An expert panel appointed by the British government recently recommended that the country lift its ban on the cloning of human beings. Mind you, what they envision is not the creation of a population of identical citizens, but “therapeutic cloning” to create human embryos for the remarkable and promising specialized cells that can be derived from them. These embryonic stem cells have the potential to become any kind of cell in the human body, and therefore promise new breakthrough approaches to treating everything from diabetes and spinal cord injury to growing organs for transplant. We all begin as the union of one egg and one sperm, and somehow the cells in the resulting embryo are correctly triggered to become skin, muscle, nerve or any of the varied cells that make up the human body. Once we understand the process by which cells differentiate into one type versus another, the next step will be to control it, and turn embryonic stem cells into whatever type of specific target cell we desire. So with so much promise, where is the hitch?

The most promising source of embryonic stem cells is human embryos, and extraction of the stem cells means destruction of the embryos from which they come. For many, human embryos have special status, so their destruction raises real ethical concerns. And to raise the moral ante, the British panel’s proposal to clone human embryos for their stem cells adds the specter of cloning. The main source for embryonic stem cells in research will be so-called ‘spare’ embryos, embryos that remain frozen and unused after

**From the Director...**

**Falling Behind in the Stem Cell Race?**

*By Jeffrey Kahn, PhD, MPH*

Since hospice was added as a Medicare benefit in 1982, use of hospice care prior to death has increased dramatically both within and outside of the Medicare program. Despite continual increases in use of the benefit, there also have been persistent concerns that many people who could benefit from hospice care do not receive it.

Concerns about use of the hospice benefit, or failure to use the hospice benefit, have resulted in a series of proposals aimed at improving the benefit. Interestingly, many of these proposals are based on assumptions and incomplete data. One of the most striking aspects of our understanding of how the Medicare hospice benefit is used is that there is very little available data on which policy statements are made and conclusions drawn.

**Hospice Use and the Medicare Program:**

*Use, Options for Change, Unanswered Questions*

*By Beth Virnig, PhD, MPH*

**Medicare**, the national health insurance program that finances health care for approximately 38 million Americans, includes a hospice benefit. Hospice is intended to provide palliative care for terminally ill individuals. Hospice is not a place but rather a system of care for providing comprehensive care to dying patients. Although designed to be largely home based, hospice care can also be provided in hospice facilities, hospitals, and nursing home settings. Comprehensive hospice care includes a number of services including pain management, social services, and home care. Medicare beneficiaries with a physician-documented life expectancy of six months or less can give up their right to curative care in exchange for comprehensive hospice care.

Since hospice was added as a Medicare benefit in 1982, use of hospice care prior to death has increased dramatically both within and outside of the Medicare program. Despite continual increases in use of the benefit, there also have been persistent concerns that many people who could benefit from hospice care do not receive it.

Concerns about use of the hospice benefit, or failure to use the hospice benefit, have resulted in a series of proposals aimed at improving the benefit. Interestingly, many of these proposals are based on assumptions and incomplete data. One of the most striking aspects of our understanding of how the Medicare hospice benefit is used is that there is very little available data on which policy statements are made and conclusions drawn.
This lack of evidence means that anecdotal evidence is the primary source of information about use of hospice and that the biased nature of such information is not explicitly recognized.

Who uses hospice? Each year, over 260,000 elderly receive services through the hospice benefit. That translates to 15.5 hospice users for every 100 deaths among elderly Medicare beneficiaries. Use of the Medicare hospice benefit is not evenly distributed across elderly populations. Use is higher among whites than non-whites, use declines with age, and use is higher among persons from wealthier areas than from poorer areas. Nationally, hospice use varies from a low of 3 hospice users per 100 deaths to a high of 35 hospice users per 100 deaths.

Hospice is not just a program for patients with cancer. While about 62% of elderly hospice users have cancer diagnoses, the remainder are diagnosed with a variety of non-cancer conditions including congestive heart failure, chronic obstructive pulmonary diseases, and Alzheimer’s dementia. These non-cancer diagnoses may be viewed as ‘non-traditional’ because many hospice programs started out with a focus on treating terminal cancer patients. There is substantial variation across areas of the country with regard to the percentage of hospice users with non-cancer diagnoses. In general, areas with a higher percentage of non-cancer (i.e., non-traditional) cases have higher rates of hospice use for both cancer and non-cancer patients.

What do differences in use imply about factors influencing hospice use? The combination of individual characteristics and local geographic variation suggests that decisions to use hospice are influenced by factors other than disease status. Geographic differences suggest that local hospice resources, competing care models (such as hospital-based care), and local practice patterns are strongly related to hospice use prior to death. For some time, hospice has been described as a program for white, middle-class individuals. This pattern is seen in Medicare populations. The underlying causes of this pattern are not yet understood. Some hospice advocates claim that cultural or religious factors are responsible for racial and economic differences in hospice use. Others claim that the home-based nature of hospice, and the need to have friends or family available to help out is a barrier for families who cannot afford for an adult to serve as a full-time caregiver. Still others suggest that physician bias and discomfort with discussions of prognosis are major barriers to hospice use.

While not dictating a policy response, observing variation across demographic or geographic groups does confirm some anecdotal claims and point to areas deserving further discussion and study. Whenever services are distributed in a non-random fashion, several questions arise: does it appear that service use fits a pattern that is consistent with just distribution of resources? Is it likely that the pattern could naturally arise out of variability in patients’ desires for the services? Does the pattern appear to be consistent with a response by providers to some incentives?

What values should be considered when evaluating modifications to the Medicare hospice benefit? Hospice advocates will often claim that hospice use is too low and that modifications to the Medicare hospice benefit are needed to increase its use. These advocates point to lower use by non-whites and persons from poorer areas as signs that barriers to use of the benefit exist. An alternate view is that hospice should be one among the range of care options offered to terminally ill patients. Appropriate care planning should include a discussion of the hospice benefit, what it includes and what it requires. With this information, patients and their families can make informed decisions about whether or not to choose hospice. This view holds that higher hospice rates are not necessarily a sign of appropriate end-of-life care, unless there is corresponding evidence that the hospice users understood their options and freely chose hospice over other alternatives. Policy changes that are aimed solely at increasing hospice use may not further patient autonomy, but may place a paternalistic view of what dying patients ought to want ahead of patient preferences. If our desire to increase hospice use gets in the way of furthering patient wishes then patients and policy makers both lose.

This work was sponsored by a grant from the Commonwealth Fund and is published in the Journal of the American Geriatrics Society.
Faculty Profile
Beth Virnig, PhD, MPH

Beth Virnig is a Faculty Associate in the Center for Bioethics, and an Assistant Professor in the Division of Health Services Research and Policy in the University of Minnesota’s School of Public Health. Dr. Virnig’s research interests include access to health care, cancer surveillance and care, and end-of-life care. Her public health research, broadly described as medical care epidemiology, naturally leads to philosophical questions about health care ethics and justice. Her goal is to conduct research that can inform and shape ethics and policy debates.

Dr. Virnig’s research on end-of-life care focuses on non-medical factors (e.g., race, income, insurance option, geography) associated with the use of the Medicare hospice benefit and receipt of other health care services. This research, supported by the Commonwealth Fund, has examined geographic and demographic variability in use of hospice services, and the impact of managed care on use of hospice. Dr. Virnig is also a mentor for the Robert Wood Johnson Foundation initiative in excellence in end-of-life care.

Dr. Virnig has both a doctorate and masters in public health from the University of Minnesota and an undergraduate degree in psychology from Carleton College. After completing her doctorate, she joined the faculty at Dartmouth Medical School’s Center for Evaluative Clinical Sciences (CECS). The diverse group of faculty at CECS helped her focus her research interest around conducting empirical research that can shape ethical and policy debates. She then joined the Department of Family Medicine and Community Health at the University of Miami School of Medicine and held a joint appointment at the Miami Veterans Administration Medical Center. Miami’s ethnically and economically diverse population was a rich environment for studying how use of health care is influenced by non-medical factors such as race, education, and income. In 1998, she returned to Minnesota and joined the faculty in the School of Public Health. She is also a member of the University of Minnesota Cancer Center and a member of Delta Omega, the Public Health Honor Society.

Selected Publications

ARTICLES


in-vitro fertilization (IVF). These embryos face four possible fates: remaining frozen indefinitely, being discarded, donation to other couples, or donation for research. Few, if any, end up being used by other couples—so many people believe that the use of spare embryos in research is no worse than either remaining frozen or ending up discarded. But even with the thousands of spare embryos that remain frozen in fertility clinics all over the world, scientists will likely still need stem cells of specific genetic makeup which can only be obtained by creating embryos.

For many, the creation of embryos for the purpose of using them in research raises its own ethical issues. In the case of spare embryos, their creation was intended for reproduction. But embryos created for stem cell research—whether clones or genetically unique—are made for the purpose of collecting the stem cells that develop from them, effectively treating them as means to achieve the ends of research. This difference in intention is morally significant to many groups and individuals. So how to balance scientific need with this moral unease?

At the moment, U.S. policy bars the use of federal monies for research on human embryos, a ban that has been in place since the early 1980s. But that doesn’t mean that embryo research is illegal in the U.S.—it’s only illegal to do it using federal dollars. In this way embryo research can proceed, albeit at a slower pace than if funding were available through the government research enterprise. So as the British consider allowing government support of “therapeutic cloning,” the National Institutes of Health (NIH) has proposed its own policy solution.

Rather than funding research on human embryos, it proposes to fund research on the embryonic stem cells that are collected from human embryos by privately funded efforts. In this nuanced way, the embryo research ban would be respected, but the major research engine of government funding could promote stem cell research. This has set up a classic test of how much we care about principles in the face of promising medical breakthroughs. No one would predict that such progress will come easily, and success in stem cell research and its policies will require not only our best science, but our best ethics as well.

*A version of this article appeared in an “Ethics Matters” column on CNN Interactive (www.cnn.com/health).*

**Center News**

**Awards**

Jeffrey Kahn, PhD, MPH, and Steven Miles, MD, were listed on the 100 Most Influential Health Care Leaders in Minnesota in *Minnesota Physician* 2000;14(5).

Jeffrey Kahn, PhD, MPH, and Susan M. Wolf, JD, were awarded an NIH Grant of $300,000 over two years for a project entitled “Genetic Testing and Disability Insurance: Ethics, Law, and Policy.” This project will complete a comprehensive investigation of the ethical, legal, and policy issues in the use of genetic information in private and public disability insurance and will make policy recommendations based on the findings.

Carl Elliott, MD, PhD, has been awarded an NIH Grant of $460,000 over two years for a project entitled “Ethnicity, Citizenship, Family: Identity After the Human Genome Project.” The grant will examine the consequence of genetic mapping for concepts of social identity. Co-investigators are Laurie Zoloth, PhD, San Francisco State University, and Paul Brodwin, PhD, University of Wisconsin-Milwaukee.

**Faculty & Associates**

Jeffrey Kahn, PhD, MPH, has been elected to the Board of Directors of the American Society of Law, Medicine, and Ethics (ASLME).

Susan M. Wolf, JD, has been named Chair of the University’s new Consortium on Law and Values in Health, Environment & the Life Sciences. The Consortium links key programs throughout the University in order to address legal, ethical, and policy dimensions of the biomedical and life sciences, including programs on genomics, ecosystem change, and public health.

Terri Peterson, PhD, has been awarded the 2000-01 Post-Doctoral Fellowship in the Center.
The Center for Bioethics at the University of Minnesota will have a one year post-doctoral fellowship available July 2001. The goal of the fellowship is to foster scholarship and career advancement in the field of biomedical ethics. The award will be $27,000 plus health care coverage for the fellow and a partial subsidy for health care coverage for the fellow’s dependents. The mission of the University of Minnesota Center for Bioethics is to advance and disseminate knowledge about ethical issues in health care and the life sciences. The Center carries out this mission by conducting original interdisciplinary research, offering educational programs and courses, fostering public discussion, providing community service, and assisting in the formulation of public policy.

The fellow will be expected to commit at least 75% time to conduct his/her defined area of research. One or more Center faculty will be available to act as advisors. Research may be conceptual/philosophical, policy analysis, empirical, or a combination of approaches.

Fellow selection criteria include:
1. Completion of PhD, MD, JD or other relevant terminal degree.
2. Evidence of academic excellence and scholarly promise.
3. Fit between the proposed area of study and the research goals of Center faculty, which include the following topics in bioethics: ethics and health policy, long term care, physician-assisted suicide and euthanasia, managed care, health care reform and allocation of services, reproductive technologies, genetic counseling and screening, genetics and genomics, advance directives and end-of-life decisions, ethics of clinical trials, research ethics, values assessment, professional ethics, relationship of law and ethics, and ethics, law and policy issues in biotechnology.

Applications must be submitted by February 15, 2001. For applications, call the Center for Bioethics, 612-624-9440, fax 612-624-9108, or e-mail: howar025@tc.umn.edu.

Position Available
Post-Doctoral Fellowship

The Center for Bioethics at the University of Minnesota will have a one year post-doctoral fellowship available July 2001. The goal of the fellowship is to foster scholarship and career advancement in the field of biomedical ethics. The award will be $27,000 plus health care coverage for the fellow and a partial subsidy for health care coverage for the fellow’s dependents.

The mission of the University of Minnesota Center for Bioethics is to advance and disseminate knowledge about ethical issues in health care and the life sciences. The Center carries out this mission by conducting original interdisciplinary research, offering educational programs and courses, fostering public discussion, providing community service, and assisting in the formulation of public policy.

The fellow will be expected to commit at least 75% time to conduct his/her defined area of research. One or more Center faculty will be available to act as advisors. Research may be conceptual/philosophical, policy analysis, empirical, or a combination of approaches.

Fellow selection criteria include:
1. Completion of PhD, MD, JD or other relevant terminal degree.
2. Evidence of academic excellence and scholarly promise.
3. Fit between the proposed area of study and the research goals of Center faculty, which include the following topics in bioethics: ethics and health policy, long term care, physician-assisted suicide and euthanasia, managed care, health care reform and allocation of services, reproductive technologies, genetic counseling and screening, genetics and genomics, advance directives and end-of-life decisions, ethics of clinical trials, research ethics, values assessment, professional ethics, relationship of law and ethics, and ethics, law and policy issues in biotechnology.

Applications must be submitted by February 15, 2001. For applications, call the Center for Bioethics, 612-624-9440, fax 612-624-9108, or e-mail: howar025@tc.umn.edu.

Visiting Faculty
Raymond DeVries, PhD, Department of Sociology and Anthropology, St. Olaf College, is a sociologist with a long-standing interest in medicine and ethics. Professor DeVries is the editor of Bioethics and Society: Constructing the Ethical Enterprise (Prentice-Hall, 1998) and has published a number of articles on the profession of bioethics. He comes to the Center as the recipient of a “Mentored Scientist Development Award in Research Ethics” from the NIH and will be working with Jeffrey Kahn on an ethnographic study of decision-making in Institutional Review Boards.

Young-Rhan Um, RN, PhD, Assistant Professor, Department of Nursing, and head of nursing in the College of Medicine, Soonchunhyang University, Republic of Korea. Professor Um will conduct research on ethical and legal considerations of biotechnological research on human embryos; identify the cultural differences in priorities of ethical issues between the U.S. and Korea; and observe how to organize and operate an IRB.

New Resource Center
The Center is pleased to announce its new Bioethics Resource Center. The Resource Center offers a collection of resource materials (paper and on-line), as well as resource expertise in bioethics for members of the University and professional communities, and to the public.

Resource Center staff can provide assistance in locating literature, videotapes, websites, and other materials, and in developing topical bibliographies for research or educational purposes. In addition, the Resource Center will act as a clearinghouse for requests for speakers for public and professional groups. Resources can be accessed by visiting the Center at N540 Boynton, on line at www.med.umn.edu/bioethics/, or by contacting Gay Moldow, RN, MSW, Resource Center Director, at 612-624-7137, or email at moldo004@tc.umn.edu.
Calendar of Events

Oct 6,16,24
Nov 16,20
The Department of History of Medicine, University of Minnesota, lecture series. All lectures will be held from 12:20–1:10 pm (except where noted) in 555 Diehl Hall on the Minneapolis campus. 10/6–“When are you Dead? 250 Years of Uncertainty in Defining and Diagnosing Death,” by Martin Pernick, PhD, 3:30-5:00 pm. 10/16–“Nurturing Empire: Medicine, Nursing and Colonialism in the Philippines,” by Catherine Ceniza Choy, PhD. 10/24–“The Hospital as House of Rituals: Historical Perspectives,” by Guenther Risse, PhD. 11/16–“Deadly Deficiencies: Dr. Joseph Goldberger’s War on Disease and Deprivation,” by Alan Kraut, PhD. 11/20–“Diabetes as Biomedical Disease: From Hit or Miss to Almost Sure Results,” by Mary Hrosckoski, MD, MA.

Oct 11-13
The Minnesota Hospice Organization will hold a conference “Hospice 2000: A Broader Vision” at the Radisson Hotel South, Bloomington, MN. For information, call 651-659-0423.

Oct 21-22
Jeffrey Kahn, PhD, MPH, will speak on ethical issues in assisted reproductive technology at the Annual Meeting of the American Society for Reproductive Medicine, San Diego, CA. For information, call 612-627-4564.

Oct 26
Dianne Bartels, RN, MA, will speak on “Who Cares About the Human Genome Project?” at the Science Museum, St. Paul, MN. For information, call 612-624-9440.

Oct 26-29
Jeffrey Kahn, PhD, MPH, will chair a pre-conference workshop on “Bioethics and the Media” at the Annual Meeting of the American Society for Bioethics and Humanities (ASBH), Salt Lake City, UT. For information, call 847-375-4745.

Nov 19-20
The Office of Research Integrity, DHHS, will sponsor a conference on research integrity in Bethesda, MD. 11/19–Jeffrey Kahn, PhD, MPH, will speak on “Assessing Training Efforts in the Responsible Conduct of Research: Status, Challenges, and Future Directions,” and Muriel Bebeau, PhD, will speak on “Influencing the Moral Dimensions of Professional Practice: Implications for Teaching and Assessing for Research Integrity.” 11/20–Jeffrey Kahn, PhD, MPH, will chair a panel discussion on “Fostering Research Integrity Through Educational Programs.” For information, call 301-670-4990.

Dec 1
Muriel Bebeau, PhD, will speak on “Treating Friends and Family: Challenges to Patient and Professional Autonomy” at the St. Paul District Dental Society Annual Meeting, St. Paul, MN. For information, call 651-697-0831.

Dec 1
Susan M. Wolf, JD will speak on “Genetic Discrimination” at the Human Rights Commission, St. Paul, MN. For information, call 651-296-5663.

Joint Degree Program in Law, Health & the Life Sciences Lecture Series
The University’s Consortium on Law and Values in Health, Environment & the Life Sciences and Joint Degree Program in Law, Health & the Life Sciences announce their 2000-2001 Lecture Series, sponsored by the law firm of Faegre & Benson. All lectures will be held at 12:15 pm in Lockhart Hall, Room 25, University of Minnesota Law School, and are open to the public. For information, call 612-625-0055 or go to http://www.jointdegree.org.

Dec 6
“Advocacy in Ecology” by Mark Sagoff, PhD, University of Maryland.

Apr 11
“The Ethics of Introduced Species” by Kristin Shrader-Frechette, PhD, Notre Dame University.

“Governing GMOs: Developing Policy in the Face of Scientific & Public Debate”
Conference on February 1, 2001
A national conference sponsored by the Consortium on Law and Values in Health, Environment & the Life Sciences; Joint Degree Program in Law, Health & the Life Sciences; and College of Agricultural, Food & Environmental Sciences, is part of the President’s Sesquicentennial Conference Series. Speakers include Roger Beachy, Danforth Plant Science Center; Perry Adkisson, Texas A&M University; Rebecca Goldberg, Environmental Defense Fund; Thomas Hoban, North Carolina State University; Rochelle Cooper Dreyfus, New York University Law School; and Paul Thompson, Purdue University.

The conference will be held from 8:30 am to 5 pm in Cowles Auditorium, Hubert H. Humphrey Institute of Public Affairs, 301 19th Avenue South, Minneapolis, MN. Space is limited and advance registration is required. For information, call 888-671-6214 or go to www.conferences.umn.edu/mn/policy.
Faculty Publications

BOOK CHAPTERS


ARTICLES/REVIEWS


Center Publications

READING PACKETS
Center packets contain an overview of legal and ethical issues, key articles, and a 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)

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.

- Ethical Issues in Managed Care (1997)—articles addressing ethical issues in managed care.
- Advance Directives (1995)—focuses on empirical research related to the dissemination, clinical use, and effects of advance directives.
- Palliative Care (1995)—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.

Reading packets are available for $5 each. All orders must be prepaid. To order reading packets or reports, make checks payable and mail to:
Center for Bioethics
University of Minnesota
Suite N504 Boynton
410 Church Street SE
Minneapolis, MN 55455-0346

Fall 2000 and Spring 2001 Semester Bioethics Courses offered at the University of Minnesota can be found on the Center’s Web site at http://www.med.umn.edu/bioethics/
Faculty and Staff at the Center

**CENTER FACULTY**

Jeffrey Kahn, PhD, MPH  
Director  
Associate Professor, Department of Medicine, University of Minnesota  
Medical School; Division of Health Services Research and Policy, School of Public Health; Department of Philosophy, College of Liberal Arts, University of Minnesota  

Dianne Bartels, RN, MA  
Associate Director  

Carl Elliott, MD, PhD  
Director of Graduate Studies, Center for Bioethics; Associate Professor, Department of Pediatrics, University of Minnesota Medical School; Department of Philosophy, College of Liberal Arts, University of Minnesota  

Steven Miles, MD  
Professor, Center for Bioethics; Department of Medicine, University of Minnesota Medical School  

John Song, MD, MPH, MAT  
Assistant Professor, Center for Bioethics; Department of Medicine, University of Minnesota Medical School  

Susan M. Wolf, JD  
Faegre & Benson Professor of Law; Professor of Law and Medicine, Law School and Center for Bioethics; Director, Joint Degree Program in Law, Health & the Life Sciences; Chair, Consortium on Law and Values in Health, Environment & the Life Sciences, University of Minnesota  

**FACULTY ASSOCIATES**

Mila Aroskar, RN, EdD  
Associate Professor, Division of Health Services Research and Policy, School of Public Health, University of Minnesota  

Muriel Bebeau, PhD  
Professor, Department of Preventive Medicine and Pediatrics, University of Minnesota Medical School; Department of Philosophy, College of Liberal Arts, University of Minnesota  

Ronald Cranford, MD  
Professor of Neurology, University of Minnesota Medical School; Medical Director, University of Minnesota Center for Spirituality and Healing; Staff Physician, Community-University Health Care Center  

Beth Virnig, PhD, MPH  
Assistant Professor, Division of Health Services Research and Policy, School of Public Health, University of Minnesota  

**VISITING FACULTY**

Raymond DeVries, PhD  
Young-Rhan Um, RN, PhD  

**POST-DOC TORAL FELLOW**

Terri Peterson, PhD  

**GRANTS COORDINATOR**

Thomas Schenk  

**RESOURCE CENTER DIRECTOR**

Gay Moldow, RN, MSW, LICSW  

**ADMINISTRATIVE STAFF**

Candace Holmbo  
Administrator  

LeeAnne Hoekstra  
Administrative Aide  

Karen Howard  
Principal Secretary  

Heather Cumings-Steen  
Senior Office Specialist  

Kristen Steiner  
Information Technician  

**RESEARCH ASSISTANTS**

Matt Bower  
Remo Ostini  
Susan Parry  
Elizabeth Trice  

The Bioethics Examiner is produced quarterly by the Center for Bioethics, University of Minnesota, free of charge. The editorial staff has sole authority over and responsibility for the content of this publication. We welcome comments, letters, and contributions. No part of this publication may be reproduced in any form, without the express written consent of the Center for Bioethics.