Dying and Homeless: What comfort would there be?

By John Song, MD

We all fear dying, to some extent. We fear the uncertainty of our lives' worth and meaning. We fear the uncertainty of what lies beyond. Unfortunately, given the state of end of life (EOL) care in the United States, we also fear the process of dying. Imagine, then, the fear of dying without loved ones to comfort you, dry your brow or wet your mouth, make difficult and life-changing medical decisions for you when you are not able to make them yourself. The fear of dying without a nurse or physician or other health care worker who respects you or even knows you. Or the fear of the dying without a warm bed or even so much as a roof over your head—instead dying, as many of your acquaintances have, under a bridge, in a dumpster, in a frozen snowbank, perhaps after being discharged from a hospital after a lengthy illness. Maybe your body will be found immediately or maybe in the spring, and when it is, maybe someone will claim your body and respect it—or maybe not.

For too many Americans, specifically those who are living without stable housing, these fears are a reality. There are several million homeless Americans on any given night, and it is estimated that 7.4% of Americans will experience homelessness sometime in their lives. Because of exposure to the elements, violence, unsanitary conditions; because of access to unhealthy food and uncertain, fragmented health care; because of poverty and neglect, these Americans die at much greater rates—3 or 4 times as high—and at much younger ages than those with homes. The average life expectancy in the US is 76.5 years. The average of death of homeless individuals in San Francisco, Boston, and Seattle is 41, 47, and 47 years, respectively. Yet, this population, as large and as vulnerable as it is, has been largely ignored in the conversation about EOL care.

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John Song, MD, MPH, MAT – Faculty Profile

John Song, MD, MPH, MAT, received a Master’s degree in teaching from Brown University, an MD from the University of Pennsylvania, and completed residency in Internal Medicine at the University of Minnesota. Following residency, he completed a fellowship in General Internal Medicine and the Greenwall Fellowship in Ethics and Public Policy at Johns Hopkins and Georgetown Universities. While at Johns Hopkins, he received a Master of Public Health degree. Dr. Song’s research interests have always included issues in underserved and disadvantaged populations. In Baltimore, his clinical appointment was at the Baltimore Health Care for the Homeless, where he focused on care for homeless persons living with HIV and worked with homeless participants to hold poetry readings throughout the city.

He convened the first US conference on homelessness and HIV/AIDS through the HIV/AIDS Bureau (HAB). The conference proceedings were subsequently published as “HIV/AIDS and Homelessness: Recommendations for Clinical Practice and Public Policy.”

In 2003, Dr. Song founded the Phillips Neighborhood Clinic (PNC), a volunteer free clinic that serves the homeless and unstably housed population in the poorest neighborhood in Minneapolis. The mission of this clinic is to provide compassionate, nonjudgmental, and culturally appropriate care to those

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“The Center is dedicated to the advancement and dissemination of knowledge concerning ethical issues in health care and the life sciences.”
I’ve written in a previous edition of the Examiner about the need to address this issue, in this population: not only so that we can better understand what is actually happening in the homeless population, but also on moral grounds—what might be the dying wishes of someone so destitute and disenfranchised, and how can they best be served?

Since my previous article, Center faculty, in collaboration with homeless service providers, have been conducting research to identify the EOL fears and desires of homeless persons, and suggest and test interventions to improve dying for those worst off in our society. We’ve examined this question qualitatively and quantitatively, through focus groups and with data from a large survey of homeless persons.

What we’ve found has been both surprising and discouraging. We asked whether homeless persons participating in a statewide survey worried about how they would be cared for if they were seriously ill or dying. Ninety-seven percent of interviewees (of a total of 3815) answered the question, with roughly half saying that they worried about this issue. Of that group, one quarter responded that they worried about this issue daily and another quarter responded they worried at least several times per month. As expected, those who were estranged from family were most likely to worry frequently.

We have also explored what homeless people worried about in EOL issues through our qualitative work. We’ve found that some of this worry and fear is similar to worries and fears that people with stable homes have expressed: fear of pain, fear of prolonged suffering, fear of losing control. Homeless persons in our studies also expressed similar desires when dying, such as desires for reconciliation with people and higher powers, compassionate care, and adequate symptom control.

However, we also found that our homeless participants more often expressed fears and wishes about EOL care that were different from what we assume everyone fears or wants when dying. They expressed some fears that can only arise out of a life of alienation and deprivation. For example, many feared dying without being found, dying anonymously, or without recognition or memorialization: “Me,” said one participant, “I just want to be remembered by someone.” Lamented another: “I see myself in that coffin, looking up, and no one is there.” They consistently expressed fears about neglectful care for their bodies after death—misconceptions about their ultimate resting place included municipal incineration, mass burial, or donation to a university. They feared dying destitute: “Right now I’m afraid of dying mostly because I don’t have nothing… ‘He was a tramp. A no good tramp.’”

Their attitudes towards their families also differed. While some wanted reconciliation, more participants did not want their families contacted while dying or after death. This desire had several origins; some, for example, did not want to burden their families emotionally or financially. Others expressed anger over abandonment and, neglected in life, did not want their families involved in dying and death. One estranged man said: “So don’t cry; help me when I breathe, not when I’m stiff and frozen.”

Estrangement led to distrust as well: “My living will says that my family will have no say or discussion of what is done. Basically, they don’t know me, so why should they have a say…” Indeed, many participants preferred service providers rather than family to serve as surrogate decision-makers. Because of alienation, advance care planning appears to have significant value in this population. Living wills, currently suffering from disfavor, are seen as essential by homeless persons, as these documents may serve as the only expression of autonomy in EOL care and protect one from unwanted interventions. These individuals often do not have family members, friends, or health care providers who will advocate for them if they are not able.
We have recently completed a pilot project to test an intervention to improve EOL care in this population, and analysis is ongoing. What has guided this pilot, and the most important lesson we’ve learned from our work thus far, is that the circumstances and context of living life destitute and at the lonely fringes of society create fears of dying, death, and EOL life care that most of us can only imagine. It is time for us to pay attention to these realities.

References
estranged from the health care system and to foster volunteerism and community participation among students from the University’s Academic Health Center. Care at the PNC is interprofessional and is provided by students and faculty from the medical, nursing, physical therapy, pharmacy, and public health schools. Dr. Song continues research on homelessness and health, including the research highlighted in this issue of the Examiner.

Dr. Song also attends on the inpatient general medicine wards. His educational efforts center primarily on bioethics, and he oversees the bioethics curriculum for the medical school and continues work in defining the objectives and goals of an interprofessional bioethics curriculum.

**Selected Publications**


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**U of M Center for Bioethics receives Grant to Plan Ethics Web Resource — Bioethics Will Serve as Initial Focus**

The University’s Center for Bioethics and the University of Minnesota Libraries received funding to design a program called EthicShare, an online environment for applied ethics scholars to communicate and share knowledge. The goal of EthicShare is to create a virtual community of scholars interested in specific fields of ethics where they can collect and rate scholarly articles, share ideas, and network in order to generate collaboration.

During the six-month grant period, bioethics will be used as the initial topic area, and other themes within the field of ethics will be added later. Faculty and staff will work to establish content areas for bioethics, such as the ethics surrounding stem cell research, and research on human subjects. The program will be assessed by a group of leaders in practical ethics who will serve as the initial user community during the planning phase and will provide feedback regarding the structure and content on the site. After the planning period, a larger proposal will be submitted to expand the program to other fields of ethics. The University of Minnesota will lead a collaborative effort among five partnering institutions:

- Georgetwon University-Kennedy Institute of Ethics and the National Reference Center for Bioethics Literature
- Indiana University-Purdue University at Indianapolis-Center for Bioethics
- Indiana University-Bloomington-Poynter Center for the Study of Ethics and American Institutions
- University of Virginia-Institute for Practical Ethics and Public Life

This project is funded by the Council on Library and Information Resources through a grant from the Andrew W. Mellon Foundation.
Faculty Position Available

Assistant/Associate/Full Professor

The University of Minnesota Center for Bioethics is seeking an individual to fill a new tenure-tenure track position. Rank is open; preference will be given to persons who have an established record of outstanding scholarship in bioethics, a strong record of extramurally supported research, and teaching experience in bioethics. Experience in any of the following is desired but not required: ethics and public health, pharmacy ethics, or research ethics. The faculty position is in the Center for Bioethics, with tenure-home appointment likely to be within the School of Public Health but negotiable depending on individual disciplinary expertise.

The successful candidate will be expected to:

1. Contribute to the development of the discipline of bioethics through research and scholarship.
2. Teach professional and graduate courses in bioethics. Ability to teach courses in ethics and public health, pharmacy ethics, or research ethics is preferred.
3. Provide mentoring and research advising for graduate students and/or professional students.
4. Assist with the development of curricula in area of expertise.

Minimum academic preparation and qualifications include:

1. PhD, JD, MD degree or equivalent terminal degree, completed before the appointment begins.
2. Two years of teaching experience at undergraduate, graduate, or professional school levels or comparable teaching experience with positive supporting data.
3. Evidence of scholarship in bioethics.

Please apply on-line at https://employment.umn.edu/ and refer to either academic requisition #146093 (tenure) or 146094 (tenure-track). Along with application, please attach a curriculum vitae and a writing sample. Questions may be directed to Carl Elliott, MD, PhD, at 612-626-5347 or email ellio023@umn.edu.

Three confidential letters of reference should be sent to:

Faculty Search Committee
Center for Bioethics, University of Minnesota
410 Church Street SE, N504 Boynton
Minneapolis, MN 55455
Telephone: 612-624-9440 / Fax: 612-624-9108
Email: ellio023@umn.edu.

The University of Minnesota is an equal opportunity educator and employer.

Ruebhausen Visiting Professorship Update!

October 8-11, 2007

Visiting professor Zach W. Hall, PhD, President, The California Institute for Regenerative Medicine (CIRM) will present public lectures on Tuesday, October 9, 2007 on the University of Minnesota campus, and at the Mayo College of Medicine in Rochester, MN, on Wednesday, October 10, 2007. The professorship is sponsored by the University of Minnesota’s Center for Bioethics and the Consortium on Law and Values in Health, Environment & the Life Sciences; and the Mayo Clinic and Mayo College of Medicine’s Biomedical Ethics Research Program.

The University of Minnesota was the first university to create a stem cell institute, and with it one of the first stem cell ethics advisory committees and processes. The State of Minnesota does not share California’s unique public funding support for stem cell research. But while the funding sources may be different, many of the practice and policy issues facing our institutions are shared. Dr. Hall’s experience in the process of the debate, discussion, and eventual approval of Proposition 71 in California and subsequent creation of the California Institute for Regenerative Medicine (CIRM), will have important implications for how institutions, governments and societies deal with controversial science and medicine. He is uniquely situated to assess how the lessons of the California stem cell experience can be brought to bear on other controversial scientific research in the US and around the world.

For information and details of this event, please contact the Center for Bioethics at 612-624-9440, at bioethx@umn.edu, or at www.bioethics.umn.edu.
**Winter Bioethics Seminar Series**

*Continuing Medical Education (CME) credit available*

Center seminars have been designated to meet University of Minnesota continuing medical education requirements and provides 1 contact hour in continuing education (.1 CME) for each seminar. Registration is suggested if you are attending for CME credit.

Seminars are held from 12:15 to 1:30 pm in 2-122 Molecular & Cellular Biology building (MCB) on the University of Minnesota campus. Previous seminars may also be accessed on our website in BREEZE format at [www.bioethics.umn.edu](http://www.bioethics.umn.edu).

**March 9**
“Addicted to Smoking: Brain Disease? Genetic Mishap? Social Failure” by Barbara Koenig, PhD, Mayo College of Medicine.

**April 13**
“Worries for An Ethics of Hope” by Margaret Urban Walker, PhD, Arizona State University.

**May 11**
Title to be announced by Eric Meslin, PhD, Indiana University.

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**Student Committee on Bioethics (CHIP) Lecture Series**

*Co-sponsored by the Center for Bioethics*

Lectures are held in Mayo 100 at 12:15-1:15 pm on the following dates:

**Feb 15**
“Pregnancy and Patient Choice: Are There Limits to Autonomy?” by Carol Tauer, PhD, Center for Bioethics, University of Minnesota.

**Mar 1**
TBA, by David Satin, MD, Center for Bioethics, and Department of Family Medicine and Community Health, University of Minnesota.

**Mar 8**
“The Living Organ Donor: Selfless or Uninformed?” by Maryam Valapour, MD, Center for Bioethics, and School of Medicine, University of Minnesota.

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**Managing Incidental Findings in Human Subjects Research**

*Sponsored by Consortium on Law and Values in Health, Environment & the Life Sciences*

**Date:** May 1, 2007  
**Time:** 8:00-5:30  
**Location:** Cowles Auditorium, Hubert H. Humphrey Center, University of Minnesota Campus

The annual symposium will present the recommendations from an NIH-funded project to the public, researchers, research subjects, and regulatory bodies such as IRBs to obtain feedback.

The full agenda, speaker bios, and registration information may be found on the conference website at [http://www.lifesci.consortium.umn.edu/conferences/incidentalfindings.php](http://www.lifesci.consortium.umn.edu/conferences/incidentalfindings.php) or call 612-625-0055.

This conference is supported in part by a grant from the National Human Genome Research Institute at the National Institutes of Health, #1R01HG003178-01A1.
Calendar of Events

FEB 26
Jeffrey Kahn, PhD, MPH, and Susan M. Wolf, JD, will participate as moderators at the “Creating Stem Cells by Research Cloning” conference at the University of Minnesota campus, Minneapolis, MN. For information, email boyle032@umn.edu.

MAR 15-16
Jeffrey Kahn, PhD, MPH, will speak on “Benefits to Patients, Risks to Donors: Ethical Considerations” at the Hematopoietic Growth Factors Conference, Bethesda, MD. For information, email bens018@umn.edu.

MAR 19
Dianne Bartels, RN, MA, PhD, will speak on “Ethical Challenges for Genetic Counselors” at the University of Otago, Dunedin, New Zealand. For information, visit www.otago.ac.nz/bioethics/.

MAR 19
Carl Elliott, MD, PhD, will speak on “Amputees by Choice” at “Re Engineering Human Biology” conference, Harvard University, Cambridge, MA. For information, call 617-496-4050.

MAR 22
Jeffrey Kahn, PhD, MPH, will speak on “Ethics of Cutting Edge Practices for Organ Transplantation” at the United Resource Networks 8th Annual Conference “Managing Patients With Medical Conditions,” Las Vegas, NV. For information, email becky.1.vidanovic@uchc.com.

MARCH 23-26
Midwest Nursing Research Society (MNRs), 2007 Annual Research Conference “Innovative Technology: Pioneering Pathways to Health,” Omaha, NE. 3/24 Joan Liaschenko, RN, PhD, FAAN, will participate on a panel “In the Mind of the Beholder: Hypothesized Effect of Intrapartum Nurses’ Cognitive Frames of Childbirth on the Utilization of Cesarean Section” and Debra DeBruin, PhD, and Joan Liaschenko, RN, PhD, FAAN, will participate on a panel “Negotiating Moral Order in Clinical Trials: Balancing the Tension Between Knowledge Production and Patient Care.” For information, call 720-898-4831.

MAR 24
Jeffrey Kahn, PhD, MPH, will speak on “Genetic Technologies: New Issues and Old Ethics?” at the Minnesota Academy of Family Physicians research forum, Maple Grove, MN. For information, email iregreh@mafp.org.

MAR 29
Steven Miles, MD, will speak on “Induced Terror: Doctors Engaged in Torture” at the Civil Liberties Union of Ohio, Cleveland, OH. For information, visit www.acluohi.org.

MAR 29
Steven Miles, MD, will participate in a panel presentation “Ethics and the Goals of Medicine” at Loyola University, Chicago, IL. For information, email dhom3@luc.edu.

APR 3
9th Florence Schorske Wald Lecture in Palliative/Hospice Care, School of Nursing, University of Minnesota, Minneapolis, MN. Carlos Gomez, MD, PhD, Associate Professor, University of Virginia School of Medicine, and Associate Director, Institute for Education and Leadership, Capital Hospice will speak on “Dying When You’re Rich; Dying When You’re Poor.” For information, visit www.nursing.umn.edu/WaldLecture/.

APR 18
Jeffrey Kahn, PhD, MPH, will speak on “The Ethics of Creating a Stem Cell Donor” at Concordia University, St. Paul, MN. For information email saylor@csp.edu.

APR 19
Jeffrey Kahn, PhD, MPH, will speak on “Conflicts of Interest in Biomedical Research” at the President’s 21st Century Interdisciplinary Conference on Medical Devices–Inventing Medical Devices,” Minneapolis, MN. For information, email iai2001@umn.edu.

APR 20
David Satin, MD, will participate as a panelist “Pay-for-Performance” at the 2007 Minnesota Academy of Family Physicians Spring Refresher, St. Paul, MN. For information, call 952-542-0130.

APR 21
Mary Faith Marshall, PhD, will speak on “Ethics in Leadership in Academic Medicine” at the Society for Executive Leadership in Academic Medicine, Bryn Mawr, PA. For information, visit www.selimernational.org/index.html.

APR 23
Carl Elliott, MD, PhD, will speak on “Guinea Pigs of the World, Untie!” at Wellcome Institute, University College London, England. For information, email c.bowen@ucl.ac.uk.

APR 25
Carl Elliott, MD, PhD, will speak on “What’s Wrong with Enhancement Technologies” at the Belgian Advisory Council for Bioethics, Brussels, Belgium. For information, call 612-624-9440.

APR 25-29
David Satin, MD, will participate in “Implementing Pay-for-Performance in a Family Medicine Residency Program: Managing Benefits and Burdens” at the 40th Annual Society of Teachers of Family Medicine Spring Conference, Chicago, IL. For information, call 800-274-2237, ext. 5415.

APRIL 26-27
Joan Liaschenko, RN, PhD, FAAN, will participate in a seminar “Nursing and Health Care Ethics: A Legacy and a Vision” at Creighton University, Omaha, NE. For information, call 402-280-2017.

MAY 5-9
5/8 Maryam Valapour, MD, will speak on “Living Donors: What Do They Understand?” at the American Transplant Congress 2007 Meeting, San Francisco, CA. For information, visit www.atcmeeting.org/.

MAY 16
David Satin, MD, will speak on “Ethical Issues in Pay-for-Performance Systems of Physician Reimbursement” at Grand Rounds, Altru Health System, Grand Forks, ND. For information, call 701-780-6000.

MAY 18
Mary Faith Marshall, PhD, will speak on “Ethics in Clinical Research” at the Clinical Research Educational Conference and Career Fair, Northwestern University, Chicago, IL. For information, visit www.medschool.northwestern.edu/nccr.

MAY 18-19
Carl Elliott, MD, PhD, will speak on “American Medicine Meets the American Dream” at the University of California “Healthscapes and Body States: Politics and Practices of Biomedicine” conference, San Diego, CA. For information, call 612-624-9440.

MAY 18
Steven Miles, MD, will speak on “A Little Bit of Torture for Your Country: Should Doctors Help?” at Harvard Medical School, Boston, MA. For information, call 617-432-1707.

OCT 8-11
Zach W. Hall, PhD, Ruebhausen Visiting Professorship will visit Minnesota. See page 4 in this issue of the Examiner.
The Spring 2007
Bioethics Examiner
submission deadline
is May 4, 2007.

Send submissions to:
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Margaret O'Neill

Recent Faculty Publications

Articles
DeBruin D, Scholder S, Kahn J,
Mastroianni A, Marshall M, Lantos J,
Sugarman J. Educational Approaches to the
Responsible Conduct of Clinical Research:
An Exploratory Study. Academic Medicine

Kempainen R, Bartels D, McCarthy Veach P.
Life on the Receiving End: A Qualitative
Analysis of Health Providers’ Illness
Narratives. Academic Medicine

Liaschenko J, Oguz Y, Brunquell D.
Critique of the “Tragic Case” Method in
Ethics Education. Journal of Medical Ethics

Moffatt B, Elliott C. Ghost Marketing:
Pharmaceutical Companies and Ghostwritten
Journal Articles. Perspectives in Biology and

Satin D. Paying Physicians and Protecting
the Poor: Pay-For-Performance Systems
Should Protect the Health of Poor Patients
and Level the Playing Field for the Physicians
Who Treat Them. Minnesota Medicine
2006;89(4):42-44.

Valapour M. Donation after Cardiac Death:
Consent Is the Issue, Not Death. The Journal