FIRST YEAR FELLOWS' SEMINAR DEPARTMENT OF CLINICAL BIOETHICS NATIONAL INSTITUTES OF HEALTH 2007-2008

Wednesdays 4:00-5:30pm

- Fall: November 28, 2007-December 19, 2007
- > Spring: January 09-May 28, 2008

* = Supplemental reading

REQUIRED TEXTS

- **1.** Beauchamp TL, Childress JF. <u>Principles of Biomedical Ethics</u>. 5th edition. New York: Oxford University Press, 2001.
- **2.** Berg, Appelbaum, Lidz, Parker. <u>Informed Consent</u>, 2nd Edition. New York: Oxford University Press, 2001.
- 3. Daniels N. Just Health Care. New York: Cambridge University Press, 1985.
- **4.** Dworkin G. The Theory and Practice of Autonomy. New York: Cambridge University Press, 1988.
- **5.** Rawls JA. <u>A Theory of Justice, Revised Edition</u>. Cambridge, MA: Harvard University Press, 1999.
- **6.** Levine RJ. <u>Ethics and Regulation of Clinical Research</u>. 2nd edition, New Haven: Yale University Press, 1988.
- 7. Julius B. Richmond and Rashi Fein, <u>The Health Care Mess: How We Got Into It and What It Will Take To Get Out</u>, Harvard University Press, 2005:
- **8.** Faden R, Beauchamp TL. <u>A History and Theory of Informed Consent.</u> New York: Oxford University Press1986.

November 27, 2007 HISTORY OF MEDICAL ETHICS EMANUEL

- **1.** Pellegrino ED. "The Metamorphosis Of Medical Ethics: A 30-Year Retrospective" JAMA 1993; 269:1158-1162.
- 2. Kass L. Is there a Medical Ethic? New York: Free Press, 1989. Chapter 9, 224-226
- **3.** Beecher HK. "Ethics and Clinical Research." The New Eng J Med 1966; 274:1354-1360.
- **4.** Vanderpool H. "A Critical Review of the Belmont Report"
- **5.** Baker R. "From Medical Ethics into Bioethics: The Belmont Report and the Deprofessionalization of the Medical Ethics."
- **6.** Emanuel E.J., The Evolving Norms of Medical Ethics
- 7. Emanuel E.J, Grady C. "Four Paradigms of Clinical Research and Research Oversight, Cambridge Quarterly of Healthcare Ethics 2006; 16, 82-96.

December 05, 2007 PRINCIPLISM

BEAUCHAMP

- **1.** Beauchamp TL, Childress JF. <u>Principles of Biomedical Ethics</u>. 6th edition: chap. 1 & 10 (the attached files)
- 2. Miller F, Brody, "The Internal Morality of Medicine" JMP 26(2001): 581-599.

December 12, 2007 FEMINISM

LITTLE

- 1. Baier AC. "The Need for More Than Justice" in *Moral Prejudices*. Cambridge: Harvard University Press 1994; pp18-32
- 2. Little MO. "Why a Feminist approach to Bioethics?" *Kennedy Institute of Ethics Journal* 1996; 6(1): 1-18

December 19, 2007 LEGAL CASES -- INFORMED CONSENT SCHWARTZ

- 1. Katz, J. Chapter 3, pp 48-84. The Silent World of Doctor and Patient
- 1. Truman v. Thomas
- **2.** Veatch, RM. Abandoning Informed Consent. Hastings Center Report 1995; 25:5-12
- **3.** Berg, Appelbaum, Lidz, Parker. Chapter 3. Informed Consent, 2nd Edition. New York: Oxford University Press, 2001.
- **4.** Canterbury v. Spence
- 5. Perna v. Pirozzi
- **6.** Moore v. Regents of the University of California
- **7.** Faya v. Almaraz
- **8.** Johnson v. Kokemoor
- 9. Kaskie v. Wright
- **10.** Hidding v. Williams
- **11.** Culbertson v. Mernitz
- 12. Grimes v. Kennedy Krieger Institute

January 9, 2008 INFORMED CONSENT: ETHICS WERTHEIMER

- **1.** Beauchamp and Childress. <u>Principles of Biomedical Ethics</u>, 5th ed. Chapter 3, "Respect for Autonomy.
- **2.** Berg, Lidz, Meisel. *Informed Consent*. Chapter 12, "Fulfilling the Underlying Purpose of Informed Consent."
- **3.** Troug R, Robinson W, Randolph, A. "Is Informed Consent Always Necessary for Randomized, Controlled Trials?" *The New England Journal of Medicine* 1999; 340(10):804-807.

January 16, 2008 MORAL THEORY RICHARDSON

- 1. Ross, W.D., The Right and the Good/ (Indianapolis: Hackett, 1988), chap. 2, pp. 16-34.
- 2. Richardson, H. "Specifying Norms as a Way to Resolve Concrete Ethical Problems," Philosophy and Public Affairs 19 (1990): 279-310.
- **3.** Richardson, H. "Institutionally Divided Moral Responsibility," Social Philosophy and Policy 16 (1999): 218-249.
- **4.** Darwall, S., /The Second-Person Standpoint/ (Cambridge: Harvard University Press, 2006), chap. 11.

January 23, 2008 HEALTH CARE SYSTEM FEIN

PLEASE REVIEW: http://www.health08.org/sidebyside.cfm

Please Read:

Julius B. Richmond and Rashi Fein, <u>The Health Care Mess: How We Got Into It and What It Will Take To Get Out</u>, Harvard University Press, 2005: Chapters **2**, **3**, **5**, **8** and such other Chapters as interest you.

Suggested readings:

*Institute of Medicine, Care without Coverage: Too Little, Too Late, 2002.

January 30, 2008 JUSTICE IN HEALTH CARE SREENIVASAN

PLEASE READ: Chapter 4

February 6, 2008 COST EFFECTIVENESS

MENZEL

- 1. Asch DA, Jepson C, Hershey JC, Baron J, Ubel PA,; "When Money is saved by Reducing Healthcare Costs, Where Do U.S. Primary Care Physicians Think the Money Goes." American Journal of Managed Care, June 2003, pp. 438-442
- 2. Menzel P.; "Allocation of Scarce Resources," the Blackwell Guide to Medical Ethics (Rhodes, L Francis, and A. Silvers, eds.), Blackwell, December 2006, pp.305-322.
- 3. Ubel PA, Nord E, Gold M, Menzel P, Prades JLP, Richardson J, "Improving Value Measurement in Cost Effectiveness Analysis". Medical Care vol. 38 (9) pp. 892-901
- 4. Ubel PA, Loewenstein G, Jepson C., "Whose Quality of Life?"; "Commentary exploring discrepancies between health state evaluating of patients and the general public". Quality of Life Research (12) pp. 599-607 2003.

^{*}Institute of Medicine, a Shared Destiny: Community Effects of Uninsurance, 2003.

^{*}Institute of Medicine, Hidden Costs, Value Lost: Uninsurance in America (2003)

^{*}Institute of Medicine, Insuring America's Health: Principles and Recommendations (2004

February 13, 2008 ALLOCATING SCARCE RESOURCES DANIELS

1. Just Health (Cambridge U Press, forthcoming), Chapters 4, 10, 12

February 20, 2008 HEALTH CARE REFORM PROPOSALS EMANUEL

- **1.** Meyer JA, Wicks EK.. <u>Covering America: Real Remedies for the Uninsured</u> Economic and Social Research Institute, June 2001; Overview pg. 6-19.
- **2.** Meyer JA, Wicks EK.. <u>Covering America</u>: <u>Real Remedies for the Uninsured Vol #2</u> Economic and Social Research Institute, November 2003; Overview pg. 5-8.
- **3.** Meyer JA, Wicks EK.. <u>Covering America</u>: <u>Real Remedies for the Uninsured Vol #3</u> Economic and Social Research Institute, December 2003; Overview pg. 7-8.
- **4.** Emanuel EJ., Fuchs VR, "Health Care Vouchers-A Proposal for Universal Coverage". NEJM 352; 12 (March 24, 2005) pg1255-1260.
- **5.** Fuchs VR, Emanuel EJ, "**Health Care Reform: Why? What? When?**" Health Affair vol 24:6, pp.1399-1414.
- **6.** Physicians' Working Group, Proposal of the Physicians' Working Group for Single-Payer National Health Insurance. JAMA August 13, 2003 vol 290, No 6, pp798-805.
- **1.** Gruber J, "The Massachusetts Health Care Revolution: A local Start for Universal Coverage," Hastings Center Report 36, no.5 (2006):14-19.

February 27, 2008 MANAGED CARE PEARSON

- **2.** Pearson SD. "Caring and Cost: The Challenge for Physician Advocacy." *Annals of InternalMedicine* 2000; 133(2):148-153.
- **3.** Robinson JC. "The End of Managed Care." *JAMA* 2001; 285(20): 2622-2628.
- **4.** Pearson SD, Sabin JE, Emanuel EJ. "No Margin, No Mission" Health-Care Organizations and the Quest for Ethical Excellence: Oxford University Press 2003; Chapter 5. Pp67-95.
- **5.** Rosenthal MB, Market Watch: Doughnut-Hole Economics Insurance often serves purposes other than risk protection. Health Affairs 2004 vol 32, 6 pg. 129-135

March 5, 2008 BIOETHICS INSIDE THE BELTWAY CHARO

- 1. Kymlicka, W. "Moral Philosophy and Public Policy." Bioethics 1993; 7:1-26.
- 2. President's Council Executive Order 13237: November 28, 2001.

- **3.** Gutmann A., Thompson D. <u>Democracy and Disagreement</u>. Cambridge, MA: Belknap Press, 1996, pp. 11-51.
- **4.** The President's Council on Bioethics: "Human Cloning and Human Dignity: Policy Recommendations", chapter 8, pp. 1-17.
- **5.** The President's Council on Bioethics: "Human Cloning and Human Dignity: Appendix personal statements, pp. 1-43.
- **6.** Warren, MA. Moral Status. Oxford: Clarendon Press, 1997, pp 1-23, and pages 148-177.
- **7.** Pellegrino E, Bioethics and Politics: "Doing Ethics" in the Public Square, Journal of Medicine and Philosophy, 31:569-584, 2006.

March 12, 2008 ABORTION LITTLE

1. Little M, "The Morality of Abortion," A Companion to Applied Ethics, eds. Christopher Wellman and Ray Frey (Blackwell, 2003).

March 19, 2008 PHYSICIAN-PATIENT RELATIONSHIP EMANUEL

- **1.** Mechanic D and Schlesinger M. "The Impact of Managed Care on Patients' Trust in Medical Care and their Physicians." JAMA, 1996; 275:1693-1697.
- **2.** Emanuel E and Dubler NN. "Preserving the Physician-Patient Relationship in the Era of Managed Care." JAMA, 1995; 273:323-329.
- **3.** Emanuel E and Emanuel LL. "Four Models of the Physician-Patient Relationship." JAMA, 1992; 267:2221-2226.
- **4.** "A Philosophical Reconstruction of Medical Morality" in ED Pellegrino and DC Thomasma, A Philosophical Basis of Medical Practice (NY: Oxford U Press, 1981), pp. 192-220.
- 5. Sulmasy DP, Bloche MG, Mitchell J, Hadley J. Physicians' ethical views about cost-containment methods. *Arch Intern Med* 2000;160: 649-657.

March 26, 2008 LEGAL CASES-TERMINATING TREATMENT FORSTER

- 1. Cruzan v. Director Missouri Department of Health
- 2. Quinlan v Supreme Court of New Jersey
- 3. Brophy v. New England Sinai Hospital, Inc.
- **4.** Annas George J, "Culture of life" politics at the bedside The Case of Terri Schiavo, NEJM 2005

April 9, 2008 GENETIC TESTING HULL

- **1.** John Robertson, "The \$1,000 genome: ethical and legal in issues in whole genome sequencing of individuals" *American Journal of Bioethics* 3(3) InFocus (http://www.bioethics.net).
- 2. Wilfond BS, Nolan K. National policy development for the clinical application of genetic diagnostic technologies. Lessons from cystic fibrosis. JAMA. 1993 Dec 22-29; 270(24):2948-54.
- **3.** Clayton et al. Informed consent for genetic research on stored tissue samples. <u>JAMA</u> 1995;274:1786

4. Eric Juengst, "Caught in the middle again: Professional ethical considerations in genetic testing for health risks," *Genetic Testing* 1;3 (1997/98): 189-200.

April 16, 2008 ORGAN TRANSPLANTATION VEATCH

1. Veatch R. "Egalitarian and Maximum Theories of Justice: Directed Donation of Organs for Transplant", Journal of Medicine and Philosophy 23 (3, 1998): 456-476.

April 23, 2008 NEUROETHICS MORENO

- 1. National Bioethics Advisory Council; Ethical issues in Stem Cell Research Sept 1999, executive summary and chapter 4.
- 2. Stem Cells and the Future of Regenerative Medicine < http://www.nap.edu/books/0309076307/html/> a 2002 Executive summary and Chapter 4.
- 3. The NEJM Perspective article on the Korean Stem Cell Hub Project (10/20/2005)
- **4.** National Academies Press; Guidelines Human Embryonic Stem Cell Research 2005, Summary and Chapter 6.

**suggested additional readings:

The NAS Guidelines for Human Embryonic Stem Cell Research (2005) http://www.nap.edu/books/0309096537/html/

April 30, 2008 ENHANCEMENT DEGRAZIA

- 1. DeGrazia D, Enhancement Technologies and Human Identify; Journal of Medicine and Philosophy 30 (2005): 261-283
- 2. Juengst ET, "What Does Enhancement Mean?"; in E. Parens (ed.), Enhancing Human Traits: Ethical and Social Implications (Washington D.C.: Georgetown University Press, 1998), pp. 29-47...

May 7, 2008 CONFLICT OF INTEREST KERN

- 1. Chaudhry S, Schroter S, Smith R, Morris J. "Does Declaration of competing interests affect readers' perceptions?" A randomized trial. BMJ 2002; vol. 325 pp1391-2.
- **2.** Steinbrook R. Conflicts of Interest at the NIH Resolving the Problem., N Engl J Med 2004; 351:955-957, Sep 2, 2004.
- **3.** Bekelman JE, Li Y, Gross GP. "Scope and Impact of Financial Conflicts of Interest in Biomedical Research". JAMA 2003, v.289 #4, pp.454-465.
- **4.** Bero LA, Glantz S, Hong MK. "The Limits of competing interest disclosures", Tobacco Control 2005; 14: 118-126

- **5.** Mello MM, Phil M, Clarridge BR, Studdert DM; Academic Medical Centers Standards for Clnical-Trial agreements with Industry. NEJM 352; 21; 2202-10.
- **6.** Turner EH, A taxpayer-Funded Clinical Trials Registry and Results Database- It already exists with the US Food and Drug Administration. PLoS Medicine 12/2004; vol 1; issue 3: 180-2.

May 14, 2008 EUTHANASIA/PAS QUILL

- **1.** Hedberg K, Hopkins D, Kohn M. "Five Years of Legal Physician-Assisted Suicide in Oregon." NEJM, 2003; 348(10): 961-964.
- **2.** Quill TE, Meier DM, Block SD, Billings JA. "The Debate Over Physician-Assisted Suicide. Empirical Data and Convergent Views." Annals of Internal Medicine 1998; 128:552-558.

Suggested reading:

DHS/Oregon –Death with Dignity Act—copy of web page is included.

May 21, 2008 PUBLIC HEALTH KASS

- 1. Wikler, D. "Persuasion and Coercion for Health: Ethical Issues in Government Efforts to Change Lifestyles." Milbank Quarterly, 1978; 56(3):303-333.
- **2.** Pellegrino, E.D. "Health Promotion as Public Policy: The Need for Moral Groundings." Preventive Medicine, 1981; 10:371-378.
- **3.** Kass, N.E. "An Ethics Framework for Public Health." American Journal of Public Health, 2001; 91:1776-1782.
- **4.** Callahan, D. and Jennings, B. "Ethics and Public Health: Forging a Strong Relationship." American Journal of Public Health, 2002; 92(2):169-176.
- **5.** Childress, J.F., Faden, R.R., Gaare, R.D., Gostin, L.O., Kahn, J., Bonnie, R.J., Kass, N.E., Mastroianni, A.C., Moreno, J.D., and Nieburg, P. "Public Health Ethics: Mapping the Terrain." Journal of Law, Medicine, and Ethics, 2002; 30:170-178

May 28, 2008 ETHICS CONSULTATION DANIS

- 1. Casarett DJ, Daskal F, Lantos J "Experts in Ethics?: The Authority of the Clinical Ethicist", Hastings Center Report 28 vol.6 (1998):6-11.
- **2.** Fletcher JC, Siegler M, "What are the Goals of Ethics Consultation: A Consensus Statement, The journal of Clinical Ethics, Summer 1996, vol. 7, 2:pp122-126.
- **3.** Moreno JD, Ethics by Committee: "The Moral Authority of Consensus", The Journal of Medicine and Philosophy 13 (1988): pp.411-432.
- **4.** Urban Walker M, Keeping Moral Space Open: New Images of Ethics Consulting, Hastings Center Report, March-April 1993, pp.33-40
- **5.** Ross JW, John MA, Glaser JW, S.T.D., et al, Case Consultation and Review: Matching Skills and Expectations. Chapter 7 pg; 91-107

- **6.** Wolf SM, "Toward a Theory of Process", Law, Medicine and Health Care vol. 20:4 (1992) 278-290.
- **7.** Ausulio MP, Arnold RM, Younger SJ, "Health Care Ethics Consultation: Nature, Goals, and Competencies". Annals of Internal Medicine 2000; 133: 59-69