# Bioethical Quandaries at the Bedside, in the Community, and Around the Globe What should we do? Who decides? And how do we assure justice?

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Wednesdays 10 AM to Noon

March 13, 2019 through May 15, 2019

Session I, March 13: Introduction to bioethics and the course, introduction to ethical principles, the elements of case analyses, distinctions between public health and private health, planning for presentations.

### Readings and links

Cases: Andrew Speaker "The Tuberculosis Traveler" and Dorothy Zauhar "Stolen Heart; Stolen Kidney"

- 1. The case of Andrew Speaker, the so-called tuberculosis traveler. You may recall reading/hearing about him.
  - https://www.nytimes.com/2007/06/08/us/08speaker.html
  - NPR coverage of the story (these are all short)

Go to www.npr.org

Type "Andrew Speaker" in the search window (make sure to use "")

Listen to the stories in chronologic order

If you don't want to listen to all of them, make sure you listen to these two key stories in the series

https://www.npr.org/templates.story/story.php?storyId=10545665 https://www.npr.org/templates.story/story.php?storyId=10538667

- Thanks, Andrew Speaker. The Scientist, 2007. <a href="https://www.the-scientist.com/column/thanks-andrew-speaker-46329">https://www.the-scientist.com/column/thanks-andrew-speaker-46329</a>
- 2. The case of the man who "stole my heart; stole my brother's kidney."
  - https://www.washingtonpost.com/archive/politics/1997/10/21/woman-alleges-fiance-stole-her-heart-brothers-kidney/21ef2f19-fe1a-43fb-a6b6-f6763ff2577c/?utm\_term=.7b872852c279
     http://community.seattletimes.nwsource.com/archive/?date=19980122&slug=2730146
- 3. MOOC, Unit 1, Patient Autonomy

Session II, March 20: Justice in healthcare, allocating limited resources, healthcare gap between haves and have-nots, patient dumping.

Is healthcare in the United States a right or a privilege? What are the pros and cons of the new boutique/concierge medical practices for patients and doctors? What are the ethical issues that such practices raise? What are the responsibilities of emergency care providers and hospitals to the uninsured? How does justice play out in healthcare?

#### Readings and links

- How Hospitals Coddle the Rich. https://www.nytimes.com/2015/10/26/opinion/hospitals-red-blanket-problem.html?\_r=0&module=inline
- Christopher Sercye. <a href="https://www.chicagotribune.com/news/ct-xpm-2003-05-02-0305020332-story.html">https://www.chicagotribune.com/news/ct-xpm-2003-05-02-0305020332-story.html</a>
- Patient dumping, <a href="https://journalofethics.ama-assn.org/sites/journalofethics.ama-assn.org/files/2018-06/hlaw1-0901.pdf">https://journalofethics.ama-assn.org/sites/journalofethics/sites/journalofethics/sites/journalofethics/sites/journalofethics/sites/
- Deamonte Driver, <a href="http://www.washingtonpost.com/wp-dyn/content/article/2007/02/27/AR2007022702116.html">http://www.washingtonpost.com/wp-dyn/content/article/2007/02/27/AR2007022702116.html</a>
- Atul Gawande. Is healthcare a right? https://www.newyorker.com/magazine/2017/10/02/is-health-care-a-right
- MOOC: Unit 2, Provider autonomy

#### Session III, March 27: Medical practices in prisons.

In the United States, hyperincarceration of minorities is a well-known fact, and structural violence in prisons is out of control. Who are the healthcare professionals who work in prisons? What is unique about the patient population there? What actions of doctors, nurses, and other providers jibe with their professional obligations to "do no harm?" Which ones seem at odds with these oaths? Is it ethical for doctors to assist with lethal injections? Is it ethical to force prisoners to take anti-psychotic drugs in order to be sane enough to stand trial ... and then possibly be executed? Is that in a prisoner's best interests? What are a just society's obligations to prisoners?

#### Readings and links

- Mr. M: NEJM, Jan 17, 2019, 205. The Structural Violence of Hyperincarceration. https://www.nejm.org/doi/full/10.1056/NEJMp1811542
- Singleton: Medicating Death Row Inmates so they qualify for Execution <a href="https://journalofethics.ama-assn.org/article/medicating-death-row-inmates-so-they-qualify-execution/2004-09">https://journalofethics.ama-assn.org/article/medicating-death-row-inmates-so-they-qualify-execution/2004-09</a>
- Sell: <a href="https://en.wikipedia.org/wiki/Sell\_v.\_United\_States">https://en.wikipedia.org/wiki/Sell\_v.\_United\_States</a>
- Opioids for prisoners. <a href="https://journalofethics.ama-assn.org/sites/journalofethics.ama-assn.org/files/2018-05/stas1-1709.pdf">https://journalofethics.ama-assn.org/sites/journalofethics.ama-assn.org/files/2018-05/stas1-1709.pdf</a>
- Opioid addiction program in RI; Jodi Rich. https://news.brown.edu/articles/2018/02/opioids
- Do Jails Kill People? <a href="https://www.newyorker.com/books/under-review/do-jails-kill-people?utm\_campaign=aud-dev&utm\_source=nl&utm\_brand=tny&utm\_mailing=TNY\_Daily\_022019&utm\_medium=email&bxid=5bd6728f3f92a41245dd722d&user\_id=26739893&utm\_ter\_m=TNY\_Daily\_021019

### Session IV, April 3: Organ transplantation.

Supply has never met demand for organs for transplantation. Currently, more than 113,000 people are awaiting organs for transplants in the United States. Who gets the organs that are available? Who donates them? How are the priority lists constructed? And who decides? How do celebrities jump the queues while awaiting organs? Is that fair? In the United States, organs cannot be bought and sold. What are the pros and cons of an open marketplace for organs? What evidence exists for a black market for organ procurement?

#### Readings and links

- www.unos.org United Network for Organ Sharing. Explore the site to learn about the history of organ transplantation, the social, political, ethical, legal, and other issues associated with transplantation, and the state of the art.
- Zell Kravinsky: (The Gift, Ian Parker, August 2, 2004, New Yorker, 54.) http://archives.newyorker.com/?i=2004-08-02#folio=054
- Jean-Pierre Bosze: <a href="https://highschoolbioethics.georgetown.edu/units/unit2\_4.html">https://highschoolbioethics.georgetown.edu/units/unit2\_4.html</a>
- Mickey Mantle: Liver transplantation.
   <a href="https://www.washingtonpost.com/archive/lifestyle/wellness/1995/08/08/mickey-mantle-tough-call/063c9eaa-4335-47e1-8cb7-089a9a24e041/?utm\_term=.34b4fc984392">https://www.washingtonpost.com/archive/lifestyle/wellness/1995/08/08/mickey-mantle-tough-call/063c9eaa-4335-47e1-8cb7-089a9a24e041/?utm\_term=.34b4fc984392</a>
- McFall v Shimp: <a href="https://people.com/archive/a-cousins-stunning-refusal-to-donate-bone-marrow-leaves-robert-mcfall-facing-death-vol-10-no-7/">https://people.com/archive/a-cousins-stunning-refusal-to-donate-bone-marrow-leaves-robert-mcfall-facing-death-vol-10-no-7/</a>
- Black market for organs. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2563357/

#### Session V, April 10: End-of-life considerations.

Prominent physician-writer Atul Gawande has gone public with the importance of having "the conversation," that is, discussing with family members and physicians what one wants at the end of life. Gawande's book—Being Mortal—and the companion PBS Frontline documentary consider why patients should develop advance directives that express their end-of-life wishes. Clearly articulated advance directives prevent the "daughter from California" showing up at the last minute to subvert the patient's plans, eliminate arguments between family members and medical/nursing staff about what should be done, and keep disputes about end-of-life preferences from ending up in courts of law. During one hour of this session, Judge Russ Canan will speak on medical ethics cases that he has adjudicated in the Superior Court of the District of Columbia.

#### Readings and links

- PBS Documentary: https://www.pbs.org/wgbh/frontline/film/being-mortal/
- Brittany Maynard:

- https://pjb.mycpanel2.princeton.edu/wp/index.php/2016/05/09/the-ethicsof-the-final-exit-the-future-of-euthanasia-and-doctor-assisted-suicide-inmedicine/
- o <a href="http://www.cnn.com/2014/10/07/opinion/maynard-assisted-suicide-cancer-dignity/index.html">http://www.cnn.com/2014/10/07/opinion/maynard-assisted-suicide-cancer-dignity/index.html</a>
- MOOC Unit 7
- MOOC Unit 8

### April 11, Thursday: Brown Bag Lunch.

Please plan to attend this lunch. Russ Canan, will talk about his new book, *Tough Cases*, in which judges from around the country describe the most difficult legal cases that they have dealt with in their careers. These cases are mostly not on medical ethics, although the first chapter of the book is written by the judge in Terri Schiavo's case.

#### Session VI, April 17: Medical research.

Advances in medicine and healthcare rely on medical research. How is research done? What are clinical trials? What is the role of hope in affecting the decisions of sick individuals to participate in trials? What are the incentives for healthy volunteers? Is truly informed consent possible in either case? How do Institutional Review Boards operate? What is the therapeutic misconception? How does the "right to try" compromise new drug development?

#### Readings and links

- Guinea Pigging by Carl Elliott, January 7, 2008, New Yorker https://www.newyorker.com/magazine/2008/01/07/guinea-pigging
- Face Lift scandal. <a href="https://www.nytimes.com/1998/06/21/nyregion/study-or-human-experiment-face-lift-project-stirs-ethical-concerns.html">https://www.nytimes.com/1998/06/21/nyregion/study-or-human-experiment-face-lift-project-stirs-ethical-concerns.html</a>
- Ethical and legal issues in research involving human subjects: do you want a piece of me? <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1860367/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1860367/</a>
- Basics of clinical trials. <a href="https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms">https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms</a>
- Timeline for significant events in human subjects research: https://highschoolbioethics.georgetown.edu/units/cases/unit3\_timeline.html

## Session VII, April 24: Vaccines, epidemics and emergent diseases.

The 20<sup>th</sup> century saw a number of new epidemics—Legionnaire's Disease, AIDS, SARS, Ebola, Toxic Shock Syndrome, others—and the response of the medical community was not always as fast and sure as the public expected. But the reality is that, although hundreds or thousands of infectious diseases exist, vaccines are currently available for fewer than fifty diseases. What is involved in vaccine development? Why are some individuals reluctant to get the ones that exist? What is herd immunity? What is the moral

obligation of individuals to get the vaccines that are available? Why did autism get linked to vaccines in children?

#### Readings and links

- Measles outbreaks: NPR
   https://www.npr.org/2019/01/28/689549375/washington-state-officials-declare-state-of-emergency-as-measles-outbreak-contin
   (Note: This story is continuing. You can look for newer stories at NPR.)
- CDC: Vaccines do not cause autism: https://www.cdc.gov/vaccinesafety/concerns/autism.html
- The worst food-borne illness outbreaks in US History. https://www.healthline.com/health/worst-foodborne-illness-outbreaks
- Causes and prevention of food-borne illness. <a href="https://web.uri.edu/foodsafety/cause-and-prevention-of-foodborne-illness/">https://web.uri.edu/foodsafety/cause-and-prevention-of-foodborne-illness/</a>
- Anti-vaccine movements.
   <a href="https://www.historyofvaccines.org/content/articles/history-anti-vaccination-movements">https://www.historyofvaccines.org/content/articles/history-anti-vaccination-movements</a>
- Anti-vaxxers. <a href="https://www.nybooks.com/daily/2019/01/31/among-the-vitamin-k-anti-vaxxers/">https://www.nybooks.com/daily/2019/01/31/among-the-vitamin-k-anti-vaxxers/</a>

### Session VIII, May 1: Genetic testing, sperm banks, 23 & Me, designer babies.

Genes are not determinative, but they do affect the risks of developing the diseases with which they are associated. What are the slippery slopes of genetic tests, both for adults and for fetuses? Do future parents have the right to jigger the genes of their unborn children? When, if ever, might tinkering with genes be appropriate? How does disease prevention differ from genetic enhancement and the concept of perfection? What issues arise within families when one family member wants to learn about disease risks but others do not? What do family members owe one another? What has happened to the anonymity once offered to sperm donors now that DNA testing reveals clear and definitive genetic associations between individuals?

#### Readings and links

- Engineering a Deaf Baby
  - The Guardian: Lesbian couple have deaf baby by choice. https://www.theguardian.com/world/2002/apr/08/davidteather
  - A World of Their Own, Liza Mundy. <a href="https://www.washingtonpost.com/archive/lifestyle/magazine/2002/03/31/a">https://www.washingtonpost.com/archive/lifestyle/magazine/2002/03/31/a</a>
     <a href="https://www.washingtonpost.com/archive/lifestyle/magazine/archive/lifestyle/magazine/archive/lifestyle/magazine/archive/lifestyle/magazine/archive/lifestyle/magazine/archive/lif
- Dani Shapiro. https://www.nytimes.com/2019/01/25/books/review/podcast-dani-shapiro-inheritance-david-treuer-heartbeat-of-wounded-knee.html
- MOOC Unit 4
- MOOC Unit 5

# Session IX, May 8: Pharma frauds, media hyperbole, public misunderstanding, and the therapeutic imperative.

A disturbing trend in contemporary medicine is the corruption of medical research and medical practice, usually linked to financial gain somewhere in the pipeline. Clinical trials are suspect, doctors receive gifts to promote new pharmaceuticals, patients are paid to participate in trials, TV advertisements tell you to "ask your doctor if drug X is right for you" without providing any clues what the drug is for, and "experts" on the internet and on TV freely give medical advice to patients they have not examined. What will it take for American medicine to return to a more trust-worthy status? What can citizens do to speed up this process? How can researchers and doctors and companies be held accountable?

#### Readings and links

- Dr. Google is a Liar. Halder Warraich. https://www.nytimes.com/2018/12/16/opinion/statin-side-effects-cancer.html
- Atlantic: The Drug Pushers, Carl Elliott, Apr 2006. https://www.theatlantic.com/magazine/archive/2006/04/the-drug-pushers/304714/
- Sloan Kettering Scandal. Season of Turmoil. <a href="https://www.nytimes.com/2018/12/31/health/memorial-sloan-kettering-conflicts.html">https://www.nytimes.com/2018/12/31/health/memorial-sloan-kettering-conflicts.html</a>
- Dr. Oz. <a href="https://journalofethics.ama-assn.org/sites/journalofethics.ama-assn.org/files/2018-05/msoc1-1702.pdf">https://journalofethics.ama-assn.org/sites/journalofethics/journalofethics/journalofethics/journalofethics/journalofethics/journalofethics/j
- Sackler/Purdue behavior. <a href="https://www.nytimes.com/2019/01/15/health/sacklers-purdue-oxycontin-opioids.html">https://www.nytimes.com/2019/01/15/health/sacklers-purdue-oxycontin-opioids.html</a> (Note: This story is continuing. If you go to the NYT site, you can probably read updates on this story.)

# Session X, May 15: Climate change & pollution, miracles in medicine, limits of medicine, summing up.

What are the health effects of air, water, and other forms of pollution? Who are the polluters? Who is most affected by polluted environments? Who is responsible for remediation? What are the effects on health of climate change? What can be done to minimize or remediate these effects?

#### Readings and links

• MOOC Unit 9, Climate Change

#### **General Resources for Bioethical Quandaries**

- Kennedy Institute of Ethics Massive Open Online Course https://kennedyinstitute.georgetown.edu/education/professional/
- Principles of Bioethics. https://depts.washington.edu/bioethx/tools/princpl.html

- Scope Notes (bibliographies for various topics). https://bioethics.georgetown.edu/library-materials/digital-collections/bioethical-issues-scope-notes-archive/
- Hastings Center. <a href="https://www.thehastingscenter.org/">https://www.thehastingscenter.org/</a>
- Kennedy Institute of Ethics. <a href="https://kennedyinstitute.georgetown.edu/">https://kennedyinstitute.georgetown.edu/</a>
- Encyclopedia of Bioethics. 4<sup>th</sup> edition. Available at Brown Science library and some public local libraries.
  - $\frac{https://www.cengage.com/search/productOverview.do?N=197\&Ntk=P\_EPI\&Ntt}{=52752796015267594241337154492835920138\&Ntx=mode+matchallpartial}$