



Meeting Thursday May 26, 2016

Greater Los Angeles Veterans Affairs Medical Center
Wadsworth Bldg. (500) 11301 Wilshire Blvd. LA
90073 Operator: 310-478-37116400 (6th floor)
SW corner San Diego Freeway (405) & Wilshire Blvd.
Exit Wilshire Blvd West from 405, right on to campus west of
freeway. Free parking in visitor lots
5:30 PM free dinner, 6:00 meeting (no RSVP needed)

1. "Soar with the Eagles" - ethics of treatment of morbid obesity and Pickwickian syndrome in the inpatient setting. Paul Schneider, MD
2. An update on CANHR v. Chapman, the court case which struck down interdisciplinary team decision making for unrepresented, incapacitated nursing home patients. Chris Wilson, JD

Upcoming Conferences

*June 4, Sat, 8am -3pm "The New Aid-In-Dying Law –A Primer for Practicing Physicians." Spanish Hills Country Club, Camarillo, sponsored by Community Memorial Health System and Ventura County Medical Association, \$49, 4 credits CME Cat.1, register by 5/31, includes workbook and short primer Julie@Venturamedical.org

* June 23-26 **Aspen Ideas Festival**, Spot Light session available, presented by the **Aspen Institute** in partnership with *The Atlantic* magazine, is public gathering place for leaders from around the globe and across many disciplines to present and discuss the ideas and issues that shape our lives and challenge our times.

Hospitals to Participate (or not) in California End of Life Option Law

As June 9th approaches, the date of the implementation of new Physician Aid in Dying (PAD) Option law, many California hospitals and physicians are deciding whether or not to participate. Most religious hospitals are expected to opt out on the basis of their core beliefs and values.

Some secular hospitals are also considering opting out. A group of medical leaders representing the physicians at Huntington Hospital in Pasadena have debated and voted thus. The executive committee of department heads submitted an amendment to the hospital board of directors stating Huntington Hospital, as an entity, has decided not to participate in

this act. Physicians, private contractors, and others who work on the property or work on behalf of Huntington Hospital would not be allowed to participate. For patients who wish to pursue PAD, Huntington would permit doctors to give them information and referrals to providers who are willing to offer those services. The hospital board—next meeting 5/26-- decides what position the hospital takes on this matter.

The medical group, Sutter Health, taking a different approach, views the new law as an option in end-of life care for terminally ill patients and encourages communication between doctors and patients regarding this option.

Kaiser-Permanente plans on pairing patients who wish to take advantage of PAD with a coordinator who will take them through the process. If a patient's physician decides not to participate the coordinator will set them up with a physician who will.

<http://www.latimes.com/business/la-fi-lazarus-20160506-column.html>

*****Weigh in with the Editor*****

Ed- in- chief: Kendra Fleagle Gorlitsky, MD

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Contributors: Richard Boudreau, MD, JD Ken Murray, MD
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Advance in Human Embryo Research Rekindles Ethical Debate

Magdalena Zernicka-Goetz and her research group at the U of Cambridge created a mixture to support the human embryo in an in vitro environment for up to two weeks, enabling scientists to research the life of an embryo during the stage of implantation. (Previously scientists were able to keep human embryos alive in vitro for up to seven days.)

This extended ability can help researchers answer questions about the workings of embryonic stem cells, etiology of miscarriages, and infertility. The advancement brought to light the **14 day rule which states that embryos can be experimented on up to the first 14 days of development**. The 14-day mark was established because--explains [Insoo Hyun](#), a bioethicist at Case Western Reserve University-- that was about the time when embryos tend to form the "primitive streak," a structure that starts to give the embryo more of a structure and individuality (and after which twinning is no longer possible.) The rule was



established at a time when it was impossible to keep embryos alive in the lab even that long. It was introduced in Britain 30 years ago, and adhered to by at least 12 other countries, aiming "to give scientists room to study human embryos, while respecting wider views on embryo research." (The Guardian 5/4/2016).

In the current research, both groups of scientists stopped the embryos from developing past 14 days because of the long-standing rule. But the new work suggests they could have kept the embryos alive longer. "If there's no other way to retrieve valuable information that could be good for humankind, I think it's definitely worth discussing the possibility of renegotiating where that stopping point ought to be," says [Hyun](#).

"The question has to be: 'Are there any limits to what we will do to human beings in order to gain scientific knowledge?' And then who counts as a human being?" queries Dr. [Daniel Sulmasy](#), bioethicist at the University of Chicago.

Hyun stresses that to satisfy moral qualms, any change to the 14-day rule would require the same kind of careful, coordinated international debate that created the rule in the first place.

<http://www.npr.org/sections/health-shots/2016/05/04/476539552/advance-in-human-embryo-research-rekindles-ethical-debate>

Pondering "What it means to be human"

On the frontier of gene editing

Scientists are granted permission to edit the genomes of human embryos for research in London, UK fertility regulators [announced](#). The UK Human Fertilisation and Embryology Authority (HFEA) represents the world's first endorsement of such research by a national regulatory authority (Nature, Feb 4, 2016)

Once prohibited for use in human embryos, CRISPR '*clustered regularly interspaced short palindromic repeats*' technology has the potential to target and correct genetic mutations leading to devastating genetic diseases. This technology can also be used to select for certain traits, bringing up the fear of misuse and the horror of eugenics.

People who suffer from genetic diseases may look to CRISPR for relief or to prevent the passing on of these diseases to their offspring. Some argue against correcting genetic mutations. A mother of a child with

Down syndrome asserted, "I ... wouldn't change him... He's so loving in a way that's unique to him."

The unknown long term consequences of gene editing raise the question of what it means to be human. Jennifer Doudna, a scientist at UC Berkeley who helped discover CRISPR believes that, while this technology has the potential for good it could also be used for nefarious purposes. When asked how the misuse of CRISPR could be regulated in the world, Doudna admitted that there was no easy answer and asserted this could be asked about any ground breaking technology

To guard against misuse, a conference was held 12/2015 at the National Academy of Sciences in Washington. Scientists from Europe, China, and North America which created guidelines for the use of CRISPR technology including the caveat that it should not be used to edit genes in human embryos intended to establish a pregnancy, stressing that any tinkering with human germline cells should come only after a "broad societal consensus" that such editing is a good idea.

https://www.washingtonpost.com/national/health-science/pondering-what-it-means-to-be-human-on-the-frontier-of-gene-editing/2016/05/03/a639b3ae-0bbb-11e6-bfa1-4efa856caf2a_story.html

Book Review

by *Keeshia Tappin*

Paul Kalanithi's, "When Breath Becomes Air"

is a moving, engaging, pensive chronicling of a life cut short, written by a 36 year old neurosurgeon on the cusps of finishing residency who finds out that he has stage 4 lung cancer. As his life comes to an end at such a pivotal moment in his career he reflects on "what makes life meaningful?" He suggests it is relationships and reflects on what brought him into medicine, his experiences as a resident, then as a patient when he is forced to abruptly face his own mortality.

Kalanithi conveys his vulnerabilities with a beautiful writing style. His ability and willingness to share his thought process make for a pleasurable read, despite its weighty content. It challenges the readers to put themselves in his position, to join his processing of the stages of grief as he moves from wellness, to sickness, to recovery, to relapse, and finally to death.

He provides personal pearls on how best to face bad news by encouraging one not to try to steam roll it with blind determination but to seek truth and acceptance. He comments on the doctor-patient



relationship-- highly relevant to me as medical student trying to discover my own practice style.

Dr. Kalnithi states a "physician's duty is not to stave off death or return patients to their old lives, but to take a patient and family whose lives have disintegrated and work until they can stand back up and face, and make sense of, their own existence." In the end, Kalanithi comes to a state of peace and acceptance.

He is unable to complete his novel before his death but, his wife closes the book with a moving epilogue reminding the reader that "Paul saw the inextricability of life and death, and the ability to cope, to find meaning despite this, because of this. What happened to Paul was tragic, but not a tragedy."

Unconsented-To Cesarean Section; Quarter Century post Angela Carter

In 1987 Angela Carder, a pregnant woman in her last few days of life, refused a C-section for the delivery of her 26 week old fetus. A court order was obtained by a physician unrelated to her case to proceed with the delivery. Two days after the delivery, mother and child died.

The court order was subsequently overturned by an appeals court which set a precedent giving pregnant women the right to refuse care. Technically this ruling only applied to the District of Columbia but, it was thought to be powerful enough to guide other states in similar cases and was set with the intention of preventing something like this from happening again. But other states have not adopted this position.

In 1999 Laura Pemberton sued a hospital in Florida for the violation her right to bodily autonomy after she was forcibly taken to a hospital and given a C-section by a court order obtained by the hospital. The court referenced the case of Roe V. Wade which gives the state the ability to intervene in the life of a fetus late in pregnancy and ultimately ruled that the hospital was justified in making the decision to deliver her baby because the safety of the fetus overruled her bodily autonomy. The court deemed that this case was unlike A.C.'s because the surgery did not cause the mother's life to be in danger. It did however contradict the concept of informed consent where the physician has a duty to explain all risks and benefits of proposed treatments and the patient with capacity has the right to consent to or refuse treatment.

In 2014 Rinat Dray filed a case against a New York on-call physician who performed a C-section against her will without a court order, with the physician having noted in the chart that the refusing patient had "capacity." Few such cases are pursued unless there is a subsequently noted significant harm to the parties, given the expense of the contingency fee model often requiring \$50,000 to proceed initially.

In 2015 attorney Lindsay Scarborough was in active labor when the on-call physician demanded a C-section. At first Scarborough refused but, then the physician warned about the dangers of cerebral palsy, threatened to call child protective service to take away her older child and to call a judge to get a court order for the surgery. After this pressure she agreed but, indicated that despite her education, generally good health, and financial stability, she felt coerced into having the procedure, illustrating the vulnerability of patients in such circumstances.

Michigan doesn't have a law directly allowing the state to intervene in cases involving an unborn fetus but, if the fetus is thought to be in danger their laws are interpreted in a way that grants this power.

Deborah Fisch a Michigan attorney who offers defense of health care providers against state disciplinary actions and is active in legislation establishing midwife practice scope asserts, "Institutions ranging from hospitals to the courts must reinforce the policy that the best decision-maker for a potential child is its parent, particularly the one in whose body it resides."

<https://msubioethics.com/2016/04/07/unconsented-to-cesarean-sections/>

From the Halls

by Richard Boudreau, MD, DDS, JD, PHD, Faculty
LMU Bioethics Institute, Dept. Theological Studies

Panel Provider Ethics

The relatively recent availability of effective treatment for previously fatal conditions has been accompanied by a dramatic rise in the prevalence of chronic disease. Approximately half of adults in the US have one or more chronic diseases, e.g. hypertension, coronary artery disease, diabetes, arthritis. By 2020, 157 million Americans are projected to have at least one chronic disease and 87 million will have two or more chronic conditions.

Chronic disease management has been defined as a system of coordinated health care interventions in which patient self-management efforts are significant,



and has become a major component of modern medicine. Unlike acute episodic care which emphasizes the unique features of each individual patient, chronic disease care focuses on evidence-based treatment guidelines. The clinical course of chronic illness is heavily dependent on patient behavior, including diet, exercise and self-managing medication use, as well as the ability of patients to correctly interpret symptoms.

Chronic disease care requires a paradigm shift in thinking from a focus on individual patients to a lens that includes the entire patient population for which a provider is responsible for ethical participation in what is commonly termed a 'panel.' This invariably includes patients who may not regularly access medical care through traditional office visits and who require proactive outreach. Moreover, health care providers, to be effective, have an ethical duty to have systems in place to monitor every patient on their panel so that evidence-based preventative care (e.g. mammography) and chronic illness care (e.g. foot checks for diabetics) can be offered and ensure that no patient 'falls through the cracks' and misses the opportunity for important health-promoting interventions.

This complex operation requires leveraging health information technology to assure that evidence-based guidelines are applied to every patient with a given chronic condition. Panels must simultaneously manage both acute episodic illness and chronic disease, and the success of this simultaneous management requires providers to rely on clinically skilled team members to whom they can delegate clinical responsibility and share ethical accountability.

Murray's Musings

Ken Murray, MD, retired Family Physician, author of "How Doctors' Die," contributor to news magazines and medical journals

Are Routines "Too"?

I recently underwent a medical catastrophe that landed me in a hospital bed for two months, involving septic shock, renal failure, and open heart surgery to repair a valve. Needless to say, I was an interested observer. I was in the hospital where I practiced, so I knew most of the doctors (I had 12 consultants), in some cases for decades. I was amazed how they fell into distinct categories.

Some approached me with caution, and flipped into "doctor mode"---just the facts, and not much of them, trying to get out of the room as quickly as possible. Some approached me as a friend, being totally clear and honest with their thinking. I felt comforted by that. I was surprised by the physical examination done by several. Some were clearly doing it by rote, forgetting that I actually know where the heart sounds are heard, and where the lung lobes are located. I wonder for what they were listening?

While I generally think the care I got was superb, there were a few hiccups. Post-surgery, I had nightly episodes of delirium. I actually ripped out a PIC line. There was a real problem with people sticking to their specialty, and not investigating why that was happening. If a cardiologist ordered a drug, no one else was going to mess with THAT! When I requested a Palliative Care consult, things changed. I got transfused, and half my drugs were dropped. No more delirium! (by the way, one of the most frightening things I've ever experienced!)

This cemented for me the value and role of Palliative Care in non-terminal care. It also made me consider that routines in care are probably best periodically evaluated.

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