

**SOC 395: Bioethics: A Sociological Perspective:
How culture shapes medical practice and development, and how
medicine impacts the human life.
Spring 2014**

Professor Virginia Adams O'Connell

Office: PPHAC 315

email: voconne1@moravian.edu

Phone: 610-625-7756

Class place and time: TR 1:10 AM-2:20 PM, PPHAC 335

Office hours: to be determined—please check Blackboard

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:

1. Howell and Sale, editors, Life Choices: A Hasting's Center Introduction to Bioethics (Georgetown University Press, Washington DC, 2000)
2. Freeman and McDonnell, Tough Decisions: Cases in Medical Ethics

Readings:

Each week, there will be a number of assigned readings from the texts identified above. There will also be readings distributed in class and/or referenced on the web. I will also be sending links to online articles/reports for your consideration before class.

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.

There will two major writing assignments--two revised papers—as well as the preparation of tough case decisions.

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.

Tough Cases Review and Presentation: After we develop the analytical frameworks for the class, we will start to use those cases to review bioethical cases from the Tough Decisions book.

You will get into randomly assigned committees to respond to a case. These will be started in class but occasionally might require some additional out-of-class time to complete. You will occasionally have to present the case to the class.

Grading:

Each assignment will be graded on the following scale:

A+ (97-100) = 4.0	C+ (77-79) = 2.3
A (93-96) = 4.0	C (73-76) = 2.0
A- (90-92) = 3.7	C- (70-72) = 1.7
B+ (87-89) = 3.3	D+ (67-69) = 1.3
B (83-86) = 3.0	D (65-66) = 1.0
B- (80-82) = 2.7	F (below 65) = 0.0

Grades will be posted on Blackboard so you should check the site regularly to make sure your grades are recorded correctly on the site once an assignment is returned. I try to be as careful as possible when recording grades, but sometimes I do make mistakes, so please review both that your grades are recorded and recorded correctly. And please be aware, it is within the instructor's purview to apply both a quantitative and qualitative judgment in determining grades for an assignment and/or for the course.

The papers and final essay will be graded on a 0.0-4.0 scale.

Class participation will be graded on a 0.0-4.0 scale.

Short assignments/activities will be graded as the fraction of points earned over the total possible points, and therefore will yield a percent that can be converted to a 0.0-4.0 scale.

At any point in the semester, you can figure your grade by averaging the posted grades on Blackboard and weighting them appropriately.

Grade distribution:

Paper #1:	25%
Final paper:	30%
Class participation:	20%
"Tough case work", other short assignments/ in-class activities:	25%

Class attendance/participation is mandatory. 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 and minimal participation will yield a class attendance grade of a 3.0 (B). Regular and engaged participation will increase that grade upwards, and patterned absences will decrease that grade. Basically, everyone will start out with a B. What you do with that B is your responsibility. Unexcused absences will result in a lowering of the B. Active participation will be assessed on the basis of volunteering thoughtful

answers on a regular basis, and passive participation as merely being there, taking notes, and looking attentive. And the “looking attentive” is key here—please do not fall asleep in my class. Even in a large class, it is very hard to hide and sleep. I understand that you might not be feeling well or had a very late night, but if you are sleepy before class, please grab a cup of coffee. Students who come to class but sleep do not get credit for class attendance—sleeping in class will earn you an unexcused absence.

Students who miss an in-class activity due to an excused absence will not get credit for the assignment but will not be penalized. Often, the in-class activities cannot be “made up” outside of class time, but you will be responsible for knowing what we did in class in case it is referenced in future classes. You will lose the designated points for the assignment which means that your other remaining assignments will count more towards your final grade. For example, if the total of all in-class activities ends up counting for a total of 200 points, but you missed an activity due to an excused absence that was worth 20 points, and your total points earned was 160 points, your final grade for class activities will be scored as 160/180 instead of 160/200. If you, however, miss an in-class activity due to an unexcused absence, you will earn a zero for that class activity and as noted above, you will not be able to “make up” the lost points.

Students who miss a class are responsible for getting notes and copies of handouts from a fellow student. I advise that every student find a partner(s) in the class that will share notes and collect handouts for them when they have an anticipated or unanticipated absence. I will not be responsible for collecting or keeping track of handouts for students who miss class, nor will every handout be scanned and posted on Blackboard. You must also collect the notes and review the material covered in class before you ask me “what did I miss the other day when I was not here.” I am not responsible for repeating one of my lectures in a private session with students who miss class. While I am happy to review material that students do not understand during office hours, you must review the material before you schedule a meeting. Do not wait until a couple of weeks have passed before you realize that you are missing certain key handouts necessary to complete an essay or assignment—trying to track down handouts a few weeks down the road can be a nightmare.

In addition to expecting regular class attendance, I also expect students to arrive to class “on time.” Patterned late arrivals will also be penalized. Being a commuter, I understand the challenges associated with traffic, accidents and other unanticipated delays, but it is your obligation to arrive to class on time. If you are commuting from the other end of campus, I understand that the new shuttle system may be a nightmare, but you need to catch the earlier bus if there is a chance that the shuttle might be a few minutes late getting up to the other end of campus. Again, I understand that “stuff happens” and you may “every now and then” arrive late, but it cannot be a regular pattern. You would not regularly arrive late for a job (it would not be tolerated by your employer and you would eventually be fired). Think of your college career as one of your current jobs. If you are late, however, come into the classroom as soon as you do get to your designation. Do not wait outside the class for some optimum time to enter as all this will do is make you miss more of the class instruction. Quietly and unobtrusively enter the classroom and take a seat.

Cheating/plagiarizing: 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. Plagiarism is easier to recognize than you might think—I have caught a number of students in the past.

Due Dates and Formatting:

I expect ***assignments to be handed in on time***, 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." A "D-quality" assignment handed in late is an F. 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 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.

More details on classroom behavior:

Recording Devices:

Students have my permission to use audio recording devices in class. I know some students like to use these devices in order to review lecture notes, so this statement serves as my "informed consent" to be taped.

Cell phone, texting, email, web surfing: 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 **one full grade** of their class participation grade (i.e. a B will drop to a C). If you engage in this behavior multiple times, then getting caught a mere three times in the course of a semester will earn you an F for class participation. For students who take notes on laptops, I know the temptation to check your Facebook page, or answer a few emails during what you might think is a less interesting part of my lecture may be overwhelmingly tempting, but please resist the urge. You may think you are pretty good at hiding this activity from me, but it is actually fairly easy to tell when a student is engaged in other activities (although I hear that students are getting very adept at texting when the phone is in your pocket!). Sometimes your neighbor actually gives you away, so why you are making sure to keep looking up at me, your neighbor might get very interested in looking at your newly posted profile picture. So best just not to do it, no matter how good you think you are at it. And even if you think you might be so good, I will not necessarily confront you in class if I catch you. I will merely dock your class participation grade and you will not be aware of the penalty until the end of the semester.

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.

“Facilities” Break: I have had the experience of students regularly leaving class for what I can only assume is a “bathroom” break, leaving class for a few minutes during basically every class period. Unless there is an underlying medical issue, I do think it is necessary for students to regularly leave the class for what is often only a one-hour ten-minute class period. Since this class will run for two class periods, we will take a break halfway through, so feel free to use the facilities then or before the beginning of class. If you do have some underlying medical condition that requires you to regularly leave class, then please make sure I get a note from disabilities support (see contact information below). If I do not get official notification from disabilities support, then the regular bathroom break will be considered a series of “unexcused” absences and will result in a lowering of your class attendance grade. I have absolutely no problem with an occasional bathroom visit, but please limit your visits.

In-class Activities/Short Assignments: We will have a number of **in-class activities** throughout the semester—this is another reason why regular class attendance is so important. These activities will help to solidify the concepts of the course. There will also be **sporadic short out-of-class activities**. These two kinds of assignments will constitute the short assignment grade. I expect people to keep up with the readings for the class, otherwise you will not be able to successfully complete the in-class activities.

If I suspect that students are not keeping up with the readings (this suspicion arises when the professor asks a question about the reading and no one responds...), I have the habit of distributing **pop quizzes**. I do not think that pop quizzes are “unfair, unjust!” They are just one tool to help keep you on track and to help cement the concepts. I would like to treat you like college students and not as high school students, so please make sure that you keep up with the work and I will not feel compelled to give pop quizzes.

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 your individual performance. Few things are as frustrating for me then 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. 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. You also need to make sure that your mailbox does not reach its limit as you will be unable to receive emails once it is full.

Students with Disabilities:

Students who wish to request accommodations in this class for a disability should contact Elaine Mara, assistant director of learning services for academic and disability support at 1307 Main Street, or by calling 610-861-1510. Accommodations cannot be provided until authorization is received from the Academic Support Center.

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

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

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)

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

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.

Wolpe, P. R., *The Triumph of Autonomy in American Bioethics: A Sociological View*, (D&S, Chapter 3)--handout

Jennings, B., "Autonomy and Difference: The Travails of Liberalism in Bioethics," (D&S, Chapter 13)—handout

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?

Capron, Alexander Morgan, "The Burden of Decision" (Life Choices)

Hardwig, John, "What About the Family?" (Life Choices)

Blustein, Jeffrey, "The Family in Medical Decisionmaking" (Life Choices)

Tough

Freeman and McDonnell, Tough Decisions, Chapters 4, 7 and 10

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 led 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, then what is the implication for our broader understanding of the human experience?

Life Choices, pp:177-214, 375-460

Freeman and McDonnell, Tough Decisions, 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.

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 though 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.

Life Choices: pages 461-518

Tough Decisions: Chapter 3

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.

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?

13. Genetics

Life Choices, pp: 519-594

Freeman and McDonnell, Tough Decisions, 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 led 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, Against Relativism: Cultural Diversity and the Search for Ethical Universals in Medicine (Oxford University Press, New York, 1999)

Some Helpful WebSites

University of Pennsylvania Center for Bioethics
www.bioethics.net, www.bioethics.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