



University of Michigan Health System

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UNIVERSITY OF MICHIGAN JOINT CBDSM & BIOETHICS PROGRAM NEWSLETTER

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MAKING DECISIONS ABOUT THE END OF LIFE



The Bioethics Program's **Maria Silveira, MD**, is the lead author on a study showing that more than one in four elderly Americans lacked the capacity to make their own decisions at the end of life, published April 2010 in the *New England Journal of Medicine*.

The research has been covered extensively in the media including National Public Radio, Associated Press, New York Times, Chicago Tribune, and MSNBC.

Those who had advanced directives - including living wills or durable powers of

attorney for healthcare - received the care they wanted most of the time, says Silveira. "Prior to our study, no one knew exactly how many elderly adults may need others to make complex medical decisions on their behalf at the end of life," says Silveira. "Our research shows a substantial percentage of elderly adults need someone else to make decisions about their receipt aggressive, limited, and/or comfort care."

"This study underscores the need to prepare oneself and one's family for all possibilities. It also suggests that the time spent to craft living wills and appoint a durable power of attorney for health care can be worthwhile."

Of the subjects studied, 68 percent had advance directives. Of

those, more than 90 percent requested either limited or comfort care at the end of life. 83% of those requesting limited care and 97% of those requesting comfort care received care that was in line with their wishes, Silveira says.

The subjects were elderly Americans living at home or in facilities across the US who died between 2002 and 2006 and participated in the Institute for social research's health and retirement study.

"Folks with a living will or durable power of attorney for health care were less likely to be hospitalized or get aggressive care - But that is what most of them wanted," she says.

While most elderly in the study completed some kind of advance directive, 33 percent of the subjects had no form of advance directive whatsoever.

The study showed that among the handful of subjects who indicated a preference for aggressive care, half did not receive it.

"Some might say that this finding suggests that advance directives are used to deny wanted health care, but in many cases, aggressive care is not an option, despite the patient's wishes," Silveira says.

Silveira says many patients expect their physicians to initiate the conversation about end of life care, and that physicians should be supported in their attempts to do so. The recent effort to add Medicare reimbursement for end-of-life discussions was a good start, she says.

"The health care system should ensure that providers have the time, space, and reimbursement to conduct the time-consuming discussions necessary to plan appropriately for the end of life. Most elderly patients want and expect this," she says.

Additional authors on the article were **Kenneth M. Langa, MD, PhD** and **Scott Kim, MD, PhD**.

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FEATURED FACULTY

PROGRAM FACULTY

BIOETHICS

Andrew Barnosky, DO, MPH
Raymond De Vries, PhD
Michael Fetters, MD, MPH, MA
Susan Dorr Goold, MD, MHSA, MA
Scott Kim, MD, PhD
Naomi Laventhal, MD, MPP
Kathryn Moseley MD, MPH
J. Scott Roberts, PhD
Maria J. Silveira, MD, MA, MPH

CBDSM

Mick Couper, PhD, MSS, MA
Angela Fagerlin, PhD
Jennifer Griggs, MD, MPH
Sarah Hawley, PhD, MPH
Reshma Jagsi, MD, DPhil
Scott Kim, MD, PhD
Ken Langa, MD, PhD
Beth A. Tarini, MS, MD
Peter A. Ubel, MD
Melissa A Valerio, PhD
Michael Volk MD, MSc
Brian Zikmund Fisher, PhD

MEET RAYMOND DE VRIES



Raymond De Vries, PhD, is a core faculty member of the Bioethics Program and a professor with joint appointments in the Department of Obstetrics and Gynecology, the Department of Medical Education, and the Department of Sociology. Currently, with funding from the National Library of Medicine, he is at work on a critical social history of bioethics. His other research projects include a study of the export of western bioethical ideas to the developing world, research on the way the premedical years provide a moral education to future physicians, an examination of ethical aspects of elective surgical birth, and a study of the ways medical students learn bioethics.

He was educated at University of California, earning a PhD in sociology, writing a dissertation on the licensing of midwives. Prior to joining the University of Michigan faculty he was a professor of sociology at St. Olaf College in Northfield, Minnesota, and a senior fellow at the Center for Bioethics at the University of Minnesota in Minneapolis.

Dr. De Vries is internationally recognized for his extensive research on maternity care and midwifery.

HOW DID A MEDICAL SOCIOLOGIST GET INTERESTED IN BIOETHICS?

In Dr. De Vries' case it was the result of two things: a long-standing interest in ethics (as an undergraduate he flirted with a major in philosophy), and research on the relationship between the professions of midwifery and medicine. In his study of midwifery in the United States (*Making Midwives Legal*, Ohio State University Press, 1995), De Vries discovered American physicians using unfair political tactics to prevent midwives from practicing, thus denying underserved populations access to maternity care. Here was a moral problem – a profession using its powerful political position to protect, not patients, but its own monopoly – that cried out for a bioethical response, but none was forthcoming.

Noting this lack of bioethical interest in the structural problems of medicine and medical research, De Vries turned his attention to the sociology of bioethics. His study of midwifery in the United States led him to look at the way maternity care was organized elsewhere. Supported by a grant from the Fogarty Center at the National Institutes of Health, De Vries studied midwifery in the Netherlands, where about one-third of births take place at home, most attended by midwives. His book *A Pleasing Birth* (Temple University Press, 2005) explains how the social and cultural features of the Netherlands conspired to preserve a way of birth long-abandoned by other developed nations.

A handwritten signature in black ink, appearing to read 'R De Vries'. The signature is stylized and fluid.

RESEARCH UPDATES

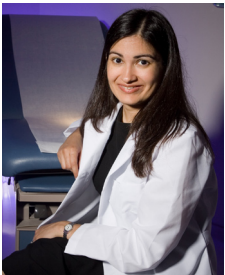
Holly Witteman



Holly Witteman, Research Fellow at CBDSM, has been awarded a \$25,000 Robert Derzon Post-Doctoral Grant from the Foundation for Informed Medical Decision Making for her project entitled “Development and Evaluation of Interactive Interfaces for Values Exploration and Clarification.” Pending IRB approval, the project is slated to commence in spring 2010. Witteman has been

working since fall 2009 under the mentorship of **Angela Fagerlin**, PhD.

Reshma Jagsi



Reshma Jagsi, MD, DPhil, is the lead author on a new study showing that breast cancer patients who have had mastectomies and need radiation are less likely to receive these treatments than patients who have had lumpectomies. Dr. Jagsi has been interviewed by many media outlets about this finding. The article appears in the *Journal of Clinical Oncology* (online March 29, 2010). Additional authors are Paul Abrahamse, Sarah T. Hawley,

Jennifer J. Griggs, Steven J. Katz, Monica Morrow, John J. Graff, and Ann S. Hamilton.

Brian Zikmund-Fisher



Brian Zikmund-Fisher, PhD, is the senior author on a study led by Donna M. Zulman, MD, that reveals about a third of doctors and their patients with diabetes do not agree on which of the patient’s health conditions is most important. In the study, 38% of physicians (compared to 18% of patients) ranked hypertension as the most important condition. Patients were more likely to prioritize symptoms such as pain and depression.

The article appeared in the *Journal of General Internal*

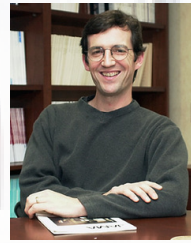
Medicine. Additional authors are Eve A. Kerr, Timothy P. Hofer, and Michele Heisler.

Angela Fagerlin



Angela Fagerlin, PhD, talked recently with *Financial Planning* magazine about how research on decision aids in health care might be used to help financial planners convey complex information to their clients. She discussed specifics: use of absolute vs relative risk data, frequencies vs. percentages, and graphical representations such as bar graphs and pictographs.

Peter A. Ubel



Peter A. Ubel, MD, Director of CBDSM, spoke recently at the DeVos Medical Ethics Colloquy at Grand Valley State University in Grand Rapids, Michigan. Dr. Ubel’s presentation, “Rationing vs. Rationalizing Health Care,” was covered by news outlets in western Michigan. To see a clip from television reports, go to www.peterubel.com.

Ian Wall



Ian Wall, CBDSM Research Associate, has been awarded a prestigious National Science Foundation Graduate Research Fellowship for his upcoming doctoral work in sociology at the University of Wisconsin, Madison. The three-year award includes an annual stipend, tuition allowance, and travel allowance. Ian, who works with **Scott Kim**, MD, PhD, and **Ray DeVries**, PhD, will be starting his program at Madison in fall 2010.

Susan Dorr Goold



As a Gheens Foundation visiting scholar in Humanism **Susan Goold**, MD, spoke at the University of Louisville on “Allocating Scarce Resources During a Pandemic.”

Dr. Goold along with Nancy Baum, PhD, recently published their findings of a focus group study characterizing public perceptions about social distancing measures likely to be implemented during a pandemic. “Listen to the People: Public Deliberation About Social Distancing Measures in a Pandemic” was published in *The American Journal of Bioethics*, November 2009.

Scott Kim



Scott Kim, PhD, delivered the George Kirby Collier Memorial Lecture, University of Rochester Medical Center, Department of Psychiatry, Rochester, NY, March 30-31, 2010. The lecture was titled, “Without Consent: The case for and against surrogate consent for neuropsychiatric research.” Using results from his ongoing NIH funded studies, Dr. Kim challenged the conventional wisdom that, for research involving adults with dementia, surrogate consent is ethically inferior to independent consent by competent subjects with dementia.”

DECISION OF THE MONTH STUDENT UPDATES

SEEN ON A BILLBOARD!

Check out the latest interactive Decision of the Month at www.cbds.org/doms

What is the impact of medical advertising that is directly targeted at patients? What information do consumers of medical products and therapies need in order to make informed decisions about their health?



Scenario: Ms. J, a healthy 50-year old woman, drives by a billboard that advertises low-dose spiral computed tomography (CT) scanning to screen for lung cancer. Although

she has no family history of cancer and has never smoked, several of Ms. J's friends have been diagnosed with cancer recently. She worries that she herself may have an undetected malignancy.

Responding to this advertising, Ms. J decides to pay out-of-pocket for a CT scan at the imaging center advertised on the billboard. The radiologist at this imaging center profits from the number of scans interpreted

As a result of the CT scan, an abnormality is found, and Ms. J undergoes a biopsy of her lung. A complication occurs from this procedure, but Ms. J recovers, and the biopsy comes back negative. She is relieved to learn that she does not have lung cancer.

After reading this scenario and thinking about direct-to consumer medical advertising, which of the following statements best represents your views? Visit www.cbds.org/doms to vote!

This Decision of the Month is based on a recent article: Jagsi R., Conflicts of interest and the physician-patient relationship in the era of direct-to-patient advertising. *Journal of Clinical Oncology* 2007;25:902-905.

Sarah Lieber, UM medical student, will be doing a summer 2010 research project at CBDSM with **Michael Volk**, MD, on social support in relation to liver transplant patients.

Jeffery Gross completed his undergraduate degree at the University of Michigan and is currently a first year medical student at Fienberg School of Medicine, Northwestern. Jeffery's article with **Ray de Vries**, "*The Winnowing Fork of Premedical Education: Are We Really Separating the Wheat from the Chaff?*" was published in the *Virtual Mentor*, November 2009.

Yasaswi Paruchuri (LSA senior) and **Leslie Rott** (Sociology graduate student) along with **Raymond de Vries** published "Normative environments of international science." *In International Research Collaborations: Much to be Gained, Many Ways to Get in Trouble*.

Jennifer Torres is a graduate student in sociology. Jennifer and **Ray de Vries'** article "Birthing ethics: What mothers, families, childbirth educators, nurses, and physicians should know about the ethics of childbirth" was published in the *Journal of Perinatal Education*, Winter 2009.

Nancy Baum was awarded her PhD in Health Management and Health Policy from University of Michigan's School of Public Health. Her dissertation research on resource allocation in public health practice was funded by the Robert Wood Johnson Foundation.

David Shalowitz, 4th year medical student with a focus in bioethics, who will begin his obstetrics and gynecology residency fall 2010 at Brigham and Women's Hospital/Massachusetts General Hospital.



IN THE NEWS

The Cost of Human Nature

Imagine for a moment that you are in charge of the U.S. health care system and must decide whether to pay for a new cervical cancer screening test, let's call it PapFinder. For every \$800,000 spent on PapFinder, health care providers will add one year of life to the population of women receiving this test. Given this information, would you choose to add PapFinder to the standard diagnostic arsenal?

About a decade ago, I presented a national sample of U.S. physicians with a question like this, and almost of them stated that PapFinder (a hypothetical test, by the way) was too expensive, bringing benefits so rarely that they would not offer this test to their own patients. The desire to prevent and treat cancer, it seems, had limits.

Or did it? I presented a random sample of these physicians with a different choice. I asked them whether they would offer annual pap smears (well-established tests in routine clinical use) if they learned that the tests cost more than \$800,000 to save one year of life – a figure that came directly from the medical literature. Given this information, physicians were nearly unanimous in saying they would offer their patients this test.

Same cost, same infrequent benefit, but very different attitudes. What's going on here? And what do the results of this decade-old study tell us about the recent hubbub around mammography screening and, indeed, about the ongoing health care reform debates?

For starters, health care economists are nearly unanimous in holding that interventions that cost more than \$800,000 per life year are not a wise use of resources. (Most endorse cost-effectiveness thresholds closer to \$100,000.) That means that doctors' attitudes toward PapFinder appeared quite rational: lots of money, little benefit ... not a smart idea.

Why, then, did doctors remain enthusiastic about pap smears even after learning

about the \$800,000 figure? As a physician working in behavioral economics, I am quite familiar with the irrational forces influencing people's attitudes towards health care interventions. In this case, a lot of such forces were at work.

For starters, physicians were influenced by loss aversion. People don't like having things taken away from them. Doctors were used to providing annual pap smears to their patients, and they knew that their patients would be upset if they no longer offered such tests. We see parallels in current mammography debates, with many women in their 40s responding anxiously to the idea of no longer receiving annual mammograms.

Second was the belief that earlier detection of cancers is always better than later detection, a belief that has also influenced the mammography controversy. This idea is not supported in the medical literature.

In fact, medical science has discovered that some early cancers pose little threat to people's lives, with the cancers growing so slowly that any intervention to thwart them would cause more harm than benefit. We've even learned that some cancers can regress over time. But these cold hard medical facts stand little chance against the hot passions of cancer psychology: doctors and lay people, understandably frightened by the thought of cancer, cannot believe that early detection could be anything but good.

Third was the limited human attention span. When we contemplate important decisions, it is difficult to consider all of the relevant factors, and thus we focus our attention on the most obvious ones. Deciding whether to live in Michigan or California, for instance, we think about the weather while ignoring other important differences between these two states – differences in daily commuting, for example, a factor that has been shown to have far more impact on people's lives than

climate.

Similarly, when people make decisions about cancer screening, they focus most of their attention on cancer – if the test detects cancer, they conclude it must therefore be worthwhile. People don't pay as much attention to other aspects of the test. If it mistakenly characterizes a benign lesion as cancer, for example, it will cause undue anxiety or even lead to unnecessarily and potentially harmful treatments. But we don't give such factors much weight when contemplating whether to utilize the tests.

Everyone who cares about this country should care about finding ways to reduce health care costs. The recent debates over mammograms reveal just how difficult it will be to achieve this goal, for controlling costs will require us to overcome very powerful psychological forces. The biggest impediment to successful reform of our health care system, thus, is not blue dog democrats or obstinate republicans. It is human nature.

-Peter A. Ubel, PhD

Originally published in The Hastings Center, *"Health Care Cost Monitor Blog"*, December 9, 2009

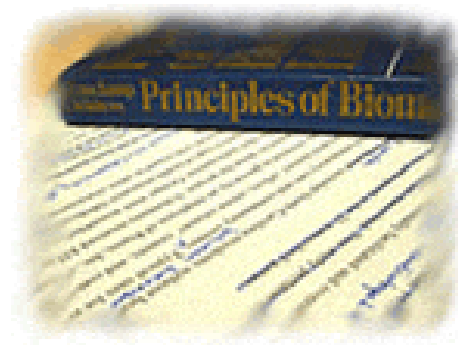
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EVENTS

Bioethics Research Colloquium, Friday, May 21, 2010

9:00am to 3:00pm, Alumni Center (200 Fletcher St., Ann Arbor, MI.)

“Medical Progress: How Much Can We Afford?”



Keynote address by **Daniel Callahan**, PhD, Senior Research Scholar, President Emeritus and cofounder of the Hastings Center, and co-director of the Yale-Hastings Program in Ethics and Health Policy

The remainder of the conference will be devoted to presentations of research in or about bioethics conducted by University faculty and students.

Schedule:

9:00 a.m. - 9:30 a.m. Coffee and Refreshments

9:30 a.m. - 11:00 a.m. Keynote Address/Q&A

11:00 a.m. - 12:00 p.m. Presentations by UM Faculty and Students

12:00 p.m. - 1:00 p.m. Lunch

1:00 p.m. - 3:00 p.m. Presentations by UM Faculty and Students

Lunch will be provided for those who RSVP to ethics@umich.edu by May 17, 2010

TRANSITIONS

CBDSM said farewell to research staff member **Aleksandra (Sanja) Jankovic** in February 2010. Sanja returned to her native country of Serbia after nearly seven years of dedicated work at CBDSM as a data analyst. She was an author on a dozen scholarly articles with UM faculty and also provided exceptional photographs for our publications.

In April 2010, CBDSM sent administrative assistant **Caitlin Weber** off to Seattle, where she will be attending Bastyr University to study acupuncture. Caitlin will also be marrying Larry Mayotte in May. Caitlin was with CBDSM for two years, during which time she won a major departmental award for her outstanding performance.

CBDSM welcomes **Lisa Smith** as a part-time staff member working with **Michael Volk**, MD, and Rachel Tocco on liver transplantation research. Lisa holds dual master's degrees, in social work and public health, from the University of Michigan.

CONGRATULATIONS TO....

Raymond De Vries was named Sackler Lecturer at the Mortimer and Raymond Sackler Institute of Advanced Studies at Tel Aviv University in Israel for 2011-2012. As a Sackler Lecturer Dr. De Vries will travel to Tel Aviv next year for two weeks to deliver lectures.

Kathryn Moseley, MD, who completed her Masters in Public Health in December 2009.

Andrea Fuhrel-Forbis and Mike Forbis on the birth of Caitlin Ann Fuhrel Forbis. Baby Caitlin was born prematurely on February 8, 2010, and is now home and doing very well. Andrea is a CBDSM Research Fellow working on risk communication under the mentorship of **Angela Fagerlin**, PhD.

Julie Parow, who graduated in April from Eastern Michigan University with her master's degree in counseling. Julie is a CBDSM staff member helping conduct research on decision making related to prostate cancer with a project of **Angela Fagerlin**, PhD.

Darryn Fitzgerald, who graduated May 1 from the University of Michigan with a bachelor's degree in communications and Spanish. Darryn has been a workstudy for more than two years, doing complex data entry and helping with liaison to international scholars visiting CBDSM.

Mark Swanson, who graduated from the University of Michigan in December 2009 with a degree in Japanese studies. Mark is a part-time computer programmer with CBDSM who specializes in advanced Flash applications in risk communications graphics, working with **Brian Zikmund-Fisher**, PhD.

Knoll Larkin and Carrie Copeland, who recently became engaged and are planning a September 2011 wedding. Knoll is a research staff member with the Bioethics Program, working especially on projects with **Susan Goold**, MD.

Brenna Smith, who received her BS in biomedical engineering from the University of Michigan on May 1. Brenna has been a workstudy at CBDSM for two years and has particular skills in complicated transcriptions.

