Change can be good, and as you can see we are making some changes here at the Center. First, this publication has a new design and some new content to go along with our new Web site (http://www.med.umn.edu/bioethics/) and the Center’s new name. Our latest news is that after a national search we have appointed a new member to our faculty. Carl Elliott, MD, PhD, will join the Center in July 1997. Dr. Elliott brings a wealth of experience in bioethics research and education, and an impressive record of scholarship. He will take on the task of administering the Graduate Minor in Bioethics, with a view towards expanding graduate education in bioethics at the University. We look forward to his arrival this summer.

We’ve changed our name and our look to reflect the constantly changing and contemporary nature of our work. What hasn’t changed, however, is our commitment to advance the understanding of cutting edge issues in bioethics and to serve as a vital resource for meeting new challenges in the field. All this bodes well for the future of the Center and for bioethics at the University, in Minnesota, and for what we can offer as a nationally prominent Center.

Freedom, Privacy, and Dignity in Long-Term Care: Can and Should These Values be Emphasized for Elderly People?

*By Rosalie Kane, DSW*

Long-term care refers to any personal care or routine nursing service that might be needed over a sustained period of time to compensate for functional impairments. Such functional impairments include deficits in basic self-care abilities such as dressing, bathing, eating, using the toilet, or getting in and out of bed. Long-term care users also may be unable to independently cook, clean, do laundry, shop, communicate on the telephone, transport themselves places, or take medicine. By far the greatest public investment in long-term care is for nursing home care, a more than $50 billion bill, which is half covered by federal and state money, mostly under Medicaid for those whose long-term care costs exceed their incomes and assets. Substantial public and private money is also expended for in-home care, but paid long-term care services at home are dwarfed by the care and help provided by family members without compensation.

In the last decade, new forms of residential long-term care have become available for older people, including care in private family homes (sometimes known as adult foster homes), in boarding homes, and in apartment-type settings. The term assisted living is sometimes used to connote models of residential care that are organized along social rather than medical lines, and the trend toward licensing assisted living and subsidizing its care is marked by lively debates about who can safely be served in such settings. Another recent trend in long-term care is to provide resources directly to older low income people needing the care of family agents so that clients can purchase the help they need. This development is accompanied by concerns. What if the money is spent unwisely, clients hire incompetent care providers, professional oversight is insufficient, or family members exploit vulnerable older people?

Long-term care in nursing homes is an unloved program, widely dreaded and abhorred by its beneficiaries. In contrast, Americans seem to admire and respect hospitals and physicians while worrying about the personal and societal
cost of modern medicine and whether they will have access to its wonders. But nursing homes are the fall-back position when authorities view a home care program that would be equivalent or less in price than the nursing home setting. If a licensed nurse needs to visit a home four times a day to administer a medication, this service alone usually exceeds the price of a Medicaid nursing home day, leaving aside any personal care or housekeeping help that might be required. Whether people without nursing licenses should be able to give medicines or do other nursing tasks — thus bringing the price of care down — is formulated as a safety issue (Kane, O’Connor & Baker, 1994).

The intent was that case managers take 15-20 minutes to systematically explore both the content and strength of client preferences in the following areas: everyday routines, activities in and out of the home, personal privacy, involvement or non-involvement of family members in their care, pain control, and the tradeoffs between protection and safety versus freedom. The protocol also aimed to develop care plans that were differentiated (i.e. less “cookie cutter”) and more responsive to client preferences. After a start-up period when the assessments and related interventions were incorporated into practice, a comparison was made between newly enrolled clients in the experimental group and matched comparison program in the same state. The findings, not yet published, show some modest benefits of the effort.

More recently, we studied long-term care plans for people living in the community. With the involvement of Medicaid waiver programs in two states, we developed and tested a protocol by which case managers who authorize and allocate in-home services added to their routine assessments a brief discussion of each older person’s own values and preferences related to their care. The study was designed to be important, were pessimistic about being able to alter the situation.

By and large, ethicists have paid little attention to long-term care and the characteristics preferred in somebody helping with care.

An analysis of more than 800 completed values assessment protocols revealed that elderly long-term care clients vary in their preferences and that the importance of preferences was statistically related to the content. (Kane & Degenholtz, in press). For example, those who prefer a highly organized daily routine are more likely to rate this “very important” than those who describe a preference for a varying and flexible daily routine. The privacy area tended to be rated as very important, but the elaboration showed different meanings of privacy — bodily privacy, being alone, privacy around possessions and finances. Many clients were ambivalent about the safety-freedom tradeoffs; about 1/3 preferred to sacrifice safety in order to come and go as they please, 1/3 preferred the opposite, and almost 1/3 were unable to choose, saying they wanted both safety and freedom.

The fielding of the values assessment protocols was done in the context of a demonstration project to determine whether systematic attention to assessing client values and preferences could lead professional case managers to develop care plans that were differentiated (i.e. less “cookie cutter”) and more responsive to client preferences. After a start-up period when the assessments and related interventions were incorporated into practice, a comparison was made between newly enrolled clients in the experimental group and matched comparison program in the same state. The findings, not yet published, show some modest benefits of the effort.

By and large, ethicists have paid little attention to long-term care other than to examine end-of-life issues that eventually arise in long-term care settings and for long-term care clientele. The work in ethics done at the University of Minnesota’s Long-Term Care Resource Center, a little of which has been summarized here, is dedicated to everyday life of the person needing long-term care. At the policy level, we are examining how long-term care might be organized to promote choice, dignity, independence, and “normal lifestyles.” Safety concerns loom large as the rationale for the dominant pattern of services for a population deemed vulnerable. Such safety issues are linked to costs. For example, if people were not packed two to a room and bath in nursing homes, the revenue generated would be insufficient for even current staffing standards.
Worthy of attention are questions such as: Under what circumstances should an older long-term care user be able to make an informed decision to waive a professional prescription for a safe plan? When are such waivers, sometimes called “managed risk contracts” tantamount to accepting negligent care? Must safety always trump, and are we using too narrow a view of what is safe?

References
Kane RA and Degenholtz H. (In press). “Assessing values and preferences: Should we, can we?” Generations.

Faculty Profile
Rosalie Kane, DSW

Rosalie Kane, DSW, is a professor in the Division of Health Services Research and Policy at the School of Public Health and a Faculty Associate at the Center for Bioethics. A researcher and policy analyst concentrating on long-term care, since 1988 she has directed the National Long-Term Care Resource Center (LTCRC) which examines, as part of its mandate, ethical issues related to long-term care programs and policies. Current projects with ethics implications include: a focus group study of consumer perspectives on privacy in assisted living (funded by the American Association of Retired Persons); an exploration of the tradeoffs between safety and freedom in long-term care (funded by The Retirement Research Foundation); and an examination of appropriate roles for family members in long-term care (an outgrowth of a study funded by the National Institute on Aging). In the past 5 years, the LTCRC has studied Nurse Practice Acts, looked at positive and negative relationships between long-term care regulations and personal autonomy of long-term care clientele, and examined the legal and moral implications of professionals giving or refraining from giving direct recommendations and advice about long-term care providers. With funding from the Robert Wood Johnson Foundation, Dr. Kane is presently conducting a far-reaching evaluation of assisted living programs in the state of Oregon where, by design, the service incorporates privacy and risk-taking for frail elderly long-term care clients.

Selected Publications:

Books


Chapters in Books


Registration is underway for the MIBC, a course designed for those interested in gaining both a foundation in bioethics and a deepened understanding of current issues in bioethics. The course, hosted by the Center for Bioethics, University of Minnesota, is jointly sponsored by the Bioethics Centers at the University of Wisconsin and the Medical College of Wisconsin. Sessions include: a history of bioethics; theoretical background of bioethics; the history of informed consent; ethics in nursing; challenges of race, ethnicity, and gender for bioethics; interrelationships between law and bioethics; legal, moral, and professional views on agency, loyalty, and trust; reproductive health care; genetic technologies; ethical issues in long term care; confidentiality; managed care; access, priorities, and conflicting values in financing and delivery of health care; ethics committees & ethics consultants; development of organizational ethics plan; research ethics throughout the health care system; medical decisions at the end-of-life; advance directives; medical futility; and physician-assisted suicide.

Course faculty include: Mila Aroskar, RN, EdD, Dianne Bartels, RN, MA, Muriel Bebeau, PhD, Allen Buchanan, PhD, R. Alta Charo, JD, Ronald Cranford, MD, Patricia Crisham, PhD, RN, Arthur Derse, MD, JD, Kathy Faber-Langendoen, MD, Robert Gatter, JD, MA, Jeffrey Kahn, PhD, MPH, Rosalie Kane, DSW, David Mayo, PhD, Steven Miles, MD, Robyn Shapiro, JD, and Susan Wolf, JD.

The University of Minnesota Office of Continuing Education is the accrediting sponsor. Continuing education credits available: 25.5 credit hours for physicians; 30.5 contact hours for nurses; and 3.0 Continuing Education Unit (CEU) for other professions.

Registration is available by telephone, mail or fax. Tuition fees are: residential $1200 (includes lodging Sun-Wed nights) and non-residential $950. Fee includes reception, daily continental breakfast and lunch, accreditation and processing, course materials and refreshment breaks. Group discounts are available to organizations registering five or more people.

Course location is the Sheraton Metrodome Hotel, 1330 Industrial Boulevard, Minneapolis, MN. Brochures and the course schedule are available from the Center. Contact the Center for Bioethics at the University of Minnesota to reserve your place or to receive further information.

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The University of Minnesota National Long-Term Care Resource Center

The University of Minnesota National Long-Term Care Resource Center was established in October 1993 as a partnership of the Institute for Health Services Research at the University of Minnesota’s School of Public Health and the National Academy for State Health Policy. The Center’s mission is to promote effective long-term care (LTC) decision-making by persons seeking long-term care and their families, LTC professional practitioners; and LTC program administrators, planners, and policymakers. The Center is dedicated to facilitating responsive, inventive, and effective approaches to LTC. The Center conducts technical assistance, training, research and development, and information dissemination. Through the Center activities, Center staff strive to help state and local long-term care officials, administrators, and practitioners with:

• Identifying and resolving ethical issues that arise at the policy, programmatic, or practice levels;
• Designing flexible LTC programs that foster consumer choice and autonomy;
• Building skills in LTC program development, policy analysis, and case management;
• Keeping up with current LTC research findings;
• Exploring best practices models;
• Examining LTC in light of federal and state policy directions;
• Interpreting LTC implications of acute-care policy;
• Linking LTC to acute care, rehabilitation, housing, and aging services

For further information and a list of publications, please contact:
Health Services Research and Policy Division, University of Minnesota School of Public Health, 420 Delaware Street SE, Box 197, Minneapolis, MN 55455.
Telephone: 612-624-5171; Fax 612-624-5434.
Center News

Chris Herrera, PhD, has been awarded the 1997-98 Post Doctoral Fellowship in the Center. Dr. Herrera will begin the fellowship on July 21, 1997. His research will center on the ethics of human subjects research, primarily focusing on how the ethics of particular professions may result in different standards for the ethics of research.

Wayne Hartley, research assistant, won the Class of 1954 Clerkship Award for his paper "Evaluation of Integration Opportunities for Allina Child and Adolescent Behavioral Health Sciences" from the Health Care Consulting Division of Kurt Salmon Associates, Inc.

The editor of the Bioethics Examiner is soliciting "letters to the editor" on topics in bioethics. Please send articles, questions and comments to the editor.

Faculty News

Steven Miles, MD and Susan Wolf, JD, were among 49 bioethics professors signing a friend of the Court brief to the United States Supreme Court arguing that neither the right to refuse life-sustaining treatment nor the right to terminate a pregnancy requires or supports the existence of a constitutional right to physician-assisted suicide.

Steven Miles, MD, and Stuart Youngner, MD, of Case Western Reserve University, have been appointed Adjunct Professors of Medical Science at the University of Havana, Cuba. They are the first US professors to receive such appointments since Fidel Castro came to power. They have traveled to Cuba on a number of occasions with US government permission to teach and work with Cuban medical educators to modify the training in bioethics in Cuban medical schools.

Recent Faculty Publications


Faber-Langendoen K. “A Multi-institutional Study of Care Given to Patients Dying in Hospitals: Ethical and Practice Implications.” Archives of Internal Medicine, 1996; 156:2130-2136.


Visions for Ethics & Humanities in a Changing Healthcare Environment

November 5 - 9, 1997

The joint meeting 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, in Baltimore, MD. The theme for this year’s meeting is meant to provoke reflection on both the perils and possibilities inherent in the rapid changes now taking place in the American healthcare system, and in healthcare systems throughout the world. Three themes will organize the featured sessions: institutions, technology, and culture. Sessions include case presentations, paper presentations, workshops, works in progress, and posters.

For information, contact the SHHV, 6728 Old McLean Village Drive, McLean, VA 22101. Telephone: 703-556-9222. Email: shhv@aol.com.
Calendar of Events

April 25
Susan Wolf will participate in a panel on physician-assisted suicide at Princeton University’s 250th Anniversary Event “Princeton and the Healing Arts: From Lab to Leadership.” For information, contact the Center for Visitor & Conference Services, Princeton University at 609-258-3901.

April 28
Jeffrey Kahn will speak on “Ethical Issues in Genetic Testing for Alzheimer’s Disease” at the Alzheimer’s Disease: A Multidisciplinary Challenge conference at the Department of Veterans Affairs, Minneapolis, MN. For information, contact Carol Kluevein at 612-725-2051.

May 1
Jeffrey Kahn will be faculty for a half-day symposium on “Practical Clinical Research Ethics” at the 20th Annual National Meeting of the Society of General Internal Medicine in Washington, DC. For information, contact the Center for Bioethics, University of Minnesota.

May 6
Jeffrey Kahn will speak on “Of Vulnerability and The Collective Good: The Case of Cold War Radiation Experiments,” in the University of Minnesota course, BIOL 5951, Social Uses of Biology. For information contact the Center for Bioethics, University of Minnesota.

May 7-18
Illusion Theater presents it’s acclaimed production of “For Our Daughters.” The play combines filmed interviews of breast cancer survivors along with theatrical scenes illuminating the journey from detection through recovery. For information, contact: Illusion Theater, 528 Hennepin Avenue, Suite 704, Minneapolis, MN 55403. Telephone: 612-339-4944.

May 12
Steven Miles will speak on “Ethics and the American Health Care System” at the Cooperative Older Adult Ministry (COAM) Life Enrichment Series at Bethel Lutheran Church, 4120 17th Ave South, Minneapolis, MN. 10:45-11:45 am. For information, phone 612-721-5786

May 14
Steven Miles will speak on “Healthcare for the Under-served” at the United Hospital Conference, 3:00-4:15 p.m., at the United Hospital Heart Lung Conference Center in St. Paul, MN. For information, phone 612-992-2000.

May 14
Jeffrey Kahn will speak on “From Atomic Experiments to Heart Transplants: A Short History of American Bioethics,” for the Sarah D. Wangensteen Lecture Series, University of Minnesota. For information, contact Elaine Challacombe at 612-626-6881.

May 15
Steven Miles will speak on “The Human Condition: An International Perspective” at the St. Thomas Senior Citizens Education Spring Program, on the University of St. Thomas campus, Brady Center Auditorium, 10:00-12:00 p.m. For information, phone 612-962-5188.

June 4-8
The Association for Practical and Professional Ethics will sponsor a workshop, “Graduate Research Ethics Education,” at Indiana University. For information, contact: Brian Schrag, PhD, Project Director, Graduate Research Ethics Education, Association for Practical and Professional Ethics, 410 North Park Avenue, Bloomington IN, 47405. Telephone: 812-855-6450.

June 7
Susan Wolf will speak on feminism and bioethics at the American Society of Law, Medicine & Ethics Annual Health Law Teachers Conference in Newark, NJ. For information, phone Celia Leonard at 617-262-4990.

June 18
Jeffrey Kahn will speak at a seminar on “Confidentiality of Substance Abuse Patient Records” in Minneapolis, MN. For information, contact Lisa Forman at 414-798-5242.

June 22-26
The Midwest Intensive Bioethics Course (MIBC), at the Sheraton Metrodome in Minneapolis, MN. For registration material or information, contact the Center for Bioethics, University of Minnesota.

June 25
Susan Wolf will deliver the keynote address on “Race, Ethnicity, and Gender: The Challenge to Bioethics” at the Advanced Bioethics Day workshop, “Cultural Diversity in Health Care Ethics,” sponsored by the Center for Ethics and the Humanities at Michigan State University. For information, phone Dr. Leonard Fleck at 517-355-7552.

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 4-8
“European Bioethics Seminar: Health Care Issues in Pluralistic Societies,” in Nijmegen, The Netherlands. For information: Dr. B. Gordijn, Catholic University of Nijmegen, 232 Dept. of Ethics, Philosophy and History of Medicine, P.O. Box 9101, 6500 HB Nijmegen, The Netherlands. Tel: [31] (0)24-3615320. E-mail: b.gordijn@efg.kun.nl

September 11-13

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

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

VIDEO TAPES
A series of 12 educational video tapes (VHS) from the conference, “Managing Mortality: Ethics, Euthanasia and the Termination of Medical Treatment,” (December 1992). The tapes provide family perspectives on ethical issues at the end-of-life. Tapes are $20 each or $200 for the complete set.

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.

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 1991)
No. 6: Resuscitation Decisions (revised February 1993)
No. 7: The Determination of Death (revised February 1993)

BOOKS BY FACULTY
Feminism & Bioethics: Beyond Reproduction edited by Susan M. Wolf, Associate Professor of Law & Medicine, University of Minnesota Law School; Faculty member at the Center for Bioethics. A volume of original essays explores how feminist analysis can transform bioethics. Scholars in bioethics and feminist theory take gender-aware work in bioethics beyond its traditional domain — reproduction — to tackle the full range of bioethics issues. New York: Oxford University Press, 1996. ISBN #0-19-509556-1.

END OF LIFE CARE
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 and articles describing and comparing hospice care to conventional care for terminally ill persons.
• What Minnesotans Think About Health Care Resource Allocation—a synopsis of findings from an extensive Harris Poll survey of Minnesotans (March 1994).
• Advance End-of-Life Treatment Planning: A Research Review—a synopsis of empirical studies of the use of advance directives and their effect on the provision of health care at the end of life. This publication replaces 49 Things That Are Known About Advance Directives (and IX things that are not known).
• Managed Care Outcomes Bibliography—compares the outcomes of managed care organizations with those of traditional fee for service reimbursement insurance. The bibliography contains peer-reviewed articles and is periodically updated.

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.


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, 2221 University Avenue SE, Suite 110, Minneapolis, MN 55414-3074. All orders must be prepaid.

The Summer 1997 publication deadline is June 15. Please send inquiries, comments and announcements to Candace Holmbo at the Center for Bioethics.

E-mail: holmbo006@tc.umn.edu

Feminism & Bioethics
Edited By Susan M. Wolf