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UNIVERSITY OF UTAH
SCHOOL OF MEDICINE

MEDICAL ETHICS IN UTAH

Spring Edition 2016

Educational Points/Reflections from "Native Voices" Evening Ethics, November 2015

Although health disparities due to race, ethnicity, and socioeconomic factors are increasingly being recognized and addressed in the United States, one segment of the population that receives less attention is American Indians and Alaska Natives (AI/AN). More than 20% of AI/AN adults were living at or below the poverty level in 2009, about 2.5 times greater than whites living in poverty, according to a 2014 special issue of the *American Journal of Public Health* focusing on AI/AN health. Compared to white, black, Asian, and Hispanic adults, AI/AN were "more likely to have poorer health, unmet medical needs due to cost, diabetes, trouble hearing, activity limitations, and to have experienced feelings of distress in the past 30 days," according to *National Health Statistics Reports*. The AI/AN population has a 50% higher mortality rate than non-Hispanic whites. Native Americans are more likely to die from tuberculosis, chronic liver disease and cirrhosis, accidents, diabetes, pneumonia, suicide, and homicide. The prevalence of diabetes is 16.5 percent higher in AI/AN adults than in other non-white populations. At the other end of the spectrum, life expectancy for a Native American at birth is "2.4 years less than that of all U.S. populations combined," reported the U.S. Department of Health and Human Services in 2010.

These statistics point to a pressing need not only nationally but particularly in Utah. The health disparities of AI/AN people, write the authors of an editorial in the *American Journal of Public Health* special issue, are "amplified in urgency by the legacy of social, environmental and cultural injustices that have been inflicted on these populations." Illustrating the national article was a photograph of three high school boys in Monument Valley, UT. The Navajo Nation is "our backyard," Michael Lei, manager of Global Outreach for the University's John A. Moran Eye Center, reminded participants at a recent ***Evening Ethics Discussion***. Phyllis Pettit Nassi, M.S.W., manager of special populations at Huntsman Cancer Center where she oversees Native American outreach, noted that 78% of Native Americans don't live on reservations. *These statistics represent people who are likely to be our neighbors.*

By: Susan Sample, MFA, PhD

Ethical Issues around Video Remote Sign Language Interpretation (VRI)

Teresa Blankmeyer Burke, Ph.D., Associate Professor of Philosophy at Gallaudet University and bioethics advisor to the World Federation of the Deaf, and the National Association of the Deaf (U.S.A.), facilitated **Evening Ethics** discussion in January on "The Ethics of Video Remote Sign Language Interpreter Use in Medical Settings." Focusing discussion was the lawsuit of Margaret Weiss, a deaf, pregnant woman who wanted a live sign language interpreter for the delivery of her second child rather than a video remote interpreter (VRI) offered by the Florida hospital. Ms. Weiss was particularly nervous about complications as her first child had required an extensive stay in the NICU after birth. Ms. Weiss preferred a real person who could crouch down and be right next to her rather than a portable laptop with a person on a screen translating in American Sign Language. (ASL)

Is this case an ADA violation or more about patient wishes for comfort, to help relieve anxiety? If we believe that Ms. Weiss deserves a live sign language interpreter, what sort of precedent does this set for ADA interpreter requirements? Teresa Blankmeyer Burke, herself deaf, stressed that in both live and remote interpretation, fluency and certification are important, as ASL has many levels of complication. Since interpreters are privy to much private medical information, in cases where protection of privacy is a major concern, such as small towns where everyone knows everyone else, VRI may be preferred. On the other hand, technological problems with a portable VRI system can cause important elements of translations to be missed.

INSIDE THIS ISSUE:

Max and Sara Cowan Memorial Speakership

Wylie Burke, MD, PhD

Our 2016 Cowan Memorial Lecturer is **Wylie Burke, MD, PhD**, Professor in the Department of Bioethics and Humanities at the University of Washington (UW). Dr. Burke is also Adjunct Professor in the Departments of Medicine and Epidemiology and a Member of the Fred Hutchinson Cancer Research Center, and is a member of the Institute of Medicine and the Association of American Physicians. She served on the Secretary's Advisory Committee on Genetic Testing (1999-2002) and the National Human Genome Advisory Council (1999-2003), and was President of the American Society of Human Genetics in 2007. She is Principal Investigator of the University of Washington Center for Genomics and Healthcare Equality, an NIH Center of Excellence in Ethical, Legal and Social Implications (ELSI) Research .

Wylie Burke will present the following two lectures and facilitate an Evening Ethics Discussion. All are invited. CME is available at all three events:

Evening Ethics Discussion

Wednesday, March 23, 5:30-7:00pm, Research Administration Building

Using data to stigmatize: What are our collective responsibilities?

Current research on the cognitive function includes the use of sophisticated genomic research techniques to identify genetic variation associated with cognitive ability. Some of the research, published in highly reputable journals, uses questionable methods, such as "proxy phenotypes" – for example, the use of educational attainment as a proxy for cognitive ability. Some interpretations of the emerging data propose that they may explain why average IQs are lower in African countries than in European countries. Discussion of the controversial assumptions in such interpretations is often absent.

What is our collective responsibility to address the questions and concerns raised by such research, as ethicists, as researchers, and as members of the public?

As background reading for this discussion, please read "Can research on the genetics of intelligence be 'socially neutral'" by D. Roberts. (Hastings Cent Rep 2015; 45 (No.5):S52-54.) For an example of questionable data interpretation, you may also like to read "A review of intelligence GWAS hits: Their relationship to country IQ and the issue of special autocorrelation," by D. Piffer. (Intelligence 2015;53: 43-50.) For copies of both articles, please contact Linda Carr-Lee Faix at linda.carrlee@hsc.utah.edu

Internal Medicine Grand Rounds

Thursday, March 24, 7:45-9:00am, HSEB 1750

Genomics through the lens of practical clinical wisdom

Genomic information is touted as transformative, and is seen as a cornerstone to the concept of "precision medicine," in which genomics and other new technologies are used to individualize care. Viewed from the perspective of the practical wisdom gained in clinical practice, however, genomics may also obstruct high quality care at both the individual and the societal level. As the research advances, there will be an increasing need for analytic, technical, and clinical strategies that allow us to find within the genome the small amounts of health information that can improve care, while avoiding the large amounts of poorly predictive and misleading information that are also present.

Cowan Public Lecture

Thursday, March 24, noon-1:00pm, Eccles Genetics Auditorium

The deceptive appeal of personal genomics

A person's genome has been described as an "instruction manual" that can tell each of us about the health risks we face so that our medical care can be individualized. The concept is appealing – and makes intuitive sense because we all observe individual differences in health that are not readily explained. But more than a decade after completion of the Human Genome Project, we see that the reality is more complex and perhaps more prosaic.

Evening Ethics: Genetics Hot Topics

Cancer Moonshot, Precision Medicine Initiative, 21st Century Cures...: What's data got to do with it?

- February 23, 2016 Research Administration Building #117 4:00-5:30p


Bob Cooke-Deegan, MD

Robert Cook-Deegan, MD is a research professor at Duke University in the Sanford School of Public Policy, with secondary appointments in Internal Medicine (School of Medicine), and Biology (Trinity College of Arts & Sciences). He was the founding director for Genome Ethics, Law & Policy in Duke's Institute forGenome Sciences & Policy from July 2002 through December 2012. He is the author of *The Gene Wars: Science, Politics, and the Human Genome* and an author on over 250 articles.

Dr. Cook-Deegan's areas of expertise include genomics and intellectual property, history of genomics, global health, science and health policy, and health research policy. His current research focuses on policy implications of genomics, bioethics, intellectual property, and innovation.

This UCEER Genetics Hot Topics will explore "the squabbles in building a medical information commons: who owns the data? Who has obligations to share with whom." Background reading materials can be found on the UCEER website including:

https://www.whitehouse.gov/the-press-office/2015/01/30/fact-sheet-president-obama-s-precision-medicine-initiative

David Green Memorial Speakership


Jeffrey Brosco MD, PhD

Jeffrey P. Brosco MD PhD, is our 2016 David Green Memorial Speaker. Dr. Brosco is Professor of Clinical Pediatrics, University of Miami Miller School of Medicine and Associate Director, Mailman Center for Child Development. Dr. Brosco's research includes an analysis of the history of health care for children in early 20th century Philadelphia, the historical epidemiology of intellectual disability, and the history of newborn screening in the US. His current work integrates history, ethics, and clinical practice to forge systems-level approaches to improving child health, especially regarding large-scale screening programs.

Please join us for Dr. Brosco's two, CME sponsored events:

- Wednesday, April 13, 2016, Evening Ethics Discussion, 5:30pm-7:00pm, Large Conference room, Research Administration Building: *"Against Informed Consent? The case for paternalism in genomic newborn screening"*
- Thurs., April 14, 2016, Pediatric Grand Rounds, 8:00am, 3rd floor PCH Auditorium: *"Justice and Child Health: The Obligations of Pediatric Clinicians."*

Keep the Date: Guest Speaker Larry Cripe MD


Larry Cripe, MD

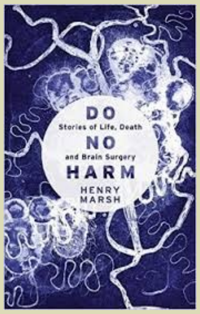
Larry D. Cripe, MD, Associate Professor of Medicine, Division of Hematology/Oncology, Indiana University Hospital, (IU), Medical Director, Palliative Care, IU, and Founding Director of *CompleteLife*, Indiana University Simon Cancer Center, will be visiting Utah **April 26, 2016**. Dr. Cripe's research interests include drug development (clinical and translational trials), supportive care measures such as music therapy, and the role of spirituality in the care of individuals with cancer.

In addition, Dr. Cripe writes and reads *Grace Notes*, radio essays on end-of-life care, broadcast through the nationally syndicated radio program, *Sound Medicine*. Watch for more information on the following opportunities to meet Dr. Cripe:

- 7:00am, April 26th, Dr. Cripe will speak to HCI Supportive Oncology Grand Rounds
    - 5:30-7:00pm, April 26th, Dr. Cripe will lead an Evening Ethics Discussion

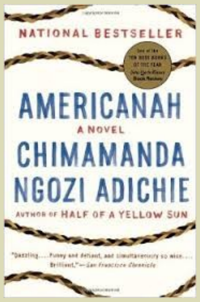
Physicians Literature and Medicine Discussion Group

February 10, 2016
University of Utah Hospital Large Conference Room #W1220 6:00-8:30p, Facilitated by Susan Sample, MFA, PhD
Do No Harm: Stories of Life, Death and Brain Surgery by Henry Marsh



“Henry Marsh is recognized as one of Britain's leading neurosurgeons and his memoir is ranked among the top 100 books for 2015 by the New York Times. It is a "frank and absorbing account [that] combines biography, descriptions of operations and considerations of policy." Each chapter begins with a definition of the medical term that serves as the title. Many are commonly known—"Aneurysm" and "Glioblastoma"; others--"Angor anima"--not so much. The stories that follow, however, are unique, as the 65-year-old surgeon describes not only technical difficulties of operations in intimate detail but the emotional predicaments. "The surgeon is now a villain and perpetrator, or at best, incompetent, no longer heroic and all-powerful," he writes after visiting a patient he "damaged." What sets Marsh's memoir apart is the candor of his reflections. As he notes in "Hubris," "this was the time when I became a little sadder but, I would like to think, much wiser." Whether physicians, other health-care professionals, or the public, readers certainly benefit from Marsh's honesty and insight. For our discussion, I suggest we focus on the chapters: "Melodrama," "Tic douloureux," "Hubris," Photopsia," and "Tyrosine kinase."

March 9, 2016
University of Utah Hospital Large Conference Room #W1220 6:00-8:30p, Facilitated by Rachel Borup, PhD
Americanah by Chimamanda Ngozi Adichie



Chimamanda Ngozi Adichie’s novel Americanah tells the story of a young Nigerian couple, Ifemelu and Obinze, who leave their home country and painfully part ways to pursue their separate academic and professional dreams in the U.S. and England. Adichie, a Nigerian-born Princeton-educated writer who continues to split her time between the U.S. and Nigeria, has a keen eye for the difficult and even ridiculous ways in which immigrants and people of color must navigate the complex issue of race. Ifemelu never felt “black” until she came to America; her blog posts, which form part of the novel, offer her frank and sometimes funny observations on the way race comes up in everyday interactions in the U.S. The story comes full circle when Ifemelu and Obinze return to Nigeria and try to reconcile who they once were with all that they’ve become.

April 13, 2016
University of Utah Hospital Large Conference Room #W1220 6:00-8:30p, Facilitated by Susan Sample, MFA, PhD
Lasting: Poems on Aging Edited by Meg Files

This unique anthology encompasses work by more than 100 respected poets who describe in language vivid and poignant, profound and downright funny, different facets of the aging, a topic that has been requested by discussion group participants. The authors keenly observe the bodies of parents and recollect grandparents' storied lives. They translate complaints of old friends into warnings and wisdom; they imagine the lives of strangers with empathy and hope. The writers also turn inward, reflecting on their own identities as they move into and out of their 50s, 60s, 70s, and 80s. What emerges is a prism of the aging process that shows the inevitability of death but more exquisitely, refracts time into myriad small, rich moments of lived experience that endure.
This is an anthology about the lasting quality of life.

Even if poetry is not your favorite genre, I encourage you to read through this collection with impunity. If you don't like a particular poem, turn the page; find a different writer giving voice to a different perspective. I think you'll find these poems accessible and provocative, providing topics for discussion that all may join in. For example, the anticipation of loss and the relationship between words, memory, and loss are addressed respectively in "A Brief History of Fathers" and "Living Room." Other poems in the book's first section I'd suggest reading include: "Zahkia," "The Elders" and "Elegy, Kahuku." In the second section, which centers on first-hand experience of aging, we'll discuss: "Silent Heart Attack," "That's Not Me," "The Lost Garden," "The Art of French Cooking," "From Hafiz on Aging…," "The Bookshelf," "Old Man," "A Woman Like Yourself," and "Fana Al-Fana." In the last section on mortality and the finality of aging, we'll consider: "Burial Rites," "Station," "Hawksbane," and "Out Here."

The 2016 Schedule of Readings will be posted on our website:
http://medicine.utah.edu/internalmedicine/medicalethics/

CALENDAR OF ACTIVITIES AND PROGRAMS

Resident Ethics Conferences **12:30-1:15 pm**	
Resolving Interprofessional and Interdisciplinary Disagreements	
IMC: Jay Jacobson, MD	Wed. Feb .17
VAMC Tsagaris Conference room: Brent Kious, MD, PhD	Tues. Feb. 23
UUMC Cartwright Conference room: Brent Kious, MD, PhD	Thurs. Feb. 25
Difficulties in the Resident Patient Relationship (difficult patients) (forum theater)	
IMC: Jay Jacobson, MD	Wed. Mar. 16
UUMC Cartwright Conference room: Gretchen Case, PhD	Tues. Mar. 22
VAMC Tsagaris Conference room: Gretchen Case, PhD	Thurs. Mar. 31
Medical Futility	
IMC: Jay Jacobson, MD	Wed. Apr. 20
UUMC Cartwright Conference room: Sam Brown, MD	Tues. Apr. 26
VAMC Tsagaris Conference room: Brent Kious, MD, PhD & Leslie Francis, JD, PhD	Thurs. Apr. 28
***The Physicians Literature and Medicine Discussion Group** **6:00-8:30 pm**	
Do No Harm: Stories of Life, Death and Brain Surgery by Henry Marsh, Facilitated by Susan Sample, MFA, PhD	
U of U Hospital Large Conference Room #W1220	Wed. Feb. 10
Americanah by Chimamanda Ngozi Adichie, Facilitated by Rachel Borup, PhD	
U of U Hospital Large Conference Room #W1220	Wed. March 9
Lasting: Poems on Aging Edited by Meg Files, Facilitated by Susan Sample, MFA, PhD	
U of U Hospital Large Conference Room #W1220	Wed. April 13
***Evening Ethics: Genetics Hot Topics with Robert Cook-Deegan, MD** U of U RAB #117 4:00-5:30p	
Cancer Moonshot, Precision Medicine Initiative, 21st Century Cures...: What's data got to do with it?	Tue. Feb. 23
Cowan Memorial Speakership with Wylie Burke, MD, PHD	
• ***Evening Ethics Discussion:** 5:30-7:00pm, Research Administration Building #117	Thurs. March 23
Using data to stigmatize: What are our collective responsibilities?	
• **Internal Medicine Grand Rounds:** 7:45-9am, HSEB 1750	Thurs. March 24
Genomics through the lens of practical clinical wisdom	
• **Cowan Public Lecture:** Noon-1:00pm, Eccles Genetics Auditorium	
The deceptive appeal of personal genomics	
David Green Memorial Lectureship with Jeffrey Brosco, PhD	
• ***Evening Ethics Discussion:** 5:30-7:00pm, Research Administration Building #117	
"Against Informed Consent? The case for paternalism in genomic newborn screening"	Thurs. April 13
• **Pediatric Grand Rounds:** 8:00am, 3rd floor PCH Auditorium:	
"Justice and Child Health: The Obligations of Pediatric Clinicians."	Thurs. April 14
Guest Speaker: Larry Cripe, MD	
• **HCI Supportive Oncology Grand Rounds**	Tues. April 26
• ***Evening Ethics Discussion:** 5:30-7:00pm, Research Administration Building #117	Tues. April 26

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Physicians Literature and Medicine Reflections

At January's Physicians Literature and Medicine Discussion group, **Mark Matheson, D. Phil**, facilitated discussion on, *Reclaiming Conversation: The Power of Talk in a Digital Age by Sherry Turkle*. As we strive to do our best, for patients, families, and all those causes we care about, the quotations, below, by Thomas Merton that Mark Matheson shared, are well worth pondering:

> "There is a pervasive form of contemporary violence to which we most easily succumb: activism and overwork. The rush and pressure of modern life are a form, perhaps the most common form, of its innate violence. To allow oneself to be carried away by a multitude of conflicting concerns, to surrender to too many demands, to commit oneself to too many projects, to want to help everyone in everything, is to succumb to violence. More than that, it is cooperation in violence. Our frenzy neutralizes our work for peace. It destroys the fruitfulness of our own work, because it kills the root of inner wisdom which makes work fruitful."
>
> "In the end, it is the reality of personal relationship that saves everything."
>
> --Thomas Merton

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DIVISION MEMBERS ON THE ROAD AND IN PRINT

The well-known Utah playwright Julie Jensen's new play, WINTER, is based on a short story by **Peggy Battin**, "Robeck," written in the 1970's but not published until 2005 in her collection of essays Ending Life. A reading of WINTER with a professional cast, starring Anne Cullimore Decker, will be held at the Salt Lake Acting Company on Monday, February 1, 7:00. The play will be produced by SLAC and is scheduled to run October 12 to November 13. Admission is free.

Peggy Battin will present at a conference in Prague, March 19-20, "What can we learn from historical sources about the ethical issues in suicide?" She will present in Chicago, March 31, at the American Association of Suicidology, "The Role of Suicide Prevention in an Age of Death with Dignity," She also will attend the San Francisco, Pacific Division, American Philosophical Association, April 1-3.

Through the Valley of Shadows: Living Wills, Intensive Care, and Making Medicine Human by **Samuel M. Brown**, will be available in April 2016.

A study showing that *"Family Visitors to ICU patients help in recovery,"* research by **Samuel Brown** and colleagues, is featured on local Fox News.