Southern California Bioethics Committee Consortium Newsletter
"The Balance Sheet" Jan, 2014 Vol. XXX

Next Meeting, Wed. Jan 15, 2014

Greater Los Angeles Veterans Affairs Medical Center
Wadsworth Bldg. (500)11301 Wilshire Blvd. LA 90073
Operator: 310-478-37116400 (6th floor), room 640
SW corner San Diego Freeway (405) & Wilshire Blvd.
Exit Wilshire Blvd West from San Diego Freeway,
Immediate right on to campus west of freeway
Free parking in visitor lots
5:30 pm dinner 6:00 meeting
Agenda: 1. Bioethics Committees as Innovators: Reflections on Asian Bioethics Darryl Macer, Ph.D. Provost, American University of Sovereign Nations, Scottsdale, AZ
Director, Eubios Ethics Institute, New Zealand, Japan & Thailand
Director, Intern'l Peace & Development Ethics Centre, Thailand
Research Fellow Center for Ethics of Science & Tech, Thailand
2. Announcements
3. Discussion of the Jahi McGrath case.
Should SCBCC sponsor a community-wide conference on the ethics of brain death?
4. **Presentation (Cases from the field)** 8:30 adjourns

Controversies

"Are Medicaid recipients worse off than their uninsured?" asks and suggests a study done in Oregon and published in the *NEJM*. Dr. Jha, in a Health Care Blog, postulates reasons for this, including red tape that makes some good and plain practicing doctors prefer to do charity work rather than sign up to get the poor compensation and endless paper work required of Medicaid which also has stipulations making it difficult for Medicaid recipients to receive such charity care without placing the doctor in jeopardy of fraud. Read about it in the Health Care Blog 12/31/2013 - http://thehealthcareblog.com

Movers and Shakers

Latoya Ruby Frazier and the ethics of community responsibility

This young artist (born in 1982) combines visual arts with searing messages including the obligations that a hospital has for its ailing community. Braddock, PA, declined with the steel industry in the 1970's, eventually losing the majority of its population. Frazier's photographs document the decline as well as the ravages of cigarettes, addiction, and chronic occupational illnesses. One of her works compares the demolition of the hospital to the body's deterioration. Prints portray residents' response to the hospital's closing, and ironic references to a Levi's jeans advertising campaign set in Braddock: Levi's slogans, "Go Forth" and "Everybody's Work is Equally Important," contrasted with images of the town's struggle for economic opportunity and access to health care. See more at: **http://tinyurl.com/n6zr7t6**

Latoya Ruby Frazier

Murray's Musings by Ken Murray, MD

I deal with the media on a weekly basis, and I generally find them to be respectful, educated to the topic, and cautious in conclusions. *But not always*. An example is the recent *LA Times* article that blasted the headline: **More think doctors should try to extend lives, no matter how painful.** It describes the results of a Pew Research Center poll (which generally find does good polling). It started by saying: *"A growing minority of Americans believes that doctors should do anything possible to save a life, no matter what, instead of saying there are some situations in which a patient should be allowed to pass away, the Pew Research Center found in a survey of nearly 2,000 adults. In addition, an increasing number of people say that even if they were suffering an incurable disease and were in severe pain, they would not ask their doctors to halt treatment."*

However, what they did not say is equally important; on the Pew website, it says this: *"This modest uptick stems largely from an increase in the share of the public that expresses a preference on these questions; the share saying they would stop their treatments so they could die has remained about the same over the past 23 years."*

So much for the headline!

I am also bothered by the Pew question: *"If a person has an incurable illness, would you want a doctor to do everything to make a person live?"* By definition, there is NO intervention that will make such a person live! (there is nuance, but you get my point)

The Times article also included a wonderful statement by Paul Schneider that addressed futile care.
http://www.latimes.com/local/la-me-1122-end-of-life-20131122,0,82488.story#ixzz2lNxQuyyG

The takeaway lesson is that if your gut tells you that something is wrong in the premise of the question you are being asked, it probably *is* wrong. And remember, the writer of a newspaper article has NO SAY over it's title (that's done by the editor)!

**** Call For Presentations ****

Coalition for Compassionate Care of CA
In preparation for their 6th annual Conference
"Exploring New Horizons in Palliative Care" 4/10-11/2014 info@coalitionccc.org

Weigh in with the Editor: kfgorlitsky@gmail.com
Contributors: Ken Murray, M.D., Richard Boudreau, M.D, .Jessica Freidman, MS3 KSOM

Southern California Bioethics Committee Consortium Newsletter
"The Balance Sheet" Jan, 2014 Vol. XXX

Student's Corner Query by J. Freidman

One of the most important ethical questions medical students face in their third and fourth years is, "How far into my personal life should I allow my patients; and to what extent is my learning about their medical care--that I am not personally providing--a violation of their privacy?

Case in point:

A man with complications of alcoholic hepatitis and many comorbidities, became my patient for a week and a half while he was on our service. We arranged to meet in the lobby Friday morning after his discharge so that I could give him his order for the lab draw. I gave him my phone number and told him to call me with any questions. Later in the week he called with an appropriate question which I answered A week later, I called to inform him that a Dermatology appointment had been scheduled. (He had severe plaque psoriasis.) This conversation was cordial, brief, and professional. Was this lucky? Could it have gone badly? Several weeks later, on my next rotation, I looked in our hospital's EMR to see how his follow-up GI/Liver appointment had gone. His response to corticosteroid treatment was "intermediate." I wonder how he's doing, if he responded to his corticosteroid treatment, if he was able to stop drinking, and if he is compliant with his psoriasis treatment. It would be very easy for me to look him up in our EMR. But is this appropriate? Does my curiosity and concern justify learning about a person who is no longer my patient, and without his permission? Please email me at jessickf@usc.edu with any thoughts or insight.

From the Halls

Observations by The Bioethics Institute
Department of Theological Studies LMU, U. Hall 4500

Jahi McMath – Thoughts, Comments, Recommendations

Richard Boudreau, MA, MBA, DDS, MD, JD, PHD

Regardless of extensive medical efforts, mortality is a reality for each human, and medical futility is the belief that mortality is imminent. Even in the presence of life-sustaining technologies, the decision sometimes has to be made that "enough is enough."

Discussion of Quality of Life v. Sanctity of Life is a beneficial approach to understanding this heartbreaking case. In McMath, lawyers and personal relations management took the forefront, rather than grief counselors and like personnel to maintain the focus on educating the family on Jahi's lack of a purposeful existence, and letting her pass with dignity while maintaining parental autonomy.

There is no cookie-cutter approach – each case must be approached individually and methodically. A conundrum exists, regarding efforts to reconcile the medical-spiritual positions at issue which can be frustrating and taxing.

Families may resort to prayer according to the dictates of their faith which should be respected. The focus should be on dealing with the reality of saying goodbye. Lawyers and PR consultants should not interfere with the natural grieving process guided by a team including physicians, grief counselors, social workers, and clergy.

Defining brain death is not well understood by the lay public which requires education, especially by bioethicists. "Should SCBCC sponsor a community-wide conference on the ethics of brain death?" Yes. Although McMath hinges on religious beliefs (miracles), the issues, in broad part, affect the secular populous as well.

Issues to be considered for presentation/discussion include:

1. **Death defined** in terms of cardiopulmonary cessation or by brain/brain stem cessation.
2. **'Whole brain death'** coined as legal death by the presidential bioethics council.
3. **In California, the family may not make the decision to maintain the ventilator beyond a 'reasonable period'** to accommodate the family.
4. Distinguishing well known cases, to wit: **Quinlan, Cruzan, Schiavo** regarding PVS (not brain dead).
5. McMath is distinguished by the family insisting on **blocking the hospital's position of discontinuing life support, based on religious belief (1st Amend.)** that miracles happen.
6. **New York and New Jersey permitting religious beliefs to use cardiorespiratory criteria for death** which would support McMath.
7. **Distinguishing brain death** (irreversible brain & brain stem function), **coma/vegetative state** (brain activity exists) necessary for public awareness enabling better understanding of 'brain death' cases.
8. Medically **interrupting life support** has been viewed from murder to a merciful act.
9. **Harvesting organs** can be viewed as the prime motivation; hence, brain dead patients are considered disposable.
10. Dealing with family being subjected to allegations **from extreme denial to blatant opportunism**.
11. The family (as a victim) looking for **someone to blame.**
12. Allegations of malpractice loom large and will likely be unwound as a civil suit progresses But for now, the **hospital is viewed as the 'bad guy.'**
13. View **monetary costs to maintain a brain dead** patient and use of utilities that may better serve patients not brain dead.
14. HIPPA prevents the hospital from disclosing patient information without family consent which was not given in this case making for an **unbalanced presentation**.
15. The hospital's continued **refusal to Trach & PEG**.
16. In the field of bioethics, we often appeal to concepts such as benefit and burden analysis, proportionality, or double effect, concepts commonly associated with the Catholic moral tradition. (Terri Schiavo, Karen Quinlan, and Nancy Cruzan were all Catholic.) The Catholic tradition offers **two competing viewpoints on the morality of withholding or withdrawing ANH**. Consider ANH as morally obligatory v. morally optional.

Southern California Bioethics Committee Consortium Newsletter
"The Balance Sheet" Jan, 2014 Vol. XXX

CME and Advanced Training Opportunities

Wed. 3/19 ETHICS OF CARING: Lead From Where You Stand: Ethics and Effecting Change
Carnesale CommonsUCLA Conference Center
Registration: https://www.ethicsofcaring.org

Another Side…

FORT WORTH —At 33, Marlise Munoz was [reported to be] brain-dead after collapsing in November from what appeared to be a blood clot in her lungs. She was 14 weeks pregnant. At least 31 states have adopted laws restricting the ability of doctors to end life support for terminally ill pregnant women, regardless of the wishes of the patient or the family, according to a 2012 report from the Center for Women Policy Studies in Washington. Texas is among 12 of those states which require that life-support measures continue no matter how far along the pregnancy is.

A crucial issue is whether the law applies to pregnant patients who are brain-dead as opposed to those in a coma or a vegetative state. The law, passed by the Texas Legislature in 1989 and amended in 1999, states that a person may not withdraw or withhold "life-sustaining treatment" from a pregnant patient."It's not a matter of pro-choice and pro-life," said Mrs. Munoz's mother, Lynne. "It's about a matter of our daughter's wishes not being honored by the state of Texas."Mrs. Munoz's father, argues "All she is is a host for a fetus. I get angry with the state. What business did they have delving into these areas? Why are they practicing medicine up in Austin?"

"If she is dead, …I don't see how we can be talking about treatment options for her," said Thomas W. Mayo, an expert on health care law and bioethics at the Southern Methodist University law school in Dallas. Arthur L. Caplan, director of medical ethics at NYU Langone Medical Center in Manhattan, agreed. "The Texas Legislature can't require doctors to do the impossible and try to treat someone who's dead," Mr. Caplan said. Critics of the hospital's actions also note that the fetus has not reached the point of viability outside the womb and that Ms. Munoz would have a constitutional right to an abortion. "These laws essentially deny women rights that are given others to direct their health care in advance and determine how they want to die," says Atty Katherine Taylor. "The law can make a woman stay alive to gestate the fetus." Jeffrey P. Spike, professor of clinical ethics at the University of Texas medical school in Houston, said there were some known examples of fetuses having been kept alive while a terminally ill or brain-dead mother was on a respirator. But in every case he knew of, those steps were in line with the family's wishes. Mr. Machado said he had been told by the hospital's medical team his daughter might have spent hour or more without breathing adequately before her husband woke and discovered her, a situation he believes has seriously impaired the fetus.

Mrs. Machado said the doctors had told her that they would make a decision about what to do with the fetus as it reached 22 to 24 weeks, "That's very frustrating for me, especially when we have no input in the decision-making process," Mr. Machado added. *NY Times*, Jan 7, 2014

Glossary: *What's in a Phrase? Brain Death*

Brain Death Really *Is* DeathArthur Caplan & David Magnus
brain-death-really-is-death/#ixzz2qDNrHuXe
Read more: http://ideas.time.com/2014/01/03/why-

Approaching the Bench:

Timothy E. Quill physician specializing in palliative care at the University of Rochester Medical Center in New York. board member of the Death with Dignity National Center in Portland, Oregon, the lead plaintiff in a case that eventually reached the Supreme Court of the United States in 1997, *Vacco v. Quill*, in which the Court decided that a state law against physician-assisted suicide was constitutional.[1]In 1991, Quill published an article in *The New England Journal of Medicine*[3] describing how he assisted in the suicide of [1]a 45-year-old leukemia patient *(who)* refused chemotherapy. She shortly thereafter decided that she wanted to kill herself rather than have a "lingering death" which doctors had told her may be a matter of weeks or months away. Quill …referred her to the Hemlock Society and a week later she requested barbiturates to help with "insomnia." He gave her a prescription and told her the amount required to treat both insomnia and the dose required to bring about death. Some time after getting the prescription, she said her final goodbyes to Quill and her family and took the barbiturates alone. No charges or indictments were brought against Quill.

Adjunct Resources

The California State Association of Public Administrators, Public Guardians and Public Conservators (CAPAPGPC) is now accepting presentation and workshop proposals for the annual PAPGPC Training and Certification Conference September 22-25, LA, CA

CAPAPGPC is the certifying body for over 700 members from 58 counties responsible for thousands of individual estate & medical/personal decisions.

Conference attendees are professionals looking for presentations that provide basic, intermediate and advanced levels of information, education and knowledge they can put to use. Proposals should include

- Presenter(s) name & employer/affiliated organization
- Presenter(s) CV or Resume
- Presentation Title
- Type of Presentation (single speaker, panel presentation)
- Presentation Abstract (max. 250 words)
- Estimated length of presentation
- Audio-Visual Needs
- Date availability and/or of preference of date and time to present

CAPAPGPC is a non-profit organization with limited funds for presenters. Those requiring financial assistance to participate as a presenter must indicate expenses need covered or reimbursed. akdiaz@co.santa-barbara.ca.us