The recent death of Jesse Gelsinger has served as a wake-up call for researchers, research institutions, government regulators, and the public about how research is carried out in the United States. Mr. Gelsinger was an 18-year-old man from Arizona, with a genetic disorder that prevented his body from properly metabolizing ammonia. He enrolled in a clinical trial at the University of Pennsylvania that was attempting to use gene therapy to correct the disorder. But rather than curing him, the technique apparently caused his death. The chain of events that has followed—including the shutdown of all research at Penn’s Institute for Human Gene Therapy—call into question not only the safety of the techniques of gene therapy, but the conditions and protections under which all clinical research is carried out in this country.

Within the US, the scandals at Willowbrook and Tuskegee stand as powerful reminders of the ways in which convenient and vulnerable populations can be exploited in medical research. One common objection to both of these cases is that although the ostensible target of the research focused on the specific diseases of hepatitis and syphilis respectively, the research itself relied on the maintenance of ongoing social deprivations that set the background conditions for the prevalence of those diseases in the first place. Rather than attempting to relieve some of the fundamental burdens posed by those social deprivations, the researchers in these cases chose to exploit those social conditions for the sake of possible advances in medical knowledge. As a result, the...
An important ethical concern about genetics research is how it will change the way that we think about ourselves and how others think of us, and whether the changes will make us better off or worse off. For instance, think of the discovery of a genetic basis for alcoholism: how would it make me feel if I’m dependent on alcohol, knowing then that my behavior might be partly genetic? How would it change the way that others perceive me, knowing that I might be genetically predisposed to drink heavily? Research into the genetic origins of alcoholism confronts us with those questions, as many alcoholics are all too aware. Surprisingly, it also raises issues about the identities of alcoholics that concern their gender.

According to recent studies, people dependent on alcohol tend to display the extremes of traditional gender characteristics: aggressiveness and impulsiveness for men, emotionality and neuroticism for women. The research implies that they are identifiable not only in terms of excessive alcohol consumption but also in terms of harmful gender traits. Ultimately, then, the ethical issue of how that research will impact on people’s identities is partly feminist.

One implication of this research is that genetics plays a lesser role in female alcoholism than in male alcoholism. Some researchers have challenged that finding and argued for a new type of alcoholism in women: an early onset type that has a strong genetic component (see Hill 1995). Although similar in some ways to Type II alcoholism in men, it does not mimic it entirely. The claim is not that women who have the new type of alcoholism have the personality traits associated with Type II.

It is important to realize, moreover, that researchers deem the links between gender traits and alcoholism to be genetic. It is not that a socially determined quality of “emotionality” or low self-esteem is tied to alcoholism, especially in women. The claim is that the personality type and the alcoholism type are both genetic, and might even have similar genetic origins (see Heath et al 1997, 139, 140). If the personality traits were mediated by social factors only, one might be less inclined to believe that the different types of alcoholism are genetic. One might question, for example, whether social influences that make many men emotionally detached also make them prone to alcoholism.

However, by claiming that the gender traits are genetic, the researchers subject themselves to serious suspicion from people with feminist concerns. From a feminist perspective, there is good reason to question that genetically speaking, women who are alcoholics are more likely than their male counterparts to be neurotic and emotional, whereas male alcoholics are more likely to be aggressive and promiscuous.

One worry from a feminist ethical perspective is that the new research will multiply the stigmas of being an alcoholic to include traditional gender stigmas, such as the "neurotic female" or the "overly aggressive male." The disease model of alcoholism—now a genetic model—was meant to reduce the social stigma of being an alcoholic. Some people assume (wrongly) that it allows the alcoholic to say, “My genes made me do it.” But that model seems to create more stigma than it removes. For female alcoholics, potentially, it creates an association in people’s minds between neuroticism and alcoholism. We might find out a woman is an alcoholic and immediately assume that she's neurotic as well.
Profile
Carolyn McLeod, PhD

Carolyn McLeod, PhD currently has postdoctoral research fellowships with the Center for Bioethics and with the Social Sciences and Humanities Research Council of Canada. Last August, she defended her PhD in philosophy from Dalhousie University in Halifax, Nova Scotia. She received both her MA ('95) in philosophy and her BAH ('92) from Queen's University in Kingston, Ontario.

Dr. McLeod’s research interests have focused largely on the intersection of feminist ethics and reproductive health care. A manuscript she has been working on, “Self-Trust and Reproductive Autonomy,” combines those interests. In it, she argues that patient self-trust is an important condition for autonomous decision-making, yet it is often undermined by forces relating to women’s oppression in reproductive medical contexts. Narratives of women’s experiences in those contexts ground her theoretical claims, and some of the narratives are based on the experiences of patients she met while doing a clinical practicum in obstetrics during her doctoral studies.

Dr. McLeod also has research interests in the ethics of addiction treatment and research, and ethical issues in international treatment and research. Her postdoctoral work is on addictions, the ethics of genetic research into their origins, and our moral attitudes toward people with addictions. Her recent work in this area is “The Integrity of People with Addictions: A Feminist Relational Perspective” (under review). Concerning the ethical debates on global issues in research and treatment, she is interested in how theories of social justice should inform them, and has been invited to speak on that topic at the International Congress of the World Federation of Hemophilia this summer in Montreal.

Dr. McLeod has had extensive teaching experience in both bioethics and environmental ethics, and has been active in a number of professional organizations. She is currently the newsletter editor for the Canadian Society for Women in Philosophy and a member of the equity committee for the Canadian Philosophical Association.

Selected Publications

Selected Articles


Clinical research that targets the specific needs of developing world populations in an achievable, real world clinical context can itself be an important tool for fostering social and economic progress.
Alex London, PhD is a 1999-2000 postdoctoral fellow at the Center. In July he will join the Philosophy Department at Carnegie Mellon University as an Assistant Professor where he will continue to pursue his interests in ancient and contemporary ethics.

Dr. London came to the Center from the University of Virginia where he received his PhD in Philosophy in 1999. There he studied ancient philosophy, ethical theory, and bioethics, and began to focus his research on the way that ancient approaches to ethics and moral psychology can illuminate contemporary problems in applied ethics. Since 1997 he has been an officer for the Society for Bioethics and Classical Philosophy. He received his BA in Philosophy and Literature from Bard College in 1994.

The immediate focus of Dr. London’s current research deals with the relationship between theoretical and practical ethics and various ethical issues in cross-cultural medical research. With respect to this first area, he is editing a special issue of the Theoretical Medicine and Bioethics, tentatively titled “The Place of Theory in Practical Ethics.” In the area of cross-cultural medical research, Dr. London is currently working on a paper that takes a closer look at the role of equipoise in the evaluation of international human subjects research.

He is also working on a book manuscript, tentatively titled Aristotelian Practical Ethics. Here important aspects of Aristotle’s ethics are explored for their implications in various areas of applied ethics. For instance, the book will explore Aristotle’s conception of the emotions, their relationship to reason, and the implications of this relationship for theoretical and practical approaches to applied ethics. Additionally, Aristotle’s conception of the role of physiology in the realization of emotional states is used to shed light on the ethics of using psychopharmacology to enhance human affective traits and to enliven our evaluation of the effects of depression on end-of-life decision making. Additional topics include ethical issues in managed care and the place of applied ethics in liberal democracy.

While at the Center, Dr. London was an instructor in the ethics portion of Clinical Medicine I for first-year medical students and he is currently teaching a graduate seminar on the ethics of research on human subjects in the Department of Philosophy and the School of Public Health. He has also been an active participant in the Center’s outreach activities. He and Tracy Ellinwood will be married in June.

Selected Publications:

**Book Chapters**


**Articles**


As in all clinical research, informed decision making by potential subjects is a critical but elusive goal. The investigation following Jesse Gelsinger’s death purportedly uncovered evidence of incomplete and inaccurate disclosure of the risks of that form of gene therapy. Even when information is adequate, studies show that subjects tend to overestimate the potential benefits of research while at the same time underestimating its risks. This is a dangerous combination when we are asking patients to put themselves in harm’s way primarily for the good of patients who will come after them, with only a limited chance that they will receive benefit themselves.

A growing complication in these types of high tech clinical research is the blurring of lines between researchers and the pharmaceutical or biotechnology companies who fund their research projects. There are increasing numbers of outright conflicts of interest when researchers have a financial stake in biotechnology start-ups that are created to develop and market their discoveries, creating incentives for recruitment of patients as much in the interest of researchers’ financial gain as for the interests of particular subjects.

A key concern of regulators is what looks like a widespread and alarming failure to report harmful side effects to subjects in gene therapy trials at Penn and elsewhere. While such reporting is a required part of federal oversight of research, there are grumblings from inside the beltway that current policies may not be enough. The question then is whether we need greater adherence to existing rules, additional new tighter regulation and oversight, or both. Following existing rules would certainly be a good start.

Never before have issues of protecting research subjects been so carefully scrutinized or taken so seriously, and the ongoing gene therapy case at the University of Pennsylvania has created a drama whose cast includes medical researchers, the US Congress, disease group advocates, and federal bureaucrats. Each has a somewhat different stake in the outcome of all the attention being paid to the medical research process, but whatever the outcome, all must keep their eyes on the ultimate goal—high quality, careful research conducted in ways that respects the rights and interests of subjects. Otherwise we face the prospect of a research enterprise that subjects us to science rather than carrying out science in service to us.

A version of this article appeared in an “Ethics Matters” column on CNN Interactive (www.cnn.com/health).
Midwest Intensive Bioethics Course (MIBC) 2000
July 20-22, Minneapolis, MN
Ethics of Sexuality and Reproduction in Health Care

MIBC 2000 is taking a new direction. Participants and bioethics faculty will interact with experts who bring new and diverse perspectives to the course. This two-and-a-half day course will focus on ethical issues that arise at the intersection of health care and human sexuality and reproduction. It will examine the ways in which these issues differ for adolescents, the elderly, and those in the middle of their lives. It will also emphasize the ways in which different sociopolitical, ethnic, and economic factors, as well as technological innovations, influence our views on issues of sexuality and reproduction.

In addition to bioethics faculty from the four sponsoring Centers, major presenters for the conference will include:

James B. Nelson, Professor Emeritus of Christian Ethics, United Theological Seminary of the Twin Cities, who will address, “Sexual Values & Health Care: Committed Partners or Strangers in the Night?”

Robert Blum, M.D., M.P.H., Ph.D., University of Minnesota, who will address, “Adolescents and Sex: What Does Ethics Have To Do With It Anyway?”

Eli Coleman, Ph.D., Program in Human Sexuality & Behavioral Sciences, University of Minnesota, who will address “The Third Sexual Revolution” and its impact for health professionals and policymakers.

Maureen Reed, M.D., Medical Director, HealthPartners, who will address how decisions about reimbursement are made in managed care settings.

The MIBC will be hosted by the Center for Bioethics on the University of Minnesota campus in Minneapolis, M.N. The course is cosponsored by the Program in Medical Ethics, University of Wisconsin, Madison; the Center for the Study of Bioethics, Medical College of Wisconsin; and the Medical Ethics and Humanities Program, Northwestern University Medical School.

Tuition for the course is $700. Two student scholarships for people pursuing careers in bioethics will be made available by a grant from the Medtronic Foundation. To apply, letters regarding interest and career goals should be submitted to:

Dianne Bartels
Associate Director
Center for Bioethics
University of Minnesota
Suite N504 Boynton
410 Church Street SE
Minneapolis, M.N. 55455
Fax: 612-624-9108

Accrediting Sponsor
Department of Continuing Medical Education, University of Minnesota—Continuing education credits have been requested.

Rooms are held at the Radisson Metrodome (612-379-8888) at a rate of $97 per night for a single or double room and at the Days Inn (612-623-3999) at a rate of $65 per night for a single or double room. Both hotels are within walking distance of the campus—The Radisson is located one block from the course location and the Days Inn is located approximately 1/2 mile from the course location.

For more information or registration materials, visit the Center’s Web site at http://www.med.umn.edu/bioethics/
Phone 612-624-9440, e-mail: bioethix@tc.umn.edu.
Upon discovering that a man is an alcoholic, we might think, “Better watch out for him. He’s probably dangerous.”

For male alcoholics who are overly aggressive as well as promiscuous, an association between alcoholism in males and the supposedly genetic traits of aggressiveness and promiscuity brings back the old excuse that “Hey, I’m a guy. I can’t help myself.” Rearing its ugly head in the literature on genetics and alcoholism is the view that some men are simply programmed to be abusive and insensitive.

The subject of gender and alcoholism has received little attention from feminist bioethicists, but not for a lack of ethical content of interest to them. The need for greater feminist input in that area is substantial, I think, especially given the expanding authority of genetic science. A feminist analysis can raise awareness about the potentially harmful social implications of genetic findings that link alcoholism with stigmatizing gender identities.

Notes

References


The following bioethics courses will be offered during Intersession and Fall Semester at the University of Minnesota. For more information on these courses, see the Center’s Web site (www.med.umn.edu/bioethics).

**Intersession and Fall Bioethics Courses**

**INITIAL**

**Fall**

**Dent 5412**
Professional Problem Solving
1 cr given upon completion of course sequence, Bebeau

**Dent 6414**
Professional Problem Solving
1 cr given upon completion of course sequence, Bebeau

**Law 6853**
Law, Medicine, and Bioethics
2 cr, Wolf

**PubH 5742**
Ethics in Public Health: Practice, Policy and Research
2 cr, Aroskar and Kahn

**PubH 5743**
Ethics in Healthcare Administration
2 cr, Aroskar

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**Faculty**

**Jeffrey Kahn, PhD, MPH**, has been appointed to the Oversight Committee for the Geographic Information System (GIS) for the Long Island Breast Cancer Study Project (LIBCSP).

**Patricia Crisham, PhD, RN**, Faculty Associate in the Center, is retiring after 25 years on the faculty in the School of Nursing at the University of Minnesota. Prior to joining the faculty, she was a Clinical Specialist at Psychiatric-Mental Health Nursing, Catholic University of America. She received her BSN from the College of St. Catherine, St. Paul, MN; an M S in Psychiatric-Mental Health Nursing from Catholic University of America, Washington, DC; and a PhD in Developmental Psychology from the University of Minnesota.

In 1985, she worked with colleagues at the University of Minnesota Academic Health Center to establish the Center for Bioethics. Since that time she has represented the School of Nursing as a Faculty Associate in the Center. In the School of Nursing, she has been responsible for ethics education for graduate programs. Her ethical decisionmaking model is used by clinicians in health care professional curricula, ethics committees, and interdisciplinary task forces developing positions on health care issues. She has published in prestigious journals and presented papers at national conferences on ethical dilemmas in health care throughout her career.

Recognized as a scholar in the psychology of moral development and nurses’ response to ethical dilemmas in clinical practice, her Nursing Dilemma Test is widely used nationally and internationally. She has received numerous teaching and service awards for her work.

**Selected Book Chapters**


**Selected Articles**


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**Patricia Crisham**

Patricia Crisham, PhD, RN retires after 25 years at the University of Minnesota.
Calendar of Events

**APR 14,26**
**MAY 3,4**
The Center for Bioethics Seminar Series will be held from 12:15-1:30 pm on the University of Minnesota campus, Minneapolis, M N. Speakers include: April 14- Abby Wilkerson, PhD, George Washington University. Title TBA. April 26-Mary Mahowald, PhD, The MacLean Center for Clinical Medical Ethics and University of Chicago, will speak on women and genetics. May 3- Jonathan Moreno, PhD, University of Virginia, will speak on “The Involvement of Persons with Mental Disorders in Clinical Research.” May 4- Jonathan Moreno, PhD, University of Virginia, will speak on “Medical Research and National Security During the Cold War.” For further information and room locations, contact the Center.

**MAY 11**
John Song, MD, PhD, will speak on “Ethics and the Patient Experience in Clinical Research.” Both presentations will be held at Park Nicollet Clinic, St. Louis Park, MN. For more information, call 612-993-3538.

**MAY 13**
Jeffrey Kahn, PhD, M PH, will participate on a panel discussion “The Ethics of Living Donation” at the ASTS (American Society of Transplant Surgeons) Transplant 2000 Conference, Chicago, IL. For information, call 856-608-1106.

**MAY 19**
Jeffrey Kahn, PhD, M PH, will speak on “Clinical Research Ethics: The Move from Protection to Access.” Dianne Bartels, RN, MA, will address genetic issues in “Ethics and the Patient Experience in Clinical Research.” Both presentations will be held at Park Nicollet Clinic, St. Louis Park, MN. For more information, call 612-993-3538.

**MAY 23**
Jeffrey Kahn, PhD, M PH, will deliver the Samuel G. Dunn Lectureship for the Humanities, entitled “Responsible Research in the Age of Biotechnology” at the University of Texas Medical Branch, Galveston, TX. For information, call 409-77-2376.

**APR 24-28**
Muriel Bebeau, PhD will speak on “Influencing the Moral Dimensions of Dental Practice: Implications for the Professions” at the American Educational Research Association (AERA) meeting in New Orleans. For information, call 202-223-9485 or visit their web site at: http://www.aera.net/meeting/am2000/.

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**JUN 9**
Jeffrey Kahn, PhD, M PH, will be presenting at the Transplant Society’s Annual Provincial Renal Transplant Day in Vancouver, Canada. For information, call 604-877-2144.

**JUN 12-16**
The University of Washington, Seattle, Department of Medical History and Ethics will sponsor a course “Ethics of Research with Humans: Past, Present, and Future.” For information, call 206-616-1864 or e-mail: nbarnard@u.washington.edu.

**JUN 19-22**
The Center for Bioethics in partnership with the American Society on Aging, and the Minnesota Area Geriatric Education Center, presents “The Upper Midwest Summer Series on Aging,” Concordia University, St. Paul, MN. For information, call 605-974-9600, fax 605-974-0300 or e-mail: info@asa.asaging.org.

**JUL 20-22**
The Center for Bioethics will host the Midwest Intensive Bioethics Course (MIBC) 2000 in Minneapolis, M N. Co-sponsored by the Program in Medical Ethics, University of Wisconsin, Madison; the Center for the Study of Bioethics, Medical College of Wisconsin; and the Medical Ethics and Humanities Program, Northwestern University Medical School. For information, call 612-624-9440 or e-mail: info@sfh.kun.nl.

**JUL 31-Aug 4**
The University of Washington, Seattle, Department of Medical History and Ethics will hold the annual Summer Seminar in Health Care Ethics. For information, call 206-616-1864 or e-mail: nbarnard@u.washington.edu.

**OCT 21-22**
Jeffrey Kahn, PhD, M PH, will speak on ethical issues at the American Society for Reproductive Medicine Annual Meeting, San Diego, CA. For information, call 612-627-4564.

**NOV 16-18**
The University of Nijmegen, The Netherlands, will hold an Advanced European Bioethics Course, “Ethics and Genetics.” Specialists from various countries will discuss ethical aspects of genetics. For information, call 0031-24-3615320, fax 0031-24-3540254, or e-mail: n.steinkamp@efg.kun.nl.

*TBA—to be announced*
Recent Faculty Publications

ARTICLES


Center Publications

READING PACKETS

Center 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 (August 1997)

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

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

No. 4: Distributing Limited Health Care Resources (April 1997)

No. 5: Resuscitation Decisions (June 1997)

No. 6: The Determination of Death (May 1997)

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

Managed Care and End-of-Life Care Packets

A Center program addressing ethical issues in managed care has led to the publication of annotated bibliographies on end-of-life care that are available for $5 each.

- Ethical Issues in Managed Care—articles addressing ethical issues in managed care.
- Advance Directives—focuses on empirical research related to the dissemination, clinical use, and effects of advance directives.
- Palliative Care—articles describing clinical, legal, and ethical issues in pain control for terminally ill persons and articles describing and comparing hospice care to conventional care for terminally ill persons.

REPORTS

In October 1998, the Center organized a meeting that brought together representatives from Minnesota’s health care organizations to address implementation of Minnesota’s health care directive law. To receive a copy of the proceedings “Summit on Implementing Minnesota’s New Health Care Directive Law” contact the Center. This report is available at no charge.

All orders must be prepaid.

Ordering Information.

To order reading packets or reports, make checks payable to: Center for Bioethics University of Minnesota. Send to: Center for Bioethics University of Minnesota Suite N 504 Boynton 410 Church Street SE Minneapolis, MN 55455

Visit the Center’s Web site at http://www.med.umn.edu/bioethics.

All editions of the Bioethics Examiner are posted on the Web, let us know if you would prefer to access it on the Web rather than receive it by mail.
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