

Advocate Health - Midwest

## SHARE @ Advocate Health - Midwest

---

Historical Documents - Combined

Advocate Health - Midwest History

---

### Making the Rounds, 1995, V1 N3, October 9

Advocate Aurora Health

Follow this and additional works at: <https://institutionalrepository.aah.org/alldocuments>

---

# MAKING THE ROUNDS

IN HEALTH,  
FAITH,  
& ETHICS

VOLUME 1, NUMBER 3

PUBLISHED SEMIMONTHLY BY THE PARK RIDGE CENTER

OCTOBER 9, 1995

## Baboon-to-Human Transplants: Should We Proceed?

*Robert M. Arnold and Rebecca Dresser*

It sounds like something out of a science fiction movie—"AIDS Patients Cured by Baboon Transplant." In reality, a baboon bone marrow transplant to reconstitute an HIV-seropositive patient's ravaged immune system is scientifically plausible. Having received approval from the Food and Drug Administration (FDA) and the local institutional review board (IRB), the first experiment is scheduled this fall at the University of California at San Francisco (Pennisi 1995).

The theory behind the experiment is deceptively simple: give HIV-seropositive patients a new immune system. Baboons are ideal sources, because they appear resistant to HIV-1. The trick is to transplant baboon bone marrow into humans successfully. The primary investigator, Dr. Suzanne Ildstad at the University of Pittsburgh, has shown that it is possible to graft immune cells from one species into another species' immune system without the long-term use of immunosuppressive drugs.

The proposed experiment's goal is to reconstitute the AIDS patient's immune system by transplanting baboon stem and facilitator cells into the patient's immune system. The protocol requires short-term irradiation and multiple immunosuppressives to prepare the human's immune system for the graft. The result should be a chimera that is able to resist further infection by the HIV virus as well as fight opportunistic infections (Nowak 1994). This innovative therapy raises complex ethical issues, however, which merit careful professional and public examination.

*What level of proof is sufficient to justify human clinical trials?* It is always difficult to know when it is appropriate to move from animal to human studies. Laboratory research and animal studies are required both to establish biological plausibility for believing the experiment may work and to lay an adequate scientific foundation for learning from the human experiment.

*Robert M. Arnold is associate professor of medicine, Division of General Internal Medicine, Center for Medical Ethics, University of Pittsburgh, Pittsburgh, Pennsylvania.*

*Rebecca Dresser is professor at the School of Law, the Center for Biomedical Ethics, and the School of Medicine, Case Western Reserve University, Cleveland, Ohio.*

The Pittsburgh group conducted numerous experiments transplanting mice stem and facilitator cells into rats to determine the experiment's feasibility. Further information to test their theory, they argue, requires human experimentation. The IRB's role in determining whether there are sufficient data to proceed with innovative therapy will always be contentious. Some argue that adequately informed patients, not IRBs, should decide whether a proposed intervention's potential benefits outweigh its risks. AIDS activists believe that terminally ill patients with no other therapeutic options should be allowed to make their own decisions regarding whether to proceed with risky therapies.

Others believe that IRBs have a special obligation to assess the appropriate risk-benefit ratio for terminally ill patients. Attorney-ethicist George Annas argues that such patients are too vulnerable to weigh risks and benefits rationally, "because an offer of 'life' from a physician . . . is an offer dying patients are in no reasonable position to refuse" (Annas 1987:100). According to Annas, IRBs should allow only research that offers terminally ill subjects a reasonable probability of improving their health or well-being (Annas 1992). This proposal, if instituted, would preclude many initial experimental human trials on the critically ill, such as phase-I trials on cancer chemotherapy designed to determine the absorption and metabolism of a drug and its toxicity.

Current regulations governing IRBs adopt an intermediate position. IRBs do perform a risk-benefit analysis on research to determine if prospective subjects should be allowed to consent to research, but they do not scrutinize proposals involving terminally ill subjects more carefully. Moreover, in determining a study's benefit, an IRB must consider both "anticipated benefits, if any, to subjects, and the importance of the knowledge that may reasonably be expected to result from the research" (DHHS 1993, *italics added*). Current regulations thus permit approval of the baboon transplant study even if it is unlikely that the experiment will provide therapeutic benefit to the subjects.

*What constitutes adequate informed consent?* Ensuring informed consent is particularly important in groundbreaking research. Although important scientific information may be gained from such research, initial attempts have universally failed. The prospective sub-

(continued on page 3)

## Doctors' elevator talk— unelevating

"Would you have trust in a doctor if you overheard him say: 'I have to learn to use the stupid thing, so it might as well be tonight.' Or, 'I worked 16 hours yesterday, went home, had some beer, and before I knew it, I was back here. I don't think I can make it all night.' Or, 'He must have been on drugs last night; he couldn't even read a chart.'"

"Probably not. But such comments by doctors and nurses are common in hospital elevators, said Dr. Peter Ubel of the Center for Bioethics at the University of Pennsylvania.

"Ubel overheard such disturbing remarks by medical personnel in 14 percent of the 259 elevator rides he took in five Pennsylvania hospitals.

"Hospital workers should be aware that their comments may not only violate patient confidentiality but may also treat patients disparagingly, reflect poorly on their profession, or cause other passengers to worry about the hospital's clinical competency, Ubel reported in the *American Journal of Medicine*."

(*Chicago Tribune*, 13 August 1995)

## D-I-Y diagnoses on the information superhighway

"People with home computers can buy any number of programs designed to make it possible for them to diagnose their illnesses. . . . Easy-to-use medical-testing kits, some based on new technologies, are bringing laboratory standards into the home. Cholesterol-testing kits, blood-pressure monitors and pregnancy testers are already commonplace. Within the next year, AIDS testing may be done easily by mail order, with telephone confirmation. Hospital hardware, from intravenous drips to special beds for the elderly, is now readily available to the private shopper.

"Put these trends together with the spread of computerized communications (the 'information superhighway') and it is not so far-fetched to imagine the affluent and wired consumer of a decade hence organizing most of his medical needs from his own

home, . . . dialing up a doctor or hospital or pharmacy only if the need arises."

(*The Economist*, 4 February 1995)

## Family values: "The way we weren't"

"Throughout the nineteenth century, at least as much divergence and disruption in the experience of family life existed as does today, even though divorce and unwed motherhood were less common. . . . Not until the 1920s did a bare majority of children come to live in a male breadwinner—female homemaker family, and even at the height of this family form in the 1950s, only 60 percent of American children spent their entire childhoods in such a family."

(Stephanie Koontz, "The Way We Weren't: The Myth and Reality of the 'Traditional' Family," *National Forum: The Phi Kappa Phi Journal*, Summer 1995)

## Lincoln on abortion?

Many in America believe that the abortion "debate" is actually an abortion standoff, with a limited number of familiar arguments and little thoughtful discussion between opposing sides. George McKenna, in a well-reasoned article, likens abortion to slavery, a similarly controversial institution in our nation's history, and looks to Abraham Lincoln for guidance in addressing the issues directly. McKenna provides a model position for pro-life politicians that reads in part:

Abortion is morally wrong. . . . I will not try to abolish an institution that the Supreme Court has ruled to be constitutionally protected, but I will do everything in my power to arrest its further spread and place it where the public can rest in the belief that it is becoming increasingly rare. I take very seriously the imperative, often expressed by abortion supporters, that abortion should be rare. . . . I will support all reasonable abortion restrictions that pass muster with the Supreme Court, and I will encourage those who provide alternatives to abortion.

McKenna sees this position as "unequivocally pro-life even as it is effectively pro-choice" and a philosophically consistent, if currently

politically incorrect, position for liberal Democrats. His thoughtful contribution can provide a starting place for genuine public dialogue on a highly contentious issue.

(*Atlantic Monthly*, September 1995)

## Uninsured number 43 million

A new report from the Employee Benefit Research Institute estimates that one million Americans lost their health insurance last year, bringing the total number of uninsured Americans to 43 million. Two major causes were loss of employer-sponsored insurance benefits and decreased state spending for Medicaid.

(*American Hospital Association News*, 4 September 1995)

## A different kind of heart disease

Assessing "sickness and health" in this century, columnist Robert E. Burns lists the dreaded diseases that have been overcome and suggests that progress on the physical side has been "nothing short of dazzling." His list of particulars confirms that judgment. And while advancement on the social front is much more a "mixed bag," he still finds that great strides have been made in the United States on labor and civil rights fronts. Still, one pervasive illness has made considerable gains:

A terrible sickness, which like carbon monoxide gas, poisons quietly without raising an alarm. A hardness of heart, sometimes even a meanness that once was considered unbecoming to Americans, seems to have infected all too many of us. . . . We hear, often and disturbingly, "I've got my own problems; let them take care of their own." Increasingly, we're annoyed rather than concerned at the sight of homeless people sleeping on city sidewalks or staggering toward us in search of a handout. We hear, "She got pregnant by herself . . . let her take the consequences."

Burns ponders whether this different kind of heart disease strikes the faithful and faithless equally; he concludes only that self-examination will be the first step toward healing.

(*U.S. Catholic*, September 1995)

Editor Martin E. Marty  
Associate Editor Barbara Hofmaier  
Managing Editor Sandy Pittman  
News Editor Stephen M. Hudson  
Case Stories Editor Arthur W. Frank  
Design/Production Micah Marty  
Publisher Laurence J. O'Connell  
Associate Publisher John F. Taylor

*Making the Rounds in Health, Faith, and Ethics* (ISSN #1082-1015) is published semimonthly, except monthly in July and August, for \$29.95 per year by the Park Ridge Center for the Study of Health, Faith, and Ethics, 211 E. Ontario, Suite 800, Chicago, Illinois 60611. Application to mail at second class is pending in Chicago, Illinois, and additional entry. POSTMASTER: Send address changes to *Making the Rounds in Health, Faith, and Ethics*, 211 E. Ontario, Suite 800, Chicago, Illinois 60611, attention subscription fulfillment. © 1995 The Park Ridge Center. Printed on recycled paper. TO SUBSCRIBE: send a check for \$29.95 per subscription per year (payable to the Park Ridge Center; please add \$20.00 per year for non-U.S. subscriptions) to the above address or call 312/266-2222 to order with Visa or MasterCard.

(continued from page 1)

jects must therefore understand that the primary goal of the research is to obtain scientific data to help future patients rather than to help them. As with all experimental protocols, the patients must also understand the procedures entailed by the protocol, its risks and potential benefits, and the other medical options.

Given the low probability of success and the numerous expected and unexpected complications that can befall the subjects, advance care planning should be part of the informed-consent process. Health care professionals' views regarding when it is appropriate to forgo life-sustaining treatment may differ from those of terminally ill patients, particularly if the physicians are invested in the new treatment's success. Advance care planning will allow the subject, while competent, to determine when the goal of therapy should change from fighting the disease to promoting comfort.

*Is the use of nonhuman primates ethical?* The proposed transplant also raises questions about the ethical justification for using nonhuman primates in research designed to benefit human beings. The distress and other harm to the baboon associated with the removal of bone marrow is significantly less than what many laboratory animals experience. However, the Centers for Disease Control and Prevention and the FDA have requested that the animal be sacrificed to ensure complete storage and archiving of all body parts. This is not a necessary part of the experiment, and the investigators are developing efficient non-lethal methods of harvesting baboon cells to transplant. This obviously would be preferable from the animals' point of view.

If this procedure is successful, there will be a great demand for captive, pathogen-free baboons. Broader ethical issues are raised by proposals to develop colonies of baboons in relatively confined and sterile environments. Because primates have a high level of cognitive and social development, some people question the moral justification for depriving these animals of the opportunity to live out their lives in a natural setting.

*What are the public health risks?* Many scientists are concerned that viruses from the baboon sources could infect the immunocompromised host and then spread into the human population (Allan 1995). Experts believe that the recent Ebola epidemic in Zaire may have begun when the virus was transmitted from a nonhuman to a human primate. One way to avoid this would be to use only disease-free baboons for transplantation. Unfortunately, such animals are impossible to find. A great danger may arise from baboons carrying undiscovered viruses. Unknown pathogens having little or no negative effect on baboons may turn out to be lethal to humans. Moreover, if the effects of such a disease were slow to materialize, the virus might be transmitted to many people before the risk became apparent. This is probably what happened with HIV, the very disease the marrow transplant is intended to treat.

In response to these concerns, the FDA Advisory Committee recommended requiring investigators to ensure that the baboon sources were as "clean" as possible, to monitor and store blood samples from the sources and recipients, and to submit follow-up data to a xenograft registry. Recipients would be asked to limit sexual contact and practice "safe sex." The committee did not address more contro-

versial issues such as whether health care providers should be monitored for disease or whether recipients' liberty should be restricted in any way. Although the recommended measures could reduce the public health risk of xenografts, some undefined risk remains. If the procedure works and becomes more common, the public health risks will become greater as the probability of viral transfer increases. For example, it may be possible to monitor initial recipients intensively, but problems are certain to occur if monitoring is attempted on a larger scale.

Although we do not ordinarily consider risk to the public when reviewing individual research projects, such risks are ethically relevant to this intervention. How does one weigh a theoretical risk to the public against the possible benefit to the recipients? Is it just to expose members of the public to this unknown but potentially serious threat without their consent or awareness? What would constitute consent?

*Who should regulate xenotransplants?* Until now, xenotransplant research has required review by the local IRB only. In this case, the FDA claimed a responsibility to intervene

because the study involves manipulation of cells outside the body and poses public health risks. Despite the fear that national oversight will lead to overregulation and thus stifle research, we believe there is adequate justification for a national review process, analogous to what occurs for gene therapy research. Individual IRBs may lack sufficient expertise adequately to review these proposals; moreover, it would be difficult to assemble numerous local expert committees to perform this task. In the past, IRBs have been ineffective protectors of patients' rights in innovative transplantation research because of the committees' lack of expertise and the tremendous institutional pressure to proceed with the experiments (Fox and Swazey 1992). Finally, given that the public health risks go far beyond the local institution, it makes little sense to allow local IRBs to develop their own policies on this research.

Medicine's plunge into the world of science fiction poses ethical quandaries, which, like the scientific problems that produced them, are unlikely to be resolved in the near future. Xenograft experiments, while offering great potential benefits to patients, risk unleashing new infectious agents. This added risk complicates our traditional research ethics and should lead us to take a careful and cautious approach to xenograft proposals.

## REFERENCES

- Allan, Jonathan S. 1995. "Xenograft Transplantation and the Infectious Disease Conundrum." *ILAR Journal* 37, no. 1: 37-47.
- Annas, George J. 1987. "Death and the Magic Machine: Informed Consent to the Artificial Heart." *Western New England Law Review* 9:89-112.
- . 1992. "The Changing Landscape of Human Experimentation: Nuremberg, Helsinki, and Beyond." *Health Matrix* 2:119-40.
- Department of Health and Human Services. 1993. Protection of human research subjects. 45 C.F.R. [Code of Federal Regulations] sec. 46.
- Fox, Renée C., and Judith P. Swazey. 1992. *Spare Parts: Organ Replacement in American Society*. New York: Oxford University Press.
- Nowak, Rachel. 1994. "Xenotransplants Set to Resume." *Science* 266:1148-51.
- Pennisi, Elizabeth. 1995. "FDA Panel Oks Baboon Bone Marrow Transplant." *Science* 269:293-94.

*Two theological responses to this article appear on page 4.*

## Is it just to expose members of the public to this potentially serious threat without their consent or awareness?



## A Christian Response

Philip Hefner

Three questions came to mind as I read Robert Arnold and Rebecca Dresser's analysis of ethical issues that emerge from the proposal of baboon-to-human bone marrow transplantation. All are theological questions because they push us finally to the most fundamental consideration of what life is about and what place humans have in the scheme of life on planet earth.

1. *What is a species for?* Is it to serve other species, as colonies of pathogen-free baboons would serve us? Is this problematic only because baboons are primates with "a high level of cognitive and social development" and hence deserving of the "opportunity to live out their lives in a natural setting"? Is it really less problematic to colonize cattle and pigs, or to domesticate dogs, for human purposes? By invoking the most humanlike attribute of primates, we argue that only the human species is an end in itself, to serve no other species, because the justification for treating primates differently rests almost always on their similarity to humans. Primates have more

**We realize that God created us in a complex interrelationship with all other living creatures; the qualities that constitute the "image of God" in humans are not in any abstract sense "ours alone."**

independent integrity than cattle because they are more like us.

And what of *Homo sapiens*? Are they never to be subservient to the well-being of other species? I am reminded of an industrial biochemist who suggested that God created the entire biosphere to serve the well-being of humans, since the latter are the only creatures who are created in the image of God. In the same breath he asserted that this is the reason the Word of God became incarnate in a human being, Jesus of Nazareth, because that is where the image of God resides. This is an obscurantist theological judgment in my opinion. In an evolutionary and ecological worldview, we realize that God created us in a complex interrelationship with all other living creatures; we must be cautious in making overly sharp definitions because the qualities that constitute the "image of God" in humans are not in any abstract sense "ours alone."

A further question: Are baboons any less subservient to human purposes if they are exempted from supplying us with "reconstituted" immune systems? An exemption would come only by our decision, and any setting in which they live exists by that same decision and subsequent interventions.

2. *How are species interrelated?* Anthropocentrism and individualism inevitably shape the discussion. The reference to "public health risks" is a statement from the point of view of our species, and it is introduced as a check to the more common individualistic view that the bone marrow transplant is simply a strategy for individuals threatened with death. The public health issue points to a relationship between two species, a relationship marked by

(continued on page 8)

Philip Hefner is professor of systematic theology at the Lutheran School of Theology at Chicago and codirector of the Chicago Center for Religion and Science.

## A Jewish Response

Stacy K. Offner

Robert Arnold and Rebecca Dresser write of the possibility of curing people with AIDS by transplanting bone marrow from the HIV-resistant baboon into the HIV-positive human being. This possibility of cure is a miracle in the midst of an otherwise barren landscape of death, disease, and despair. It is an offering of hope to those who are ill; it allows for the possibility that, at long last, there are people with AIDS who will one day be able to recite *Birkat HaGomel*, the traditional prayer of the Jewish people upon being rescued from great danger.

*Pikuach nefesh*, the commandment to save human life, is paramount in Jewish life and supersedes other commandments if necessary. Nevertheless, ethical issues are raised by the notion of using baboon marrow to save human lives. Interestingly, however, the issues raised in the context of Jewish life differ somewhat from those raised by Arnold and Dresser.

The most compelling question concerns what it means to be human. If baboon marrow can be transplanted into humans, it is important to recognize the future possibility that all human body parts could be replaced by animal parts. At what point would the human being cease to be a human being? The question involves definitions of humanness that go beyond beating hearts and functioning brains. Judaism has always understood the human soul to enter the body at birth. This definition suggests that the essence of a person is not harmed by nonhuman transplantation.

There is also in Judaism a law against the mixing of breeds. It might appear that, on the basis of this law, baboon transplants into humans would be forbidden. However, in the biblical and subsequent literature, it is clear that the prohibition as applied to the animal kingdom refers specifically to the *mating* between animals

***Pikuach nefesh*, the commandment to save human life, is paramount in Jewish life and supersedes other commandments if necessary.**

of different species (*Yoreh Deah* 297 in Freehof 1971:217). Animal-to-human transplants do not create a new species.

Arnold and Dresser ask: "Is the use of nonhuman primates ethical?" The question raises issues about the killing of animals, the raising of animals in captivity, and the treatment of animals in general. The corpus of Jewish law has much to say about the appropriate treatment of animals. Provided that the baboons receive appropriate treatment, and given careful assurance against extinction of a species, Judaism would hold the use of animal parts to be not only justifiable but preferable to the use of human body parts. Rabbi Solomon Freehof, in a discussion of the use of an animal heart valve in a human body, makes it clear that use of animal transplants "would be superior to the present practice of transplanting human heart valves into human bodies" (1971:217).

Ultimately, all five of the issues raised by Arnold and Dresser—

(continued on page 8)

Stacy K. Offner is rabbi of Congregation Shir Tikvah, Minneapolis, Minnesota, and adjunct professor of Jewish ethics, Hamline University, St. Paul, Minnesota.

# The Promise and Peril of Self-Disclosure in Pastoral Care

Barbara Jo Sorensen

Recently while serving as trauma and intensive care unit (ICU) chaplain in a large, urban, religiously affiliated acute-care hospital, I encountered a patient and family situation that had uncanny similarities to my own journey and family of origin. In the course of ministering to that patient and family over the span of a month, I felt compelled to share with them a part of my own experience.

Here I attempt to examine that pastoral encounter in the light of some basic understandings about both chaplaincy and traditional therapy and to explore what it was that compelled me to share part of my own journey. My hope is to convince the reader that judicious self-disclosure in the pastoral care setting can promote psychospiritual healing.

Let me begin by telling you about Mary Ann (pseudonym), her family, and my pastoral intervention.

## Mary Ann's Narrative

Mary Ann arrived in the emergency room comatose as a result of an overdose of psychotropic drugs followed by an automobile accident. She remained in a coma and therefore unable to speak for herself or communicate her own needs and desires during her entire hospital stay. She was 34 years old, single, extremely obese (over 300 pounds), and the second-oldest of seven siblings in an Irish Catholic family in which both parents were deceased.

As family members began to arrive, I discovered that Mary Ann had been in treatment for severe depression for four months preceding this incident. Her self-inflicted injuries were extremely critical and potentially lethal. She was intubated (put on a ventilator) and admitted to the ICU, where she was treated aggressively.

Her injuries involved almost all of her organ systems—kidneys and liver, brain, lungs, bones, and skin—and involved the care of many specialists—an internist, trauma surgeon, nephrologist, neurologist, pulmonary specialist, and orthopedist. There was confusion and at times conflict among these specialists about who was in charge of the case, that is, who was the primary physician with decision-making responsibility. They also expressed radically different understandings on three major issues: (1) benefit versus futility of treatment, (2) the capacity of Mary Ann's body to heal, and (3) her potential for quality of life. The medical complexities, the conflict among the physicians, and the patient's young age created chaos and emotional strain for her day-to-day caregivers and for Mary Ann's five brothers and one sister, who began to come in from all over the country within a day of Mary Ann's arrival in the ICU.

About two weeks into Mary Ann's hospitalization, the family requested an informational conference with all of the treating physicians. They were getting mixed messages from different doctors and were genuinely confused about Mary Ann's prognosis. They were in the midst of a deep and painful struggle to decide whether to continue to allow their sister to be treated aggressively. By now, Mary Ann

was also on kidney dialysis and had gangrene, which would need surgical intervention to prevent sepsis—a life-threatening systemic infection.

The end result of the conference was more confusion than resolution. The family appeared to be overwhelmed by all the men (in this case all the physicians were male) wearing white coats standing against one wall while family members were seated at a conference table. I made several attempts to have the doctors sit with the family to achieve a feeling of partnership. But, even though there was ample seating, the physicians (following the lead of the coordinating physician-ethicist) chose to stand, arms folded across their chests, responding with medical jargon to the timid questions of family members.

After the physicians left the conference room, I stayed behind with the family to help sort out the issues and to translate some of the medical jargon. Eventually the discussion led to what Mary Ann would want if she were able to speak for herself at this moment. Mary Ann's siblings, like the physicians, differed radically in their perceptions of her capacity to heal and have a worthwhile existence. The oldest brother, an assertive man who assumed the role of spokesperson, had not seen Mary Ann for seven years. A couple of the other brothers had not seen her for three or four years. Jean, the only sister, lived with Mary Ann and felt she knew Mary Ann well. Unfortunately the sister was also the youngest sibling and had the "smallest" (least-valued) voice in this family gathering. Mary Ann had no living will or power of attorney. As far as anyone knew, she had never discussed end-of-life issues or whether or not she wanted machines to sustain her life.

It was in the midst of this postmedical conference with the family that I chose, quite deliberately, to share with Mary Ann's siblings a piece of my own journey. The decision to speak out of my own experience came after a statement by the oldest brother: "[Mary Ann] has been depressed for such a long time. This suicide attempt was a clear, though nonverbal statement from her about what she wants. I don't think we should interfere with what she wants. I think we should tell them we want them to turn off the respirator. Even if she can recover from her physical injuries, she will never be happy. She will never be able to have a normal life."

## The Chaplain's Narrative

When I first became aware of Mary Ann's admission to the ICU, her diagnosis, and her family configuration, my heart literally skipped a couple of beats—after which it began to beat faster. The similarities between what was happening before my eyes and my own experience some 15 years earlier were almost eerie. What was even more remarkable to me was that as the ICU chaplain I was being called on to walk a short piece of this journey with this family and with the medical staff. I had the very real sense of being called to be in that place at that particular moment. I experienced grace. I believed it was more than coincidence that led me in my pastoral care ministry to that particular

I had the very  
real sense of being  
called to be in that  
place at that  
particular moment.  
I experienced grace.

*Barbara Jo Sorensen is coordinator of spiritual care services for the Visiting Nurse Association of Wisconsin, Milwaukee, and is a fellow of the College of Chaplains. She has worked in the pastoral care setting for eight years.*

family. Pausing to regroup spiritually and mentally, I prayed that my own journey would allow me to be sensitive to this family's issues in a special way, and I prayed for wisdom and courage.

Simultaneously, I feared I was almost too close to the situation. That very identification might block my capacity to be an effective caregiver. It was with some trepidation that I went forward, relying on my pastoral care training, Divine Light, and a capacity for honest self-reflection.

I too had been in an intensive care unit, ventilator dependent, in another hospital in another city when I was 34 years old. Following the ingestion of a large amount of psychotropic drugs, I had been clinically dead (meaning I had no respirations or heartbeat) and had been resuscitated. I too had been in treatment for depression for a long

**When I first saw  
Mary Ann alone,  
my eyes filled with  
tears as I took and held  
her hand. The tears  
welled up and ran  
down my cheeks as  
I remembered the  
profound pain of  
not wanting to live.**

time—years more than Mary Ann. I had five brothers and one sister, and while not Irish, I was born and raised Catholic. I too was second in birth order and have a sister who is the youngest in the family and whose voice is the least valued.

When I first saw Mary Ann alone in her ICU glass-enclosed cubicle, my eyes filled with tears as I took and held her hand. The tears welled up and ran down my cheeks as I remembered the profound pain of not wanting

to live. I wondered what in Mary Ann's life had brought her to this moment. Though she was comatose and unable ever to speak with me, I stroked her forehead, which was warm and moist, and leaned over to let her know that she was not alone. I said that I was sorry her life was so painful that she wanted to die. I told her I knew what it felt like to want death more than life. "I have been where you are now and I understand how bad that feels." Holding her hand alone in the ICU for a few more moments, I said goodbye and told her I would come back again. She did not respond in any perceptible way, but studies have shown and I am convinced from experience that people do hear and are aware at some level of what is happening to them even while they are unconscious or in a coma.

## Sharing My Story with Family Members

When Mary Ann's oldest brother expressed his belief that the family should honor her wishes as expressed nonverbally in her suicide attempt, I felt I could remain silent no longer. It was not a matter of making a plea for Mary Ann's life, because at this point I was fairly convinced that she would succumb to her physical injuries or, at best, remain in a coma.

I chose that moment, two weeks into this month-long process, to share a small piece of my own journey, because it seemed important that Mary Ann's siblings be clear about their decision and the factors influencing their thinking. Before speaking, I mentally sat back for several moments and asked myself some questions about the strong feelings I was experiencing.

What did I hope to accomplish by sharing with them? Whose needs would be served by such sharing? Additionally, I was aware of feeling fearful . . . fearful that sharing my own journey through emotional illness would fall on unresponsive, condescending, disdainful ears and that I might therefore lose all capacity to function effectively with them as a professional. There always is a risk in sharing such intimate material. Deciding if the benefits to them were worth the risk to me was part of that mental process.

The family members and I were still seated at the conference table in the room where the earlier meeting with the physicians had occurred. I felt a lump in my throat as I began to speak. At that moment I was aware of strong, negative feelings toward the older, spokesperson brother. My experience of him over the past two weeks was that he was insensitive, judgmental, and eager to hurry the process along so he could get on with his life. Mary Ann was an embarrassment to him. Mary Ann's brother seemed to want to wash his hands of the whole messy business and be done with it. Pushing aside my fear and dislike, I began to speak.

I am going to take a risk here. I don't often do this, but I want to tell you a little bit of my story. I was once in a position almost identical to Mary Ann's. I was in an intensive care unit close to death, and I suffered from depression as she does. But I am here today—happy, whole, and healthy. I'm telling you this because I want you to know that it is possible for people to feel so depressed that they try to kill themselves and to recover despite that. I'm telling you because four months is not a long time to struggle with clinical depression—I struggled for many years and eventually overcame it. It is possible with love and support from friends and family and with professional care to overcome even horrendous bouts of clinical depression. I believe that where there is life there is hope, and the potential to heal and to seek life exists in all of us while we still breathe. I'm telling you this because I hope you won't make your decision about her continued care based solely on whether you believe she can recover from her profound depression. I don't know if she can recover from her physical injuries. They are extremely critical and life threatening as the doctors just told us. All I want you to hear is that her emotional injuries, her deep pain, do not have to be terminal. If she could recover from her physical injuries, and that's a huge if, she could also potentially recover from her depression.

The oldest brother shot back angrily, "Don't tell us that. We don't want to know it. That only confuses the issue. That doesn't help."

Hearing those words and the energy with which they were conveyed made me instantly wonder if I had judged wrongly about the efficacy of sharing my journey. The other four brothers simply looked down at the table. Mary Ann's sister looked at me with tears in her eyes, nodded affirmatively, but said nothing.

As the family continued to struggle with their decision in the 13 days that followed that interchange, the oldest brother never made a single reference to that conversation nor were there any further references to Mary Ann's psychological state. In conversations with me or the medical staff, the family discussed only the physical and biological things that were happening to Mary Ann's body. These became the basis for their day-to-day struggle. This suggested to me that sharing my story had allowed them to shift from seeing Mary Ann's death as something "she wanted" to seeing it as something tragic. I continued to minister to them and was with them at the bedside shortly after Mary Ann died on the 29th day of her hospitalization. We prayed and wept together. Mary Ann's family was never able to come to a consensus on whether they should request that she be taken off the respi-

rator. Instead they made a decision not to go forward with the surgery to amputate her gangrenous right hand. They verbalized their full understanding that if the hand were not amputated, systemic sepsis would cause Mary Ann's death. And that is in fact what happened.

## Analysis of the Interchange

I will never be certain about the path of openness and mutuality I chose with Mary Ann's family. Because of the intensity of the eldest brother's response, I never pursued the issue further. His anger made me wonder if I had chosen correctly.

Following that conversation there were subtle differences in how the eldest brother related to me. He became more willing to deal with me and utilize my intervention, as evidenced by his asking direct questions of me or asking for my help communicating with the medical team. Before that, he had merely tolerated my presence. Other family members, particularly Mary Ann's sister, were more open to my ministry from the beginning.

One of the goals in sharing with them was to help them see Mary Ann in more holistic terms—as mind, spirit, and body. Prior to my self-disclosure, the family was predominantly focused on her depression, her capacity to recover from it, and her potential for a life free of emotional pain. The family's shift in focus from Mary Ann's psychological condition to her physical condition seemed more appropriate to her clinical situation.

In retrospect I can say that given my strong identification with this patient and her family, it would have been wise to seek the counsel of a colleague or supervisor before the moment of sharing arrived. The sharing arose out of the moment, however, and was not anticipated or planned.

## Reflections

It is as a healed wounded healer who has reflected extensively and deeply on my own journey and who has succeeded in transforming that journey into a creative and vital ministry that I have offered this reflection on the role of self-disclosure in this case and others like it. As I see and experience pastoral care ministry, ministering out of one's own journey can be one part of an authentic and mutual healing relationship in the pastoral care setting.

Pastor and psychologist Robert Randall believes that the judicious use of self-disclosure offers some promise for healing and is possible for caregivers "whose selves are experienced as cohesive, vital, and harmonious. A healthy self is that essential psychological base from which pastors are able to reach out marvelously beyond their own views and hurts with an embracing empathy for others that is of salvation's very essence" (1988:13). Teacher of pastoral psychology Edward Wimberly names self-disclosure a "pastoral technique." He believes that "stories from the pastor's life and experience which have been so sufficiently worked through emotionally that the pastor can tell them without fear . . . can be the source of another's healing" (1991:82).

Carter Heyward, in her prophetic and at the same time problematic book *When Boundaries Betray Us* (1993), has something to add to this conversation. She suggests, "it is time for women clinicians, clergy, and other practitioners to start exploring together how we might act differently—more mutually, more as co-subjects—in our work." She calls for an exploration of the implications of "radically relational psychological, theological and ethical theory for the actual practice of both ministry and psychotherapy" (1993:146). While Heyward

addresses her remarks to women, I would like to suggest that such pastoral or therapeutic relationships based on authenticity and mutuality are appropriate for anyone so engaged.

Unlike Heyward, I believe there are and must be limits to mutuality within pastoral and therapeutic relationships. Used injudiciously, indiscriminately, or in an unexamined manner, the peril of self-disclosure is that it will impede healing or at best serve only the caregiver's own needs. Further, such use of self-disclosure violates the very mutuality and right relationship that the sharing attempts to gain. Rather than achieving identification and a sense of "you understand because you've been there," it places the recipient in the position of needing to care for the caregiver!

The problem of self-disclosure is created by what we understand as the traditional therapeutic stance, one of distance and objectivity, or as professor of practical theology Don Browning puts it, one of "abstinent, yet interested attention" (1966:141). Traditional therapy presents a power-over model. I advocate a power-with model.

In my pastoral care practice over the years, I have developed some personal guidelines for sharing from my own journey. They are gleaned from my formal clinical pastoral education training and from experience. Before choosing to self-disclose, I have found, I should step back from the situation and ask myself these questions:

1. What is the self-disclosure about?
2. Will it help the situation?
3. Am I simply identifying with the person?
4. Whose needs are being served by this self-disclosure?

It is important to be very clear about what my motives are and whose needs are being served. If each of the above questions can be asked and answered with honesty and some measure of objectivity, then self-disclosure can be appropriate. If possible, I recommend seeking the guidance of a supervisor, peer, or mentor before proceeding.

Out of my experience, I offer the following tentative claims: First, that within what I call necessary but not inhibitory boundaries, sharing out of the depths of my own healing and journey can be and often is life giving when used appropriately; and second, that as healer and pastoral caregiver, I also am healed when I am being my most authentic self. It is the combination of healing and at the same time being healed that to me implies a basic mutuality. That mutuality is what I understand pastoral care ministry to be about.

## REFERENCES

- Browning, Don S. 1966. *Atonement and Psychotherapy*. Philadelphia: Westminster Press.  
Heyward, Carter. 1993. *When Boundaries Betray Us*. San Francisco: Harper.  
Randall, Robert L. 1988. *Pastor and Parish: The Psychological Core of Ecclesiastical Conflicts*. New York: Human Sciences Press.  
Wimberly, Edward P. 1991. *African American Pastoral Care*. Nashville: Abingdon Press.

*To our readers: If you have a story about self-disclosure by care providers or a response to Sorensen's article, we invite you to share it with us. We will include selections from readers' responses in a future issue.*

**Used injudiciously,  
indiscriminately, or in  
an unexamined manner,  
the peril of self-disclosure  
is that it will impede  
healing or at best serve  
only the caregiver's  
own needs.**



## Inside: Baboon-to-Human Transplants • Self-Disclosure in Pastoral Care

### **Baboon-to-Human Transplants: A Christian Response** (continued from page 4)

interdependence and danger. The baboon has the potential to be of another species, but this potential is defined and realized only by the efforts of members of that "other" species. Is this potential of baboons any less the result of manipulation by humans than the potential of cattle to feed humans? Humans, in turn, are shown to be dependent upon another species for the reconstitution of something so significant for well-being as an immune system; but this dependence is made real only when the beneficent baboon species is made dependent in its actual living conditions on the recipient human species.

The interrelationship between species is given a new quality by the bone marrow transplant issue. In a sense the two species become one biotic commonwealth, in which certain undesirable immigrants, in the form of pathogenic viruses, do harm only when they become naturalized citizens in the domain of the other species. The public health risk demonstrates that what is at stake here is not just a manipulation to cure humans of a disease but the interrelationships of species within a larger biospheric community. Neither man nor any species is an island; every one is a piece of the continent (to paraphrase John Donne).

3. *What are the limits of our attempts to cure diseases in humans in order thereby to prolong their lives?* Must we not simply accept that dying is a part of the life of every species and individual, even when that death comes too early and is the consequence of evil,

unfairness, or accident? To what extent is the baboon-to-human transplant a strategy to cure disease and enhance human well-being, and to what extent is it a strategy of denying death? Christian faith holds firmly that death is not an end to be feared—"whether we live or whether we die, we are the Lord's" (Romans 14:8).

Obviously, these questions allow no easy, unambiguous answer. Nevertheless, they must be asked, and even an unsatisfactory response to them is wholesome if it is rendered in full awareness of why the questions are necessary. In this full awareness, the theological character of these questions, which I have left implicit in these brief reflections, becomes clear.

### **Baboon-to-Human Transplants: A Jewish Response** (continued from page 4)

use of human clinical trials, adequate informed consent, use of nonhuman primates, public health risks, and regulation of xenotransplants—speak to the tension between two values articulated in Judaism: the value of *pikuach nefesh*, saving a life, and the value of safeguarding the sanctity of the human being. When weighing these values against each other, one must be cautious but always bear in mind the talmudic dictum that nothing must stand in the way of saving a life (tractate Yoma 82a).

#### REFERENCE

Freehof, Solomon. 1971. *Modern Reform Responsa*. Cincinnati: Hebrew Union College Press.