SOC 395: Bioethics: A Sociological Perspective: How culture shapes medical practice and development, and how medicine impacts the human life. Spring 2010

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Abstract:

Our cultural concept of what defines a "human being," and what defines both normal and desired life experiences impacts not only the practice of medicine, but also our pursuit of new medical technologies. And once those technologies are created, they may in turn impact our experience and change previous expectations and understandings. The past few decades have brought about a substantial change in the practice of medicine. We have witnessed a dramatic increase in the number of people undergoing cosmetic surgical procedures in light of what many social scientists argue is a new age of age discrimination. We have new disease categories such as ADHD which have impacted the experience of childhood in America, so the once "unruly" or "squirmy" child is now medically controlled. Among developed nations, the United States holds the distinction of reporting the largest percent of its adult population on antidepressants. This medical response to stress and sadness is in part a response to the general American perception that sadness impedes productivity. And think about how America's fascination with both physical and intellectual prowess is leading us closer to genetic engineering. Short of these measures, consider our current debates about whether or not we should all take drugs like Ritalin and Adderall to increase productivity and performance.

In this class, we will explore how wider cultural forces impact the development of medical technologies, and how once a technology exists, society has to decide how to use it and encourage or restrict access. The practice of medicine and science does not occur in some objective, rational bubble, but our medical institutions are interwoven within and greatly impacted by wider social norms, by our political and economic institutions, by power struggles, and by the ever-changing definition of what it means to be a "human being" at different points and time in human history.

We will explore the development of the field of bioethics in the United States, and how the American brand of bioethics differs from other countries. By exploring some cross-cultural comparisons, we will see how the differences have compelled some bioethicists to argue for a global standard for what constitutes ethical medical practice. For example, how do we address the problem of Americans and Europeans "shopping" for kidneys in India?

Texts/Books:

- Raymond DeVries and Janardan Subedi, editors, <u>Bioethics and Society:</u> <u>Constructing the Ethical Enterprise (Prentice Hall, Upper Saddle River, 1998</u>) D&S (copy of selected chapters will be provided)
- 2. Howell and Sale, editors, <u>Life Choices: A Hasting's Center Introduction to</u> <u>Bioethics</u> (Georgetown University Press, Washington DC, 2000)
- George Weisz, editor, <u>Social Science Perspectives on Medical Ethics</u>, (University of Pennsylvania Press, Philadelphia, 1990) Weisz (selected readings on Blackboard)
- 4. Freeman and McDonnell, <u>Tough Decisions: Cases in Medical Ethics</u>

Readings:

Each week, there will be a number of assigned readings. There are also occasionally a number of *Recommended* readings. You are not responsible for *Recommended* readings. Some individuals may find these supplemental readings helpful for their research papers or for additional information on particular topics.

Subscribe to the AJOB online weekly updates: I will expect every student to subscribe to the American Journal of Bioethics online weekly news updates. These updates will keep us up-to-date on what bioethicists are discussing during the course of the semester. I will send out directions on how to subscribe.

Assignments:

I want the class to be based a great deal on class participation so attendance is vital. To be an informed class participant, it is imperative that you complete the readings prior to class. I will be taking attendance at least until I learn everybody's name. If you will miss a class, please let me know ahead of time. You will be responsible for getting notes from a fellow student.

There will three major writing assignments, two revised papers and a final essay.

Paper #1: (approximate length-7-10 pages)

Within the first week of class, pick a topic of "bioethical" interest to you. Using the readings from the first four weeks, examine this issue as a sociologist. Take a broad look at the issue incorporating some of the readings we have done so far and using information about the issue from other sources including mass media, or web sites.

Outline the relative forces, concerns, structural constraints, and wider social issues that involve your chosen issue. How does this issue affect the patient, the family, the caregivers, the wider society, the medical industry, family relationships, work and occupations, etc.

I will encourage all students to take the draft version of this paper to the Writing Center for review. An outline of the paper format will be provided. You will have the opportunity to revise the paper twice—once before its original submission and again later in the semester since Paper #1 becomes the framework for the final paper. Since Paper #1 extends the length of the course, make sure you chose a topic that will sustain your interest and about which you can find some information.

Final Paper: (approximate length 20-25 pages)

Use the readings we have done throughout the semester, other sources of information, and the comments on your first draft (Paper #1) to expand your analysis of your bioethical issue. In addition to these traditional sources of information, I also want you to incorporate information and comments from **at least six interviews** with family members, fellow college students, etc. to garner their views about the issue. In this paper you will be expected to make some comments on the differences or similarities between the views of your interviewees and other sources of information about your topic. We will discuss this in greater detail.

Again, you will be provided with a paper outline which will help you to incorporate the interview material and analysis into the main body of the paper. Final papers will also be reviewed at the Writing Center.

All students achieving a "B" or better on their final paper will be encouraged to submit their paper for consideration for publication to The Penn Bioethics Journal. A description of the journal appears below. Some students may also be encouraged to submit their papers for possible presentation at a regional academic conference.

The Penn Bioethics Journal

About the Journal

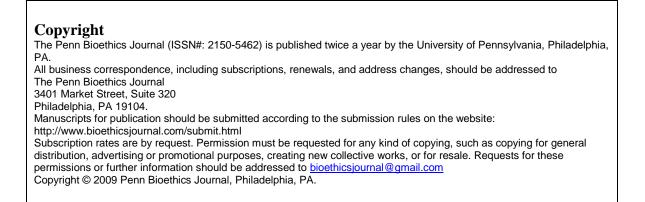
The Penn Bioethics Journal is the nation's premier peer-reviewed undergraduate bioethics journal. The journal was established in Spring, 2004 with the first issue published April 1, 2005 as part of the National Undergraduate Bioethics Conference hosted by Penn. The editorial board has included undergraduates from all four schools at the University of Pennsylvania with faculty advisors Jonathan D. Moreno, Ph.D. and Connie Ulrich, Ph.D., R.N.

The Process

The editors select a theme for each bi-annual issue of the journal. The theme of the journal is not decided until after all the articles are submitted and normally features an Editorial or Paper. Submissions are not required to correspond to the selected theme. Additionally, many issues of the journal feature one or more interviews with prominent professionals in fields related to the issue theme. Our acceptance process is very competitive with submissions undergoing an initial review, a small-group review, and, if warranted a final review by the full editorial board of approximately 30 students.

Publication

The journal's call for papers goes out internationally, with publication in professional journals and posting on related websites. Faculty members on campus, around the country, and abroad are advising students with superb term papers to submit them for publication. While the board does not release specific statistics, we receive a large number of submissions for each issue and carefully select the small number that are ultimately published. For more information on submitting, please see our submit section.



Final exam: (approximate length 5-7 pages)

Prior to the final, you will be assigned a bioethical case study either from the Harvard Bioethics Discussion group or from some classic examples of "tough cases." You will prepare a sociological analysis. Part of this preparation will include an in-class discussion with a group of students assigned the same case study. You will write up this analysis and respond both as a sociologist and as a bioethicist. This will be an essay about bioethics in practice. How well did the discussants address all the relevant issues? Can you think of factors that no one else considered? You will be required to cite articles in support of your analysis. This analysis will test to see how well you can draw upon all the topics and issues we covered over the course of the semester to view the bioethical issue.

An outline of the format for the final exam will be provided. The first draft of this essay will be due on the last day of class. Students will then have until the end of the finals' period to revise their essay based on feedback from the professor.

Paper Due Dates:

Paper # 1: Final Paper: Final Essay:

Grade distribution:

Paper #1:	25%
Final exam:	20%
Final paper:	35%
Class participation:	20%

<u>Class attendance/participation is mandatory</u>. If you are going to miss a class, I expect that you will contact me prior to class to let me know, either by phone or email. Although I understand that people might occasionally miss class due to illness or personal emergencies, patterned absences will result in a lowering of your class attendance/participation grade and I will contact your advisor/the dean's office. Regular attendance will yield a class attendance grade of a 3.0 (B). Participation will increase that grade upwards, and patterned absences will decrease that grade. Basically, everyone will start out with a B.

<u>Cheating/plagiarizing</u>: If any student is caught plagiarizing, you will automatically fail the class. If there are any questions about what constitutes plagiarism, please review drafts of your assignments with me. Please also see Moravian College's Academic Honesty policy (on the website) to review the institution's definitions of cheating and plagiarism.

Assignments:

I expect <u>assignments to be handed in on time</u>, on the day that they are due. Late assignments will be docked one full grade for each day that they are late. So an "A-quality" assignment that was due on Tuesday that is handed in on Wednesday will drop to a "B." If handed in on Thursday, the grade will drop to a "C." I know students occasionally run into computer/printer problems, and if you are in this situation, email me as soon as possible. If you are having a printer problem, you can send me your assignment as an attachment so that you can still get full credit for handing the assignment in on time. I do not have much sympathy for students who wait until a few minutes before class begins to print up their assignment and then discover that they are having trouble. So try to make it part of your schedule that you will finish and print up your assignments at least the night before the assignment is due. This way, you will have time to either solve your problem or contact me.

I also expect assignments to follow whatever *formatting and page instructions* given when the assignment is assigned. For example, if I assign an essay question that I suspect will take at least two pages to answer, I expect a full two pages of writing will constitute your response. This is two pages, word processed, double-space, one inch margins, Times New Roman, 12-point font, without additional spaces between your name and date at the top of the page, and between the title of your essay. Assignments that fall short of the page requirement will automatically lose points.

<u>Cell phone, texting, email, web surfing:</u> I expect that students will NOT be using their cell phones, texting, sending emails or web surfing during class time. Students who are caught engaged in any of these activities will immediately lose <u>one full grade</u> of their class participation grade (i.e. a B will drop to a C).

There are some circumstances under which I will allow students to take a phone call or surf the web during class.

Phone calls: I know some students occasionally have family, work and/or personal obligations that may need their immediate attention. For example, there may be students who have a sick child at home and need to be reachable during class time in case there is an emergency. If you find yourself in this kind of situation, please contact me before class via email or approach me at the beginning of class. I will expect your phone to be on vibrate, but I will allow you to leave the room to take the call.

Web surfing: Sometimes a class activity might actually involve searching the web for resource materials. In this case, I may ask students with laptops to help search for a piece of data or reference during class. But I will expect that students will be searching for the task assigned and not looking up newly posted videos.

Professor/Student dialogue: I highly value good communication between us, and I therefore encourage you to contact me at any time in the semester to talk about the class in general or about your individual performance. Few things are as frustrating for me than to get to the end of the semester to find out someone struggled with some aspect of the course (for example, understanding the assignments!). If you do not understand some aspect of the course material, or my assignment instructions, then please send me an email, call, or stop by my office hours. I am more than willing to read and respond to drafts of your work, so please take me up on my offer to read work before final due dates. I typically ask for at least one week to turn work around.

Blackboard and Email: Moravian College recognizes email as a form of official communication between faculty and students and I will use both Blackboard and email as a communication device. I will occasionally send out a message for you to take a look at an article online, or check a new posting on Blackboard before the next class. And as we work on our projects, I will often need to check in with you between classes. Therefore it is your obligation to regularly check your email account for messages from me. You should check your email accounts at least once a day. Failure to complete an assignment/request because "I did not see your email—I did not check my account," will not suffice as a legitimate excuse.

Week by Week Outline of Readings and Topics

1. Introduction to Sociology: Themes and Methodology

This week we take a brief look at the fields of sociology. What do sociologists study and why? We will also look briefly at the methodology used by sociologists—how do sociologists study social organizations?

Copy of the Nuremberg Code Hippocratic Oath

2. Brief History of and Introduction to Bioethics

Rothman, David, "Human Experimentation and the Origins of Bioethics in the United States," in Weisz Fox, Renee, "The Evolution of American Bioethics: A Sociological Perspective," in Weisz Weitz, Rose, "Chapter 13: Issues in Bioethics" Introduction, Weisz Rachels, James, "Introduction: Can Ethics Provide Answers?" (Life Choices) Elliott, Carl, "Where Ethics Comes From and What to Do About It." (Life Choices)

3. Social Sciences, Bioethics and the Goals and Allocation of Medicine

Light, D. W., and McGee, G., "On the Social Embeddedness of Bioethics" DeVries, R., and Conrad, P., "Why Bioethics Needs Sociology" Hoffmaster, Barry, "Morality and the Social Sciences" Raphael, Dennis, "Ten Tips for Better Health" The Goals of Medicine: Setting New Priorities: Executive Summary, Setting New Priorities, and Specifying the Goals of Medicine. (Life Choices)

<u>4. Language and Thought in Bioethics: Definitions of health and illness, normal and abnormal, desired and shunned</u>

At different times and at different points in human history, what we consider beautiful or desired changes, whether we are talking about height and weight, or about the various sizes and shapes of our reproductive organs. Also, behaviors that we consider normal or abnormal on the basis of gender or age also change. What we as a society define as health or illness, normal or abnormal, desired or shunned, greatly affects the medical technologies we create and the number and level of interventions we are willing to make. This week, we will explore these impacts by looking at testosterone replacement therapy, growth hormones, and potential brain enhancement therapies. We will also review the classical four principles of bioethics defined by Beauchamp and Childress.

<u>Underpinnings of Medical Ethics</u>, Edmond A. Murphy, James J. Butzow, and Edward L. Suarez-Murias (Johns Hopkins University Press, Baltimore, 1997) Wolpe, P. R., The Triumph of Autonomy in American Bioethics: A Sociological View," (D&S, Chapter 3) Jennings, B., "Autonomy and Difference: The Travails of Liberalism in Bioethics," (D&S, Chapter 13)

5. Informed Consent

Informed consent is a term thrown about all the time in medical settings. We are continuously asked to provide our signature as evidence of our informed consent. But what does this term even mean, and can true consent ever be given?

Veatch, Robert, "Abandoning Informed Consent," (handout) Lemonick, Michael and Andrew Goldstein, "At Your Own Risk," (handout) Lupton, Deborah, "Risk as Moral Danger: The Social and Political Functions of Risk Discourse in Public Health" (handout) Capron, Alexander Morgan, "The Burden of Decision" (Life Choices) Hardwig, John, "Whjat About the Family?" (Life Choices) Blustein, Jeffrey, "The Family in Medical Decisionmaking" (Life Choices) Tough Freeman and McDonnell, <u>Tough Decisions</u>, Chapters 4, 7 and 10

Patient tissue sample consent form (Blackboard) Patients do not read consent forms (Blackboard)

6. Human Sexuality and Medical Technologies

This week we will be exploring the effect of American's culture on sexuality on the creation of medical technologies to address sexual impotence or underperformance. We will look at data on the prime reproductive age range for human beings, and explore all the various "treatments" for decreased sexual performance and desire. We will talk about the puzzle of a "natural" decrease in sex drive and performance associated with aging with the numerous advertisements for the use of Viagra and penile dysfunction.

7. The Bioethics of Reproduction

This week, we will talk about how the changing culture that promotes women delaying their childbearing to pursue educational opportunities and careers has lead to an increase in the need for fertility treatments—again, we need to treat the human animal who has passed out of their prime reproductive age. We create medical interventions to fix what are in many ways social organizational effects.

We will also talk about how our human identity is becoming more linked to our imperfect understanding of the effects of our "genes" on our identities—we will discuss some of the classic debates of nature versus nurture, and the debate on whether genes are a malleable blueprint. If genes are truly deterministic, than what is the implication for our broader understanding of the human experience?

Life Choices, pp:177-214, 375-460 Freeman and McDonnell, <u>Tough Decisions</u>, Chapters 14 and 15

8. Moral Entrepreneurs and the Cupcake Tax: Addressing Obesity in America

We are in the midst of an obesity crisis in the US. The average (normal) weight of the US population has been steadily increasing for the past few decades. Two factors behind our increasing weight are the scientific developments in food production (and extension of shelf life) due to "technological" developments, and to an increasingly sedentary work day. What are some of the "fixes" we have generated for this problem--gastric bypass surgery, liposuction, and fats that cannot be absorbed.

Becker, H., "Moral Entrepreneurs" (handout) John B. McKinlay, "The Case for Refocusing Upstream: The Political Economy of Illness," (handout) Other assorted current articles on the obesity epidemic will be distributed in class.

9. Cross-cultural comparisons: Brain Death and Organ Transplantation

This week we will talk about the different ways countries define death and the implications of that definition for medical practice (specifically organ transplantation).

We will look at the reasons why even thought the science of organ transplantation can cross country borders, the experience and "appropriateness" of the procedure is culturally bound.

China has acknowledged publically that it has executed prisoners to harvest their organs.

Wertz, D. C., "International Research in Bioethics: The Challenges of Cross-Cultural Interpretation," (D&S, Chapter 8) Morioka, Masahiro, "Reconsidering Brain Death," (handout) Life Choices: pages 461-518

Tough Decisions: Chapter 3

Recommended:

Fox and Swazey, "Medical Morality is Not Bioethics: Medical Ethics in China and the United States" (Blackboard)

10. The definition and experience of death in the United States: "Rage, rage against the dying of the light"

Following our discussion of brain death, we will talk about the experience of death in the US. How do most people die, and how do most people report that they would like to die? When and how did we come to view death as the enemy rather than the friend that came to release us at the end of our lives? And given that on average, the majority of health care dollars spent on an individual are spent during the last years of life, are we "wasting" our medical dollars? Do we all eventually have a "duty to die?"

Reading:

Last Acts: A Vision for Better Care at the End of Life. Students will review the findings from this Robert Wood Johnson study on dying in America.

http://www.rwjf.org/pr/product.jsp?id=20938

Hardwig, John, "Is There a Duty to Die?" (Life Choices)

Callahan, Daniel, "Terminating Treatment: Age as a Standard" (Life Choices) Lynn and Childress, "Must patients always be given food and water?" (Life Choices) Caplan and Cohen, "Deciding Not to Employ Aggressive Measures" (Life Choices) Doerflinger, Richard, "Assisted Suicide: Pro-Choice or Anti-Life?" (Life Choices) Tough Decisions: Chapters 2 and 8

11. Ethics committees

This week we will get into our groups to talk about the cases for the final exam. I will present you with a collection of classic tough cases, and your group will have to decide which case to tackle.

Bosk, C. L., and Frader, J., "Institutional Ethics Committees: Sociological Oxymoron, Empirical Black Box," (D&S, Chapter 6)

12. Theology and Bioethics: A Role for Religious Belief?

Is there a role for religion in bioethical debates, even in our secular society? Might "allowing religion in the door" be important since both the discipline of "ethics" and "bioethics" finds their origin in theology? And what of the current proposal that religious belief is wired into our neural circuitry?

American Academy of Pediatrics Committee on Bioethics, "Religious Objections to Medical Care," (handout) Callahan, Daniel, "Religion and the secularization of bioethics," (handout) Campbell, Courtney, "Religion and moral meanings in bioethics," (handout) Nicholas Wade, "The Evolution of the God Gene," NYT, November 15, 2009

13. Genetics

Life Choices, pp: 519-594 Freeman and McDonnell, <u>Tough Decisions</u>, Chapters 16

14. Cross-cultural/cross-country research

The world is becoming increasingly "small" and human beings move about the world with greater frequency and ease. The amount of movement has tremendous implications for the management of disease. We will explore some of the epidemiological models for disease transmission using SARS, the Bird Flu, and the most recently, Swine (H1N1) Flu as examples.

We will also explore how different definitions of risk and benefit at the country level have lead to the globalization of medical research. Research that would be considered unethical by an American ethics committee is not necessarily considered unethical by a similar committee in Tanzania. The lack of a global definition of "ethical" research encourages American drug companies, for example, to conduct research on "foreign" soil where ethical rules are more lax.

Excerpts from Macklin, Ruth, <u>Against Relativism: Cultural Diversity and the Search for</u> <u>Ethical Universals in Medicine (</u>Oxford University Press, New York, 1999) WMA Declaration of Helsinki, Ethical Principles for Medical Research Involving Human Subjects (handout) Singer and Benatar, "Beyond Helsinki: a vision for global health ethics," BMJ, Vol. 322, 31 March 2001 (handout) Barkes-Ruggles, Erica, "The Globalization of Disease," (handout)

Recommended:

Nuffield Council on Bioethics: The Ethics of clinical research in developing countries.

Some Helpful WebSites

University of Pennsylvania Center for Bioethics <u>www.bioethics.net</u>, <u>www.bioethics</u>.org

National Bioethics Advisory Commission (NBAC) Homepage www.bioethics.gov

The National Center for Genome Resources www.ncgr.org

NIH-DOE Working Group on Ethical, Legal, and Social Implications of Human Genome Research, Task Force on Genetic Testing www.med.jhu.edu

Helpful Publications:

The Hastings Center Report American Journal of Bioethics