With increasing ease and frequency, people whip out smartphones to film or record events, including medical encounters. An October Evening Ethics discussion, facilitated by Leslie Francis and Jill Sweney, explored the ethical issues raised for healthcare professionals when it’s a medical encounter being recorded. Given the ubiquity of recording devices, many commentators have claimed that there’s no longer a reasonable expectation that we are not being recorded—a sentiment that was echoed by one clinician participant in the discussion. Others contend that despite the ease of recording, it is still important for there to be limits on their conduct and use.

What laws apply to such situations?

Not surprisingly, participants wanted to know some of the legal background governing recording. It’s both complex and limited. The constitutional protection against reasonable searches and seizures applies to state actors (governments and those working for them)—and so may mean that warrants are needed for recordings to be made by police or health care workers in public institutions. In the US, there’s a federal statute prohibiting wiretapping—but it permits private individuals to record conversations as long as one party consents. That consenting party could be the person doing the recording. Some states have passed laws requiring additional consent; Utah is a state that still has a one-party consent law, however. HIPAA—the federal statute and rule protecting the confidentiality of patient medical information—requires health care providers to obtain patient authorization for many uses and disclosures of identifiable health information, which photographs and films typically are. Because filming may capture more than one patient, it poses particularly acute HIPAA problems for health care institutions, which must take appropriate steps so that information about their patients is appropriately handled. Given these restrictions on health care providers, it seemed counter-intuitive, even unfair, to some discussion participants, that the consent of health care professionals to be filmed is not required by law.

Participants also were concerned to know about what patients—or their families or friends—might do with films they have made. In Europe, a comprehensive privacy regulation applies to activities such as posting identifiable material on social media sites or YouTube. In the US, protections are far more limited. There’s the Federal Trade Commission restriction of unfair or deceptive trade practices, which requires these sites to adhere to any privacy policies they have posted. And there’s the possibility of suing for damages, if individuals have been harmed by the public disclosure of embarrassing private facts. But the bottom line is that we have much less protection in the US than we would in Europe against what people decide to put up online about us.

What are the positives and negatives of filming?

Many health care workers remain uncomfortable about recording, even when it casts them in a favorable light. Looking at the potential positives and negatives of filming/recording can help us to understand the reasons for this discomfort.

Filming medical encounters might positively impact healthcare in the following ways:

- By providing an additional way of learning—educating patients, families, and trainees. Films could help families to recall and understand information, especially that shared in stressful, grief-laden end of life conversations where there are many contributors, ideas, or complex situations to consider. Since we now, typically, provide written patient instructions, some people regard filming as an unnecessary add-on, but since some people learn better via video and the spoken word rather than the written word, to allow filming—or to provide it ourselves—could provide an additional method of education. Filming could increase adherence and personal engagement, as well as be a tool for training purposes.

Inside this issue:

- What to do when you are being recorded
- Evening Ethics
- Informed Consent Play
- Health Law Rounds
- Hot Topics
- Green Memorial Lecture
- Physicians Literature & Medicine Readings
- Calendar
- Division Member updates
By providing an alternative or addendum to physician documentation that may be helpful in any future lawsuits.

By providing a check on professionalism—when someone is “watching” are we more professional, less likely to abuse? (This is one part of the reasoning behind using police video cameras.)

Or, it might negatively impact healthcare by:

- Developing a culture of distrust between healthcare providers and their patients, where providers become suspicious of their patients’ motives, rethink their better judgments and practice defensive medicine due to fear over lawsuits.

- Worsening healthcare, as some people are made nervous, anxious, or less efficient when filmed. For example, might interns be less likely to ask questions of their attendees for fear of looking stupid on film, and thus learn less? It is important to note that at this point, we don’t have any empirical evidence to tell if or how filming impacts patient care. We do know that people respond very differently to being recorded with some asking, “Can I refuse to treat this person?” to others not minding at all, even encouraging colleagues to “Get over it.”

- Enabling people who are upset or who disagree with medical advice to take these recordings out of context. (The solution to this might be through professional recording/filming to provide an additional perspective to the patient one.)

How ought our healthcare institutions and staff respond to requests to film?

Our society generally allows freedom of expression except where it causes harm. We do not censor. On the other hand, our society does regulate for the common good. A policy to not allow videotaping, period, will likely convince few and possibly make people who want to tape suspicious and angry at being censored for no applicable reason. Many may react to such a broad policy with, “What are you trying to hide?”

How might we control situations to maximize the positive benefits of recording while minimizing the negatives? Prohibiting recordings seems appropriate when (1) it violates the privacy of another patient, (2) it disrupts patient care as shown to be the case by evidence-based research, or (3) it puts staff or patient safety at risk. Could we have safe spaces, such as ERs, where filming might not be allowed, where even policemen are known to turn off their video cameras upon entering, because recording might likely create discomfort for patients who fear being collaterally filmed? Additionally, could we have safe spaces where conversations and interactions, carefully controlled to reduce collateral privacy invasion for patients and for staff safety, could be filmed?

If we in healthcare want to protect ourselves, we can—and perhaps should—videotape ourselves in these controlled environments, letting people know upfront that taping is going on, so that our tape can be seen in addition to theirs. That way, if context or followup or relevant information ever becomes edited out of a patient taping so as to use it in an incorrect, unfair, hurtful way, we have counter information and perspective. But even if we do tape sessions—even share them with patients—many at the discussion thought that patients should not be prohibited from recording except where regulated to disallow harm.

We might hope that we in healthcare would not edit out unfavorable parts of our recordings but history has shown us that not all healthcare professionals are as professional as they could be. Patient recordings could help ferret out and change these unprofessional behaviors in healthcare, however infrequent or frequent they may be. We should remember that there are inherent power differentials in medicine and that monitoring it is not a bad thing. For us to assume that patients should trust healthcare professionals (and so not need to record anything for their protective backup, education, interest, desire to “video scrapbook” their lives, etc.) while healthcare professionals need not trust patients because patients may be litigious—even though, malpractice is uncommon—is an untenable position of double standard.

Clearly, an angry, distrusting, litigious patient (or family member) seeking to ascertain that any problems are recorded is very different from someone who wants to film their GoPro experiences and blog about the narrative of their lives online. It was suggested that staff might ask potential filmers, “Why are you recording this?” to get a sense of whether the intent of filming is benign or malignant. One problem with this is that what starts off as friendly intent, may frequently change as the diagnoses/treatments/outcomes change.

This discussion begins to create an ethical foundation on which our guiding policy about recording of medical encounters might rest. We must be careful that this policy is applied consistently, whether the results of filming are complimentary, benign, or even beneficent.
Utah Presents, the Department of Theatre, the Center for Clinical & Translational Science, and the Division of Medical Ethics and Humanities are collaborating to bring to Utah a staged reading of the acclaimed new play, "Informed Consent," an exploration of the boundaries between research and privacy. In anticipation of this upcoming reading, the DMEH will hold an Evening Ethics Discussion, “Informed Consent: The Importance of the Havasupai Indian Tribal Case” on Monday, November 14th, 5:30-7:00 pm, RAB 117. The Evening Ethics Discussion is free and open to the public.

**Evening Ethics**

**“Informed Consent: The Importance of the Havasupai Indian Tribal Case”**

**Monday, November 14, 2016**

5:30pm-7:00pm, Research Administration Building, Room #117

The play, “Informed Consent,” by Deborah Zoe Laufer, which will be read on November 18th, 7:30pm at the University of Utah College of Law, is a fictionalized version of the Havasupai Indian Tribal Case that has been widely discussed in the field of research ethics and regulation. The case involved academic researchers who acquired information and blood samples from tribal members for research on diabetes. However, the specimens were used by other investigators for sensitive studies including mental health research and for projects that assessed the ancient historical migration patterns of the tribe. Both of the secondary research uses were conducted without the specific consent of tribal members. This Evening Ethics, in anticipation of the play later in the week, will invite discussion of the controversial aspects of this case and the current status of regulations governing genetic research with biospecimens. Moderators of the session will be two medical students, Lily Boettcher and Anna Cassell, and Dr. Jeffrey Botkin.

**Evening Ethics**

**“Is Proxy-Witnessing an Ethical Way to Remember the Holocaust and Prevent Future Atrocities?”**

**Wednesday, January 25, 2017**

5:30pm-7:00pm, Research Administration Building, Room #117

The death last July of Elie Wiesel, 87, a Holocaust survivor and winner of the Nobel Peace Prize, was a reminder that soon, there will be no eyewitnesses still living. How then do we heed what has been called humanity's "ethical imperative" to not forget so that the atrocities of the Holocaust will never reoccur in the future?

Literature scholar Susan Gubar suggests in her book *Poetry after Auschwitz: Remembering What One Never Knew* (2003), the possibility of "proxy-witnessing." Writers who did not participate in the Holocaust "testify...for those who cannot testify for themselves" by exercising their moral imagination. Through poetry's images and words, emotion and intellect, readers are transported to a communal memory of the past and then returned to the present where they may ethically look to the future. Proxy-witnessing may be applicable to other artistic mediums as well. Photography in particular has been discussed in relation to memory and representation. So, too, has tourism to Holocaust memorials, museums, and monuments; visitors are "secondary witnesses" and "producers of collective memory, historical knowledge, and ethical reflection" (Reynolds 2016).

Our discussion will begin with contributions from the University of Utah community. Jeff Botkin, M.D., M.P.H., associate vice president for research integrity and chief of the Division of Medical Ethics and Humanities, and Susan Folsom, a fourth-year medical student, both visited Auschwitz last summer with the program Fellowships at Auschwitz for the Study of Professional Ethics. We also will discuss the title poem, "Conversations with Survivors," from a collection by Jacqueline Osherow, Ph.D., U of U distinguished professor of English, whose writing is included in Gubar's book.

**Background Reading:**


**Additional optional readings:**

The Division of Medical Ethics and Humanities, in cooperation with the Center for Law and Biomedical Sciences and the Vice-Dean for Medical Education, are sponsoring a series of “law rounds” for medical students and other interested participants. The goal of the series—which meets from 7-8 am the first Monday of the month (breakfast included!)—is to acquaint physicians and other health care providers with basic legal concepts and tools. The first session was a discussion of medical malpractice law and how to respond to it, led by Suzette Goucher, the University of Utah’s Director of Risk Management. Upcoming sessions will deal with reproduction and the law (Nov. 7; Leslie Francis, Professor of Law) and the legislative process (Dec. 5; Jason Perry, UU Vice President for Legislative Relations and Director, UU Hinckley Institute of Politics). Anyone interested is welcome to attend the sessions, which will continue throughout the spring.

**Health Law Rounds at the School of Medicine**

The Genetics Hot Topics discussion was held on October 27 with a focus on gene editing technologies and their ethical and social implications. A relatively new approach to gene editing termed CRISPR-Cas9 provides a range of opportunities for biomedical science and for the treatment of genetic conditions. But this tool also presents a number of significant ethical concerns in a number of different domains. CRISPR-Cas9 enables gene editing in whole tissues, reproductive cells, stem cells, and embryos. Accordingly, the makeup of whole organisms can be altered to add or subtract genes to study the effects of those genes, but also to custom design microorganisms, plants, animals, and even human embryos to serve various human projects. In conjunction with tools such as “gene drives,” CRISPR-Cas9 could be used to alter or eliminate whole species from local or global environments, such as, for example, the elimination of mosquitoes for the purpose of preventing the burdens of mosquito-born diseases.

Dana Carroll, PhD, Professor of Biochemistry, and David Grunwald, Professor of Human Genetics, provided a brief overview of gene editing and progress to date. Jeffrey Botkin, Professor of Pediatrics, initiated the discussion of key ethical issues. A primary concern is whether gene editing will be feasible and desirable for either curing genetic conditions in human embryos or “enhancing” embryos for socially desirable characteristics. The discussion illustrated some disagreement in the group about whether we are inevitably heading toward this type of application. The participants also discussed the prospects for the use of “gene drives” to significantly alter populations of plants or animals in the wild. While the advantages are clear for human disease for eliminating certain organisms like disease-carrying mosquitoes, it was widely recognized that humans have a limited ability to predict the potentially broad range of secondary and unanticipated effects from such profound interventions in the natural order.

The speakers and the audience thought it might be valuable to revisit these issues in a year or two as scientists and society gain more experience with gene editing technologies in humans, animals and plants.

**Keep the Dates: 2016-17 David Green Memorial Speaker, Mary E. Fallat, M.D.**

Mary E. Fallat, M.D., will visit Utah February 16th and 17th, 2017 as our David Green Memorial Speaker. Dr. Fallat is the Hirikati S. Nagaraj Professor and Chief of Pediatric Surgery, University of Louisville, and Surgeon-in-Chief, Kosair Children’s Hospital. Opportunities to interact with Dr. Fallat include:

- Thursday, February 16, 2017 David Green Memorial Lectureship (Peds Grand Rounds) 8am-9am
- Wednesday, February 15, 2017 Evening Ethics, 5:30-7:00pm
**Physicians Literature and Medicine Discussion Group**

**November 9, 2016**  
*University of Utah Hospital Large Conference Room #W1220 6:00-8:30p, Facilitated by Rachel Borup, PhD*

**We are All Completely Beside Ourselves: A Novel** by Karen Joy Fowler  
Rosemary Cooke and her twin sister Fern had a happy childhood until they were five years old and Fern was mysteriously sent away from the family, a loss that devastated young Rosemary. What readers of Karen Joy Fowler’s novel, *We Are All Completely Beside Ourselves* soon learn is that, while Rosemary is human, her “sister” is a chimpanzee and their unusual living arrangement has been orchestrated as a scientific experiment by her father, an animal behavior researcher. Inspired by similar experiments in the 1970s, Fowler’s novel explores ethical dilemmas in scientific research and the complex relationship between humans and other animals. By turns outrageously comic and deeply sad, the novel reveals the surprising impact of Fern on Rosemary and the way grief can act on a family.

**December 14, 2016**  
*University of Utah Hospital Large Conference Room #W1220 6:00-8:30p, Mark Matheson, D. Phil.*  
**Rosemary: The Hidden Kennedy Daughter** by Kate Clifford Larson  
In *Rosemary: The Hidden Kennedy Daughter* (2015), Kate Clifford Larson tells the story of a special-needs child in a famous American family. The third child and first daughter of Joseph and Rose Kennedy, Rosemary experienced serious developmental and intellectual delays, and this set her apart among her high-achieving siblings. Larson sketches the cultural milieu that influenced how the Kennedy parents attempted to deal with Rosemary’s needs. These include the Catholic Church, Irish Boston politics, and various early twentieth-century efforts to understand and address the problems faced by children with disabilities. Larson explores the complicated dynamics of the Kennedy family, including the marriage of Joe and Rose and the very high parental expectations they imposed on their children. The book is a portrait of an American family of great consequence, and Larson offers a thought-provoking exploration of the evolving medical and educational responses to special-needs children during the twentieth century.

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### DMEH Calendar of Activities and Programs

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<th>Event</th>
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| **Resident Ethics Conferences**                                      | 12:30-1:15 pm      | **Intro to a few important healthlaw changes** | VAMC Tsagaris Conference room: Teneille Brown, JD  
UUMC Cartwright Conference room: Leslie Francis, JD, PhD  
IMC: Jay Jacobson, MD                                                 | Wed. Nov. 16  
Thurs. Nov. 17  
Wed. Nov. 23                                                        |
| **Leaving Against Medical Advice (role play)**                        |                    | **VAMC Tsagaris Conference room: Gretchen Case, PhD  
UUMC Cartwright Conference room: Gretchen Case, PhD  
IMC: Jay Jacobson, MD**                        | Wed. Dec. 7  
Wed. Dec. 14  
Wed. Dec. 28                                                        |
| **When Doctors Advise or Treat Their Relatives**                     |                    | VAMC Tsagaris Conference room: Teneille Brown, JD  
IMC: Jay Jacobson, MD  
UUMC Cartwright Conference room: TBD                                | Wed. Jan. 18  
Wed. Jan. 25  
Thurs. Jan. 26                                                       |
| **The Physicians Literature and Medicine Discussion Group**          | 6:00-8:30 pm       | **U of U Hospital Large Conference Room #W1220** | We are All Completely Beside Ourselves: A Novel by Karen Joy Fowler  
Rosemary: The Hidden Kennedy Daughter by Kate Clifford Larson Facilitated by Mark Matheson, D. Phil.  
2017 schedule to be announced soon: [http://medicine.utah.edu/internalmedicine/medicaledethics/](http://medicine.utah.edu/internalmedicine/medicaledethics/) | Wed. Nov. 9  
Wed. Dec. 14 |
| **Evening Ethics**                                                    | 5:30-7:00p         | **U of U RAB #117**                      | **“Informed Consent: The Importance of the Havasupai Indian Tribal Case”** | Tue. Nov. 14  
Tue. Jan. 25                                 |
| **“Is Proxy-Witnessing an Ethical Way to Remember the Holocaust and Prevent Future Atrocities?”** |                     |                                         |                                                      |            |
| **Informed Consent Staged Reading**                                  | 7:30p              | **Moot Courtroom, SJ Quinney College of Law** |                                                      | Fri. Nov. 18 |
| **Health Law Rounds**                                                 | 7:00-8:00a         | HSEB 2928                               | Reproduction and the Law with Leslie Francis, JD, PhD  
The legislative process with Jason Perry, Director Hinckley Institute | Mon. Nov. 7  
Mon. Dec. 5 |

**CME Statements Accreditation:** The University of Utah School of Medicine is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians. AMA Credit: The University of Utah School of Medicine designates these live activities for a maximum of 1.5AMA PRA Category 1 Credit(s)™. Physicians should claim only the credit commensurate with the extent of their participation in the activity. NONDISCRIMINATION AND DISABILITY ACCOMMODATION STATEMENT: The University of Utah does not exclude, deny benefits to or otherwise discriminate against any person on the basis of race, color, national origin, sex, disability, age, veteran’s status, religion, gender identity/expression, genetic information, or sexual orientation in admission to or participation in its programs and activities. Reasonable accommodations will be provided to qualified individuals with disabilities upon request, with reasonable notice. Requests for accommodations or inquiries or complaints about University nondiscrimination and disability/access policies may be directed to the Director, OEO/AA, Title IX/Section 504/ADA Coordinator, 201 S President’s Circle, RM 135, Salt Lake City, UT 84112, 801-581-8565 (Voice/TTY), 801-585-5746 (Fax). 1.5 CME for Evening Ethics and Literature & Medicine.
Susan Sample gave a talk on "Bringing Compassionate Care to the Disenfranchised Grief of Drug Overdose through Medical Ethics and Re-narration" at the Caring Connections Conference on Those Bereaved by Drug Overdose Death at the University of Utah College of Nursing Sept. 30, 2016. Dr. Sample also presented a paper on how "Insider-Outsider Status of Physician-Trainees Provides Critical Distance for De-medicalizing End-of-Life Care through Personal Narratives" at the 18th annual meeting of the American Society for Bioethics and Humanities (ASBH) in Washington, D.C., October 7.

Jim Tabery participated in a panel discussion following the Park City Film Series' showing of Unlocking the Cage.


Peggy Battin spent the month of September 2016 in residence at the Brocher Foundation, a bioethics research think tank in Hermance, Switzerland, working on her book Sex and Consequences. Dr. Battin attended the ASBH meetings in Washington DC in October, and was a speaker at the first known conference on VSED–Voluntary Stopping Eating and Drinking–held in Seattle October 14-15, 2016. Her presentation was titled "Aid in Dying's Enemies: What can we learn from them?"