

## SOME MUST DIE

by Stuart J. Youngner

*Abstract.* The transplantation and procurement of human organs has become almost routine in American society. Yet, organ transplantation raises difficult ethical and psychosocial issues in the context of “controlled” death, including the blurring of boundaries between life and death, self and other, healing and harming, and killing and letting die. These issues are explored in the context of the actual experiences of organ donors and recipients, brain death, the introduction of non-heartbeating donor protocols, and the increasing reliance on living donors. The author draws on a thematic analysis of the way that organ transplantation is presented in the media, films, and science fiction and on his clinical experience as a psychiatrist working with transplant patients, their families, and the nurses and physicians who care for them.

*Keywords:* cannibalism; culture; death; Sigmund Freud; myths; nurses; organs; self.

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With the advent of organ transplantation, the myths, fantasies, and nightmares of past generations have become not only a reality but also a banality in the clinical and economic life of modern medical institutions. Organ transplantation, today the standard of care for many life-ending diseases, has become a growth industry. Dying persons desperately want it, third parties pay for it, the news media promote it, and increasing numbers of medical centers clamor to join the no-longer-elite circle of transplant centers that provide it.

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However, human body parts, the natural resources necessary for transplantation, are in short supply. The tensions created by this shortage remind us that transplantation retains magical, irrational, and frightening aspects, which dog its progress like shadows—shadows that can darken when the bright lights of rationality and utilitarianism propel public discourse in the effort to obtain more and more organs. Thus, for example, while public service announcements and human-interest stories extolling transplantation multiply, so too do grisly cartoons, jokes, and tabloid horror stories about the same subject.

Our society views organ transplantation simultaneously from two distinct and often contradictory perspectives. The first is the rational ethos of the Enlightenment, appropriated not only by medical science, academia, and public policy but also by mainstream religions. The second is the messier and less well articulated world of emotion, superstition, and magic. In the context of human psychology, neither perspective is right or wrong. They simply exist and function together, an important and unavoidable quality of the human condition. With cool rationality alone, we would be computers or robots. Without it, we would be prey to our emotions and fantasies, unable to cope. Our experience with human organ transplantation is an excellent illustration of the dynamic and often uneasy relationship between these two ways of seeing and understanding the world.

#### PRIMARY- AND SECONDARY-PROCESS THINKING

Sigmund Freud's notions of primary- and secondary-process thinking provide a helpful framework for understanding society's apparently contradictory attitudes toward organ transplantation. Secondary-process thinking is the most immediately familiar of the two. As Charles Brenner notes, "It is ordinary conscious thinking as we know it from introspection, that is, primarily verbal and following the usual laws of syntax and logic" (Brenner 1973, 52).

Primary-process thinking, in contrast, characterizes unconscious or preconscious thinking and dreaming. Compared with the secondary process, it is less objective and organized and "is ruled by emotions and hence full of wishful or fearful misconceptions . . . remote from any logic (Fenichel 1972, 47). Primary-process thinking is carried out more through pictorial, concrete images; representation by allusion or analogy is frequent; and a part of an object may be used to stand for the whole. Similarities are not distinguished from identities, and mutually contradictory ideas can coexist peacefully. Primary-process thinking is a magical type of thinking. Not only may wish be equated with deed and fantasy with action, but the perpetrator of a crime or misdeed will be punished with the same injury he or she inflicted. In primary-process thinking, there is no sense of time; past, present, and future are all one (Brenner 1973, 52).

Primary-process thinking is easily recognizable in infants and small

children, in seriously disturbed psychiatric patients, and in dreams, where fantasies and other internal stimuli are projected onto other persons or the environment as delusions or hallucinations, indistinguishable from reality. Psychoanalysts from Freud to the present have observed that primary-process thinking is an integral, though subordinate, part of normal adult mental life, where it becomes visible in dreams, games, jokes, and slips of the tongue.

The primary and secondary processes are in dynamic rather than static equilibrium. When the capacity of the secondary process is attenuated by sleep, metabolic disturbances, drugs, or severe anxiety, the primary process breaks through. Under these circumstances, the wishes and fears of the unconscious are perceived as real, and rational thought is replaced with magical thinking. Conversely, the irrational fears and delusions of the unconscious can be diminished by strengthening the secondary process, for example, through education or the reassurance of a trusted person or authority.

The inherent nature of transplantation provides both a stimulus and rich material for the primary process. In order for some to live and benefit from transplantation, others must die. When organs are transplanted, conventional boundaries between persons are violated. When organs are taken from newly dead bodies, bodies are mutilated. While the organ shortage grows, our increasingly desperate efforts to create new sources of organs inevitably provoke additional discomfort. For example, by recognizing brain death, we have created a new class of dead persons whose hearts continue to beat for days, weeks, even months. And by taking organs from baboons, chimpanzees, and pigs, we violate boundaries between species. I argue that, at an even more subterranean level, organ transplantation represents a form of nonoral cannibalism.

Circumstantial evidence of the impact from these issues can be found in the very fact of the organ shortage, which persists despite widespread medical and legal acceptance of organ transplantation, a radical expansion of criteria for determining death, laws that require health professionals to give families the donation option, and a federally funded nationwide organ procurement and sharing system. This essay provides a more direct exploration by examining (1) the experience of patients who are waiting for or who have received organ transplants, (2) the treatment of organ transplantation in popular culture, (3) the link between American society's rapidly evolving but highly controversial acceptance of mercy killing and new methods of organ transplantation, (4) the experience and behavior of health professionals involved in procuring organs from brain-dead patients, and (5) the use of language in transplantation.

#### CASE STUDIES

*Mr. Anderson.* I first met Mr. Anderson when I performed a routine psychiatric examination as part of his evaluation for heart transplantation.

He was a large, well-built man in his late fifties who appeared surprisingly healthy considering he was in the end stages of a cardiomyopathy—a progressive weakening of his heart muscles, most likely the result of a viral infection. Mr. Anderson lived in central Ohio, a two-and-a-half-hour drive from Cleveland, where our transplant program was situated. He had been a career Marine Corps officer who retired at age fifty to become the manager of a small dry-cleaning business. He was married and had two children and four grandchildren.

Mr. Anderson's exam was unremarkable. He denied any psychiatric or social problems and had a positive attitude about transplantation. He expressed no concerns about taking an organ from another person into his body. I saw no evidence of depression or anxiety. I felt almost embarrassed when I asked him a routine question about whether he had ever had hallucinations. He was silent for a minute and then said, "Not exactly." He then recounted the following story.

One month before, when he had come to Cleveland for his first evaluation visit, he had been informed that, if he were put on the waiting list, he would have to carry an electronic pager so that he could be reached instantly if a heart became available. He was also told that in order to save critical time he would be flown by emergency helicopter to Cleveland.

This information made him quite anxious. He had been in two helicopter crashes, once in Korea and once in Vietnam. The Vietnam crash had been the more serious. He was the gunner in a helicopter that was flying into a battle zone to pick up wounded soldiers. Coming in low over the trees, the helicopter had been shot out of the air and crashed in flames. Miraculously, he had been thrown clear of the wreck with "hardly a scratch," but the pilot and copilot had burned to death.

Mr. Anderson denied any symptoms of posttraumatic stress disorder other than a fear of flying in helicopters. He had not been in one since the crash in Vietnam. While he drove back home, he had worried about flying again in a helicopter. When he arrived at home, his nine-year-old grandson greeted him, full of questions about the transplant. When the child asked him where the heart would come from, the patient somewhat uncomfortably explained that it would come from a person who has died "in an accident or something." His grandson was surprised. He had assumed that "they just have them on the shelf in the operating room." He then asked his grandfather if he would still love him once he had another person's heart in his body. "Of course I will," Mr. Anderson had replied.

That night he went to bed ruminating about the questions his grandson had raised. Later he awoke with a start when someone tapped him on the shoulder. The patient assured me he had not been dreaming. "I was awake," he said. "No doubt about it." He had sat up in bed to find the pilot and copilot of the helicopter that had crashed in Vietnam in his room. They stood silently in full battle gear, stared at him for a few minutes, and then

beckoned with their hands for him to come. Mr. Anderson was terrified and began sweating profusely. The two men gradually faded away, leaving him trembling as he sat on the side of the bed.

Because of his Vietnam experience, Mr. Anderson was especially vulnerable to unconscious and primitive feelings of responsibility and guilt. As Renee Fox has remarked, organ transplantation is both lifesaving and death-ridden (Fox 1988, 170). The vast majority of organs come from persons who have died from sudden, unexpected head injuries. Something must happen to one person for another to be saved. Of course, our rational minds tell us that these deaths are linked to organ procurement only after the fact. To Mr. Anderson the linkage became more problematic for several reasons. Like many survivors of catastrophic events, he harbored a tremendous sense of guilt and responsibility for the deaths of his helicopter pilot and copilot. The horror of this earlier episode both fueled and was fueled by the transplant situation, in which Mr. Anderson would have to take another fateful helicopter ride that would end with himself saved at the expense of another's death.

Mr. Anderson's defenses were further weakened when he saw transplantation through the eyes of his grandson, who hoped that hearts were to be found like equipment, on the shelf of the operating room, and innocently feared that his grandfather's love for him might disappear when the elder's original heart was discarded. Under the mantle of sleep, his primitive thinking gained ascendancy, awakening him to a terrifying hallucinatory morality play.

*Ms. Jones.* Ms. Jones, an uneducated woman in her sixties, began having a recurrent nightmare months after she had received a kidney transplant. In her dream, a dead man approached her calling her name, and, like Mr. Anderson's fellow Marines, beckoned her to join him in death. She would awaken terrified and remain anxious during the day. She was certain that the dead man in her dream was the person from whom she had received a kidney; she had been told he had died in a car accident.

In our discussions, she revealed that twenty-five years before, her six-year-old son had run out in traffic and was struck by an automobile. He had been taken to the hospital and placed on a mechanical ventilator, where it was determined that he had no brain function. This had occurred in the early 1960s, before brain death was widely accepted and before health professionals felt comfortable removing dying patients from ventilators (many are still uncomfortable doing this). Ms. Jones insisted that she had been told that there was no hope but that if she wanted the plug pulled, she would have to do it herself.

"I wanted to do it, but I was afraid," she told me. Her son died two days later, but she had always felt guilty—that she had not prevented the car accident and that she had wanted to turn off the ventilator but had not done so. After she verbalized her guilt about her son's tragic death, she was

able to connect this guilt with her nightmares and the death of a donor. As a result, her nightmares subsided.

*Ms. Smith.* A twenty-five-year-old woman with a psychiatric diagnosis of borderline personality disorder was referred to me because of overwhelming anxiety. Ms. Smith had received a kidney transplant two years before and was now in the hospital because her body was rejecting it. When I spoke with her, she told me that she had become obsessed with the thought that her grandfather had been murdered and that she had received his kidney, which was now rejecting her. During our talk, Ms. Smith told me that when she was a child she had been removed from her parents' home because they were sexually abusing her. She had been sent to live with her grandfather and uncles. Her grandfather was a "very nice man" but did nothing to protect her when her uncles sexually abused her.

She had loved her grandfather (who had died several years before), but she was also very angry at him for not protecting her. Her anger and guilt were reflected both in the fantasy that he had been killed to save her and the fear that his kidney was now rejecting her.

For most patients, concerns about the death of the donor surface in a less disturbing manner. Many of the people I interview volunteer that they are distressed that someone has to die. Several patients have assured me, without my asking, that they had signed organ donor cards since finding out that they would need a transplant. Naturally, many persons suppress their fears and fantasies or are reluctant to share them with psychiatrists or others who are screening them for transplantation suitability. Evidence indicates that complete suppression of these concerns may be a useful coping strategy in the perioperative period (Mai 1986, 1159). However, when patients are bothered by their fears, health professionals can be a source of education and reassurance. For example, a liver transplant candidate in her middle thirties was worried that the donor of her organ would come back to "haunt" her. By talking with staff and with patients who had already received liver transplants, she was able to overcome her fears.

Examples of the ambivalence and guilt about donor deaths can be found in the medical literature as well. James Levenson and Mary Ellen Olbrisch (1987, 399) report "gallows humor" among patients waiting for transplant: They not uncommonly "talk about fantasies of standing on the roof of the hospital with a rifle" or ask hospital staff "whether they have had any opportunities to run down pedestrians on their way to work." In several instances, candidates for transplantation or their relatives "have coped by identifying 'healthy specimens' among the house staff and inquiring as to their body weights and blood types." Robert Frierson and Steven Lippmann (1987, 347) report that "patients often found themselves hoping for inclement weather because of a greater likelihood of fatal accidents to afford more organ donations. This so-called 'rainy day syndrome' was often accompanied by significant feelings of guilt."

## POPULAR CULTURE

The legacy of Burke and Hare, two Englishmen who killed people so that they could sell their bodies for anatomical dissection, and the modern myth of Frankenstein described so vividly by Ruth Richardson (1996) and Leslie Fiedler (1996) are very much alive in our collective consciousness. Stimulated by the steady diet of upbeat news stories, sermons, and public-service announcements about transplantation and the need for more organs, fears that people will actually be killed for organs find free rein in popular culture. Horror books and movies tell tales of powerful and maniacal physicians (either functioning independently or as agents of even more powerful scoundrels) who take advantage of patients or other, weaker persons to obtain their organs. A recent series of the comic strip "Dick Tracy" concerned a nefarious conspiracy in which homeless people were shanghaied from a city shelter, killed, and used as organ sources (Locherand and Collins 1991).

As noted earlier, the fears are often expressed as humor. In the movie *Monty Python's The Meaning of Life*, a group of medical people ring the doorbell of a family home. When the father answers the door, they ask him if he has signed a card donating his liver. When he replies in the affirmative, they barge into the house, tie him to the kitchen table, and proceed to remove his liver—without anesthetic and in front of his horrified family.

Fears about killing for organs are given impetus by proposals to allow criminals condemned to death to donate their organs as part of the execution process. Some prisoners serving life sentences have even asked to be executed so they could both end their miserable existence in prison and donate organs. In fact, allowing condemned inmates to donate their organs upon execution is a pet project of Dr. Jack Kevorkian, known to the American public as a crusader for physician-assisted suicide (Kevorkian 1991). Of course, such killings can be rationalized as different from the killings in *Coma* (Cook 1977), a novel and movie in which patients are killed and kept in suspended animation so that their body parts and fluids can be used. After all, in the horror movies and books, the organ sources are unwilling victims of murder. In real life, the prisoners give consent or even initiate requests to have their organs taken.

These subtleties, however, are lost on the unconscious mind, where killing and organ procurement are linked concretely. Primitive but powerful associations are only reinforced by stories from China about executed criminals whose organs are taken whether or not they wanted to be donors ("Grim Commerce in China" 1994).

Even more disturbing are stories in the press about innocent persons killed for organs. In 1992, newspapers reported that hundreds of patients at a mental hospital near Buenos Aires were allegedly killed by greedy staff

members who sold their body parts and blood ("Patients Killed for Organs" 1992; "Journal: Patients at Argentine Hospital" 1992). For several years, rumors have circulated that children from various South and Central American countries are being kidnapped and taken to the United States to be "fattened up" and then killed for their organs. More recently, foreigners have been attacked in Guatemala in a panic fed by rumors that Americans were coming to kidnap children, cut out their vital organs, and ship them to the United States for transplantations ("Behind the Kidnapping" 1994; "Guatemala Gang" 1994). An article in *Asiaweek* titled "Life for Sale" (1994) described the extensive and legal sale of kidneys (single kidneys from live donors) in India. It went on to describe a disturbing story from Bangladesh:

Last year 400 children disappeared in Chittagong city, according to police. It's suspected that most of them were kidnapped for their organs. In October police in suburban Dhaka rescued 49 people and arrested two human traffickers. The men confessed that they were going to smuggle the group into India under the guise of finding them work. Once there they planned to sell some of them to human organ traders who operated through some hospitals in Bombay and Madras. The victims would be forced to donate their kidneys, eyes, hair and blood. (1994, 49)

None of these stories has ever been verified by reliable sources, and the transplant community in the United States has vehemently denied their veracity. Furthermore, no one has seriously proposed that any of these ghoulish practices actually occurs in the United States. But the newspaper stories and rumors keep coming. Horror movies and novels continue to be produced and sold. The stories find their way to the collective unconscious, where they percolate, resonating with the popular myths that Fiedler describes (1996), breathing new life (or death) into the psychic legacy of body snatching for dissection, which Richardson so vividly portrays (1996), and playing on the fears not merely of the paranoid and insecure but of the poor and disadvantaged as well. Examining the historical relationship between organ transplantation, the determination of death, and treatment-limitation decisions helps to explain the darker side of American society's reaction to organ procurement.

#### PLANNED DEATH AND ORGAN PROCUREMENT

Aside from living donors (who provide about 20 percent of donated kidneys in the United States), solid vascularized organs such as the kidneys, heart, and liver come from patients who are brain dead but whose hearts continue to beat. Brain death is a legal and clinical concept introduced in the 1960s that subsequently achieved widespread acceptance throughout the United States. The reasons for introducing it were quite rational: (1) to facilitate organ procurement and (2) to avoid legal concerns about turning off ventilators (Ad Hoc Committee 1968, 337; Youngner 1992, 570).



A patient who suffers a massive brain injury (for example, in a car accident or following a heart attack) can now be resuscitated and put on a mechanical ventilator. Moreover, physicians and nurses in the intensive care unit can now perform many of the integrative functions previously carried out automatically by the brain, such as regulating body temperature and blood pressure. Brain-dead patients are legally dead in every jurisdiction in the United States, yet they are a wonderful source of organs because their hearts beat spontaneously, pumping warm, richly oxygenated blood throughout their living bodies until their organs can be removed and quickly put on ice.

Brain death raises a profound problem that is relevant to our general discussion, which I consider later—namely, the cognitive dissonance engendered by the overwhelming signs of life in these “dead” patients. For the moment, however, I turn to new methods organ transplanters have employed to increase the donor pool.

#### NEW METHODS FOR OBTAINING ORGANS

As organ transplantation has become more popular, the supply of brain-dead patients has not kept pace. In response to the organ shortage, transplanters have developed new techniques for retrieving organs from traditional corpses—so-called non-heart-beating cadavers (NHBCs). The University of Pittsburgh Medical Center has implemented a protocol in which the time of death (not brain death, but death by cardiopulmonary criteria) is controlled so that it occurs in the operating room, where organs can be quickly removed before they are damaged (Youngner and Arnold 1993, 2769; Arnold and Youngner 1993a, 103). Patients who are potential candidates for organ donation under this protocol are ventilator dependent but not brain dead. They might be severely brain injured but still have identifiable brain function, or they might have completely intact cognitive function but are unable to breathe spontaneously (for example, patients who are quadriplegic from high spinal injuries). In either case, after the patient’s family (or the patient when competent) asks that life support be removed, they can also request that organs be donated for transplantation. After an elaborate informed-consent process, the patient is taken to the operating room (if organ procurement were not in the picture, ventilator removal and death would occur in the intensive care unit), prepped for surgery, and the ventilator turned off. Two minutes after the heart stops beating, the surgeons come in and remove the organs as quickly as possible to reduce warm ischemia time, during which organs are damaged.

Controlling the timing of death in this way would have been hardly imaginable a quarter century ago, when turning off machines that kept people alive was very controversial. To many persons, it seemed too close to killing. Health professionals and health-care institutions were reluctant

to turn off mechanical ventilators for fear they would be sued or prosecuted for murder. (In countries that have had less experience with medical technology, the level of controversy remains high.)

Clinical practice and the law have undergone dramatic evolution over the past two and a half decades. Competent patients or their surrogates may refuse any form of life-sustaining treatment, including mechanical ventilators and artificially provided fluids and nutrition. Today we turn off the ventilators not only of brain-dead patients but also of still-living patients with clinical conditions ranging from terminal illness to quadriplegia. However, this evolution in attitude and behavior has likely not run its course and has special relevance to organ procurement under protocols like the one in Pittsburgh.

At preconscious and unconscious levels, our society has accepted increasingly active forms of physician-assisted suicide and euthanasia, paving the way to open acceptance. Local newspapers and television news programs regularly feature stories about Kevorkian and his assisted suicides. National polls reflect a growing public acceptance of physician-assisted suicide and euthanasia, which have become widespread and socially sanctioned practices in the "civilized" Netherlands. Prestigious medical journals such as the *New England Journal of Medicine* have published articles in which physicians have openly admitted helping patients end their lives and set forth comprehensive guidelines for this practice (Quill 1991, 691; Quill, Cassel, and Meier 1992, 1380). While voter initiatives to legalize physician-assisted suicide and euthanasia have been narrowly defeated in two states, one was recently approved by Oregon voters. In sum, then, it appears likely that physician-assisted suicide and euthanasia will be explicitly or implicitly tolerated in many jurisdictions in the United States within the next decade.

If this prediction proves accurate, one can easily extrapolate the likely scenario for organ procurement. If we ask patients, as the Pittsburgh protocol does, to become donors when they ask that their ventilators be turned off, why would we not allow them the same prerogative when we help them to commit suicide or put them to death at their own request (Arnold and Youngner 1993b, 263)? Unless something unforeseen intervenes to disrupt it, the evolution from an ever-expanding array of treatment limitations to an equally expanding array of voluntary suicides and mercy killings seems inevitable. The decision to allow euthanized patients to donate their organs would follow quite naturally, once the more controversial practices of suicide and mercy killing were to become sanctioned.

By controlling the time and place of death, the Pittsburgh protocol takes a critical symbolic step: It links the planned death of one human being to the procurement of organs for another. The transplantation of tissue from electively aborted fetuses is a second example. What makes the Pittsburgh protocol legally and morally acceptable is that both the death of the donor and the taking of his or her organs are voluntary. This same protection

could exist if organ donation were linked to physician-assisted suicide or voluntary active euthanasia. An extensive informed-consent process and the total absence of coercion would be necessary to prevent the killing for organs, about which both Richardson and the modern myths of popular culture warn and for which they, perhaps, prepare us.

#### PUBLIC POLICY PROTECTIONS

From early on, the government and the transplant community have tried to dispel concerns that people will be killed or exploited for their organs. The National Organ Transplant Act of 1984 made clear that care of the potential donor and care of the potential recipient must not be provided by the same persons and that transplant personnel should in no way be involved in treatment decisions before the donor's death.

In contrast with the Organ Transplant Act, the dead-donor rule evolved as an informal policy, but, like the Organ Transplant Act, it is intended to reassure the public that people will not be taken advantage of so that their organs can be used (Arnold and Youngner 1993b, 263). The dead-donor rule has two aspects: first, people must not be killed by or for organ retrieval; and, second, with the exception of completely healthy family members, people can have their organs taken only after they are dead, even if taking the organs will not kill them. So, for example, we are unwilling, even with a family's (or the patient's prior) permission, to take a single kidney from a patient in a permanently unconscious state.

Nonetheless, public opinion polls regularly reflect the fear of many persons that their care will be compromised so that they can become a source for organs (Prottas and Batten 1986; Prottas and Batten 1991, 121). Such fears are greatest among minority groups, who have good historical reasons for mistrusting organized medicine or for doubting that they will be protected by the law (Collender, Hall, Yeager, et al. 1991, 442). Already, demagogues in the African-American community have sought to play on these fears (see "Farrakhan Links Race" 1994). Appeals to informed consent and protection of the law are more likely to quell the irrational fears of those members of society who have the power, privilege, and experience to exploit those protections more successfully.

#### BRAIN DEATH: ANOTHER LAYER OF CONFUSION

When news media report on brain death, they regularly refer to legally dead patients as being "kept alive" on life-support systems or "in critical condition." Such ambiguous language is the rule rather than the exception. I recently witnessed a television anchorman describe a severely brain-damaged patient as "in critical condition but technically brain-dead."

Such confusion is common even among health professionals, who stubbornly persist in describing patients who have lost all brain function as

brain-dead rather than simply dead. These patients, who are considered legally dead in all fifty states, are also characterized as being kept alive on “life” support and as “dying” after that support is removed. Even though the legal time of death occurs when the patient is determined to have irreversibly lost all brain function, health professionals regularly fill in the death certificate with the time the heart stopped beating (after life support is stopped).

I alluded earlier to the cognitive dissonance stimulated by the phenomenon of brain death. Before the advent of medical technology, numerous indicators of death occurred more or less at once. So, for example, a person with a fatal heart attack would lose consciousness, stop breathing, become motionless and unresponsive, and have no detectable pulse all at approximately the same time. All the vital signs of life would vanish together. Now, however, medical technology has forced us to choose which signs of life are sufficiently important that their loss constitutes the death of the patient, while other signs of life persist.

The traditional view rejects the notion of brain death altogether, arguing that vital fluid flow—the movement of air and blood through the body—indicates life. Thus, the persistence of cardiac and pulmonary function sufficiently demonstrates that the patient is still alive. In the United States, this view receives considerable support in the fundamentalist Christian and Orthodox Jewish communities. In contrast, the more recent view holds that even with a spontaneously beating heart and air flow in and out of the lungs (by means of a ventilator), irreversible loss of all brain function (brain death) signals the death of the patient.

However, in the intensive care unit (ICU), where brain-dead patients are maintained, and in the operating rooms, where their organs are removed, nurses, house officers, and anesthesiologists are often confused and sometimes dismayed by these paradoxical patients. In the ICU, nurses and physicians must “treat” these dead patients quite aggressively in order to maintain them for transplantation. They must attach them to breathing machines, monitor them for heart rhythm and blood pressure, give them fluids and nutrition, and, when indicated, administer antibiotics and other medications. The medical staff must also closely monitor and adjust the patients’ blood chemistry and oxygen levels. These dead patients are even candidates for full resuscitation should they suffer cardiac arrest. Yet, in the next bed may lie a completely conscious patient who, at her own request, does not want to be resuscitated. ICU nurses often talk to brain-dead patients and are concerned when they are subjected to painful procedures.

Brain-dead patients pose an even greater emotional challenge for operating-room personnel, who must maintain them through organ retrieval surgery. Such a patient is prepped like any other surgical candidate and draped to reveal only the operative field. An anesthesiologist stands at the

head of the patient to manage the mechanical ventilator and maintain homeostasis by giving fluids and drugs. The surgeons use sterile technique, tie off or cauterize bleeding blood vessels, and carefully cut and separate tissue planes. The patient's chest rises and falls with the rhythm of the ventilator. And it is not uncommon to give the dead patient a transfusion of fresh blood while his or her organs are being removed.

These similarities between brain-dead and regular surgical candidates add emotional force to the differences as the process unfolds. Instead of diseased tissue, healthy organs are removed, and then the meticulous attention to detail comes to an end. It becomes concretely clear that the purpose of the surgery is for another patient, not the one in the room. The mechanical ventilator is turned off, and the patient's newly emptied body is closed in one pass with coarse retention sutures. Some nurses and anesthesiologists describe the turning off of the ventilator as the most emotionally intense moment. Some say that not until then does the patient's spirit leave the room. Others frankly describe it as the second death of the patient. It is most upsetting for the unprepared and the uninitiated—young nurses or anesthesiologists or those who work at smaller community hospitals where organ procurement and transplantation are rare events.

The resulting confusion and cognitive dissonance were reflected in a study of ICU and operating-room physicians and nurses. Almost all participants intellectually accepted that brain-dead patients were indeed dead. However, when asked what makes brain-dead patients dead, fully one-third gave answers indicating that they really believed such patients to be alive, for example, "the patient will die soon, no matter what we do," or "the patient's quality of life is unacceptable" (Youngner, Landefeld, Coulton, et al. 1989, 2205).

Cognitive dissonance was magnified in the case of an eighteen-year-old woman, whom I will call Janet, twenty-two weeks pregnant, who suffered a spontaneous ruptured cerebral aneurysm and was admitted to the ICU, where an unequivocal diagnosis of brain death was made within twenty-four hours. Here, nurses and physicians cared for dead mother and living fetus. Eight weeks later, a healthy baby was delivered by cesarean section, following which the young woman's heart, liver, pancreas, and kidneys were removed and transplanted into four waiting patients, three of whom were cared for in the same ICU that had maintained the dead mother.

Because the care of Janet was going to be both clinically and emotionally challenging (the first such case for the ICU), a small group of nurses volunteered to provide it. Heavily identified with the tragedy, they became very attached to both the dead mother and the living fetus, who had already been named. For many of the staff, taking care of the patient was a religious experience. Its mystical nature was enhanced by the fact that Janet had anticipated her death a week before it occurred, when she told her family that "if anything happens to me, I want them to do everything

to save the baby.” The ICU staff’s mission was to bring a healthy baby out of the tragedy, and they constantly watched and worried over it. But they were also preoccupied with the baby’s mother.

One nurse described what the day-to-day care of Janet was like: “We kept her immaculately clean and neat, even had her mother bring in a silk robe in which to dress her. I washed her hair every week. It was long, beautiful red hair, and it grew for eight weeks. I could sense the presence of her soul in her body.” Another nurse sensed the presence of a soul hovering over the body, “watching us.”

The nurses developed rituals, including putting a picture of the dead mother on the wall. They played music in the room, “for the baby,” but were convinced that the mother’s heart rate changed in response to it. The physicians, who spent much less time with the patient (the nurses worked one-on-one with the patient in ten-hour shifts), were less emotionally involved, although one of the obstetricians was clearly convinced that “the whole thing [had] a preordained purpose.”

Not surprisingly, the medical staff constantly used speech indicating that the patient was alive. “Our job was to keep the mother alive until the baby was born,” one physician told me. A nurse said, “We all *knew* she was dead, but we *felt* she was alive.” The patient’s mother told a physician, “Every time I leave, I think she is going to finally die, and each time I return to the ICU, she is still with us.”

What is reality for family members who watched the living body of a dead girl nurture, grow, and issue forth a healthy baby? While Janet’s hair grew longer and the nurses washed and combed it, was she really alive or dead to them? They could rationally say that she was dead and explain why; the signs of life told another story.

#### THE LANGUAGE OF ORGAN TRANSPLANTATION

Richardson argues (1996) that the language of organ transplantation is sometimes intended to disguise its darker side. Language can also provide an unwitting representation of transplantation’s more disturbing but subterranean aspects. The persistence of the term *brain-dead* to describe patients whose hearts continue to beat but who have lost all brain function, and the habit of referring to them as *alive* only to describe them as *dying* when their ventilators are turned off, does not reflect mere ignorance of the facts. The transplant community correctly perceives that, by using the term *brain death* instead of simply *death*, health professionals and journalists encourage the notion that a difference exists—that brain-dead patients are not dead but constitute some other category of being. They are mistaken, however, in thinking that mere education will either eliminate the use of the term or solve the problem.

The fact that experienced transplant surgeons and nurses make the same “slip” on a regular basis is evidence that something more powerful than

lack of knowledge is at work. The physicians and nurses who cared for Janet were intellectually aware that she was legally dead and that the fetus inside her was alive. They persisted in referring to both mother and fetus as alive because of the abundant signs of life emanating from both. As mythologist Wendy Doniger insightfully commented when I described this phenomenon to her, “Why, it’s just the way we persist in describing a sunset, when we know full well on the intellectual level that the earth is moving around the sun, not vice versa.”

Other words are viewed as politically incorrect by the transplant community because of their unpleasant connotations. Procurement of organs has an unsavory association with commodities and commerce, even prostitution. Some persons have suggested organ *retrieval* as preferable, but others have objected that retrieval implies that the organs belonged to someone other than the donor patient and that we are merely taking them back. Terms such as *heart-beating cadaver* or *neomort* (Gaylin 1974, 123) are offensive to many persons because they seem ghoulish or crude.

Another example supports the notion that transplant language can be sanitizing: most cadaver “donors” are, of course, no such thing. They often have given no indication of what they want done with their organs when they die. The organs are most often donated by their families. It is more comforting, of course, to think of them as organ donors than as organ sources. Rather than view the language of transplantation as a product of ignorance or intentional disrespect, however, we should understand it as an inevitable expression of the complex and dynamic interaction between the rational-utilitarian and emotional-symbolic ways in which we understand or try to understand this wonderful and terrifying miracle of science.

#### CANNIBALISM

Richardson suggests that the word *harvesting* presents too benign an image of organ procurement. Some persons disagree, arguing that the word is disrespectful to the dead donors, implying that they are vegetables rather than human beings. An even more disturbing interpretation is possible—that harvesting imports the notion of cannibalism. Of course, in an entirely concrete sense, organ transplantation *is* a form of nonoral cannibalism, that is, the taking of the flesh and blood from one person into another. Historically, two general categories of cannibalism have existed: survival cannibalism and ritual cannibalism.

*Survival Cannibalism.* Of the two categories, survival cannibalism is metaphorically closest to organ transplantation—taking in the flesh of another as the only means of preserving one’s own life. Examples of survival cannibalism abound throughout history. Two that are part of our public consciousness concern the notorious Donner party, in which human

cannibalism was widespread among a group of pioneers trapped by a winter snowstorm in the Sierra Nevada in the late nineteenth century (Stewart 1986), and the more recent story of a group of Uruguayan rugby players and their families stranded in the Andes Mountains after an airplane crash. The latter story was published in a bestselling book (Read 1974) and has been made into two popular movies. The inherent drama and tragedy of these situations are not the only things that capture the public imagination; these situations also depict well-meaning people who overcome their own sense of repugnance and violate a strict social taboo in order to survive. In such cases, society seems to understand and forgive—as long as those consumed died naturally and were not unjustly killed.

Examples of survival cannibalism also offer insight into how rituals can be created or adapted to help overcome the extraordinary and terrifying nature of the act. For example, the rugby team (the Old Christian Club) used a cannibalistic ritual at the very heart of Christianity, communion, to make their own cannibalism more acceptable. “It’s like Holy Communion,” one of them said. “When Christ died, he gave his body to us so that we could have spiritual life. My friend has given us his body so we can have physical life” (Read 1974, 83).

When death is planned and manipulated (this is, when people are killed for their flesh), the emotional and moral stakes are raised. Examples of cannibalism abound in British naval history and provide examples of how reasonable people in unreasonable circumstances (for example, starvation in a life boat) rationalized their choice of whom to kill (Simpson 1985). The “fairest” way was the drawing of lots—for both the person to be killed and the killer. Less judicious were decisions to kill individuals because of their race or because they were children. One way to make such deaths more tolerable was to identify people who were “about to die anyway,” thereby diminishing the harm to them. Sometimes these murders were rationalized as mercy killing.

One could argue that this same reasoning underlies our current acceptance of brain death. That is, in patients who have lost all brain function, we have identified a group of severely injured and dying persons who are so “beyond harm” that we feel justified in killing them in order to obtain their organs (Arnold and Youngner 1993b, 263). Because we would rather not think that we are killing them, we simply gerrymander the line between life and death to include them in the latter category.

Conceptual gerrymandering is even more apparent in proposals to label anencephalic infants (born with no cerebral hemispheres but entirely functioning brain stems) as dead, precisely so that their organs can be taken for transplantation (Fletcher and Truog 1989, 388). Recently, the American Medical Association took a more candid approach: “It is normally required that the donor be legally dead before permitting the harvesting of organs. The use of the anencephalic infant as a live donor is a limited exception to



the general standard because of the fact that the infant has never experienced, and will never experience, consciousness” (“Anencephalic Infants” 1994; “Council: Use of Anencephalic” 1994, 9).

The AMA did not suggest that anencephalic infants were dead but rather that they were beyond harm and, therefore, could be killed for their organs. Of course, the AMA did not use the word *killed*.

*Ritual Cannibalism.* Ritual cannibalism is often performed with the intent of incorporating desired qualities of the person who is eaten. While incorporation of the donor’s personal characteristics (other than the health of his or her organs) is not the *intent* of organ transplantation, the early transplant literature is replete with examples of patients who either feared incorporating unwanted characteristics or were convinced it had actually happened. Renee Fox (1996) points out how little the current psychiatric and medical literature comments about this issue, but it has not been ignored in lay literature, novels, or movies. Writing in the *New Yorker*, a general surgeon, Sherwin B. Nuland, describes his interview with a man named Cretella, who had received a heart transplant:

Toward the end of my visit, our conversation turned to a topic I had been hesitant to bring up. What does it feel like to live with another person’s heart beating in your chest? It proved to be something Cretella was trying very hard not to think about.

“I don’t know yet,” he said. “I really don’t know yet. When I catch myself thinking about it, I try to forget about it. You know—I think, What is it? A female? A male? Black? Orange? White?”

I asked him what he would want it to be.

“I don’t know that yet, either. I can’t answer any questions like that at all. I even get upset talking to you about it. When I talk about it, I get paranoid. I think mainly it’s because I don’t know what’s going to happen tomorrow, and the reason for that is that I can be sitting here feeling fine and all of a sudden something clicks and I get nervous and everything just starts going. Something in my body changes, as if somebody pushed a button. I talked to another transplant patient—he’s in his fifth year—and he says it still happens to him . . . you know, they tell you it doesn’t make any difference what kind of heart you get. And I’m sitting there thinking, I don’t believe that, I honestly don’t believe it.” (Nuland 1990, 82)

In my own experience, transplant candidates and patients often express fantasies and worries about taking on characteristics of the donor. Mr. Anderson’s young grandson, for example, was afraid that his grandfather would no longer love him after the man received a new heart. His “mistake” was an innocent and unrationalized representation of the emotional significance given to the heart throughout our society, even though we know that the brain is the real seat of our emotions. The boy expressed concretely what usually remains in our subconscious or emerges in common metaphors when we speak of losing our hearts, breaking our hearts, and having good or evil hearts. These examples, to use Doniger’s analogy, are like talking about the sun setting over a post-Copernican horizon.

Transplant candidates sometimes joke with me about adopting the sexual, ethnic, or other personal characteristics of donors. They rarely express their fears directly, either because they have successfully rationalized them or because the potential candidates are worried that candor would harm their chances for receiving an organ (in fact, it would not). Humor, of course, provides a window into the unconscious, deriving its energy from the partial exposure of what is usually hidden and forbidden. It is not surprising that cartoons and movies often present concerns about identity and transplantation in a comic as well as a horror mode.

I learned of a dramatic example of donor-personality incorporation when I was called by a producer of "The Phil Donahue Show," a somewhat sensational TV talk show. An upcoming broadcast would feature a group of heart transplant recipients in the New York City area who claimed that they not only had taken on personality characteristics of the donors but also had come to know intimate details about the donors' lives—all without having received any information about them! Accompanying the heart recipients was a psychoanalyst who had them in a therapy group. I was asked to appear as "a voice of rationality and science," to provide "balance" for the show. (I declined.)

While thoughts and fears about incorporating personal qualities of the donor (or losing one's own identity) characterize transplantation, the converse distinguishes ritual cannibalism; that is, people are eaten with the express purpose of incorporating desirable characteristics. For the unconscious mind, the concrete or literal similarities are as important as the differences. The term *cannibalism* is itself used commonly to describe taking working parts from one machine (for example, an automobile) to fix another that is broken.

The association between organs and food becomes even more concrete when transplant surgeons are seen (by other health professionals, as well as by the public when viewing television) transporting organs in easily recognized brand-name coolers usually reserved for carrying picnic lunches. Transplanters also use Tupperware® to transport tissues or wrap them in the same brand-name cellophane that sits on the shelves of our supermarkets. The Japanese film crew that taped a total body harvest in an American hospital for a Japanese national television program debating the merits of transplantation missed none of these culinary details (Lock 1996). One of my own patients made an inescapable connection when he expressed regret that someone had to die so that he could get a liver. "I wish I could go to the grocery store and buy one off the shelf," he lamented.

#### CONCLUSION

I have used the words and experiences of transplant patients, their families, and the health professionals who care for them to examine some of the

powerful but often subterranean psychological forces that exist alongside the more rational, tidy, and “constructive” view of the official transplant and public-policy communities. Neither is right or wrong. Each must be understood on its own terms. To ignore the more rational side is to miss the wonderful opportunity transplantation offers to save, extend, and improve the lives of thousands of people. To ignore or dismiss the more subterranean side is to build transplant policy on an unrealistic view of the human psyche that is not only insensitive but also ineffective because of its naivete.

The tragic and often violent death of others, the taking in of another’s flesh to live, the confusion of boundaries, the mutilation of dead bodies, and the cognitive dissonance of brain death are all disturbing but inescapable aspects of transplantation and organ procurement. Society adjusts and accepts new practices, even when they stimulate powerful fears and taboos. Richardson has chronicled how it took England four centuries of dissection to become comfortable enough for voluntary donation to triumph. Her observations about the Anatomy Act of 1832 and her view that it set back voluntary donation by a century should give us pause while we pursue public policies that ignore the deeply held fears and taboos of our society.

#### NOTE

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