I recently came across an article in the New York Times describing an annual interventional cardiology conference in Washington, DC, called the "Transcatheter Cardiovascular Therapeutics" meeting. (Kolata, 1998) According to the report, this is a meeting that looks like a typical scientific meeting, with scientific sessions devoted to issues in invasive cardiology. But rather than the usual schedule of presentations of results of the latest research, the program is developed by peer-review selection of submitted abstracts, this meeting is entirely devoted to the kinds of marketing presentations usually seen in conference exhibit halls. What makes this approach troublesome is that there is no overt distinction between research presentations and marketing and, in fact, the sessions can be described as marketing dressed to look like scientific presentations. Along with information, these presentations offer physicians financial inducements to enroll their patients in trials of new drugs or devices. It is not so much the message that is troubling but the means by which the message is delivered, and the implications of the offers for clinical practice and the physician-patient relationship.

As the newspaper account of the conference points out, some of the practices associated with this meeting violate the voluntary AMA ethics guidelines. First, as part of...
Nondirectiveness has long been a guiding value for counselor practice, yet it has been a source of considerable discussion among genetic counselors in recent years. (Bartels, LeRoy, McCarthy, Caplan, 1997) It is not clear how this norm is translated into clinical practice.

To examine the norm of nondirectiveness, we surveyed practicing genetic counselors about the importance and meaning of nondirectiveness in their practice. More than 95 percent of respondents believe that nondirectiveness is very important. Their definitions included three consistent themes. First, nondirectiveness means giving adequate information about all options. Second, client values, not counselor values, should influence genetic decisions. Finally, many respondents indicated that they must be objective, presenting information in a non-biased way. We then asked counselors whether they were ever directive in their practice. Surprisingly, 72 percent of counselors indicated that they have, at times, been directive. Many counselors wrote lengthy, often apologetic descriptions of specific situations in which they responded directly.

The most frequently mentioned problem was uncertainty about whether all verbal and nonverbal responses could ever be nondirective. They also were directive in recommending genetic testing in search of a diagnosis or in recommending medical care or further counseling to address an identified problem. Finally, although mentioned infrequently, counselors were directive in interactions with clients who were not able to understand, were unable to select a course of action, or weren't empowered to make an autonomous decision.

How one responds to assist unformed or disempowered people needs careful considerations. Genetic counselors have expertise in genetics, but do not necessarily have cultural or moral expertise to assist such troubled clients. An alternative to a directive response is to seek assistance from people within the client's families or communities. They could help the client to examine the issues from a perspective of commonly held values.

In most of the incidents in which counselors reported they acted directly, they intended to provide clients with relevant information, medical assistance to diagnose a problem, or to present alternatives that could prevent a severe problem in the future. One counselor indicated that she would only be directive where a child's health was at risk. An example was to recommend to parents that they follow a specific diet that would prevent the development of disease symptoms in a child.

Counselors indicated concern about ever being directive. But recommending further tests or encouraging medical treatment to avoid medical harm are certainly appropriate behaviors for all health care professionals. Holding a standard of universal nondirectiveness ignores the fact that counselors must be directive about the process of genetic counseling. Clients who seek genetic counseling deserve a process that will give them sufficient information and support to make difficult decisions. If the process is managed well, clients will be prepared to make health outcome decisions that are free from coercion and consistent with their own values.

References

Center Awarded Grant on “Genetics in Primary Health Care: Addressing Professional and Ethical Challenges”
Principal Investigator Dianne Bartels and Co-Investigators Bonnie LeRoy and Patricia McCarthy Veach have been awarded a three year $368,106 grant from the Josiah T. Macy, Jr. Foundation to support their research on genetic counseling.

Genetic counseling and screening are becoming an important tool for primary care practitioners, yet little systematic work has been done to identify the ethical concerns of professionals in the field. The project will conduct focus groups and national surveys to identify salient ethical issues in providing care to clients with genetic concerns. In the final phase, educational materials will be developed to educate primary health care practitioners about the professional and ethical issues inherent in genetic counseling services and to offer them a rationale and strategies for addressing these challenges.
Faculty Profile
Dianne Bartels, RN, MA

Dianne Bartels has been Associate Director of the Center for Bioethics since 1987. Her undergraduate nursing programs were at St. Mary's School of Nursing, Minneapolis, MN and Marycrest College, Davenport, IA. She received her Master's degree in psychosocial nursing from the University of Washington in 1975. Her experiences in nursing and nursing administration prompted her to study bioethics. "All of the unanswered and challenging questions finally seemed to fit into a pattern of ethical concerns," says Bartels.

She was an early member and one of the founders of the Minnesota Network of Ethics Committees. Her participation in ethics committees and ethics consultation confirmed that understanding ethical theories and principles can contribute to the quality of daily life for patients, families, and employees in health care facilities.

Another way she addresses challenging ethical questions is by conducting research. In her research, she has focused primarily on ethical questions that arise at the "edges of life." Under a project entitled Humane Care of the Dying, she and Kathy Faber-Langendoen, MD and their collaborators conducted several studies that examined end-of-life treatment and decision-making in hospitalized patients. M. Bartels' other current research focuses on the roles of genetic counselors and the norms that drive practice, in collaboration with University of Minnesota colleagues Bonnie LeRoy and Patricia McCarthy Veach. She concludes from these projects that her life, as well as her scholarship, is greatly enhanced by working with people from diverse backgrounds and professional roles.

Ms. Bartels is currently enrolled in the University of Minnesota's doctoral program in Family Social Science. Her work focuses on how health care challenges at both the beginning and at the end of life are clearly family matters. She believes that the real challenge for the future of health care will be to develop systems and models of care where family and community count.

Selected Publications:

Books

Book Chapters

Articles
The debate over whether to legalize physician-assisted suicide reached new intensity with the litigation of Washington v. Glucksberg and Vacco v. Quill in the Supreme Court last term. The Court’s June 1997 decisions found no constitutional bar to state bans on assisted suicide and returned the issue to the states. But the Justices’ opinions raised a host of questions and fueled a larger policy debate over what the states should do now.

To address these issues, the Minnesota Law Review presents a symposium on “Physician-Assisted Suicide: Facing Death After Glucksberg and Quill” in its April issue. Center faculty member Susan Wolf organized the symposium as Chair-elect and now Chair of the Association of American Law Schools (AALS) Section on Law, Medicine and Health Care. The Section presented the authors on a panel at the annual meeting of the AALS in January. Both the panel and the printed symposium were partly supported by the Center for Bioethics.

The symposium featured a wide range of perspectives:
- Foreword: Facing Death by Susan Wolf
- On the Meaning and Impact of the Physician-Assisted Suicide Cases by Yale Kamisar
- The Death with Dignity Movement: Protecting Rights and Expanding Options after Glucksberg and Quill by Kathryn Tucker
- Physician-Assisted Suicide in the Courts: Moral Equivalence, Double Effect, and Clinical Practice by Howard Brody
- Disorder in the Court: Physician-Assisted Suicide and the Constitution by Robert Burt
- The Future of Euthanasia and Physician-Assisted Suicide: Beyond Rights Talk to Informed Public Policy by Ezekiel Emanuel
- Empowering and Protecting Patients: Lessons for Physician-Assisted Suicide from the African-American Experience by Patricia King and Leslie Wolf
- Birth and Death: Doctor Control vs. Patient Choice by Sylvia Law
- Pragmatism in the Face of Death: The Role of Facts in the Assisted Suicide Debate by Susan Wolf

1998 Midwest Intensive Bioethics Course
Methods in Bioethics: Philosophy, Law, Narrative
July 13-17, Chicago, IL.

This intensive educational experience in biomedical ethics is practical, but also stimulating and pleasurable. The course will explore issues concerning decision-making for neonatal and pediatric patients, the process of informed consent, ethical issues raised by managed care, end-of-life decision making, and reproductive technologies. These are the issues, but the theme will be the approaches that health care professionals, philosophers, lawyers, and narrative theorists take to address these problems. Case discussion, history, literature, and film will be used to illuminate the ethical problems of health care delivery within an interactive, problem-solving environment.

The MIBC will be hosted by Northwestern University Medical School in downtown Chicago, and is co-sponsored by the Center for the Study of Bioethics, Medical College of Wisconsin; the University of Minnesota Center for Bioethics; and the Program in Medical Ethics, University of Wisconsin. Faculty include Tod Chambers, Art Derse, Carl Elliott, Norm Fost, Rob Gatter, Kathryn Hunter, Carl Junkerman, Jeff Kahn, Mark Kuczewski, Skip Nelson, and Robyn Shapiro.

Tuition for the five day course is $700. A limited number of partial tuition scholarships are available. Students may attend for $250. A block of rooms have been arranged at a hotel nearby for $79/day. Dormitory accommodations are also available at $21/day. For additional information, contact Kristen Tym at the Medical College of Wisconsin by email: ktym@mcw.edu, phone: 414-456-4299, or fax: 414-456-6511. Continuing Education Units (CEUs) and Nursing Contact Hours are being sought.
New Faculty
Gregory Plotnikoff, MD, MTS, and Jonathan Cohen, MD, MPH, have been appointed as faculty associates at the Center.

Dr. Plotnikoff is Assistant Professor in Internal Medicine and Pediatrics, University of Minnesota Medical School, and Medical Director of the University of Minnesota Center for Spirituality and Healing.

Dr. Cohen is Assistant Professor, Department of Medicine, University of Minnesota, and Director of Emergency Medicine and Urgent Care, Minneapolis VA Medical Center.

Both join the Center's group of faculty associates who provide a wide range of perspectives and knowledge of bioethics.

Spring Quarter Course Offerings
For information on these and other courses, see the Center's web site, or call the Center for Bioethics at 612-624-9440.

PHIL 5760:
Ethics and Psychiatry
Elliott
Focuses on ethical issues in psychiatric treatment and research.

NURS 5609:
Cultures, Faith Traditions, and Healthcare
Plotnikoff
Examines the cultural and spiritual implications of health care practices of selected native and immigrant populations in Minnesota.

Conference attendance, physicians are given assorted gifts by device manufacturers, such as computer cases and concert tickets—this violates the guideline that physicians should not receive gifts that do not primarily entail a benefit to patients and should not be of substantial value. Second, there is substantial financial support for speakers' meeting expenses by device manufacturers—this violates the guideline that direct or indirect subsidies from industry should not be accepted to pay for costs of travel, lodging or other personal expenses. This meeting is the latest but certainly not the only form of direct marketing in medicine. Every news weekly has pages of advertisements for the latest prescription drug for hypertension or to reduce cholesterol. In a more disturbing trend, prescription drugs are now being directly marketed to patients with mental illness.

What is so bad about these types of overt marketing meetings and direct advertising to patients? First, marketing incentives to physicians undermines the physician-patient relationship by introducing additional financial incentives for treatment decisions. The gatekeeper role physicians are increasingly asked to fill brings with it tensions arising from responsibility for resource utilization and cost consciousness. When financial incentive for patient recruitment is added, it is difficult to argue that patient advocacy can be adequately served, and can only further erode the waning trust patients express in the physician-patient relationship.

Second, encouraging both physicians and patients to use or demand expensive new drugs or therapies drives up medical costs, which further exacerbates the need for medical gatekeepers and further strains the physician-patient relationship. Third, such marketing is a way to shortcut the typical path for the adoption of new technologies or approaches, effectively creating a standard of care by demand and incentive rather than by research and consensus. Last, when physicians offer “new” but unproven devices or drugs as part of patient care, they are recruiting patients to be research subjects. Because the physicians may not be engaged as researchers themselves, there is even greater risk that patients will be confused that the new approach is an innovative improvement rather than the subject of research. Yet patients assume just as much risk when they are recruited by their treating physicians as when they receive care at a research hospital. The challenges of cost containment, rational adoption of new technology, and the evolution of the physician-patient relationship are all increasingly complex in the changing health care environment. Incentives that undermine our efforts to face these challenges do a disservice to us all.

References
Calendar of Events

APR 19
Steven Miles, MD, will speak on "Issues of Bioethics in Corrections" at the Ages of Corrections: Health Care Under Lock and Key national conference in St. Paul, MN. For information, call Jeanne Schumacher at 937-586-3708.

APR 20
Jeffrey Kahn, PhD, MPH, will participate on a panel, "A Healing Journey," at the St. Paul Jewish Community Center in St. Paul, MN. For information, call Laurie Kramer at 612-698-0751.

APR 21
Steven Miles, MD, will speak on "Ethical Dilemmas and Changing Times" at the American Nephrology Nurses Association meeting in Mankato, MN. For information, call Kathy Sonnek at 507-389-4615.

APR 23
Susan Wolf, JD, will speak on "Physician-Assisted Suicide" at the Harry Rogers Educational Conference in Edina, MN. For information, call Judy Stitt at 612-924-5109.

APR 24
Steven Miles, MD, will speak on "Managed Care in the New Millennium: Ethical Perspectives" at the St. Luke's Hospital and Regional Trauma Center in Duluth, MN. For information, call Cheryl Jurick at 218-726-5449.

APR 28
Jeffrey Kahn, PhD, MPH, will participate in the Minnesota Public Radio Civic Journalism Initiative Symposium, "What Role Should Religion Have in Public Life?" at the University of Minnesota, MN. For information, call Leonard Witt at 612-290-1262.

APR 29
Jeffrey Kahn, PhD, MPH, will deliver the keynote address, "Paying for Health Insurance in the Future: Ethical and Policy Issues," at the Minnesota Department of Employee Relations Conference in Bloomington, MN. For information, call Dave Haugen at 612-296-3159.

APR 30
Jeffrey Kahn, PhD, MPH, will speak on "Dealing with Today's Bioethics Issues" at the University of Minnesota Chapter of the Gama Sigma Delta recognition program at the University of Minnesota. For information, call Alan Hunter at 612-624-7455.

APR 30
Mila Aroskar, RN, EdD, will speak on "Current Issues in Bioethics" at the Lake Minnetonka Area Women's Club in Minnetonka, MN. For information, call Jo Damhof at 612-476-5232.

MAY 1
Steven Miles, MD, will speak on "Ethics Committees and Alternative Therapies and Re-humanizing Nursing Homes" at the Minnesota Health Educators Conference in Alexandria, MN. For information, call Janet Jaeger at 320-231-2950.

MAY 8
Steven Miles, MD, will speak on "Managed Palliative Care in the Nursing Home: A Work in Progress" at the American Geriatrics Society's 1998 Annual Meeting in Seattle, WA. For information, call Enid Ringer at 212-961-9740.

MAY 9
Steven Miles, MD, will speak on "Physician-Patient Relationships in Managed Care: Solving Ethical Problems" in Sacramento, CA. For information, contact Leah Morris at 916-922-4755.

MAY 15
Steven Miles, MD, will be the opening speaker at the Minnesota Association of Patient Representatives 1998 Spring Conference in Prior Lake, MN. For information, call Dee Hance at 612-682-1212.

MAY 21
Steven Miles, MD, will speak on "Ethics of Managed Care" at Sholom Home West in Minneapolis, MN. For information, contact Doris Sherman at 612-593-2600.

MAY 22
The Center for Bioethics, University of Pennsylvania presents, "Families on the Frontier of Dying" at the Ritz Carlton Hotel in Philadelphia, PA. The conference is co-sponsored by the University of Minnesota Center for Bioethics. For information, contact: Center for Bioethics, UPHS, 3401 Market Street, Suite 320, Philadelphia, PA, 19104. Email may be directed to rouse@mail.med.upenn.edu

JUN 3-7
Indiana University hosts its "Graduate Ethics Education Workshop" on the campus of Indiana University in Bloomington, IN. For information, contact Brian Schrag at 812-855-6450.

JUN 6
Susan Wolf, JD, will speak on "Cloning" at the Annual Health Law Teachers Conference in Houston, TX. For information, call Cathy Ruph at 713-743-2106.

JUN 16-JUL 24
Michigan State University hosts its 13th annual "Medical Ethics and the History of Health Care" program in London, England. For information, call 517-353-8920.

JUN 29
Jeffrey Kahn, PhD, MPH, will speak on "Ethical Issues and Medical Mistakes" at the University of Minnesota Law and Politics Seminar in Minneapolis, MN. For information, call Julie Snykin at 612-335-8808.

JUL 10
Steven Miles, MD, will speak on "Medical Ethics" at the University of Minnesota Orthopedic Surgery Grand Rounds. For information, call Marcy Cook at 612-625-2157.

JUL 13-18
The Midwest Intensive Bioethics Course will be held in Chicago, IL. For information, call the Center for the Study of Bioethics, Medical College of Wisconsin at 414-456-8498.
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.

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 (August 1997)
No. 2: Withholding or Withdrawing Artificial Nutrition and Hydration (July 1997)
No. 3: Termination of Treatment of Adults (September 1997)

No. 4: Baby Makers: The New Ethics of Reproduction (October 1995)
No. 5: Distributing Limited Health Care Resources (April 1997)
No. 6: Resuscitation Decisions (June 1997)
No. 7: The Determination of Death (May 1997)

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:

• References on 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


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, University of Minnesota, Suite N504, 410 Church Street SE, Minneapolis, MN, 55455. All orders must be prepaid.

Recent Faculty Publications


Faculty and Staff at the Center

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Dianne Bartels, RN, MA  
Associate Director

Carl Elliott, MD, PhD  
Associate Professor  
Co-Director of Graduate Studies

Steven Miles, MD  
Associate Professor, Center for Bioethics; Department of Medicine, University of Minnesota Medical School; Staff Physician, Department of Internal Medicine, Regions Medical Center

Susan Wolf, JD  
Associate Professor of Law and Medicine, University of Minnesota Law School and Center for Bioethics

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**AMERICAN ASSOCIATION OF BIOETHICS**

The AAB has merged with the Society for Health and Human Values and the Society for Bioethics Consultation to form the American Society for Bioethics and Humanities (ASBH). For information, contact: ASBH, 4700 West Lake Avenue, Glenview, IL 60025, 847-375-4745.

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