Dealing with the Deluge:
Care for Persons with Dementia and their Families
By Muriel Ryden, PhD, RN

We are seeing “the failure of our success” as improvements in public health and medical science have enabled more and more people to live to an age where they become vulnerable to Alzheimer’s Disease, the most common dementing illness. The relentless increase in the prevalence of Alzheimer’s Disease that accompanies aging assumes epidemic proportions among the old-old. The ripple effect that has been felt throughout society by the needs and demands of baby boomers as they moved from infancy to maturity is about to further roil the waters as this group reaches late life. Foresighted policy makers and leaders in health care anticipate with trepidation the troubling consequences of a future deluge of dementia.

Hubert Humphrey said, “The moral test of government is how it treats those who are at the dawn of life, the children; those who are in the twilight of life, the aged; and those who are in the shadow of life, the sick, the needy, and the handicapped.” For family networks, communities, and society at large, thorny ethical concerns compound the challenges confronting us as we deal with the care of persons with dementia and their families.

Recently there have been promising new developments in the science of understanding Alzheimer’s Disease. However, in the absence of cure, care remains the predominant treatment we have to offer for this devastating degenerative disease. Caring as a treatment implies a therapeutic intent and the probability of a desired outcome. Caring is “a nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility” according to Swanson’s mid-level theory of caring. It is possible to be a caregiver—to do for another, providing assistance with...
activities of daily living and treatment for illness-without ever caring. An ethic of care integrated with a principle-based morality offers a comprehensive approach to working with persons with dementia and their families. In early stages of dementia, autonomy issues include the right of the person to know the diagnosis and the discussion of advance directives before there is a critical loss of decisional capacity.

An ethic of care suggests the need to provide ongoing support to the individual and family-preventing feelings of abandonment, maintaining dignity, and preserving personhood.

As increased cognitive impairment limits the range of autonomous function, protective caring (beneficence) becomes predominant, with more surrogate decision making. However, maintaining a sense of control over many everyday activities is still possible. As the level of cognitive function decreases, the appropriateness of the quantity and quality of environmental stimuli becomes more crucial to adaptive behavior and tolerable affect. If behavioral problems are associated with disease progression, a burden-benefit analysis may be needed to determine the least restrictive strategies to prevent harm to the individuals themselves and to those around them. These should avoid inappropriate use of psychotropic drugs and physical restraints. Informed caring, based on an understanding that even disturbed behavior has meaning, can guide interactions to prevent or reduce such behavior. The obligation to comfort, to assess and treat pain, becomes a particular challenge when verbal skills are lost.

As the inexorable progression of Alzheimer’s Disease leads eventually to a total inability to care for the self or to perceive and interact with the environment, ethical issues of quality of life and questions about aggressive or limited treatment inevitably arise. Antibiotics for an infection? Hospitalization for congestive heart failure? A feeding tube when oral intake becomes inadequate? An order not to resuscitate if heart and breathing stop? Caring at this point means helping families cope with difficult decision-making and ensuring that the goals of providing comfort and respect at the end of life for the person with dementia are predominant.

Further Reading

Muriel Ryden, PhD, RN Receives Minnesota Nurses Association Research Award

Professor Ryden received the Nurse Researcher Award from the Minnesota Nurses Association at the 1999 annual meeting held in Mankato, MN on October 17-20, 1999.

The Nurse Research Award honors a nurse who has made a significant impact on nursing practice through the use of research as a basis for a practice innovation. Dr. Ryden epitomizes that effort. Her research in the field of long-term care is an example of the perfect marriage between theory and practice. She has studied persons with Alzheimer’s Disease and developed a highly successful tool for measuring aggressive behavior. With results from her research on the understanding and use of CPR orders in long-term care facilities, she has made clear recommendations for the discussion of advanced directives.
Faculty Profile
Muriel Ryden, PhD, RN

Muriel Ryden is a Morse-Alumni Distinguished Teaching Professor of Nursing, a Faculty Associate in the Center for Bioethics, and a Faculty Associate for the minor in Gerontology. She is a Fellow of the American Academy of Nursing and a Fellow of the Gerontological Society of America. Formerly the holder of the endowed Long-Term Care Professorship and Director of the School of Nursing Research Center for the Long-Term Care of Elders, Professor Ryden is retiring after 30 years at the University of Minnesota.

Professor Ryden received her undergraduate degree in nursing from the University of Minnesota and her master’s degree in education from Columbia University. Her doctorate in education is from the University of Minnesota, with post-doctoral work as a Faculty Fellow at Andrus Gerontology Center, University of Southern California. She has been on the faculty at South Dakota State University and the University of Colorado and served as a visiting professor at the University of South Florida.

Selected Publications:

Book Chapters


Articles


Professor Ryden’s research and teaching at the undergraduate and graduate level have focused on the intersection of ethics and gerontology as well as communication in health care. Her research interests have included the morale and autonomy of nursing home residents, policies and practices regarding resuscitation in long-term care facilities, and ethical issues in dementia care, including the prevention and reduction of behavioral problems. Grants from the Alzheimer’s Association, the American Heart Association, and the National Institutes of Nursing Research and Aging within the National Institutes of Health have supported her research. Dr. Ryden developed an integrative approach to teaching ethics in undergraduate nursing called Multi-Course Sequential Learning with funding from the Fund for Post-Secondary Education, US Department of Education. Her education-related research has dealt with measurement of moral reasoning in nursing students, strategies for teaching ethics and interpersonal communication skills, assessment of the needs of nurse educators regarding gerontology, and employer support for continuing education for nurses.
the connection between donor and recipient be before donations are unethical, and how can we assure that living donations are truly voluntary?

The main issue in living organ donation is donor safety. How much risk should healthy people be allowed to undertake for health benefits that will go to someone else? Organ donation requires major surgery under general anesthesia, and no matter how skillfully performed, it exposes the donor to pain, recovery time, and potentially serious health effects. The offsetting benefit to the organ recipient may be great, but the fact that the donor bears all the risk and the recipient reaps all the health benefits should cause us to ask how much risk is too much? We don’t allow people to donate their hearts to their children—even fully informed of the consequences—because it will lead to the death of the donor.

Of course donors who give kidneys or parts of other organs enjoy the benefits of a wonderfully altruistic act, but we should wonder whether that is enough to overcome the age-old stricture on physicians to avoid harming patients unless it leads to sufficient benefit to them.

The experience with living kidney donors points to looser definitions of what counts as a “related” donor. Early on in the history of living donation, only genetically related donors were allowed—parents and children or siblings. Then the notion of relative was extended to include donors related by marriage—spouses, in-laws, or cousins. Now “community” or “social” relatives, members of church or social groups, co-workers, or friends, can donate kidneys. Past thinking was that donors more closely related to recipients had more to gain from the improved health of a relative or loved one, so that the splitting apart of risk and benefit was less of an issue. But such concerns have all but disappeared, as evidenced by the first two living kidney donations this summer from donors who were complete strangers to the eventual recipients.

The pressure continues to find greater numbers of organs for transplant, and until we can grow organs in the lab or use organs from animals, living donors will continue to be a burgeoning source. But as we undertake practices that will increase the numbers of healthy people undergoing major surgery to give up all or part of an organ, we must be sensitive to what might go wrong.

There is real risk to donors, especially in more complicated donations for portions of livers, pancreas and lungs. We must be on the lookout for strained and strange relationships between donors and recipients—including the possibility of pressure among relatives and payment or even extortion in a black market—and create preventive policies and ways to screen potential donors accordingly.

How far will be too far? When we run a significant risk of trading one patient’s health or even life for that of another—the trick is in determining when that level of risk is reached. Some tradeoffs are beyond what we can allow people to make, even if they willingly enter into them. When it comes to living organ donation, giving until it hurts may be exactly what we need but more than we can ask.

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

Post-Doctoral Fellow
The Center for Bioethics at the University of Minnesota will have a one-year, post-doctoral fellowship available beginning July 2000. The goal of the fellowship is to foster scholarship and career advancement in the field of bioethics. 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 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, advance directives and end-of-life decisions, ethics of clinical trials, research ethics, values assessment, professional ethics and relationship of law and ethics, and ethics law, and policy issues in biotechnology.

Applications must be submitted by February 15, 2000.

For an application, call the Center for Bioethics, 612-624-9440, fax 612-624-9108, or e-mail: bioethix@tc.umn.edu

Faculty Position
The University of Minnesota invites applications for a faculty position in the Center for Bioethics and in the School of Nursing. This position is a tenured/tenure-track position at the Full, Associate, or Assistant Professor level, depending on qualifications. The appointment will be approximately 50% in the Center for Bioethics and 50% in the School of Nursing. Salary and rank commensurate with experience.

The person in this position will be expected to join in the Center’s educational, research, and service activities, particularly in the area of the ethical issues involved in the delivery of clinical care. The successful applicant will have a track record of scholarship and teaching in nursing and bioethics. Applications received prior to February 29, 2000 will be assured full consideration, though applications will be considered until the position is filled.

Start date on or after July 1, 2000. Send a letter of application, CV, and names of three references to:

Search Committee
Center for Bioethics
University of Minnesota
Suite N 504 Boynton
410 Church Street SE
Minneapolis, MN 55455-0346

For more information contact:
Dianne Bartels, RN, MA
Associate Director
Center for Bioethics
University of Minnesota
Suite N 504 Boynton
410 Church Street SE
Minneapolis, MN 55455-0346
Telephone 612-624-9440
Fax 612-624-9108
E-mail: barte001@tc.umn.edu

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.

The University of Minnesota is an equal opportunity educator and employer.
Researchers and educators from 13 foreign countries joined U S scholars attending the 25th annual meeting of the International Association of Moral Education held in Minneapolis, November 18-22. Hosted by the University of Minnesota’s Center for the Study of Ethical Development, Center for Bioethics, and Silha Center for the Study of Media Ethics and Law, the conference featured three stimulating plenary sessions in addition to member presentations, poster sessions, and roundtable discussions.

To open the conference, Professor Bill Babcock of the University’s Silha Center organized the first plenary, “The Role of the Media in the Development of a Moral Community,” featuring invited presentations by Professors Jane Kirkley, University of Minnesota and Jan Schaffer, Executive Director, Pew Center for Civic Journalism. A lively discussion monitored by Professor Babcock prepared the attendees for the second plenary, “Integrating Philosophy and Psychology,” featuring presentations by Professor Tom Beauchamp, Kennedy Institute of Ethics, Georgetown University; and Professor Dan Lapsley, Department of Educational Psychology, Ball State University. The session, chaired by Professor Muriel Bebeau, University of Minnesota, explored recent psychological advances in moral philosophy that have influenced research and theory in moral judgment development. Professor Kenneth Strike, Philosophy of Education, Cornell University, presented the Kohlberg Memorial Lecture “How to be a Liberal Communitarian: In Praise of Kindness.”

Selected presentations from the conference will be published in a forthcoming issue of the Journal of Moral Education, the official journal of the AME.

Call for Papers

Journal on Medical Ethics, Harvard Medical School

Are you interested in how medical ethics can affect the practice of medicine? Are you concerned about how current policies can affect the quality of care that your patients deserve? Submit your ideas to the Journal on Medical Ethics. The journal is soliciting medical students to contribute essays, articles, letters, case discussions, empirical studies, or opinions for publication.

The deadline for submissions for the Spring 2000 issue is February 1, 2000.

For submission guidelines or questions, contact:
Journal on Medical Ethics
Harvard Medical School
Office of Student Affairs
260 Longwood Avenue
Boston, MA 02115
E-mail: journal@student.hms.harvard.edu.

Student Committee on Bioethics

20th Annual Winter Lecture Series

This year's series will feature many of Minnesota's and the country's most distinguished scholars in bioethics as well as scientists from the cutting edge of their fields. Speakers include: Dianne Bartels, RN, MA; Frank Cerra, MD; Martin Gundersen, PhD; Jeffrey Kahn, PhD, MPH; Virginia Lupo, MD; Glen McGee, PhD; Tim Schacker, MD; and Susan M. Wolf, JD.

Lectures will be held on Thursdays at 12:15 pm in Moos Tower 6-650 on the University of Minnesota east bank campus. Dates are January 20, 27; February 3, 10, 17, 24; March 2, 9, 16, 23. Please contact the Center for a detailed schedule or for additional information, e-mail Jeff Lander at land0185@tc.umn.edu.
Midwest Intensive Bioethics Course (MIBC) 2000
July 20-22, Minneapolis, MN
Ethics of Sexuality and Reproduction in Health Care

The MIBC 2000 is a two-and-a-half-day course that 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 conception of the importance of sexuality and reproduction. Specific sessions will deal with a range of issues that emerge in various health care settings, including:

- how do these concerns shape the way we think about sexuality among the elderly, especially within long-term care institutions?
- what criteria should be used to decide whether sexually related interventions (Viagra, new reproductive technologies, contraception, and sex-reassignment surgery) are necessary medical treatments or mere enhancements?
- how do perspectives on sexuality and reproduction bear on the use of new reproductive technologies and what can we do to make clinical practice more sensitive to such concerns?

The MIBC will be hosted by the Center for Bioethics on the University of Minnesota campus in Minneapolis, MN. 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 Medical Ethics and Humanities Program, Northwestern University Medical School.

Cost for the course will be $700. A block of rooms are held at the Radisson Metrodome, (612-379-8888) and the Days Inn (612-623-3999). For more information, visit the Center’s Web site at http://www.med.umn.edu/bioethics/ Phone 612-624-9440, e-mail: bioethix@tc.umn.edu.
Awards

Bonnie S. LeRoy, Dianne M. Bartels, and Pat McCarthy have been granted a one-year award of $50,000 from the Jane Engelberg Memorial Fellowship through the National Society of Genetic Counselors for the development of a genetic counseling helping skills training manual and supplementary videotape.

This project will involve the creation of a training manual and videotape for use by genetic counselor educators and supervisors to aid in the development of genetic counseling helping skills in their students. The manual will address several of the psychosocial, practice-based competencies established by the American Board of Genetic Counseling including communication skills, ethical issues, personal awareness, and diversity. Instructional materials about these issues specific to genetic counseling are sorely lacking.

This manual and videotape will be the first of its kind in the profession. For more information on this project, contact Bonnie LeRoy at leroy001@tc.umn.edu.

Center News

Awards


Faculty

Jeffrey Kahn, PhD, MPH, has been appointed to the Boards of Directors of the National Marrow Donor Program, and the American Society of Bioethics and Humanities.

Susan M. Wolf, JD, has been appointed to the Editorial Board of the new Journal of Women’s Health and Law.

Beth Virnig, PhD, MPH, has been appointed as a Faculty Associate in the Center. She is Assistant Professor, Division of Health Services Research and Policy, School of Public Health, University of Minnesota. Professor Virnig’s current work in bioethics is on the use of empirical data to help focus ethical debate and on issues in end-of-life care.
Spring Semester Bioethics Courses

The following bioethics courses will be offered during Spring Semester at the University of Minnesota. For more information on the following courses, see the Center’s Web site (http://www.med.umn.edu/bioethics) or call the Center.

**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

**Dent 6416**  
Professional Problem Solving  
1 cr given upon completion of course sequence, Bebeau

**GCD 8914**  
Ethical and Legal Issues in Genetic Counseling  
3 cr, Bartels and LeRoy

**Law 6605**  
Health Law  
3 cr, Wolf

**Phil 8320**  
Seminar on Medical Ethics  
3 cr, Kahn and London

**PubH 5780**  
Ethics in Public Health: Practice, Policy and Research  
2 cr, Aroskar and Kahn

**PubH 8803**  
Long Term Care: Principles, Programs, and Policies  
2 cr, Kane

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**patenting life:**

*GENES PRIVATE PROPERTY PUBLIC POLICY*

A symposium sponsored by the Joint Degree Program in Law, Health & the Life Sciences, University of Minnesota

**Friday, March 3, 2000**  
9 AM - Noon

Lockhart Hall, Room 25  
University of Minnesota Law School  
229 19th Avenue South, Minneapolis

For more information, call 612-625-0055 or email: jointdgr@tc.umn.edu

**Speakers to include:**

Professor Rebecca Eisenberg  
University of Michigan Law School

Professor Jeffrey Kahn  
University of Minnesota Center for Bioethics

Professor Harry Orr  
University of Minnesota Institute of Human Genetics

Professor Dan Burk  
University of Minnesota Law School

Professor Susan M. Wolf  
University of Minnesota Law School
Jan 27-29
Susan M. Wolf, JD, will speak at the University of San Diego, School of Law as part of a conference on genetics and justice. For information, call 619-260-2317.

Mar 6
Jeffrey Kahn, PhD, MPH, will speak on bioethics to the students of the Mentor Connection Program at the Intermediate School District 287, Plymouth, MN. For information, call 612-550-7166.

Mar 11-12
Susan M. Wolf, JD, will speak at Vanderbilt University, Nashville, TN, as part of a conference on "Fetal Surgery and the Moral Presence of the Fetus." For information, call Helen Gleason at 615-936-2686.

Apr 6-8
The University of Nijmegen, The Netherlands, will hold an Advanced European Bioethics Course, "Ethics and Palliative Care." Specialists from various countries will discuss ethical aspects of palliative care. For information, call 0031-24-3615320, fax 0031-24-3540245, or e-mail: b.gordijn@efg.kun.nl.

May 19
Jeffrey Kahn, PhD, MPH, 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, MPH, will speak on "Ethics of Scientific Research," at the Samuel G. Dunn Lectureship for the Humanities, University of Texas Medical Branch, Galveston, TX. For information, call 409-772-2376.

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.

Jul 20-22
The Center for Bioethics will host the Midwest Intensive Bioethics Course (MIBC) 2000 in Minneapolis, MN. Co-sponsored with 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, Chicago, IL. For information, call 612-624-9440/e-mail: bioethix@tc.umn.edu/ web site: http://www.med.umn.edu/bioethics.

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.
Recent 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. 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. 7: New Frontiers in Genetic Testing (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.

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 N504 Boynton,
410 Church Street SE,
Minneapolis, MN,
55455.

All orders must be prepaid.
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Associate Director

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Carolyn McLeod, PhD

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