Efforts to increase organ donation were in the news again recently, with the American Medical Association (AMA) calling for a pilot study to assess whether incentives would increase people's willingness to donate organs. At the same time, an article I co-authored in the New England Journal of Medicine argued for new thinking about whether incentives for organ donation are appropriate. All the writing and policy considerations are being driven by the widening shortage between the need for organs for transplant and the number of organs donated after people die. So how should we think about increasing the rate of organ donation?

Even after all the efforts at increasing donation through education, the many campaigns and programs haven't been terribly successful, and the overall rate of organ donation after death has remained relatively constant over the last few years. The problem is that the need for organs continues to grow, meaning longer waiting times for transplants. One proposed solution is so-called presumed consent, a practice in which organs are collected after death unless individuals or families object. Such an approach has never been tried in the U.S., and is unlikely to be acceptable in a country where citizens expect that their permission will be sought for anything even remotely invasive of their privacy and certainly of
ethics consultations. A misguided soul may lead to destructive hubris like the Nazi bioethic of racial hygiene that convened ethics committees to authorize murdering disabled persons.

A soul for Bioethics? Why bother? Most bioethicists are humane and likable. They are accountable in their own way to the norms and aspirations of professions like teaching, clinical care, and law. Isn’t it enough to evaluate Bioethics by its works? Bioethics has taught well, proposed good policies, improved its earlier work, and taken on new issues. It has improved the care of dying persons and proposed worthy laws such as those barring genetic discrimination. Perhaps, we should just let bioethicists tend to their own souls. Even so, inspecting Bioethics’ soul might illuminate neglected aspirations or acts of omission to inform future work. There is such an immense smorgasbord of bioethics issues. Bioethics deftly uses its utensils of fairness, respect for persons, and respect for moral differences to handle our chosen repast, but it is easy to be a picky eater at a big smorgasbord. Bioethics needs a balanced diet to be healthy.

The Soul in Bioethics: “Metaphysician, heal thyself?” Healthy soul-tending defies easy definition. A soul’s stature arises from its grounding in a community’s most profound moral vision. In Christianity, souls belong to individuals though there is a collective moral identity that reflects the broader commitment of the moral community. Bioethics speaks of the moral commitments of a physician-as-physician. A physician who ignores such commitments might be said to lack the soul of a Physician. Can we say that same about bioethicists-as-bioethicists?

Historically, the ‘care of souls’ refers to holistically promoting spiritual, mental and physical well-being. It stressed a harmony between the course of one’s life and the health of the soul. The last century has shaken the foundations of soul. Global culture has eroded western parochialism. Existentialism and post-modernism hammered the foundations of values. After the destruction wrought by the secular religions of fascism and materialism, some psychiatrists trumpeted the need for soul. In 1933, Carl Jung’s widely read Modern Man in Search of a Soul argued that the loss of a sense of meaning lay beneath much personal psychic pain and pointless violence in modern culture. Viktor Frankl’s popular 1946 work, The Doctor and the Soul argued the controversial proposal that physicians must tend to the soul of patients by fostering belief in meaning.

It’s hard to imagine a book called The Bioethicist and the Soul emerging from this generation of Bioethics. ‘Boomer’ Bioethics is reticent about its fundamental moral commitments. The thirty-year-old Hastings Center says that it “addresses fundamental ethical issues in...health, medicine, and the environment as they affect individuals, communities, and societies... [and helps public and private policymakers]...in analyzing the ethical dimensions of their work.” The American Society of Bioethics and Humanities is similarly reserved. Recent ethics consultation standards point to improving medical care and then it identifies essential knowledge and skills for facilitating moral consensus. Statements of conscience by the feisty writers of PEN or brave Turkish physicians resisting medical torture show professions’ souls that are accountable to stern gods.

There is disingenuousness about Bioethics’ reticence towards its moral commitments. During the 20th century, Bioethics’ commitment to personal choice enabled it to provide (sometimes unwelcome) leadership. It found in this commitment, the duty to promote respect for patient choice—even those that were socially controversial. It has promoted this value to change public policy on consent to treatment and the use of human subjects. This is a value, not the annihilation of value.

In what shape is Bioethics’ Soul (if it exists)? There is no point in discussing Bioethics’ soul if Bioethics is simply analytic work. By so defining itself, Bioethics would be limited to teaching, technical analysis, mediation, and research. This would be an ironic limiting for a discipline with such an ostentatious name. It would certainly seem to stifle the articulation of new commitments. It may even erode Bioethics’ canonical commitment to respecting autonomy if a skepticism about new commitments is taken to mean that prior commitments were improperly taken. Bioethics’ sense of its mortality may lie in awareness of this kind of finitude. Can a cautious middle-aged profession enter the new millenium in hope of articulating a moral vision without trying to found a church?

If Bioethics has a soul, is that soul healthy? On first inspection, Bioethicists’ enthusiasm for their work and respect for diverse moral visions suggests so. A closer look at what we have chosen from the smorgasbord is worthwhile. Bioethics writes a tenth as often on the 45 million Americans who are uninsured as it does on the care of the two million persons who are dying each year. In the last decade, Medline lists 300 Bioethics articles on assisted reproduction, 100 on gene therapy and less than a dozen on health care ethics facing two million prisoners in the United States. There is robust work on gender, but little on the poor, communities of color, or
Faculty Profile
Steven Miles, MD

Steven Miles, MD, began his career in bioethics as a Medicine Resident at Hennepin County Medical Center in the late 1970s. His widowed grandfather was dying of prostate cancer with painful bone metastases and refused to go to a nursing home or hospital. There were no hospices. His oncologist would not make home visits and his grandfather was in too much pain to go to a clinic. Dr. Miles was reluctantly pressed into a medical role with his grandfather. A search led him to the English hospice literature and a description of the “Brompton’s cocktail,” a now obsolete palliative elixir of alcohol, morphine, thorazine, and cocaine. He persuaded the hospital pharmacy to compound the mixture and arranged for aides that the family hired to regularly administer it. His grandfather’s suffering dramatically decreased even though several aides (subsequently fired) took some for themselves. This first-hand experience with end-of-life care shaped his career in bioethics.

A year later, Dr. Miles saw the notation “DNR” chalked in on the resident’s signout board as medical care was turned over to the night call team. Steve and Dr. Ronald Cranford wrote a hospital policy for using this order, which was widely disseminated in the medical literature and health facility policies.

Today, Dr. Miles is a Professor of Medicine at the University of Minnesota Medical School. He is an internist and geriatrician and on the faculty of the Center for Bioethics, the Graduate School, and the University Council on Aging.

Dr. Miles has served as President of the American Association of Bioethics and the Board of the American Society of Law, Medicine, and Ethics. He received the Distinguished Service Award from American Society of Bioethics and Humanities for his leadership and work to create the Society.

His bioethics work focuses on end of life care, reducing restraints in nursing homes, and improving access to health care. He is most proud of the role he played as President of Minnesotans for Affordable Health Care, a group instrumental in passing MinnesotaCare: the model for the federal CHIP program that expanded insurance for working people and children. He has worked in refugee care for twenty years with the American Refugee Committee for whom he directed medical services at a Cambodian refugee camp of 45,000 persons. He is currently co-coordinating an HIV prevention program in Sudan, and chairs the research committee of the Center for Victims of Torture.

He has just finished a book examining the meaning of the Hippocratic Oath in its own time and hopes to have this published in late 2002 or early 2003.

Selected Publications:

Book
Miles S. Oath: How the Greeks Invented Medical Ethics, Oxford University Press, forthcoming.

Articles


their body. If education programs offer limited promise, and presumed consent is unlikely to be accepted, we are left looking for ways to give families additional incentive to be altruistic when faced with the decision about whether to donate organs.

The question is what form such incentives ought to take. Direct payment is unacceptable under federal law, motivated by two types of ethical concerns. First is the potential for exploitation of families for whom even a small payment may be so enticing as to make them ignore their concerns about donation of a loved one’s organs. Second, allowing a true market in organs would not only create the potential for exploitation, but would make for inequitable distribution of organs, since those with greater ability to pay for organs would get first access to them—violating the sorts of fair allocation we require for the distribution of other scarce public resources.

What we need to work towards are mechanisms that recognize the family making the decision to donate their loved one’s organs and that foster the altruism that such donations entail. This might include donations to the charity of the family’s choice or other incentives that aren’t direct financial payments to the family. Whatever the additional incentives, recognition of family’s with awards, plaques and ceremonies would go a long way toward making clear that their altruism is both valued and appreciated. What any incentive program needs to avoid is the practice or perception of paying for organs, and in the process creating a policy that turns body parts into a commodity.

Even if the most thoughtful approaches were adopted, what would be the impact on society of incentives for organ donation? Would they increase interest in, and willingness to donate, or decrease public support for a system that seems destined to treat organs as part of a free market? Pilot studies like those proposed by the AMA can help provide answers to these questions. But whatever the outcome of such research, the goals of any incentive programs must be to recognize families whose altruism is the foundation upon which organ donation is predicated, and in so doing preserve the sense that organ donation is truly a gift of life.

A version of this article appeared in Dr. Kahn’s column, “Ethics Matters” which appears bi-weekly on CNN.com

“"A Follow-up on African Genealogy & Genetics conference”

By Steven Miles, MD

The Center for Bioethics hosted a conference on the science and ethics of exploring African American Genealogy that was an extraordinarily successful and moving collaboration with a community group serving a disadvantaged, multiracial urban neighborhood. The conference featured national and local speakers, and poster presentations from children in the neighborhood.

Conference proceedings are now being prepared for website posting and publication. Visit the Center’s website at www.bioethics.umn.edu.

The Center for Bioethics, University of Minnesota, and the Phillips/Powderhorn Cultural Wellness Center gratefully acknowledge the generous support of the partners and funders for this conference:

Allina Foundation
Community Action of Minneapolis
The Greenwall Foundation
Insight News
McFarlane Media Interest, Inc.
The Minneapolis Foundation
National Institutes of Health
University of Minnesota: Office of Continuing Medical Education; Roy Wilkins Center for Human Relations and Social Justice; Humphrey Institute of Public Affairs; Medical School Office of Minority Affairs
Continued from Page 2

migrants. A handful of articles probe the relationship between bioethics and human rights. There is a large body of work on research ethics in poor nations but much less on such countries’ access to biotechnology, health aid, or on economic sanctions that interdict medicines and public health supplies.

This selectivity suggests a partial moral vision. Bioethics earned its respect based on its forthright commitment to a particular moral relationship between biosciences and the individual. Bioethics is muted about the moral relationship between the biosciences and the community.

This critique of American Bioethics is too harsh. Some bioethicists have engaged issues of social justice and community. Some bioethicists help health societies and policymakers address communitarian issues that are marginal to the field’s main interests. Even so, we are quite beholden to our sponsoring institutions and national culture. Politicians, not bioethicists, ensconced in health centers, condemned the practice of dumping patients from hospitals. American Bioethics partly reflects a national culture in which respect for liberty often eclipses a sense of social justice. Bioethicists’ substantial focus on issues like genetics or new reproductive technologies over issues like unaffordable health care reflects this culture. We are analytically fair in discussing the issues we choose to address but less so in the choices themselves.

Bioethics Soul: 2020. In 2020, the Boomer Bioethics will leave this profession to its heirs. In what shape will they find the soul of Bioethics? Bioethics’ reticence about the moral relationship between the biosciences and the community feels like a choice that has been deferred rather than one that can be avoided.

Threats to community. Bioscience is part of the widening gap between the rich and poor in the United States and between developed and underdeveloped countries. American Bioethics has been remiss in not trumpeting the distinguishing moral failure of our health care system to assure universal access to health care. Costly new bioscience products to enhance physical or cognitive status will increase the life opportunities for the privileged compared to those who are less fortunate. The just allocation of these technologies must be addressed.

Threats to the biosphere. Nuclear weapons were the first technological threat to human culture. Global warming poses a comparable threat to the biosphere. The dissemination of genetically created life-forms requires the exercise of another kind of global responsibilities for the biosphere. Here too, a substantive moral vision, perhaps as Jonas proposed in The Imperative of Responsibility: In Search of an Ethics for the Technological Age.

Wars against public health. Biosciences are the core of biological and chemical warfare. The titered application of economic sanctions to obstruct access to medicines, health expertise, and supplies needed for public health systems directly targets public health of civilians.

The most daunting challenge to Bioethics is not the 21st century issues themselves but whether it will shoulder its responsibility to articulate values to engage these issues. Bioethics must consider articulating a moral commitment that is as relevant to the societal issues of the new century as the autonomy ethic Bioethics brought to bear on the personal issues of the last century.

American Bioethics may choose otherwise. It may continue to focus on patient rights and keep communitarian ethics at its periphery. This option marginalizes bioethics into its past. It may teach, analyze, research, or mediate on the new issues without articulating a moral center for the shift from personal to societal issues. This option courts analytic sterility. It may simply assert that its professionalism is the professional virtues of its constituent teachers, clinicians, and lawyers. This option disaggregates the field into a multi-disciplinary interest group without a coherent, unifying professional moral center of its own.

Bioethics found its earlier commitment to respect for individuals in its partnership with the clinical community. This history suggests a path for the future of Bioethics. First, it could collaborate more closely with lay groups, non-governmental agencies, the international organizations, and civil rights groups. Second, Bioethics must remedy its own conflicts of interests with regard to corporate, academic, and governmental sponsors who are profoundly shaping the bioethics agenda. Third, American Bioethics must create stronger relationships with Bioethics communities in other countries to address the parochialism of the American moral vision, especially with regard to global concerns.

“Soul” is a way of speaking about the struggle to live a morally aware and accountable life. In facing the issues of this new century, Bioethics is more likely to flourish by articulating commitments that address communitarian concerns. Souls can survive, even flourish, in doubt and debate. They can be extinguished by a nihilistic skepticism. Death occurs when the soul leaves the body. The same holds for this middle-aged profession facing its second 50 years.
Calendar of Events

**Jul 27**
Jeffrey Kahn, PhD, MPH, will speak on “Little Cells, Big Issues: The Ethics of Stem Cell Research” at the Aspen Allergy Conference, sponsored by the Given Institute of Pathobiology, Aspen, CO. For information, call 303-282-0491.

**Jul 30**
Jeffrey Kahn, PhD, MPH, will speak on “Ethics, the Human Genome and Stem Cell Research: Where We Are and Where We’re Going” at the Seventeenth Annual ROSE Seminar, sponsored by Reinsurance Outcomes and Service Experts, St. Paul, MN. For information, call 651-486-7515.

**Sep 13**
Jeffrey Kahn, PhD, MPH, will speak on “Biomedical Ethics of Genetic Testing and Pharmacogenetics” at the Annual Spang Family Lectureship, sponsored by the St. Mary’s/Duluth Clinic Health System, Duluth, MN. For information, call 218-786-3854.

**Sep 19**
Jeffrey Kahn, PhD, MPH, will speak on “Ethics of Living Donors and Non-Heartbeating Donors Transplantation” at the 5th International Congress on Lung Transplantation, Paris, France. For information, call the Department of Pulmonary Medicine, University of Minnesota, 612-624-0999.

**Sep 23**
Carl Elliott, MD, PhD, will participate in a colloquium, “Perspectives on Medical Ethics” for the Boston University Colloquium on Philosophy of Science. For information, call 617-353-2604.

**Sep 24**
Jeffrey Kahn, PhD, MPH, will speak on “The Role of Institutional Rules, Guidelines and Education in Promoting RCR” at the Office of Research Integrity Conference, Philadelphia, PA. For information, call 301-294-5534.

**Oct 18**
Carl Elliott, MD, PhD, will speak on “Amputees by Choice” for the Medical College of Wisconsin’s “Ethics for Healthcare Psychologists Program.” For information, email: molson@mcw.edu

**Oct 24**
Jeffrey Kahn, PhD, MPH, and Carl Elliott, MD, PhD, will participate at the American Society for Bioethics and Humanities (ASBH) Annual Meeting, Baltimore, MD. Jeffrey Kahn will speak on “Ethics in Public Health: A New Curriculum” and Carl Elliott will participate in a panel on “Self-Creation and Bioethics.” For information, visit www.asbh.org.

**Nov 12**
Jeffrey Kahn, PhD, MPH, will speak on “Ethics in Public Health: A New Curriculum” at the American Public Health Association (APHA) Annual Meeting, Philadelphia, PA. For information, visit www.apha.org.

**Nov 22**
Joan Liaschenko, RN, PhD, will speak on “At Home with Illness” at the Ethical Challenges in Home Care Nursing Conference, sponsored by the University of Levy, Quebec, Canada. For information, call 612-624-9440.

**Feb 20**
“The Limits of Personal Privacy: Biomedical Information in Public Health, Population Genomics, and Mass Disasters,” sponsored by the Joint Degree Program in Law, Health & the Life Sciences, Consortium on Law and Values in Health, Environments & the Life Sciences University of Minnesota Law School; Center for Bioethics and School of Public Health, University of Minnesota. For information, visit www.jointdegree.umn.edu.

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**Hold the Date – October 16-18, 2002**

“Medicine/Culture/Power: Medical Anthropology at the Beginning of the 21st Century”

The University of Minnesota Department of Anthropology will convene a conference exploring the contemporary challenges of practicing and understanding medicine.

Registration and more information at www.cla.umn.edu/anthropology/medical2002.

Sponsors: University of Minnesota, Department of Anthropology, Academic Health Center, Center for Bioethics, Office of the Executive Vice President and Provost, Institute for Global Studies Humanities Institute, College of Liberal Arts, Consortium on Law and Values in Health, Environment & the Life Sciences.
Reading Packets

Center packets contain an overview of legal and ethical issues, key articles, and an annotated bibliography.

**No. 1:** Organ Transplantation (August 1997)

**No. 2:** Withholding or Withdrawing Artificial Nutrition and Hydration (July 1997)

**No. 3:** Termination of Treatment of Adults (September 1997)

**No. 5:** Distributing Limited Health Care Resources (April 1997)

**No. 6:** Resuscitation Decisions (June 1997)

**No. 7:** The Determination of Death (May 1997)

**No. 8:** New Frontiers in Genetic Testing and Screening (August 1999)

Annotated Bibliography

Ethical Issues in Managed Care (1997) — articles addressing ethical issues in managed care.

Reading packets are available for $5 each. All orders must be prepaid. To order, make checks payable and mail to:

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