Reflections on Kimberly Myers’ talks about “Edges of Light: Images of Breast Transformation”
By: Linda Carr–Lee Faix

Kimberly Myers, Ph.D., associate professor in the Department of Humanities at Penn State, and faculty at the Doctors Kienle Center for Humanistic Medicine, visited the University of Utah in conjunction with the opening of the exhibit, “Edges of Light: Images of Breast Transformation”, that is showing through May 17, 2015 at the Spencer S. Eccles Health Sciences Library. At an Oncology Grand Rounds, an Evening Ethics, and a Humanities presentation, Kimberly Myers shared with us her thoughts as both an academic and as a patient who has experienced breast cancer.

Kimberly Myers was diagnosed with breast cancer 3 years ago. Although she had no family history of breast cancer, she had feared it for over 20 years. Given our high cultural awareness of breast cancer, she is surely not alone in this anxiety. As Kimberly lived the specifics of the “something that came,” her anxiety has dimmed and transformed into a joy of educating and helping others who deal with breast cancer, patients and practitioners, alike. This exhibit is a unique, artistic, and educational gift.

Four days after being diagnosed with breast cancer, numb from the news, Kimberly danced for the four-hour shoot photographed by Wendy Palmer that initiated the birth of the exhibit you see. Kimberly wrote the reflective poems that accompany each photo much later, noting that the camera lens provides a second set of eyes through which you see things in yourself of which you were previously unaware. She reflected carefully and chose each phrase, word, and syntax meaningfully. One photo, shown here, she titled “Resolute.”

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Reflections on the first Interprofessional Education (IPE) elective course,
Health Law for Non-Lawyers
By: Leslie Francis, JD, PHD

This year, Teneille Brown and Leslie Francis pioneered a health law for non-lawyers course. Professors Brown and Francis are both members of the Division of Medical Ethics and Humanities and faculty members at the University’s S.J. Quinney College of Law. The course was an interdisciplinary health sciences offering and we enrolled students from medicine, nursing, and pharmacy. Ten students enrolled in the course pilot and we are happy to report that everyone stayed with it until the end. To accommodate the different schedules and locations of students, the course was taught in fully virtual fashion; the Utah Education Network was a great help and after a few hitches we all found that the synchronous distance learning format encouraged participation and discussion.

The course aimed to foster understanding of basic issues in health law and how lawyers understand them. We tried to emphasize the similarities as well as the differences in how providers and lawyers think; a great strength of the course was our ability also to draw on differences among the health care professions. We began with an overview of the US legal system, the Affordable Care Act, and health care reform. Then, we zeroed in on specific issues in the provider-patient relationship, such as the duty to treat, quality of care and malpractice, informed consent, and confidentiality. We also discussed anti-discrimination law, in particular the Genetic Information Nondiscrimination Act, and its implications for providers. We ended the course with end of life decision-making and aid-in dying as an illustration of constitutional law and its impact on health care today. Whenever possible, we incorporated genetic case studies, (reproductive technologies, confidentiality, end of life, etc.)

Students rated the course very highly and we plan to offer it to a larger group in the upcoming academic year.
Her poem: “Let’s Roll.” She explained that some will recognize this phrase’s allusion to the last words heard from the 911 passengers who decided to take on the terrorists before their plane crashed in Pennsylvania farmland. Their heroic words: “Let’s Roll!” Analogously, Kimberly determined to take on an important survival challenge, not knowing the outcome, but she carefully chose a “period” rather than an “exclamation point” after the recognized phrase because hers was a sense of determination to do what must be done, rather than one of bravery. Resolute. Period. It is a sense to which many who have faced cancer can relate.

Kimberly believes that the best coping strategy for cancer is to show patients that they are not alone. She illustrates the shared journey that those diagnosed with breast cancer travel. The exhibit is a creative expression of bringing beauty out of pain, of bringing to life how cancer changed her, physically and viscerally, of her epiphany that “nothing is worth more than this day,” (even if it is one of those crummy ones!). Through the pictures and poems of the exhibit, she tells us that we will be different people through cancer. And she notes that although “celebration” may seem like an odd way to talk about cancer, some of the transformation cancer teaches is indeed, celebratory: the “if not now, when?” moments, the laughing as solidarity, the “won’t this be interesting?” attitude, the celebration of birthdays as blessings rather than as complaints. These are the graces that cancer survivors know.

As a 19 year breast cancer survivor myself, I agree with many poignancies in this exhibit— that the anxiety of not knowing is the worst, that plastic surgery does amazing and wonderful things, that cancer forces open one’s eyes and teaches life lessons that enrich our remaining years. Breast cancer is a disease whose treatment affects what others see and may judge about us—lost or changed breasts and hair—this exhibit illustrates those important externals beautifully as it does the forced focus on our own mortality and possible deaths. What this exhibit leaves me pondering is the long term, internal story of survivorship. The exhibit ends, but the story does not. With the camaraderie of not being alone, there comes an enhanced grief for those who succumb to breast cancer and do not make it to see their children grow up. How do we respond to an important loss of physical feeling, and sometimes infertility, perhaps even to survivor’s guilt? Almost always, long time cancer survivors share an almost overwhelming thankfulness to all of the researchers, healthcare workers and caregivers that allow these stories to be told.

Kimberly Myers’ desire to help others through her experience of breast cancer, a disease that so many women fear, is beneficent and admirable. Although beneficence does not necessarily mean that one must disclose so dramatically, this exhibit discloses beautifully and creatively.

Be Sure Not to Miss It:

**Edges of Light: Images of Breast Transformation**, an exhibit of photographs by Wendy Palmer and poems by Kimberly Myers, Ph.D., on display on the upper level of the Spencer S. Eccles Health Sciences Library through Sunday, May 17, 2015. The emotionally powerful photos and verbal reflections in this exhibit document Dr. Kimberly Myers’ experience after receiving a sudden diagnosis of breast cancer. The photographer, Wendy Palmer wrote: “Photos that were originally meant only to remind one woman of her story propelled us onward to further photographic sessions and much discussion about what it means to live. Our hope is that these images and words will empower women facing a similar situation to see edges of light along the way.” [NOTE: Due to the subject matter of this exhibit, it may not be appropriate for all audiences. Parental guidance is suggested.]
Dr. Mark Mercurio, our 2015 David Green Memorial Speaker, is Director of the Program for Biomedical Ethics and the Yale Pediatric Ethics Program, Professor of Pediatrics at Yale University School of Medicine, and an attending neonatologist at Yale-New Haven Children’s Hospital.

Two events will feature Dr. Mercurio and his scholarly work:

- **Evening Ethics, May 13, 2015, 5:30-7:30pm, RAB 1st floor conference room**
- **David Green Memorial Speakership, Pediatric Grand Rounds, May 14, 2015, 8am-9am, 3rd floor PCH auditorium**

All are welcome to both events!

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Evening Ethics with Mark Mercurio, 2015 David Green Memorial Speaker

“Unilateral Physician DNAR Decisions in Pediatrics”

Wednesday, May 13, 2015
5:30pm-7:00pm, Research Administration Building, 1st floor conference room
CME and refreshments provided

Decisions about resuscitation are usually made by physicians in consultation with patient, family members, and other staff. Are there ever situations where it is ethically permissible for a physician to make a decision not to attempt resuscitation, without consulting or reaching agreement with the patient or the patient's family? If so, what would be the justification for bypassing patient autonomy—or in the case of a pediatric patient, parental authority?

The discussion will begin with an article addressing the question in pediatrics, but easily extends to adult patients, and the principles utilized and the ethical and practical considerations are directly applicable to any patient. Background reading for this session is an article by Mark Mercurio, MD, MA, Peter D. Murray, MD, and Ian Gross, MD, MA: “Unilateral Pediatric “Do Not Attempt Resuscitation” Orders: The Pros, the Cons, and a Proposed Approach.” (Pediatrics, Volume 133, Supplement 1, February 2014)
May 6, 2015
LDSH Pugh Boardroom 6:00-8:30p, Facilitated by Rachel Borup, PhD
The Empathy Exams by Leslie Jamison

Leslie Jamison’s collection of essays, The Empathy Exams, covers many topics, from paid medical actors to reality TV to incarceration to sentimentality in literature to practices of self-harm, all of which lead back to her central question--how can we understand the pain of others? Jamison has been compared to Joan Didion for her emotional sensitivity and intellectual rigor. The book won the Graywolf Nonfiction Award in 2014.

June 3, 2015
U of U Hospital Large Conference Room W1220 6:00-8:30p, Facilitated by Mark Matheson, D.Phil
Destiny of the Republic by Candace Millard

Candice Millard’s The Destiny of the Republic (2011) explores a little known moment in U.S. history: the nomination and brief Presidency of James A. Garfield, who was elected in 1880. Some famous nineteenth-century figures enter the story, including Joseph Lister and Alexander Graham Bell. A young and vigorous President, Garfield was shot early in his first term. He lingered for over two months, in great suffering, before his death in September 1881. Millard’s book becomes a striking medical drama as she recounts the political and theoretical dimensions of the President’s treatment. This is arguably the best part of the book, and it will be of genuine interest to our group. Lister’s theory and practice of antisepsis had been in place in England for fifteen years, but his ideas were still not accepted by the American medical establishment, and Garfield’s death was the result of massive infection. The development of workable X-ray technology was more than a decade in the future, and Bell, who had already invented the telephone, tried to locate the bullet in Garfield’s body through the use of a primitive metal detector. A role was also played by John Wesley Powell, a good friend of Garfield’s who had passed famously down Utah’s Green and Colorado Rivers a decade before. Working with the Department of the Navy, Powell constructed an air-conditioning system to keep Garfield comfortable as he lay dying in the sweltering White House. Millard’s book provides a compelling account of American medicine in the late 1800s—at the defining moment when it is called upon to save a President—and the broader culture of the time emerges in the historical tapestry of her narrative.

July 1, 2015
U of U Hospital Large Conference Room W1220 6:00-8:30p, Facilitated by Gretchen Case, PhD
Falling Into the Fire: A Psychiatrist's Encounters with the Mind in Crisis by Christine Montross

Christine Montross, with an MD and an MFA in poetry, is ideally positioned as a physician-writer to show us into her world of inpatient psychiatry. She offers insight into the treatment of people in crisis due to mental illness, offering stories of some of her most challenging encounters as a psychiatrist. With “asylums” long gone, replaced by improved but uneven systems for promoting and preserving mental health, Montross asks hard questions about how to help.
Members of the Center for Law and Biomedical Sciences at the College of Law met with the Telemedicine team at the University of Utah hospital, and realized that there are many overlapping ethical and legal topics that interest both groups. After a great conversation, the two groups decided to collaborate in the future, whenever possible. To that end, the Division of Medical Ethics and Humanities is hosting an Evening Ethics on the ethical issues surrounding the burgeoning field of Telemedicine. This event will include members of the Telemedicine program at the U, and we invite you to join us.

The Telemedicine service at the University of Utah, also known as "telehealth," is driven by patient demand. It is offered through eleven (and counting!) different medical services, such as cardiology, neurology, rehab, and transplant. The services supported include telephone consultations, emails between providers and patients, electronic medical records, digital radiology services, and pager and cell phone communications among others.

Utah is in a unique and progressive position when it comes to the practice of telemedicine, as it is the first state to have passed the Interstate Medical Licensure Compact. This law is meant to streamline physician licensure across state lines and therefore facilitate the expansion of telemedicine practices. The development of different forms of telemedicine presents fascinating ethical questions. Among some of the questions that will be addressed at the Evening Ethics are: 1) How does telemedicine increases access to health care for our rural population in the Mountain West? 2) How does traditional telemedicine impact the relationship between physicians and patients, both negatively and positively? 3) What are the privacy and confidentiality concerns, and how can they be overcome? and 4) How should research be conducted using patient data from telemedicine conversations?

This Evening Ethics Discussion will be facilitated by DMEH faculty member, Teneille Brown, and has no preparatory background reading. As always, the Evening Ethics conversation will be casual, and we invite and welcome people with diverse backgrounds and perspectives.
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The Pacific Division meeting of the American Philosophical Association (4 April, 2015) devoted a session to Jim Tabery's Beyond Versus: The Struggle to Understand the Interaction of Nature and Nurture that involved three commentaries and Jim Tabery's reply to those commentaries. In addition, the April and June issues of the International Journal of Epidemiology, will also have sections devoted to Beyond Versus: The Struggle to Understand the Interaction of Nature and Nurture. In the April edition, there is a target article which summarizes the book as well as three commentaries (all currently available online). In the June edition, there will be Jim Tabery's reply to those commentaries.

Peggy Battin presented the following lectures: March 4-6, at Beloit College, Wisconsin, lectures on end of life and male contraception; March 23, at Johns Hopkins, the Berman Institute of Bioethics: "The Least Worst Death," April 4, at the American Philosophical Association Pacific Division meeting, a talk on "Puzzles About Disability," and on May 1, Las Cruces, New Mexico, a talk on "Starting the Conversation."

Sam Brown's group at the center for humanizing critical care published the first-ever characterization of patient reported outcomes after very severe shock (these were patients that many considered to be receiving futile care). Overall they had some physical disability but were no different from population norms in terms of mental health outcomes and were glad to be alive. See Pratt CM, Hirshberg EL, Jones JP, Kuttler KG, Lanspa MJ, Wilson EL, Hopkins RO. Brown SM (2015). Long-term outcomes after severe shock. Shock, 43(2), 128-3.

Sam Brown's essay on ICU visitation was published in the British medical Journal. See Brown SM (2015). We still lack patient centered visitation in intensive care units. BMJ, 350, h792. He is pleased that the patient family advisory counsel at his ICU is about to celebrate its first anniversary.