The Role of Bioethics and Access to US Health Care:
Is Bioethics one of Kitty Genovese’s neighbors?

By Steven Miles, MD

At a recent conference discussing ethicists’ role in the health care system, an audience member said that his rabbi had dismissively defined a medical ethicist as a person who gets called to rationalize turning off life support. Though medical ethics is much broader than end-of-life care, there is a dramatic contrast between ethicists’ extensive work on the problems, theory and practice of limiting treatment at the end-of-life and its modest contribution to the problem of securing access to health care. This is a grave problem for the field.

Access to health care in the United States continues to deteriorate. Between 1989 and 1995, our expanding economy should have insured 10 million more persons. Nevertheless, four percent more Americans under age 65 lost insurance. Most of this decline was due to employers dropping coverage of children and non-working spouses. At the same time, employers continued to cut benefits, drop employee health coverage altogether, and ask employees to pay a greater (and less affordable) share of increasing health premiums. In January, President Clinton lamely proposed to insure five of our ten million uninsured children. Last month, Congress would not tax cigarettes to insure them all.

The new federal budget agreement also cuts Medicare growth; the consequences of this cut will be magnified by our rapidly aging population. And yet, we are a rich nation that spends far more on health care than any other nation.

The consequences of not providing insured health care to all persons are increasingly clear. Our patchwork system contrives elaborate systems to bounce people with health care needs around to shift the costs of illness; these procedures are costly additional barriers to health care. Access to preventive services and health maintenance is impeded. Hospitalizations are longer, more costly, and more dangerous. Our failure to provide universal health insurance injures and kills more people each year and diss’s personal autonomy and justice more profoundly than “futility” policies could ever do. According to the 1995 MEDLINE, three times as many medical ethics articles focused on futility (123) as on the medically uninsured or health services accessibility (44). The lack of universal health insurance is the major and distinguishing moral failure of the US health care system. This failure belongs to our nation.

The New Politics of Apology

By Jeffrey Kahn, PhD, MPH

It has been said that “To err is human, to forgive, divine.” Somewhere between erring and forgiveness lies apology. We are taught the value of apology from the time we are young, both as a way of taking responsibility for our actions and to concede when those actions are wrong. Apology gives us the chance to make up for our wrongs and to start fresh with those we’ve harmed or offended. The traditional formula of apology — wrongdoer apologizes to victim — is undergoing remarkable change, however.

Recently, President Clinton formally apologized for radiation experiments conducted during the Cold War and for the Tuskegee Syphilis Study. In neither case did he nor his administration play any role, and only a very few of those wronged survived to receive the apologies. There is even a current proposal for a formal governmental apology for slavery, a practice that ended generations ago. How meaningful is such far removed apologizing and what does it do to the meaning of apology and responsibility?

These governmental apologies raise two central questions. Can one take responsibility for something in which he played no role, and can apology exist without both wrongdoer and victim? Recent experience leads to a
and thus to the community of American bioethicists.

And yet, much of the American bioethics conversation politely avoids mentioning the fiscally homeless in our own health care system. Two of the more than 50 articles and features of the last year in *The Hastings Center Report* address access to health insurance. A similar distribution is found in the *Kennedy Institute of Ethics Journal* and in the *Journal of Clinical Ethics*. There are a number of theoretical discussions on political theory, the tension between autonomy and justice, or between rights and responsibilities. But, forging detailed links between theory and duty is reserved for clinical case discussions (which rarely address the lack of access to health care) or policy issues that affect relatively few cases (such as the HIV infected doctor, or consent to research in the emergency room). Twenty times as many people lack insurance in the United States as will die this year. This omission taints the credibility and relevance of our other work. It locates our work in an ivory tower far from the broader community whose first fear is not overtreatment at death but being downsized out of the health care system entirely. It alienates our work from the important communities that work on behalf of persons with disabilities.

Shortly before he died, Benjamin Freedman wrote an essay asking “Where are the Heroes of Bioethics?” He defined a hero as a person who in the course of articulating the central commitment of a field risked a great occupational consequence. I would quibble about whether his definition conflates the act of heroism with the consequence of martyrdom. But it is fair to ask of the bioethics community, why did public policymakers ban dumping patients from emergency rooms before ethicists, many of whom were employed in elite medical centers, wrote about this common practice? Why is there no literature discussing whether cost shifting to cover indigent care may be a moral obligation and a form of public protest of a not-for-profit hospital in confronting a tidal wave of exiles from our membership only managed care plans? The silence of ethicists who profess to watch the health care neighborhood, is akin to Kitty Genovese’s neighbors who passively listened to her struggles from the safety of their houses while she was dying in the streets.

There are exceptions. Laurie Zoloth-Dorfman, Larry Churchill, Norman Daniels, Carol Levine, and Leonard Fleck, to name a few, have made this problem the centerpiece of their forceful work. But their exceptional work is too much the exception. And for that, the United States bioethics community, situated amid 45 million people without insurance, can be held accountable.
Faculty Profile

Steven Miles, MD

Steve Miles began his career in bioethics at Hennepin County Medical Center (HCMC) as the first medical student member of its “Thanatology Committee” in 1975. During his Internal Medicine residency at HCMC, he and Dr. Ronald Cranford worked on a model DNR policy that was adopted by the hospital and the state medical society. Dr. Miles and colleagues introduced the term DNR into the literature in 1981. During his residency, Steve took several courses in ethics at United Theological Seminary. After his residency, he was medical director for a large Cambodian refugee camp. On his return to the United States, he was drawn to Geriatric Medicine especially for persons with dementia or advanced chronic disease. He joined the faculty at the University of Chicago in 1986 where he taught ethics at the Center for Clinical Medical Ethics. He returned to HCMC and joined the Center for Bioethics at the University of Minnesota in 1990. In 1995, he transferred his clinical work in geriatrics to St. Paul Ramsey Medical Center.

He is Associate Professor in the Department of Medicine, faculty in the Center for Bioethics at the University of Minnesota and a staff physician in the Department of Internal Medicine at St. Paul Ramsey Medical Center. He is a Faculty Associate in the Center for Advanced Feminist Studies and a member of the University Council on Aging at the University of Minnesota. Dr. Miles was recently appointed Adjunct Professor of Medical Science at the University of Havana, Cuba.

He is President of the American Association of Bioethics (AAB) and on the Board of the Society for Bioethics Consultation (SBC). He has actively worked to consolidate the AAB, SBC, and the Society for Health and Human Values into the single American Society for Bioethics and Humanities. He has served on the Board of the American Society of Law, Medicine, and Ethics and co-edited *Law Medicine and Ethics*. He is also on the American Refugee Committee that sponsored his work with Cambodian refugees.

He is a Soros Foundation Faculty Scholar for the Project Death in America, has co-directed the Health Priorities Project for the Robert Wood Johnson and Pew Foundations’ Health of the Public Program, and received a Henry Kaiser Foundation Faculty Scholarship in General Internal Medicine.

Steve’s clinical work informs his work in bioethics. His clinical studies have focused on end-of-life care. His policy work has focused on the need for health care reform. He is best known for his work on end-of-life care, the development of portable advance directives, the Wanglie case, and health care reform in Minnesota. He is exploring a run for the US Senate in the year 2000 as he avidly tends his large garden of perennial flowers.

Selected Publications:

**ARTICLES**


**BOOK**

We are very excited to announce our move back to the heart of the Academic Health Center on campus. We will be moving into a suite of offices that will accommodate the rapid growth taking place at the Center as well as increase Center accessibility to faculty, staff, and students at the University.

New Center Fellow

Chris Herrera, PhD, will join the Center as the 1997-98 post-doctoral fellow. He arrives from the University of Oklahoma, where he completed his PhD in philosophy. His dissertation and several publications have addressed issues of informed consent and deception in human subjects research. During his fellowship year at the Center he will explore the relationship between ordinary views of common morality and professional and institutional codes of ethics. The goal of this work will be to formulate a framework for ethical assessment of human subjects research.

Applications for the 1998-99 post doctoral fellowship will be available in December 1997.

Summary of the Midwest Intensive Bioethics Course (MIBC) 1997

Twenty-eight people attended this year’s Midwest Intensive Bioethics Course (MIBC) held at the Sheraton Metrodome in Minneapolis on June 22-26. (See picture) This diverse group came to the course from both rural and urban areas in nine states and included chaplains, health care administrators, nurses, nursing faculty members, physicians, psychologists, researchers, social workers, and sociologists. Faculty and participants learned from one another in large and small group discussions, as well as in more than 30 hours of content presented over five days. Participants indicated that “intensive” aptly described both the range and amount of content, and their involvement in this learning process.

The MIBC is jointly sponsored each year by the Center for Bioethics at the University of Minnesota, the Center for Bioethics at the Medical College of Wisconsin in Milwaukee, and the Program in Medical Ethics, University of Wisconsin in Madison. Notices about next year’s course will appear in this publication and on the Center’s Web page.
Positions Available

The Institute for Ethics at the American Medical Association announces the availability of four academic fellowships for research in medical ethics and ethics-related policy. The four one-year positions are open in Fall 1997. The fellowships include a stipend of $20,000 each and are to be on-site at the AMA’s offices in Chicago. Applicants for the fellowships should have completed an MA, MPH, MD, JD, MPP or other masters-level ethics or health-policy related degree. PhD candidates in the process of dissertation writing, as well as recent post-docs, also may apply. Fellows will pursue their own independent academic research and writing and will participate in weekly seminars on bioethical topics with Institute staff and the staff of the AMA’s Council on Ethical and Judicial Affairs. Interested candidates should send a CV, a writing sample, and either two letters of recommendation or names and phone numbers of two references to: Alicia O’Brien, Manager, Employee Relations and Placement, American Medical Association, 515 North State St, Chicago, IL 60610.

The Department of Medical Humanities at the East Carolina University School of Medicine is seeking candidates to fill a tenure-track faculty position at the assistant or associate professor level. Candidates should have a doctoral degree in philosophy, or expertise in philosophical ethics and bioethics. Candidates should send a CV, three letters of recommendation, and three representative writing samples to: Search Committee, Department of Medical Humanities, East Carolina University School of Medicine, Greenville, NC 27858-4354. Screening will begin on August 1, 1997.

Call for Papers

The Department of Medical Humanities at East Carolina University School of Medicine will celebrate its 20th Anniversary by holding a conference in conjunction with the spring meeting of the Society for Health and Human Values on March 13-14, 1998 in Greenville, NC. This conference will explore the broad range of medical humanities scholarship. Abstracts for 20 minute presentations on any topic in the medical humanities are invited. Those wishing to make a presentation should send a one page abstract by October 1, 1997 to: Program Committee, Dept. of Medical Humanities, East Carolina University School of Medicine, Brody 2s-17, Greenville, NC 27858-4354.

Improving Care for the Terminally Ill is Focus of New $12 Million Grant Program

In response to overwhelming evidence that too many Americans die alone, in pain, and receiving aggressive medical treatment not justified by its benefit, the Robert Wood Johnson Foundation announced that it will award up to $12 million to innovative projects that seek to improve care for the dying. The new grant program, Promoting Excellence in End-of-Life Care, recognizes the growing commitment among health care professionals and administrators to change the status quo and is intended to help them do so. The national program office at the University of Montana is currently accepting letters of intent to apply for funding until September 1, 1997. Letters of intent and inquires should be addressed to: Ira Byock, MD, Practical Ethics Center, The University of Montana, Missoula, MT 59812. Telephone: (406) 243-5744.


The joint meetings of the American Association of Bioethics (AAB), Society for Health and Human Values (SHHV), and Society for Bioethics Consultation (SBC) will be held at the Baltimore Marriott Inner Harbor, Baltimore, MD. Keynote speakers include Ruth Faden, William May, and Kenneth Starr. There will be an on site bookstore offering discounts to attendees, career development, and mentoring opportunities. A program and brochure is forthcoming. For information, contact: SHHV, 6728 Old McLean Village Drive, McLean, VA 22101. Telephone: (703) 556-9222. Email: shhv@aol.com
July 24
Susan Wolf will participate in a Bioethics Panel at the Eighth Circuit Judicial Conference. For information, send inquiries to: Circuit Executive; PO Box 75428, St. Paul, MN 55175.

August 4-8
The University of Washington’s Department of Medical History and Ethics “Summer Seminar in Health Care Ethics.” For information, contact: Marilyn J. Barnard at 206-616-1864; Email at mbarnard@u.washington.edu.

August 25-27 & September 25-26
The NIH and the FDA workshops. August 25-26: “Workshop in Human Subject Protections: Culture and Community: Consultation and Communication in Research” at Cavanaugh’s Inn, Seattle, WA. For information, contact the University of Michigan School of Medicine 800-869-2933. September 25-26: “Contemporary Issues in Human Subjects Research” at the University of North Carolina, Charlotte. For information, contact the Office of Research at the University of North Carolina, Charlotte 704-547-2291.

September 11-13

November 5-9
“Visions for Ethics and Humanities in a Changing Healthcare Environment” sponsored by the AAB, SHHV, and SBC will be held at the Baltimore Marriott Inner Harbor, Baltimore, MD. For information, contact the Society for Health and Human Values at 703-556-9222

November 6 & December 8-9

November 18
Susan Wolf will lecture at the University of Seattle Law School Speakers’ Series. For information, contact Anne Enquist, Chair, Colloquium Committee at 206-591-2230.

August 20-22, 1998
12th annual conference of the European Society for Philosophy of Medicine and Health Care, “Philosophy of and Philosophy in Healthcare Education” in Marburg, Germany. Abstracts and registration before November 1, 1997. For information, contact: Prof. dr. Henk ten Have, secretariat ESPMH, Dept. of Ethics, Philosophy and History of Medicine, Faculty of Medical Science, Catholic University of Nijmegen, PO Box 9101, 6500 HB Nijmegen, The Netherlands. Fax: 31-24-3540254.

Recent Faculty Publications

Ethical Dilemmas & Nursing Practice, Fourth Edition, is a valuable guide that helps develop the critical thinking skills needed to become an effective patient advocate. Pinpointing the systematic methods of reasoning through an ethical dilemma, this is the ultimate resource to resolving ethical issues in a system undergoing fundamental change. This fourth edition reflects contemporary issues such as informed consent, abortion, dying and death, behavior control, and mental retardation. Stamford, CT: Appleton & Lange, 1997. ISBN 0-88385-2283-1.


Wolf SM. “Why the bioethics commission is wrong to seek a ban on cloning.” Minneapolis Star Tribune, June 19, 1997, A27.

Wolf SM. “Supreme Court decision rightly forces more talk about life’s end.” Minneapolis Star Tribune, July 6, 1997, A17.
Center Publications and Tapes

Audio Tapes
- A series of 27 audio tapes are available from the October/November 1996 conferences, “ICU Care at the End of Life: Ethics and Practice,” and “End-of-Life Health Care in Managed Care Systems.” Tapes are $10 each or $100 for the complete set.
- A series of five audio tapes are available from the June 1995 conference, “Managed Care Systems: Emerging Health Issues from an Ethics Perspective.” Tapes are $15 each or $60 for the complete set.
- A series of eight audio tapes are available from the November 1994 conference “Building Families: Ethical and Policy Issues in Adoption.” Tapes are $15 each or $60 for the complete set.
- A series of five audio tapes are available from the 1994 conference, “Sinners, Saints and Health Care: Individual Responsibility for Health—Ethical, Legal and Economic Questions.” Tapes are $10 each or $40 for the complete set.
- A series of thirteen audio tapes are available from the 1994 Washington, DC, conference “The Role of Bioethics in Health Care Policy/Broadening the Bioethics Agenda?” Tapes are $10 each or $100 for the complete set.

Managed Care and End-of-Life Care Packets
A Center program addressing ethical issues in managed care has led to the publication of documents on end-of-life care that are available for $5 each:
- Ethics of Managed Care—a continually updated annotated bibliography of articles addressing ethical issues in managed care.
- Advance Directives—an annotated bibliography focusing on empirical research related to the dissemination, clinical use, and effects of advance directives.
- Palliative Care—an annotated bibliography of articles describing clinical, legal, and ethical issues in pain control for terminally ill persons.

Ordering Information
To order reading packets, tapes, or reports, please make checks payable to: Center for Bioethics, University of Minnesota. Send to: Center for Bioethics, Suite N504, 410 Church Street SE, Minneapolis, MN, 55455-0346. All orders must be prepaid.

Reports
- The Role of Bioethics in Health Care Policy/Broadening the Bioethics Agenda, transcript proceedings from the May 1994 conference held in Washington, DC. The Greenwall Foundation makes this report available at no charge.

Reading Packets
Center reading packets contain an overview of legal and ethical issues, key articles, and a bibliography. Reading packets are available for $5 each:
No. 1: Organ Transplantation (revised September 1993)
No. 2: Withholding or Withdrawing Artificial Nutrition and Hydration (revised September 1993)
No. 3: Termination of Treatment of Adults (revised September 1993)
No. 4: Baby Makers: The New Ethics of Reproduction (October 1995)
No. 5: Distributing Limited Health Care Resources (revised April 1997)
No. 6: Resuscitation Decisions (revised June 1997)
No. 7: The Determination of Death (revised May 1997)
No. 8: New Frontiers in Genetic Testing and Screening: The Human Genome Project (August 1993)
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