befriend and counsel prostitutes. Most were childhood victims of abuse, incest, or rape, says Gateley, and one-third of all female prisoners are incarcerated for prostitution. "Meanwhile, Christian churches counsel women to 'sin no more' but offer no alternatives to prostitution,

no means of addressing its root economic and psychological causes. . . . We never ask, Why are you doing this? When were you raped?"

Gateley runs Chicago's Genesis House on "a widow's mite" and has often seen there a prostitute transformed "into a proud woman with a degree in her hand." She says: "We have preached enough. . . . We have to sit with the sin we as church and society have created until our hearts soften up. Maybe we'll soak up some of the violence and pain. . . . Jesus said that prostitutes will enter the Kingdom first, but until the church takes those words seriously, it will continue to set male over female, priest over prostitute."

(*National Catholic Reporter*, 21 June 1991)



Millions of Americans read religious self-help books. Such books, reports lawyer Wendy Kaminer in a recent issue of *Theology Today*, "are marketed as primers on personality development and psychotherapy, child rearing, spouse abuse, depression, and despair, as well as the search for love, happiness, and salvation." The books portray God as a loving parent and advise readers to acknowledge their dependence on God, to reject individualism, and to love themselves as well as their neighbors.

Nineteenth-century liberal Protestantism, for all its faults, at least encouraged people to act to shape their environments, Kaminer says. "Now popular religion, like a 12-step [recovery] group, [tells] us that we're powerless." Most of the pop religious literature is devoid of "thoughtful discussion of moral behavior." The writers provide a "laundry list of moral wrongs—abortion, homosexuality, adultery, atheism, and rebellion—but no guidance in resolving moral dilemmas."



The writers usually "claim a fellowship with their readers, admitting their own fallacies, sins, and neuroses." But they also set themselves up as authorities, even as they disclaim any higher expertise. For example, M. Scott Peck, author of the best-selling *Road Less Traveled*, "bemoans our tendency to 'let our authorities do our thinking for us,'" but clearly regards himself as an authority. He speculates that people who "slip away" from his workshops "just cannot bear that much love." Individuals who challenge him, Kaminer says, are almost always presented in his books as wrong.

Peck and other Protestant writers all stress strongly the need to surrender one's self to God. Peck maintains that there exist "only two states of being: submission to God and goodness or the refusal to submit to anything beyond one's own will, which refusal automatically enslaves one to the forces of evil"—a proposition Kaminer finds "chilling." In people's "eagerness to submit," she remarks, "not everyone can distinguish God from the devil."

(*Theology Today*, October 1991)



A committee of the nation's Roman Catholic bishops, addressing a question that has divided their ranks, issued a warning on April 2, 1992, against the increasingly widespread practice of withdrawing food and liquid from irreversibly unconscious patients. "We are gravely concerned about current attitudes and policy trends in our society that would too easily dismiss patients without apparent mental faculties as nonpersons or as undeserving of human care and concern," the statement said. But it added that Catholic theologians were divided about removing all artificial life supports, including feeding tubes, from those in a persistent vegetative state. Legitimate differences could even arise about applying well-established moral principles to specific cases, the bishops said. They urged Catholics and others to pursue these issues while, in the meantime, being "guided by a presumption in favor of medically assisted nutrition and hydration."

The Reverend Kevin O'Rourke, director of the Center for Health Care Ethics at St. Louis University Medical School, believes the bishops' statement will have the reverse effect: "People have a responsible

sense that when you've done enough, it's enough. If you equate removing feeding tubes with euthanasia, people will abandon all distinctions."

(*New York Times*, 3 April 1992)



Is your career in a slump? The hormone responsible for sex drive and aggression may determine how well you perform in certain jobs and may even influence your choice of career, says James M. Dabbs, a psychology professor at the University of Georgia. He has concluded that men and women with high tes-



tosterone levels do best in highly competitive jobs. Actors have the highest testosterone levels, followed by doctors and trial lawyers, says Dabbs. Nurses and ministers, who tend to be more cooperative than competitive, tend to have lower levels.

(*Philadelphia Inquirer*, 30 December 1991)



The next round in the national debate over the legalization of physician-assisted suicide will be taking place in California. Californians Against Human Suffering is likely to announce that it has obtained the 570,000 signatures necessary to qualify its "Death with Dignity" initiative. For the measure to go on the ballot, the secretary of state must determine that at least 385,000 of the signatories are registered voters. The initiative would allow a person with six months or less to live to sign a witnessed statement asking the attending physician to end the patient's life.

(*AMA News*, 16 March 1992)



According to a study of 14,000 Native American teenagers from 50 tribes in 15 states, one out of six

Native American teenagers has attempted suicide—a rate four times that of other teenagers. Twenty percent describe their health as poor, while 18 percent indicate that they are constantly sad. One in five Native American boys develops a drinking problem before the end of high school. In the words of one of the researchers, "This is the most devastated group of adolescents in the United States."

(*Journal of the American Medical Association*,
24 March 1992)



On the importance of the quality of sensitivity in family doctors, journalist Charlene Marmer Solomon says: "Talk with families and you discover just how much they value communication with their loved one's physician. They are exquisitely sensitive to physicians' language and non-verbal communication; they say they 'hang on every word' and 'watch every gesture.' They will tell you how a doctor looked when he told them their mother had cancer, whether he sat



in a chair or stood at the foot of the bed and what tone of voice he used. They remember the hope and reassurance. They also remember the terse words and unfeeling dismissals, the lack of presence at a crucial moment, the test results given hurriedly as the doctor walked down the hallway."

Meeting the demands of patients' families requires learning a communication style different from the one taught in medical school. "Doctors learn to be linear in their thinking. They start off identifying symptoms and go to the broader category of the disease once they understand what the symptoms add up to. Patients and their families see things the other way around: They start off with broad, sweeping questions about what's wrong, and only later are they

able to narrow it down. The whole process of fielding such open-ended questions can be a strain on the doctor."

(*American Medical News*, 11 November 1991)



More on physicians' bedside manner: A pilot program by the National Board of Medical Examiners uses mock patients to test both the competence and compassion of medical students. Students have 15 minutes to examine each of 16 subjects who have been trained to simulate ailments. The "patients," usually actors, use a checklist to grade the aspiring doctors' questions during the exam, then evaluate more subjectively such things as attitude and manner. A five-point scale measures how the mock patients feel the would-be



doctor greeted them and whether he or she "talked down" to them. Another measure is simply, "Would you want this person to be a doctor?"

The NBME aims to make the grueling situational examination a required hurdle for new physicians by as early as 1995.

(*Wall Street Journal*, 17 March 1992)



An informal, nonscientific survey of American Society of Internal Medicine members, conducted in the fall of 1991, found that one in five internists reports having taken deliberate action to cause the death of a patient. One in four has been asked by terminally ill patients for help in committing suicide. By an almost two to one majority, respondents (400 out of slightly more than 1,000) said they would vote against a measure that would legalize euthanasia, even though, by the same majority, they felt suicide was a moral option for someone in great pain. Results of the poll

were published in the March issue of *The Internist: Health Policy in Practice*.

(*AMA News*, 16 March 1992)



The American Institute for Preventive Medicine recommended 10 New Year's resolutions at the beginning of this year. Number one on their list: manage



stress. The others, in order: practice safe sex; stop smoking; avoid secondhand smoke; develop a social support network; be active; control consumption of cholesterol and saturated fat; limit your intake of red meat, eggs, and cheese; moderate alcohol use; and have a sense of purpose.

(*Philadelphia Inquirer*, 30 December 1991)



Of what significance is religion to health care? Rabbi Harold Kushner suggests one way of viewing their interrelatedness in his book *Who Needs God* (Simon and Schuster, 1989):

You and I visit the same hospital. We walk down the same corridor and we see the same things—elderly patients for whom length of days has become a curse instead of a blessing; young people whose lives have been shattered by vicious criminals or drunk-driving accidents; innocent children who are victims of genetic tragedy and will never really have a chance to live. The facts are the same for each of us, but do we really see the same things? One person will see an endless chronicle of pain and suffering, and conclude that the world is a mess and life is Somebody's idea of a nasty joke. . . . Another person, seeing the same situation, will come away having learned something about human courage and resiliency. Her conclusion will be that incurable illnesses are a painful outrage *precisely because* life is good and holy. . . . For her the courage to love in the face of the

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world's unfairness is the most profoundly human response.

For the doctor, illness and trauma are a challenge to practice the healing skills. For the chaplain, they represent opportunities to make real the presence of God as a god who loves all of His creatures, not a God of judgment or detachment. For both these people, the facts, the medical diag-

noses are the same. But the eyes with which they see those facts determine how they will act. (Pp. 27–28)

And this is because religion, according to Kushner, is primarily a way of seeing the world, of interpreting the facts of the world we live in.

(Who Needs God, 1989)

BOOKS

Larry R. Churchill

John F. Kilner. *Who Lives? Who Dies? Ethical Criteria in Patient Selection*. New Haven and London: Yale University Press, 1990.

THOSE WHO READ JOHN KILNER'S *Who Lives? Who Dies?* anticipating argumentative writing designed to resolve the problems of patient selection will be disappointed. In a book of 19 chapters and 237 pages of text, only the final chapter of 21 pages is devoted to an argument consolidating and defending a proposal identified as the author's. This is not a philosophical monograph that articulates, elaborates, and defends a position on how to select lifesaving medical resources. Nor was it intended to be. The subtitle, "Ethical Criteria in Patient Selection," more accurately describes the contents. This volume is a cataloging—for the most part a very skillful one—of positions that might be adopted in patient selection. Not a work intended to break new ground, Kilner's book offers the reader a carefully nuanced map of the ground already tilled. Read this book as an extensive encyclopedia entry or as a freestanding reference work on patient selection criteria, for this is where its strength and durability lie.

The amount of work that went into this volume is impressive. The bibliography is in itself a prodigious undertaking, with just under a thousand entries, all of them cited in the text. Moreover, the book is very well

cross-referenced, so that positions previously discussed are noted and positions yet to be discussed are anticipated throughout. The reader is consistently assisted in getting her bearings and in locating differences and similarities. Shelf this volume next to the *Encyclopedia of Bioethics* and use it in a similar way.

Still, some notable points of originality distinguish this work. One is the incorporation of studies Kilner did in Kenya. Rather than making the usual comparisons with Western European societies, Kilner contrasts U.S. practices with those of the Akamba, a Bantu people whose attitudes about patient selection are more spiritual and egalitarian than ours. Kilner uses this contrast to good effect, especially in the consideration of age as a criterion.

Another original feature is the result of surveys that Kilner conducted with transplantation program directors and dialysis directors in the U.S. He integrates the survey findings skillfully into the text and uses the results as a backdrop for discussing why certain criteria (for example, willingness) are well accepted while others (for example, random selection) are not.

In addition to these two original contributions the nuance of argument Kilner provides in discussing the views of others should be noted. A meticulous care marks the work as a whole.

The large middle part of the book is a discussion of 15 specific criteria for patient selection. These 15 criteria are discussed under four headings: social, sociomedical, medical, and personal. Kilner follows a similar format in each chapter: he presents justifications and weaknesses for each criterion, suggests "possible common ground," and illustrates the issues

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with a concluding case. The format lends a certain predictability to the text, but this allows for easy reference and for quick comparisons among the criteria discussed. On the whole Kilner achieves his aim of enabling the reader to orient himself with regard to each criterion presented and thereafter to carry on the discussion.

In his attempt to cover so much ground, it was inevitable that Kilner would treat inadequately or too briefly some of the positions he describes. I wish, for example, that the author had given more attention, or a different reading, in the following areas.

The arguments as a whole are categorized as "person oriented" or "productivity oriented," in preference to the more familiar typologies, teleological vs. deontological, utilitarian vs. egalitarian, and so on. I do not fault Kilner for eschewing the usual, and now somewhat hackneyed, recourse to ethical schools, or theories. Some new and more imaginative typologies are needed, especially when primary authors are not discussed. Generally, we do better to discuss John Stuart Mill's position and not "utilitarianism." In the absence of that, more creative renderings are desirable. The problem arises as Kilner adopts yet another dichotomous rendition. Why not three or four types of arguments—person-oriented, productivity-oriented, community-oriented, and so on? Kilner does not argue for his typology but simply presents it as more helpful than the overlap and spillage resulting from the imprecision of the older types. Yet the way Kilner uses the person/productivity division is almost indistinguishable from a deontological/utilitarian bifurcation. It is hard to see what is gained here. The limitation of the person/productivity categories is best displayed in Kilner's treatment of "social value." Here the person and productivity positions are exaggerated, and these exaggerations are not corrected in the "common ground" section designed to reconcile the extremes. For example, a conviction about the equal intrinsic worth of persons could be viewed as a reason to avoid all social value judgments, as Kilner portrays it. But equal intrinsic worth can be affirmed and can also be seen as irrelevant to patient selection because it leads to no choice at all. In this way, productivity- and person-centered concerns are not necessarily antithetical, yet Kilner's portrait is of exclusive and unbridgeable opposites.

"Age" for Kilner is categorized under sociomedical criteria, along with "psychological ability" and a "supporting environment." Although he lists it as *sociomedical*, Kilner's aim is to separate its *social* from its *medical* aspects and to disallow the legitimacy of the former and affirm the legitimacy of the latter. For example, "age" as a stand-in for reduced physiologic capacity or a chronic condition is acceptable insofar as it is medically relevant. "Age" as an expression of social value derived from a life-span norm is, for Kilner, unacceptable. Given the sophistication of the recent discussion about age, the portrait of the positions here seems inadequate. Most of us would probably agree that age is not *the* criterion for patient selection, but it is hard to see why it should never be a criterion except as a proxy for a medical disqualification. Isn't there some preference for children that is justifiable in matters of scarce health care resources?

The book closes with a proposal for ordering the various criteria for patient selection discussed in the previous chapters. The framework presented is a sound one and deserves further study. The penultimate section of the final chapter, however, contains a shift in tone and argument. Here Kilner makes an abbreviated apology for what he terms "the Judeo-Christian story" as the "larger picture" in terms of which his presentation makes sense, particularly his arguments for person-oriented over productivity-oriented criteria. This is an unfortunate detour in an otherwise very fine work. It is unfortunate because Kilner suggests that all the foregoing analysis will not be grounded anywhere without this story. This diminishes, unnecessarily, the value of the preceding 233 pages. Moreover, the term *Judeo-Christian* is jarring and suggests an intellectual if not a cultural imperialism. There are no Judeo-Christians, though there are Jews and Christians of widely varying cultural and religious convictions. To make a foundationalist claim for his analysis, without extensive clarification and argument, makes for a surprising and unnecessary confessional note at the end of a long and cogent analysis.

Despite these reservations, this work should be commended and widely used as an indispensable reference volume. It represents an extraordinary amount of work, and overall its execution exhibits balance, perceptiveness, and good sense. Every bioethicist would be wise to have a copy.

READERS' RESPONSES

The Second Opinion staff invited a number of its readers who are physicians to respond to our recent Case Stories section on medical noncompliance, which included a case story by Kevin Coleman and commentary and overview by Arthur W. Frank (Second Opinion 17, no. 3 {January 1992}). Our thanks to those who shared their reflections, a number of which have been excerpted here.

During my graduate school days, I moonlighted as a walk-in physician at one of the local health maintenance organizations (HMOs). Patients well enough not to go to the emergency room but feeling sick enough to require urgent medical attention were scheduled during the evening hours. In return for an hourly wage I would see these patients and reassure, treat, or triage them as appropriate.

As I entered one room that evening, I was confronted by an overweight white man, about 50 years old, sitting on the edge of the examination table clutching his chest, having difficulty catching his breath, and sweating profusely. He told me that he had been mowing his lawn when he stopped to take a break and go over to the fence to talk to his neighbor. The next thing he knew, he was flat on the ground, feeling like "an elephant was standing on my chest," with his wife and the neighbors gathered around him. He felt nauseated and sweaty. His wife put him in the back seat of her car and drove him to the hospital's emergency room, where he was told by the nurse that he wasn't sick enough to be seen there and should go

upstairs to the "walk-in clinic." Hence, here he was in my examination room.

I immediately gave him some sublingual nitroglycerin, applied oxygen, and began some tests. An electrocardiogram showed abnormalities. Considering the risk of a heart attack to be high, I called for a Coronary Care Unit bed. No beds were currently available, but some would be in a couple of hours. In the meantime, I put the patient into a wheelchair and personally wheeled him down to the emergency room where he could stay on a monitor until his bed was available. He was beginning to feel better from the medicine and the oxygen. I went back upstairs to finish my shift.

At the end of my shift I decided to check in the emergency room to see how he was doing, but he was gone. I asked the emergency room doctor where he was: "Dead? Upstairs, in the CCU?" "No," the doctor said, "he went home. I asked him how he was feeling, and he said 'fine.' So I asked him if he would like to go home, and he said 'sure,' so I sent him home."

Patients confronted with a serious threat to their health commonly exhibit denial. This is especially true of Type A personalities, the type usually linked to cardiovascular disease. Certainly in this case the patient was susceptible to hearing what he wanted to hear. For a busy HMO emergency room doctor, concerned about keeping people out of the hospital, this might be an opportunity. Rather than have to tell the patient his risks and benefits from hospitalization, and then risk that the patient's fears would aggravate a natural tendency for denial and noncompliance, why not just recommend discharge?

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Coleman and Frank operate with the assumption that the physicians with whom they are dealing are moral, competent, caring individuals without serious conflicts of interest. But surely the truth is closer to the old Lutheran liturgy, "we are sinful by nature and have sinned against Thee in thought, word, and deed, both by what we have done and by what we have left undone."

Consistently good outcomes—based on something other than placebo, chance, or miracle—require more than getting away with ignoring sound advice, or receiving less than optimal advice. Medicine is an art in the classic sense of an activity where not all the necessary and sufficient factors are known. Yet good outcomes can be maximized by careful attention to those factors shown necessary to provide good results. Seen in this light, noncompliance is no more palatable than malpractice. In a sense, it is malpractice by the patient against himself. It is not something to be joyous about, not something to revel in as a manifestation of the god "autonomy," but rather something to consider and guard against in the course of normal medical care.

Noncompliance is patient malpractice. If we think of proper medical ethics as a striving for the good, we cannot condone noncompliance as an ideal. Noncompliance may be a rational response in certain cases; it is usually not, however, a response of faith, hope, or love.

Timothy J. Keay

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Baltimore, Maryland



When I began the practice of medicine and was still somewhat intoxicated with the glamour of being a real M.D., I assumed that a patient's noncompliance was an act of ingratitude at the least, or else gross stupidity. Unfortunately, this assumption too often compromised the zeal with which I cared for that person. Fortunately, I've now come to view noncompliance in just the way Arthur Frank does. What a positive difference a few thousand patient encounters can make!

Kevin Coleman's story reminds me of a closer-to-home example of noncompliance. After over 70 years of married life, both my grandparents were enfeebled and in their nineties. Although they still lived in their own home, their children had to take turns staying with them, especially overnight. Then, one February day in 1957, my grandfather died. It was cold, snowy, and blustery, but Grandmother, who hadn't been out of the house for months, was determined to go to the funeral of her mate of 73 years. Her intentions were opposed by physicians and regarded as absurd by many of the family. But she went!—against medical advice and against "common sense." Two weeks later, she died of the pneumonia she acquired in going to that funeral.

In that last demonstration of choice—and non-compliance—I have always admired my grandmother. There *are* things more important than additional numbers of days, especially at age 93, but at other times of life as well. Even if Kevin Coleman had experienced a pierced bowel on his trip to Newfoundland, I would be cheerleading on his side, "Go, Kevin!"

This is not to disregard God's call to the stewardship of his marvelous creation. It is not to affirm workaholicism. It is not to support the behavior of too many of those Christian leaders whose too-busy schedules destroy their marriages and their children's lives, as well as their own health. It is simply to affirm that there is more to life than adhering to the medical protocols of professionals who hardly know us.

Willard S. Krabill

Goshen, Indiana



As a surgeon and founder of a therapy program called Exceptional Cancer Patients, I think Kevin Coleman's choice was quite appropriate and may well be a sign of survival behavior. The word *patient* means *submissive sufferer*. But I advise people to be responsible participants. One of the reasons I wrote *Love, Medicine and Miracles* and *Peace, Love and Healing* was to elucidate the characteristics of survival behavior.

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Survivors are responsible participants, not door-mats. Many have the word *uncooperative* in their medical record or are called "characters" by the medical staff. It is important, however, to be known as a unique individual, not as an "incurable disease." In his book *At the Will of the Body*, Arthur Frank says that he returned to his hospital room to find the word *lymphoma* on his door—not even the correct final diagnosis. What would your response be to this sign? I would tear it off and write "Human Being: lymphomas may be found in the pathology department."

Doctors are not natives but tourists in the patient's world. Patients are living an experience and yet we treat only the disease. For some, therefore, the treatment is worse than the disease. I am not suggesting that patients should ignore the benefits of medical science but that we create a relationship or marriage. I know a patient who committed suicide after a physician said, "You can't sail your boat, play tennis, or work anymore."

In short, I think Kevin Coleman's behavior was appropriate for him. It is his life. To listen to a teenager refuse treatment because it has made her bald, ugly, and horrible is to understand why life must remain meaningful. Otherwise why go through therapy?

For many people cancer is the event that gives them permission to live. They now give birth to their true selves. As a by-product of this new life many achieve prolonged survival and some spontaneous remissions. We must realize that feelings are chemical. Love, hope, and joy are physiologic. They alter our neuropeptides and change the incidence of side effects as well as improve the effects of therapy: the wonderful placebo response.

Women live longer than men with the same cancers. Married men live longer than single men with the same cancers. Are these accidents? No! They are related to relationships and feelings. Similarly, statistics reveal to us that people postpone death until after meaningful occasions like holidays and birthdays.

It is time physicians studied success, survivors, and spontaneous remissions. I call them cases of self-induced healing. Success does not mean living forever, but it does mean exceeding expectations. It is time to stop labeling these cases as errors in diagnosis or as miracles. Our medical schools need to have courses on communication, healing, the disease as an experience, and a course based on my patient's question—the one

that changed my way of practicing and led me to start my group therapy program: "HOW DO I LIVE BETWEEN OFFICE VISITS?"

Bernard S. Siegel

Woodbridge, Connecticut



I am surprised at the feelings of defensiveness these articles evoke in me. Somewhere along the way of my nine-year transformation from English and religious studies major to the spouse, parent, and physician I am today, I have grown sensitive to criticism of the medical profession from those who have not personally experienced its deracinating effects. The current "curious division of professionals and laypersons" that Arthur Frank so aptly identifies devastatingly affects both parties. The need of the physician to tell her story is as great as that of the patient, and both parties are silenced by the false affects of our current medical culture.

In the often disturbing world of medical residency training in which I spend 60 to 80 hours a week, *noncompliance* is a pejorative word. The case of a patient I shall call Mr. Jones was recently presented rather derisively in the medical residents' morning report. Mr. Jones may have failed to take his diuretic pill because he could not afford it, because he did not like the side effects, because he did not understand its purpose, or because he does not like his doctor, but when he arrived in the emergency room at 3:00 A.M. in florid pulmonary edema and was subsequently endotracheally intubated, the admitting resident wrote "medical noncompliance" when he discovered the omission of prescribed therapy. A subtle judgment of culpability is implied in the term. Each respiratory therapist, dietician, nurse, physician, or other health care provider who peruses Mr. Jones's chart will see the term and make subconscious presumptions about Mr. Jones. He will slip toward the "bad patient" persona in their minds; for in his act of noncompliance he is judged guilty of the outcome.

A one-dollar-a-day diuretic pill may have prevented endotracheal intubation for Mr. Jones and all the concomitant torture done in the name of medi-

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cal therapy in the intensive care unit. But can Mr. Jones truly make an informed decision? How can I convey to him the misery I've seen in the ICU, and when should I convey it? Can his 60 years of life as a husband and father providing for his family on a day laborer's wages with his sixth-grade education intersect meaningfully with my eight years of formal medical training? After he is intubated most of his autonomy will be lost. He will not be able to speak or even breathe for himself. He will be totally dependent for his care on the complex interactions of a number of highly trained health care workers with very complex machinery. He cannot meaningfully help us make the technologically subtle decisions that will sustain his life, despite the fact that his life may be profoundly altered by what we do to him.

Grace Emerson Terrell
High Point, North Carolina



Robert was an attorney suffering from multiple disabilities including a life-threatening arrhythmia that could not be controlled by standard medication. A final option was to use an experimental medication provided by a prestigious medical center in the western United States.

Joy, his wife, a Ph.D. in anthropology, had excellent research skills. Their visits to the university medical center were frustrating because she knew the literature not only better than I did, but better than any of the fragmented, ever changing medical staff. At each office visit Joy would present the latest data. Her observations were not limited by the constraints of the protocol but were guided by her careful insight and the personal experiences of her husband.

Formal medical research studies are helpful in setting *tentative* guides. The typical research protocol or treatment plan functions as if medicine were a pure science, and only a science. Both ignore the vagaries of clinical medicine and the human condition. From premed days (or before) too many physicians have been inculcated with the myth of scientific omnipotence, and thus they have difficulty in dealing with both failure and challenge. Which is heard more often: "the

patient has failed to respond," or "an ineffective treatment has been chosen"?

When next faced with the retort "in our clinical experience," don't be afraid to say: "Tell me about that experience." Take out a yellow pad and pen. Then listen. Like Joy, you might do a literature search. Your doctor will probably at first be intimidated but might learn something. She might learn another perspective, and something about you, and eventually about herself.

Robert J. Barnett
Reno, Nevada



The resistance of a physician to yield his or her position of power generates a longing in the patient for alternative treatment strategies. This resistance drives patient autonomy into an angered and unrealistic frenzy.

Noncompliance is most often a patient's unwillingness to communicate lack of acceptance of a physician's treatment plan or confusion about that plan. It is not the act of choosing an alternative to the physician's recommendation, but rather not having integrity with a choice once made. When I recommended cranial irradiation for a young woman with metastatic melanoma and she chose instead to have immunotherapy in Mexico, I did not consider her noncompliant. But when a patient with colon cancer metastatic to the brain agreed to cranial irradiation but did not tell me that he was not taking the anti-convulsant that was also prescribed, I considered him noncompliant and lost trust in our relationship. When Kevin Coleman made the decision not to take prescribed chemotherapy without informing his specialist, he felt "guilty and anxious." These are not emotions that solidify a relationship or heal disease.

Treatment decisions, especially in oncology, are made with either cure or palliation as the goal. When curative therapy is chosen by a patient, a large degree of control is surrendered to the physician and the curative "recipe," which includes strict treatment schedules and intensive, toxic therapies. In this set-

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ting, patient noncompliance markedly reduces the chances of success.

In palliative treatment, however, which attempts to help the patient feel "well," the patient retains almost complete control of the decision making. She must address all aspects of her health to achieve optimal balance. Quality of life, which the patient must define, takes priority over quantity. Because Coleman's disease was not curable, he should have been able to choose the path that led to his optimal mental, emotional, and physical health.

I believe that both Coleman *and* his physician were noncompliant within the tenets of an ideal physician-patient relationship. A lack of honesty, integrity, and compassion in the relationship led to a power struggle mired in mutual disrespect.

Robert F. Boone

Bend Memorial Clinic
Bend, Oregon



Arthur Frank's analysis misses the mark in my experience. Patients do not subordinate their lives to the "cure" while in my office, only to rediscover their selves on the way home. The office visit, even the hospital visit, is an opportunity for mutual knowing. There is a social aspect, with some chiding ("running late, eh doc?") and some giving ("You look tired"). We share a point of view when older patients advise, "Don't get old, Doc." We have a mutual fate. I too will tread this path.

Frank's fiction is that most people lead their real lives out of touch with their illness but in the doctor's office are out of touch with their real lives. Coleman's story on one level fits the model. No one at work knows he is ill. No one in the story helps to resolve his dilemma. Often this role of knowing and helping is filled by a spouse or friend. Often it can be filled by a psychologist or a physician. Coleman permitted no one the role and power to help in the communication and decision process with his radiotherapist.

Are there things he needs to say that he is not yet able to say? How do we as professionals enable him to do that? If the patient must speak—and he must—

then physicians, friends, psychologists, and spouses must hear: the need for control, the wish to be well, the inability to cure, the disappointment of illness.

With good speaking and good listening the artifice of noncompliance as a means to stay in touch with oneself can be reduced. There are better ways.

J. Brandt McCabe

Cardiology Associates of Princeton
Princeton, New Jersey



Kevin Coleman is different from patients with a chronic disease requiring significant change in lifestyle, with the possibility of severe late-stage complications. In dealing with an individual who has diabetes mellitus, for example, the physician must familiarize himself with all the aspects of the patient's life: meal times, eating habits, exercise, family situation, job demands, commuting times and conditions, etc., in order to tailor a program to achieve metabolic control. Without this information, supplied by an honest and open patient, the physician cannot consider all the elements necessary to design a care plan that will meet both their goals: the physician's—to achieve optimal short-term and long-term metabolic control and to decrease the risk and severity of long-term complications; the patient's—to be able to enjoy life with a minimum of discomfort and inconvenience from the disease and its treatment and to avoid long-range complications. The risk of "patient noncompliance," then, is minimal.

I am reminded of a former patient, a talented high school athlete with diabetes whose metabolic control was fairly well regulated while he was involved in intramural sports. He was invited to join the varsity track team, whose meets required bus rides up to four hours long. In seeking guidance on adjusting insulin dosage, meal times and content, and regular exercise schedule on meet days, he explained that successful participation on the team increased his chances of receiving a scholarship to college. With this information and his cooperation, a program was designed that met his needs, provided good metabolic control, and increased the likelihood of his compliance.

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A 39-year-old executive, whose career required frequent cross-country travel, was referred to me by his wife, who had been a long-time patient of mine. He had been diagnosed by another internist as having hyperthyroidism. That physician had placed him on antithyroid medication, explaining that he would have to come in for weekly tests to watch for a drop in white blood cell count. When the patient tried to explain that his job might require out-of-town trips that would interfere with the weekly tests, the physician replied that the patient would "just have to adjust the travel schedule," without explaining that other treatment possibilities were available. When his wife brought him to my office, I suggested that he might wish to consider other treatment options, namely surgery or radioactive iodine, which would not require such frequent and intensive follow-up care. He opted for surgery, was referred appropriately, and did well post-op.

Such flexibility or adjustment as occurred in these two cases may not always be possible. But only if the physician tries to ascertain the patient's nonmedical needs and concerns, and the patient understands the importance of treatment options, can the two of them work collaboratively on a solution to the problem.

Dorothy Rasinski Gregory
Long Beach, California



"Patients should be invited to write in their own charts," Arthur Frank suggests. This reminds me of an insightful patient, Mr. Ruhmkorff (I only mention his name because he loves to be quoted), who invariably reads and edits his own chart whenever in the hospital. One day on rounds a medical student painfully learned the art of proper charting of subjective observations. The student had examined the patient and written in the chart, "Patient examined and reassured." Mr. Ruhmkorff agreed that he had been examined but soundly disagreed that he had been reassured. I welcome patients' comments on the subjective nature of their diseases. Our office medical assistants have developed the habit of quoting the patients in the chart following phone calls. It is most

helpful when reviewing the notes later with the patient, and often the true meaning of the problem surfaces.

As a physician I have found that patients most often want to participate in making their own medical decisions. Gone are the days of the paternalistic country doctor who made pronouncements that were accepted without question or discussion. Today we treat a sophisticated, informed patient community. Often we serve as a medical lexicon to be used for the dispensing of information so patients may make these informed decisions.

Every patient will not be comfortable participating in decision making; often older patients, nurtured on the paternalistic model, ask that the decision be made without all the discussion. But I personally am moving more to the model of equal participation.

It is much easier to describe the options of treatment to the inquisitive patient. The patient becomes a part of the treating team. This team may include the nurse at the bedside and the house staff if appropriate, as well as family members. When this discussion takes place the patient becomes a part of rather than the result of the decision-making process. I often ask patients if they prefer that we, the staff, discuss their situation openly at the bedside or go to the conference room and discuss in their absence. I have yet to be asked to leave.

So how may the "mutual participation" approach have worked with Kevin Coleman? The physician could have begun with an explanation of the risks of travel with impending common bile duct blockage. "But if you must go on this important trip [spoken not sarcastically, but with sensitivity], here is what you may do. Take copies of your medical records with you; enter a medical facility if you become ill; here is my phone number; have the attending doctor call me and we can work out a solution until it is safe for you to travel home." As physicians we need to be part of the team, not always the coach; we can no longer direct without humanistic concern and caring for our patients.

Robert L. Reed
Cincinnati, Ohio



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I'm puzzled by Coleman's and Frank's use of the term *noncompliance*. Coleman describes a situation where his cancer produces a new, unpleasant, and somewhat threatening effect. He struggles to understand the developments and place them in perspective for his entire life. When a treatment recommendation seems to derail his plans, he seeks to defer the intervention to a more convenient time. This does not sound like noncompliance as most physicians throw that unfortunate term around. Coleman's response seems more like negotiation, and unfortunately the radiation oncologist reacts in a way that asserts his need to maintain control. Patients seek to make adjustments in prescribed treatment all the time, and many *physicians* "comply" readily. I don't really see the beast of non-compliance here.

Frank seems to push Coleman's distress to a level of anger I don't read in Coleman's narrative. Maybe the physician in me dulls my vision, but the sociologist in me has real difficulty with Frank's interpretation. Granted that medical professionals have extended their dominance over areas of patients' lives where they have no business mucking about, Coleman's story does not tell us enough to justify the tirade. For all we know, the radiation oncologist had an argument with his mate that morning or is simply a disagreeable person. More important, Frank misses the point in two ways, sociologically speaking.

First, some patients do make their disease, be it cancer or something else, the totality of their lives. Some aspects of the structure of Western medical systems encourage such behavior. But most patients bring their own agendas, personalities, projects, and plans with them to treatment and don't simply discard them at the door. I suspect many cancer patients make their disease their new careers at least in part in an attempt to master the assault on their lives. Frank's pieces suggest he would condemn such reactions. Medical professionals should attempt to discover and understand the patient's entire response to illness and help the patient cope in whatever way works best for the patient. We shouldn't require patients to minimize the impact of their disease.

Second, Frank writes as if discrepancies in points-of-view between powerful doctors and vulnerable patients occur exclusively in medical contexts. But sociologists, as teachers or consultants, don't always see eye-to-eye with students or clients, and professors

of sociology aren't always pleased when students don't complete assignments as expected. While the stakes are different in medicine, we shouldn't assume that power and authority problems in medical relationships can't benefit from the same sorts of steps we'd use to improve difficulties elsewhere. When the student doesn't turn in a test or paper, the reasonable teacher asks to talk with the student. Shouldn't doctors respond similarly?

Frank wants to add a layer of complexity in medical relations and insert a "coordinator" between doctor and patient. He also wants patients to enter their stories in the medical chart, by dictation if necessary. Give us a break. I think doctors should *talk* with their patients; taking as much time as needed and listening with as much skill as possible. We don't need mediators or transcriptionists. We need conversations between the two people engaged in the same project: medical care. Admittedly, many doctors don't converse very well. So we should teach them to listen better and speak more plainly, making sure we don't turn them loose on the public until they acquire the necessary skill.

I know I'm getting to be an old crank, but complex structural solutions to straightforward interpersonal problems just don't work very well. Somehow I think Kevin Coleman would have been better off with a doctor who knew how to listen and then respond appropriately than he would have been with a translator or an eloquently penned entry in his medical record.

Joel Frader

Children's Hospital of Pittsburgh
Pittsburgh, Pennsylvania



As a family physician for many years in a small New England community, I have learned to know my patients as people and not merely as medical cases. I'm reminded of Joe L., a nursing home patient who, in all respects, was much older than his chronological age of 64. Joe had suffered a cerebral accident and had to live with a hemiplegia that he always resented. In spite of that, he was an independent and determined in-

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dividual, very stubborn most of the time and extremely difficult and a bit aggressive some of the time. Joe had occasional problems with much of the staff, but he and I had developed an understanding that made my care for him comfortable and productive. I continually weighed conflicting factors and attempted to balance the problems that arose.

A strong recommendation from the staff dietician advised a diet for Joe that would certainly be unacceptable to him. Whatever time of day I visited the nursing home to see Joe or other patients, he most likely would have a cup of coffee in his good hand. The dietician strongly suggested that he limit his coffee intake and be on a virtually salt-free diet. Joe advised her in no uncertain words (fairly colorful, I might add) that he would not comply with her orders. After weighing this matter I came to the conclusion that though Joe's life span might be lengthened by an unknown amount if he followed a restricted diet, he would undoubtedly be extremely unhappy, and this would be a big price to pay. Consequently, we permitted Joe to have the dietary liberty that he wanted and provided him with the little bit of independence and quality of life that he needed at this time. Non-compliance? Yes! An acceptable decision? I think so. Joe continued with his many cups of coffee per day and a diet that was not salt-free, and he enjoyed, as well as he could, the independence and joy of living that were still his.

Walter R. Schur
Oxford, Massachusetts



Having been in the private practice of family medicine for 50 years, I have seen noncompliance almost daily. Let me list some examples.

1. Many mothers do not give their children all the medication ordered for a given illness but discontinue it as soon as the symptoms subside. They save the rest for the next episode, in spite of the danger of a secondary problem developing, like nephritis.

2. Many patients do not return for follow-up visits even when ordered by a physician who knows about the dangers related to their condition and tells them of the need for follow-up.
3. Many patients intentionally cut down on the ordered medication for chronic diseases like diabetes or heart disease because they are not having symptoms. Often this is done because of the cost of the drugs.
4. Many people on specific diets for weight control, diabetes, and heart disease cheat regularly and then cannot understand why they get into further trouble. I hear them tell of eating things not on their regular diets, like salt, sugar, and high cholesterol products.
5. I am a diabetic, and I balked for a long time over recognizing this fact; I failed to do things that I was advised to do and knew that I should do. For instance, I hated the thought of starting insulin and stalled doing so for a long time, until I was faced with the outlook for future problems if I failed to do so.

Over the years I have struggled to do the very best that I could in caring for my patients, and there have been times when I told them not to return until they were ready to follow my instructions. But I realize they have the right to decide what they will do, and that right cannot be taken from them.

Howard R. Hone
La Grange Park, Illinois



A patient needs someone who coordinates the programs. This should be the family doctor—a trusted person who knows the client well. Unfortunately, the specialist often takes away that “in

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charge" role. There is a specialist for every system, and patients often have no idea who is in charge, so they make their own decisions. I recommend that the family doctor use consultants and stay in close communication with his patient, client, and friend to interpret for her the specialist's technical language and communicate the patient's decisions. In my local church congregation, I volunteered my services to be this advocate—a rewarding experience.

Robrer Esbleman

Landisville, Pennsylvania



My reaction to Kevin Coleman's episode of noncompliance was quite mixed. I shared Coleman's disappointment in his radiotherapist, who seemed so narrowly focused on the technical aspects of lymphoma and its treatment and so uninterested in Coleman the person. Yet I also found myself sympathetic toward his physician. As a psychiatrist I frequently treat patients who fail to follow medical advice. Patients may continue to abuse drugs, to behave self-destructively in important relationships, or to resist hospitalization when suicidally depressed, while simultaneously seeking professional advice and treatment for these very problems.

But physicians who specialize in the treatment of cancer may be a special case. They literally do daily battle with death. When their treatments fail, as they often ultimately do, they must experience at some level the dual pain of technical failure and personal loss. Repeated again and again, these occupational stresses call for the development of some heavy psychological armor. One component of this armor may include a directive style: "Since we're in a life and death battle here, I take very seriously my responsibility to determine and recommend the best available treatment. I expect you to attend carefully to my advice, accept my recommendations, and follow them carefully." Oncologists may also armor themselves with a somewhat distant professional style: "It may seem to you that I'm too busy to really get to know you. Well, it's true that I'm busy. But to be honest, I have to admit I don't want to get to know you too well.

If I did, it would make it too difficult for me if we lose this battle we're in."

Additionally, we are told nothing of the difficulties the physician may experience in rescheduling Coleman's treatments or the administrative complications that may result from Coleman's failure to follow the doctor's initial recommendations.

In summary, what is missing in Coleman's detailed and revealing description of his relationship with his radiotherapist is the physician's perspective. He, too, has a story to tell, and that story also needs a sympathetic hearing if we hope to achieve deep understanding. Coleman's radiotherapist handled the situation poorly; his attitude and behavior ought not to be justified. But he should be understood. The radiotherapist in this situation is struggling too. Unfortunately, Coleman and his physician are struggling with each other rather than joining hands in what ought to be their common struggle—the struggle for Coleman's life.

Roger C. Sider

Pine Rest Christian Hospital
Grand Rapids, Michigan



When we began to discontinue chemotherapy for children with leukemia who had a sustained continuous complete remission to see if a cure had been reached (now a routine practice), we were hearing confessions of, "Well, we stopped that drug last year, because . . ." I therefore have good reasons to believe that literal compliance is effectively nonexistent in long-term cancer chemotherapy unless the drugs are administered by the doctor.

There is a sobering corollary to these observations. Our advice regarding dosage and frequency of drugs for childhood leukemia therapy is based on the statistical experience from large clinical trials. If noncompliance is widespread, our recommended dosages have that behavior factored in. If all children were suddenly to become fully compliant we could have frequent bone marrow failure from overdoses. I once submitted a grant proposal to study noncompliance. One reviewer said in his critique, "It is unthinkable that

patients would ignore medical advice when the disease is life-threatening." Kevin Coleman's story and my own experience illustrate the danger of such an attitude.

As often as not, noncompliance is caused by physicians who have an exaggerated sense of certainty about clinical data. They present their advice in a way that precludes questioning by the patient. Advice given with great conviction should always be suspect in medicine. Physicians' advice is based on experience, reason, and statistical extrapolations. Advice presented without proper humility is an invitation to noncompliance without dialogue.

Jan Van Eys

University of Texas Medical School
Houston, Texas



Coleman seems to have concluded that his radiotherapist was not treating the whole person and was putting the "needs of the institution" ahead of his own. To me, this conclusion seems very likely to have been quite wrong, for several reasons.

First, all physicians are quite familiar with patients who hear selectively. It is not at all unusual for the physician to be amazed and disappointed to hear the patient's translation of what he really said. We can perhaps never know the exact truth in this particular episode, but everyone might have been the wiser if *Second Opinion* had published a recollection about this event from the radiotherapist.

Second, available evidence suggests that the radiotherapist understood the situation quite well. His note had the key facts as they have been revealed to us. Contrary to Coleman's comment, there is no medical substance to the substitution of "obstructive jaundice" for "pierced bowel." Perforation is a recognized complication of obstructive jaundice. Coleman's comment "but more important, little validity was given to my existence outside the cancer center." The evidence seems to be to the contrary. After all, one-third of the therapist's note is devoted to "existence outside the cancer center." Of necessity, medical records are not transcripts but summaries of essential facts.

Third, Coleman seems to have concluded that the radiotherapist put the needs of the institution above his. On the contrary. The radiotherapist (presumably in the patient's mind an agent of the institution) outlined what was in the patient's best life-and-death interest. It happened that this interest interfered with an immediate goal that was overriding for the patient. Life is sometimes like that. The fact that no serious complication occurred during the journey cannot be used as evidence that delay was optimum.

Good medicine is very, very often the art of applying odds. As Frank states, "Coleman took a calculated risk and could have died as a result." Imagine if the therapist had been a party to the decision to delay therapy, and further imagine that the obstructive biliary tree had become infected far from home, and a perforation and a fatality had occurred. Would the patient have been given good advice? The patient was not hearing. He says, "Nor did I take the threat of death very seriously." Above all this, the complete physician understands and even expects some noncompliance. After all, "it is a free country," and it is a given that the patient may accept or reject the physician's advice. Only a poor physician would advise a course of action that would compromise a patient's longevity.

This does not mean that the complete physician turns his back on the noncompliant patient. He will still exert his best effort and try to tiptoe his way through the mine field of noncompliance. It may well be that Coleman and his therapist were not simpatico. If this is so, it is of course regrettable. From this vantage point, it is impossible to assign blame, if any. In general the complete physician must learn to cope with this common problem in a way that is not objectionable to the patient, but must never approve a course of action that exposes his patient to an avoidable life-and-death risk.

Howard W. Jones, Jr.

The Howard and Georgeanna Jones Institute
for Reproductive Medicine
Norfolk, Virginia



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The need for negotiated arrangements in health care becomes most evident when one works with terminally ill patients in a hospice program. The hospice addresses the whole patient and the family, community, and occupational context. Both the caregivers and the patient have the freedom to explore the broadest possible range of options for living the rest of life, including return to intensive medical care if desired. The hospice milieu gives all participants full permission to surface all the factors involved in making a decision, to be as explicit as possible about

the desired outcomes and goals, and to design a care plan that exactly meets the patient's needs. I have never heard of a noncompliant hospice patient. And I have often mused that it is unfortunate that one must be dying to receive care that so respects the entire human being.

Paul T. Werner

Wayne State University School of Medicine
Detroit, Michigan

LITERATURE DIGEST

Private suffering and public response

M. Therese Lysaught, "Patient Suffering and the Anointing of the Sick," *Cresset* 55, no. 4 (February 1992): 15-21.

BIOMEDICAL ETHICS, CLAIMS Lysaught, fails to provide the conceptual and moral tools needed to respond to human suffering. The reality of suffering, in fact, exposes the inadequacies of a biomedical ethics that advances neat principles and theories aimed at resolving practitioners' quandaries. Such ethics is perhaps best represented in H. Tristram Engelhardt's *Foundations of Bioethics*, on which Lysaught focuses her critique. Engelhardt's "pluralist biomedical ethics" is a neutral, secular framework for resolving controversies. In this framework Engelhardt employs the dualisms of mind/body, reason/desire, and public/private that structure the liberal philosophy characteristic of our pluralistic society.

These dualisms enable Engelhardt to make several claims. First, he splits morality into two tiers, that of the public "peaceable secular community" and that of the private "particular moral community." In the former, public issues are resolved by rational (that is, impartial, unprejudiced, anonymous, universal) arguments by rational beings who have risen above the particularities of their communities. Moral arguments arising from the second tier, however, should be disallowed, because the premises of this private community (which include religious commitments) are too particular to be considered "rationally authoritative." Those wishing to join the public moral discus-

sion must disengage themselves from the particularities of their community life.

Second, the mind/body dualism allows Engelhardt to offer criteria for membership in the "peaceable secular community." These criteria are rationality, self-consciousness, and a sense of worthiness of praise or blame. Only these qualify one to be a moral agent. A human *body* thus does not qualify, nor is it theoretically required, for moral agency. Lysaught points to a contradiction in this mode of thinking: While much of pluralist biomedical ethics is concerned with bodies, these same bodies do not count as a moral resource. Though they are the locus of illness and suffering and the object of medical practice, bodies are overlooked.

If biomedical ethics were to attend to the embodied suffering of patients, what might be discovered? Despite the fact that the sufferings of the sick differ in many respects, Lysaught observes that autobiographical accounts reveal three rather consistent dynamics. First, illness and suffering often reorient patients to their bodies, drawing their attention to the importance of the integrity of the body for a sense of "self" and to the fact that health and life are radically contingent. Illness may also cause patients increasingly to identify their selves with their bodies, impeding the individual's capacity to move beyond the body to the external world. This can result in feelings of alienation.

Second, patients may experience loss of "voice" because of the inexpressible nature of bodily pain. When pain is inexpressible, it is unsharable and may further isolate the patient and prevent her from adequately communicating to health professionals. In addition, the "foreign" language and customs of the

medical institution may further deter patients from communicating or force them to conform their accounts of their illness to the language of the profession.

Third, Lysaught says, suffering can be transcended by an illness narrative. This narrative, constructed by the patient with the assistance of others, will make sense of and give value to the experience of suffering. "Potential for deriving meaning from suffering lies not in some inherent quality suffering possesses, nor in the abilities of its victims. It lies rather in the resources offered by society and in the willingness of individuals to participate in this process, to enter into solidarity, to pay 'attention' to those who suffer" (p. 18).

The Christian tradition has, from its beginnings, attended to suffering. It has developed practices to respond to many of the dynamics of suffering already noted and help shape individual and communal relationships to those who suffer. The Roman Catholic tradition's Sacrament of Anointing of the Sick is one such practice. As a liturgical rite, it has a communal dimension and assures the sick that they are not alone despite the marginalization and isolation that attend illness. The sick are an integral part of the community. Further, the rite does not view the patient as a passive sufferer but rather encourages the patient to be a sign of Christ's redemptive suffering to the Christian community and thus to give meaning to suffering. Finally, it offers an alternative vision of the world and "invites those who suffer to locate their narratives in an ongoing story, to learn anew the stories of others who have suffered and the interpretations they gave their experiences, to truly hear . . . what it means to worship a God whose relationship to humanity was revealed on a cross" (p. 20).

Those who are formed by the ecclesial practices of Christian communities, concludes Lysaught, will navigate the worlds of medicine and medical ethics along a path different from that of secular philosophers like Engelhardt. More specifically, the Sacrament of the Anointing of the Sick might give health care professionals (and others) an alternative understanding of suffering. This understanding could help foster a disposition of vulnerability that would enable caregivers to reach out to a patient with a touch that heals.

—Agnes Coveney
Research Assistant

"Basic care" redefined

David C. Hadorn and Robert H. Brook, "The Health Care Resource Allocation Debate: Defining Our Terms," *Journal of the American Medical Association* 266, no. 23 (18 December 1991): 3328–31.

HADORN AND BROOK ARGUE THAT ILL-DEFINED terms muddle proposals that aim to slow increases in health care costs and improve access to care for the poor and uninsured. Seeking to clarify the issues and facilitate consensus, they propose precise meanings for *rationing*, *health care needs*, and *basic benefit plans*.

The authors build on a traditional definition of rationing: "equitable division of scarce items, often necessities, by a system that limits individual portions." They point out that rationing schemes already exist for health care services that are truly scarce, like organs for transplantation and intensive care beds. In the health policy debate, however, *rationing* no longer means justice in the face of scarcity. Instead, rationing connotes discrimination on the basis of socioeconomic status. Physician Arnold Relman has described rationing as "the deliberate and systematic denial of certain types of services, even when they are known to be beneficial, because they are deemed to be too expensive." In other instances the term *rationing* has been used to mean containing costs, setting limits in medical research, or denying services to those who can afford them. The varied uses of the term may cause confusion and miscommunication in an already contentious debate over health care distribution.

Hadorn and Brook refine Relman's formulation by creating a functional definition upon which to continue the health policy debate. They maintain that rationing is not limited to a formal policy that is "deliberate and systematic," as Relman suggests. Tolerating inequitable barriers that limit care also qualifies as rationing. Such barriers include race and sociodemographic status (but not a factor like geographic distance, which is the individual's choice).

Also, if a rationing plan seeks to provide beneficial services and eliminate useless or marginal services, some evaluation of what constitutes "beneficial" treatment is necessary. For example, the authors propose subjecting new technology to "strict evaluations of expected benefit" before extending insurance coverage.

Hadorn and Brook propose that objective criteria be agreed upon to evaluate *net benefit*—longevity plus quality of life. Concretely, they recommend that a panel develop guidelines—based on outcome data, public testimony, and expert consensus—that would designate treatments offering net benefit. “Services judged to provide only insignificant health benefits would be deemed unnecessary, and desires for such services would not be considered needs.” Hadorn and Brook argue that only with an objective description of needs can “rationing be validated” and “solutions to the access problem be evaluated.”

Having defined *health care needs* as “desires for services that have been reasonably well demonstrated to provide significant net benefit for patients with specified clinical conditions,” the authors propose a comprehensive understanding of rationing. They define rationing as the societal toleration of inequitable access to health services deemed to be necessary (according to necessary-care guidelines).

Third, the authors address the term *basic benefits*. Some sources expand the meaning of a basic benefit plan from a minimum level of health insurance coverage to a higher level of benefits that should be available to all citizens. This kind of first-class, ideal coverage is defined as “basic benefits” by groups like the Pepper Commission and the AMA’s Ad Hoc Committee on Basic Benefits of the Health Policy for the American People. At the other extreme, unions and employees’ associations may associate “basic benefits” with bare-bones health-care policies. To clarify the terms and thus facilitate communication, Hadorn and Brook suggest that *basic benefits* be used to mean a “health insurance coverage package that provides for all and only acknowledged health care needs.”

These authors suggest that a basic benefit package, if implemented by Medicaid and private insurers, has the potential to eliminate marginal and unnecessary care. Then “ensuring the provision of basic care to all would eliminate the specter of rationing.”

—Mary M. (Daisy) Boehm
Research Assistant

The hazards of rationing

Amitai Etzioni, “Health Care Rationing: A Critical Evaluation,” *Health Affairs* 10, no. 2 (Summer 1991): 88–95.

ETZIONI ANALYZES THE VALUE JUDGMENTS underpinning common justifications for rationing. He challenges often-quoted statistics that purportedly indicate a crisis in health care spending and makes a number of assertions: While increases in health care costs have surpassed the rate of inflation, this “alarming” trend may in fact illustrate the overall increase in the price of services versus the increase in the price of commodities. That Americans spend more on health care than the British does not mean America is spending “too much” on health care but may mean health care is produced inefficiently. What percentage of the GNP it is “proper” to spend on health care reflects values, not economic facts. These statements suggest that “objective” measures are often ambiguous and merit subjective interpretations.

According to Etzioni, society’s influence on health care spending depends on who is paying the bill: an individual, a third party, or the government. If individuals use their own resources, “our society abides by the code of ‘consumer sovereignty’ which dictates that we should not as a society seek to influence people’s choices unless there is a compelling social need.” Similarly, if a third party is paying for health care, and resources are overutilized, society allows those who are insured to pay the premiums and use the resources unwisely if they choose. In contrast, differing opinions on allocating tax revenues “reflect different social philosophies and personal values.” Therefore, Americans rely on the political process to implement the values of the majority. Even after 25 years of increasing government health care expenditures, in 1988 a poll found 67 percent of Americans were in favor of increasing government health care spending.

Because society will validate rationing only within the public sector, Etzioni advises that the U.S. reevaluate the whole government budget. Setting new priorities might then spare those “resources used to sustain life.” This initiative would require significant political reform, because establishing priorities has been a consistent problem within the present political

system. Even if reform were possible, central planning and government control historically have proven to be inefficient. Rather, Etzioni says, indirect and limited interventions work better. A limit on reimbursed hospital beds, for example, and a cap on the annual growth of health funds, by region, would be effective interventions. Further alternatives to rationing include cutting the 22 percent of health care funds spent on administration, reducing "unnecessary medical procedures," and curbing defensive medicine by limiting malpractice fees for lawyers. These alternatives, while providing only a "one-time-savings," must be considered because "it is morally unacceptable to cut life-extending procedures before tackling those with no such implications."

Some advocates of rationing suggest that too large a proportion of health resources are spent on high-technology acute care, and not enough is being spent on preventive measures. In response, Etzioni agrees that prevention is more economical and humane, but he argues that the social problems of homelessness, drugs, teen pregnancy, and violence are best addressed as part of a societal restructuring and moral recommitment, not as part of preventive health care. "The health care system unfortunately must take these social problems, by and large, as given."

On another front of the rationing debate, some ethicists propose that too many health care dollars are spent for "meaningless services . . . that extend life without consideration of its quality." Etzioni challenges that this may be true for persons in a persistent vegetative state and those who are at the "very end" of their lives but may not be the case for persons using services like kidney dialysis and hip replacements.

Etzioni points out that some social groups will be hurt and some will benefit from rationing. If health care is rationed, the elderly and the poor will be hurt more than other groups. Etzioni notes that in Great Britain the rationing of kidney dialysis for the elderly is discriminatory. A nondiscriminatory system would allot services based on ability to benefit as determined by medical criteria. Rationing discriminates against consumers while providers flourish. Doctors' salaries have increased 30 percent in the past five years, compared to an average 16.3 percent increase for all other full-time workers. Finally, rationing, although purporting to enhance social justice, often "denies the poor and near-poor, penalizes the middle classes, and,

as a rule, does not curb the rich, because it generally takes place through refusals to reimburse for certain treatments rather than through rationing of the actual service."

In summary, health care rationing, according to Etzioni, within our current societal structure, would not be efficient or fair. It would hurt the poor and elderly while allowing waste and abuse in other sectors to flourish.

—D.B.

Older women on the short end of rationing

Nancy S. Jecker, "Age-Based Rationing and Women," *Journal of the American Medical Association* 266, no. 21 (4 December 1991): 3012–15.

THE MAJORITY OF OLDER AMERICANS ARE WOMEN. Of those 65 and over there are 68 men for every 100 women, and of those 85 and over there are 45 men for every 100 women. Women on average outlive men by 7.5 years. Because women are disproportionately represented among the elderly, age-based rationing as currently proposed by health care planners and ethicists would disproportionately affect women. Jecker examines how rationing publicly funded life-extending care on the basis of age violates ethical standards of equality.

The denial of publicly funded life-extending care affects men and women unequally because (1) a greater number of women than men are subjected to age-based rationing, (2) older women rely more heavily than older men on publicly funded insurance and are less likely to have private health insurance, and (3) women would be denied more years of life than men. Whether these effects violate an ethical standard of equality depends on how one defines equality. Jecker discusses three facets of equality: equal treatment, equal opportunity, and equal respect.

Equal treatment implies that persons with similar health conditions receive roughly the same health care. Advocates of age-based rationing have pointed out that all individuals experience health care advantages and disadvantages through time. Differential

treatment based on gender, however, does not balance out over time because gender, unlike age, does not change.

A similar argument can be made for equal opportunity: over time, the opportunity for young and old equalizes. But sexual inequality complicates opportunities. "In many areas of life, women's opportunities are systematically fewer than men's. Unlike ageism sexism lasts throughout life and permeates many dimensions of identity and development." A rebuttal might suggest that even if women's opportunities are fewer, extending old age will not redirect women's lives nor repay past wrongs. But this proposition assumes that a male life cycle should measure the opportunities to which a person is entitled.

A third aspect of equality emphasizes equal respect for persons. Age-based rationing would affect life-extending treatment while society increased its efforts in other areas of health care. Indeed not all inequalities demean persons and diminish self-respect: "Inequality is demeaning to people only when it involves unequal access to basic goods and services." Jecker suggests, however, that public debate focusing on excluding persons, rather than services, undermines the very foundation of equal respect. Rationing by personhood presupposes that some persons are "less deserving" because of who they are—old, female, or poor. Rationing services fosters solidarity, while rationing people highlights difference, undercuts a sense of relatedness, and can create an adversarial attitude that hinders problem solving.

Although age-based rationing is "gender-blind," its consequences and the inequality it fosters are no less serious because they are unintentional. "Undeliberate rationing" and "indirect methods" may be expedient, but they hinder public debate and nurture "unjust persons [who] are unaware of injustices festering in their midst."

Perhaps such inequality can be justified because it benefits society as a whole. But a utilitarian approach would still require society to assign priorities to different groups. According to Jecker, elderly women in particular merit high priority. Elderly women have a 19 percent poverty rate, the highest for any age group in the country. Elderly women's unmarried status deprives them of emotional, economic, and social support. Also, the greater autonomy in widowhood may be a greater hardship for women, who

are "more inclined" to define themselves in terms of their relationship to others. More objectively, elderly women have higher morbidity statistics than their male counterparts. Finally, the cultural climate burdens women because their social value and status are frequently tied to their beauty, their youth, and their sexual and reproductive roles.

Even if society has no commitment to protect or advocate for its vulnerable members, Jecker maintains it should seek to "avoid worsening their conditions." Thus health policy should remain sensitive to its inadvertent effects on women and seek to do no harm.

—D.B.

A Jewish sense of justice and resource allocation

Aaron L. Mackler, "Judaism, Justice, and Access to Health Care," *Kennedy Institute of Ethics Journal* 1, no. 2 (June 1991): 143–61.

JEWISH UNDERSTANDINGS OF JUSTICE, or *tzedakah*, claims Mackler, provide an important resource for addressing the ethics of access to health care in the U.S. Through the centuries, Judaism has struggled to understand the demands of justice and develop social institutions to realize them. Although the Jewish perspective has neither binding authority nor direct applicability to the situation in this country, it can offer insights relevant to current concerns.

Central to the Hebrew Bible's notion of justice is God's concern for the weak and the poor. This concern was met in part by the institutionalization of Sabbatical and Jubilee years: slaves were to be freed, debts canceled, and (on the Jubilee) land returned to the original owners. Other practices included leaving the corners of one's fields for the poor and tithing produce to them. Justice required, in short, that no one be exploited and that each person enjoy at least a basic level of material security. The requirements of justice were rather moderate, but the demand that they be met was absolute. Justice was seen as a prerequisite for the pursuit of any other social goal.

Rabbinic Judaism further developed the Hebrew Bible's notion of justice. The Talmud states that

tzedakah is as important as all other commandments put together. That which is to be given to the poor never belongs simply to the giver but rather to God, and is owed to the poor as their right. A system of enforceable obligations arose around *tzedakah* that ensured at least a basic level of support for all.

The most basic, legally enforceable aspect of *tzedakah* was the payment of a monetary assessment. Eight degrees of *tzedakah*, formulated by the medieval legalist and philosopher Moses Maimonides, are found in the *Shulhan Arukh* and became normative in Judaism. The highest degree is to "strengthen the hand of the poor"—"to give him a gift or loan, or form a partnership with him, or find work for him, in order to strengthen his hand that he not be dependent on others" (p. 146). The next highest degree is when both donor and recipient remain anonymous to one another, thereby avoiding feelings of indebtedness by the poor. This can be achieved through communal funds, which, in fact, have been the central institution of *tzedakah* throughout most of Jewish history.

Both the *Shulhan Arukh* and the Jewish tradition in general specify the minimum levels of support required by *tzedakah* from the perspectives of both giver and recipient. The consensus position of commentators on the *Shulhan Arukh* adds that one must give at least one-fifth of one's income when one can afford to do so without difficulty and when there is pressing need, and one must give whatever is required in cases immediately involving the saving of life. Giving more than one-fifth is seen as commendable but is not demanded by foundational justice. The limits on the redistribution of resources required by *tzedakah* depend most importantly on the needs of the poor. While one is not commanded to enrich the poor, one is commanded to give him "sufficient for his need/lack, according as he needs/lacks" (p. 147). Need has been interpreted to mean food, clothing, shelter, and the opportunity for family life, though other needs are not excluded.

Among these other needs are lifesaving actions, for example, saving captives. Such actions take precedence even over general obligations of *tzedakah*. According to the *Shulhan Arukh* society has a fundamental obligation to save lives whenever possible, diverting funds from all other projects as required. Thus Jewish understandings of societal obligations toward those with acute needs would seem to support

society's responsibility to provide lifesaving medical care whenever required.

In the nineteenth century, Rabbi Eleazar Flekeles ruled that free care of the poor was not only a virtue to be expected from a benevolent physician but a legal obligation enforceable by a (religious) court. A contemporary authority, Rabbi Eliezer Yehudah Waldenberg, accepts this ruling but notes that it can be enforced as a legal responsibility only where there is just one physician in a community. Where there is more than one physician, there are other ways of meeting society's obligation, for example, by appropriating money from the general *tzedakah* fund, conducting a special financial appeal, and equitably apportioning cases to all physicians for treatment on a pro bono basis. The most praiseworthy option, in Waldenberg's judgment, is to establish a special fund to pay physicians for caring for the poor. Mackler claims that Waldenberg's analysis is consistent with the Jewish tradition of *tzedakah*. If an individual cannot afford to pay for health care, the obligation to provide for such care devolves upon society as a whole. Society may choose any of a variety of ways to meet this responsibility, so long as the responsibility is met in every case of need.

Mackler believes that the implications of the Jewish understanding of justice for access to health care are clear in their broadest outlines. First, society has a responsibility to ensure that medical care is provided to those who would otherwise be unable to receive it, just as society has the responsibility to ensure that all the basic needs of the poor are met. Those with greater needs must be provided a greater amount of health care. Somewhat problematic is the provision of preventive care, which is less clearly mandated by traditional Jewish sources than is curative care.

Second, medical care for potentially life-threatening conditions justifies extraordinary expenditures and imposes an urgent obligation on society. While some limits on expenditures may be considered, the tradition's strong presumption is the provision of all necessary resources to preserve and save life. Third, those who choose or act irresponsibly with regard to their health diminish their claims to societal support but do not forfeit them entirely. And, finally, access to health care should be provided in a manner that is consistent with personal dignity and self-respect.

Resolution of specific policy issues in any of these areas would depend on a complex process involving empirical research, policy analysis, and political deliberation.

The application of this understanding to U.S. society, observes Mackler, is somewhat problematic. Jewish law claims authoritative status only for Jews. Nevertheless, Jewish views of justice remain relevant to American society in several ways. The *tzedakah* model provides a set of understandings and practices, developed to be both principled and pragmatic, for the achievement of social justice over a fairly broad-based community. At least this model can be useful as a source of insights and guidelines that might be appropriately translated to the situation in this country. In general, "the relevance of Jewish insights on justice and health care depends on their intuitive appeal, their resonance with accepted American values, and their congruence with the perspectives of other groups and individuals" in our society (p. 155). The values of Judaism represent one important perspective within our pluralistic society and deserve to be compared with the perspectives of other groups and individuals as part of a process of developing a consensus.

—Ron Hamel

Relieving pain or hastening death?

William C. Wilson, Nicholas G. Smedira, Carol Fink, et al., "Ordering and Administration of Sedatives and Analgesics during the Withholding and Withdrawal of Life Support from Critically Ill Patients," *Journal of the American Medical Association* 267, no. 7 (19 February 1992): 949–53.

WHEN SEDATIVES AND ANALGESICS are ordered and administered during the withholding and withdrawal of life support from critically ill patients, it is usually held that the primary intention is to relieve pain and suffering, not to hasten death. This study was designed to show more precisely how and why sedatives and analgesics were administered.

The study focused on 44 critically and terminally ill, non-brain-dead patients who were expected to die in the intensive care unit (ICU) after life support was withheld or withdrawn. Clinicians and nurses were

interviewed about their reasons for ordering and administering drugs to these patients. Physicians were given five reasons for ordering drugs (to decrease pain, to decrease anxiety, to decrease air hunger, to make the family feel more comfortable, and to hasten death) and could choose as many as they wished. Nurses were questioned about their participation in the treatment decisions and their reasons for wanting to give the drugs (the same five reasons were offered).

Decisions to withhold or withdraw therapy were made by patients or, more frequently, by family members or other surrogates on the recommendation of their primary physicians and ICU physicians. Sedatives, analgesics, or both were administered to 33 (75 percent) of the 44 patients (92 percent of whom were on mechanical ventilation). When physicians ordered drugs, they often did so to decrease pain, anxiety, and air hunger, and to a lesser extent, to comfort family members. Nurses also thought that sedatives and analgesics should be given to decrease pain, anxiety, and air hunger, and were more inclined than physicians to consider the comfort of the family. But physicians also ordered—and nurses administered—sedatives and analgesics to hasten death in almost 40 percent of patients. Only patients who were deeply comatose did not receive sedatives or analgesics at all because their physicians believed they would not benefit from the drugs.

Whether death was actually hastened by the administration of drugs was unclear. The median time until death following the initiation of withholding or withdrawing life support was 3.5 hours in the patients who received sedatives and analgesics and 1.3 hours in patients who did not receive them. These differences were not statistically significant and actually suggest that death occurred earlier in the patients who did not receive drugs. These patients were the most deeply comatose, however, and might have been expected to die more quickly once life support was withheld or withdrawn. Furthermore, the median time until death in patients for whom physicians or nurses cited hastening death as a reason for ordering and administering drugs was 2.6 hours compared with a median of 3.7 hours for patients whose physicians or nurses did not cite hastening death as a reason. The difference between these times is also not statistically significant. Thus there is no evidence that death was actually hastened by the administration of drugs; neither is

there evidence that an apparent intention to hasten death actually did hasten it.

Whether drugs were given primarily to hasten death is unclear in this study. Large doses of sedatives and analgesics were ordered and administered, but such doses may well have been required to prevent or treat pain and suffering. Furthermore, although a significant percentage of physicians and nurses cited hastening death as a reason for ordering and administering drugs, hastening death was never the only reason given. Also, because they could not objectively quantify pain, anxiety, and air hunger but wanted to minimize these sensations in their patients, the physicians and nurses indicated that they preferred to err on the side of giving larger rather than smaller

doses. They also stated that they saw no reason to prolong suffering once the decision to withhold or withdraw life support was made by a patient or her family.

Ordering and administering sedatives and analgesics during the withholding and withdrawing of life support are complex and difficult practices for which formal guidelines are not available. The authors conclude that their study should help to dispel two fears: first, that drugs are not given in sufficient quantities to provide comfort to patients and their families during the dying process, and second, that drugs are given in excessive amounts primarily to hasten death.

—Edwin R. DuBose

Second Opinion Guidelines for Authors

1. The manuscript should be typed on one side only, on standard white paper, with margins of at least 1 inch. All material, including extracts and references, should be double-spaced. Manuscript length should not exceed 35 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.
8. In a separate section entitled "References" list alphabetically by author (and, within author, by year of publication) all items that are cited in the text. Give complete bibliographical information, including author's first name, publisher, and place of publication. If there is more than one reference to the same author and year, distinguish them by the use of letters (a,b) attached to year of publication, e.g., Smith 1978a.

Examples

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