(Updated: (8/2024) HCB 521 Clinical Ethics Practicum

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Semester: Fall 2024 Schedule: Tuesday 6:00-9:00 pm Where: Department of Family, Population, and Preventive Medicine, Room 067

The goals of clinical ethics are to identify, analyze, and resolve ethical problems that arise in the care of patients. While a theoretical understanding of ethical issues is essential, the details of actual clinical practice are often more complex and contextual than abstract principles would have one believe. Medical considerations, ethical and legal dimensions, comparisons with similar cases (casuistry), cultural beliefs, psychological conditions, familial circumstances, "stakeholders," time constraints, heightened emotions, communication barriers, and a host of other factors make clinical ethics a matter of getting to plausibly "good" outcomes. This course will review the development of institutional ethics committees, theories of ethical reasoning and survey various topics that arise in clinical ethics.

Readings - required text (can be purchased on Amazon. AbeBooks, Biblio, Apple Books)

- AR Jonson, M Siegler, WJ Winslade, *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*, 9th Edition (New York: McGraw-Hill, 2021).
 This is "the" classic manual that is commonly used by clinicians and the most successful "how to" book in the field.
- Relevant articles will be emailed weekly, one week prior to discussion.

Course Structure

The first several weeks of the course are introductory about the nature and function of ethics committees and clinical ethics consultations, including background about the development of modern institutional ethics committees, and the use of essential documents, such as advanced directives. The process of case mediation and the "how to" of consultation, are also discussed. The course will then turn to an array of clinical areas and cases.

Week 1 (August 27): Introduction (Phyllis Migdal MD, MA)

The historical development of clinical ethics committees, their composition, and their primary roles (policy, advisory case review, education) will be discussed. We will also introduce the function of providing clinical ethics consultation in small teams. How does this practice work? What are its strengths? How often is this service requested and by whom? What is the relationship of the ethics committee to offices of (a) Legal Risk Management and (b) Patient Advocacy?

<u>Readings:</u>

Ethics committees in health care institutions. (2016). AMA code of medical ethics opinion 10.7. Retrieved from: <u>https://www.ama-assn.org/delivering-care/ethics/ethics-committees-health-care-institutions</u>

Aulisio, M.P., & Arnold, R.M. (2008). Role of the ethics committee: Helping to address value conflicts or uncertainties. *Chest*, 134(2), 417-424.

Stony Brook Medicine "Ethics Consultation"

Who's Who in the Hospital Setting

<u>Begin reading:</u>

Jonsen, Siegler & Winslade, *Clinical Ethics* 8th *Edition: A Practical Approach to Ethical Decisions in Clinical Medicine*, **Introduction and Topic One**

Week 2 (September 3): Introduction to the Healthcare Setting, the Law of Healthcare Decisions, Informed Consent, Healthcare Agents, and Surrogacy (Robyn McKeefrey RN, MA)

We will discuss various procedures and forms developed within the healthcare setting that attempt to address common ethical issues in healthcare with an emphasis on consent forms, surrogacy, and agents designated by proxy. Various pitfalls will be addressed.

Readings:

Stony Brook Medicine Consent to Operation or Procedure and Anesthesia 2017

Stony Brook Medicine Admission Consent form

Informed Consent Forms

Ch. 16 Ethics and the Law

Robert N. Swindler, "New York's Family Health Care Decisions Act," *NYSBA Journal*, June 2010, pp. 18-27.

Stony Brook Med - The Patient's Bill of Rights

The MOLST Form (Medical Orders for Life-Sustaining Treatment)

The MOLST Form - Frequently Asked Questions

What is a MOLST Form?

New York State Health Care Proxy

Continue reading:

Jonsen, Siegler & Winslade, *Clinical Ethics* 8th *Edition: A Practical Approach to Ethical Decisions in Clinical Medicine*, **Topic Two**

Week 3 (September 10): Introduction to Case Analysis and Approaches to Ethical Reasoning

(Phyllis Migdal MD, MA)

The basics of clinical case write-ups and clinical case analysis (inductive details, ethical principles involved, casuistical dimensions, the Jonsen rubric, who decides, framing goals, shared decision making and its basis/limits, etc.) will be discussed. The ethics chart note is intended to serve multiple purposes and understanding how to properly structure one is essential to both this course and to the usefulness of any future writing in this area you might do. A template to model your clinical ethics note assignment on will also be reviewed.

Readings:

Antommaria, A.H., Collura, A., Antiel, R.M., 7 Lantos, J.D. (2015). Two infants, same prognosis, different parental preferences. *Pediatrics*, 135(5), 918-923.

Courtenay R. Bruce, et al., (2014). Practical guidance for charting ethics consultation. *HEC Forum*, *26*, 79-93.

Ethics Case Consultation Toolkit Summary Template

Exemplary Clinical Ethics Chart Note

Schumann, J.H., & Alfandre, D. (2008). Clinical ethical decision making: The four topics approach. *Seminars in Medical Practice*, 11, 36-42.

Stony Brook Med - Steps in Practical Judgement

Varkey, B. (2021). Principles of clinical cthics and their application to practice. *Medical Principles and Practice*, *30*, 17-28.

Keep working your way through topic two: Jonsen, Siegler & Winslade, *Clinical Ethics* 8th *Edition: A Practical Approach to Ethical Decisions in Clinical Medicine*, **Topic Two**

Week 4 (September 17): Ethical Case Resolution and Mediation (Clare Whitney PhD, MBE, RN)

In this week, we will discuss an approach to clinical ethics consultation through mediation. Clinical ethics mediation involves core pillars of neutrality, conflict resolution, and enhancing communication between conflicting parties. Professional mediators seek to manage and find mutually acceptable resolutions to clinical conflicts stemming from conflicting values, perceptions of disrespect, and miscommunications, misunderstandings, or other breakdowns in communication. We will discuss the framework of identifying Positions and Interests, the limitations of Principlism in the context of ethics consultation, and common communication techniques used by ethics mediators.

<u>Readings:</u>

Bergman, E. J. (2015). Identifying sources of clinical conflict: A tool for practice and training in bioethics mediation. *The Journal of Clinical Ethics*, 26(4), 315-323.

Fiester, A.M. (2015). Teaching nonauthoritarian clinical ethics: Using an inventory of bioethical positions. *Hastings Center Report*, 45(2), 20-26.

Fiester, A. M. (2015). Weaponizing principles: Clinical ethics consultations and the plight of the morally vulnerable. *Bioethics*, 29(5), 309-315.

Fiester, A. (2012). The "Difficult" patient reconceived: An expanded moral mandate for clinical Eehics. *The American Journal of Bioethics*, *12*(5), 2-7.

Fiester, A. (2007). The failure of the consult model: Why "Mediation" should replace "Consultation". *The American Journal of Bioethics*, 7(2), 31-32.

Cases for 4-Topic Presentations to be emailed

Week 5 (September 24): Ethical Issues in Clinical Pediatrics (Kathleen Culver, DNP, RN, CPNP, MA, Rina Meyer, MD)

In this week's class, we will explore the unique ethical challenges facing pediatric patients and their health care providers. In pediatrics, most decisions are made by surrogate decision-makers, calling into question the concept of "best interest of the child" and requiring us to identify the appropriate decision-makers. We will look at a case that highlights these issues. Additionally, adolescent patients are at the cusp of their ability to make autonomous decisions. We will explore what happens when these decisions differ from the decisions of either their parents or the medical team. Finally, we will look at one of the most vulnerable pediatric populations – developmentally disabled children – and explore the challenges inherent in their care, and the multiple players involved.

<u>Readings:</u>

Baines, P. (2008). Medical Ethics for Children: Applying the Four Principles to Paediatrics. *Journal of Medical Ethics*, *34*, 141-145.

Cunnings, C.L. & Mecurio, M.R. (2010). Autonomy, Beneficence, and Rights. *Pediatrics in Review*, *31*(6), 252-255.

Fost, NC. (1985). Ethical Issues in the Care of Handicapped, Chronically III, and Dying Children. *Pediatrics in Review*, 6(10), 291-296.

Continue reading:

Jonsen, Siegler & Winslade, *Clinical Ethics* 8th *Edition: A Practical Approach to Ethical Decisions in Clinical Medicine*, **Topic Three**

Week 6 (October 1): Palliative Care (Grace LaTorre DO, MS)

Palliative Care focuses on providing relief of physical, emotional and spiritual pain and distress experienced by patients with serious life-limiting illnesses, while providing support and guidance to their families/caregivers. Ethical dilemmas can often arise in the care of patients with serious illness or who are at the end-of-life. Important ethical issues that are frequently encountered will be discussed, as well as strategies on how to address these.

<u>Readings: TBD</u>

Week 7 (October 8): In class 4-Box Case Presentations

Continue reading:

Jonsen, Siegler & Winslade, *Clinical Ethics* 8th *Edition: A Practical Approach to Ethical Decisions in Clinical Medicine*, **Topic Three and Four**

<u>Readings:</u>

Cases for clinical chart note assignment to be emailed

Week 8 (October 22): (Gregg Cantor MD)

In this session we will discuss ethical issues in cardiology. We will mainly focus on pacemakers/defibrillators and their potential withdrawal in end-of-life situations. These devices can bring much benefit to a patient's life, however, can also function against a patient's wishes during end-of-life situations. Students will learn about these benefits and dilemmas and discuss the differences between the discontinuance these devices provide versus other medical therapies.

<u>Readings:</u>

Pacemakers and Defibrillators. Columbia University Department of Surgery. (A brief overview of pacemakers and defibrillators to be reviewed in class) https://columbiasurgery.org/conditions-and-treatments/pacemakers-and-defibrillators

Benjamin, MM & Sorkness, CA. (2017). Practical and ethical considerations in the management of pacemaker and implantable cardiac defibrillator devices in terminally ill patients. *Proc (Bayl Univ Med Cent)*, 30(2), 157-160.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5349811/

Bevins, MB. (2011). The ethics of pacemaker deactivation in terminally ill patients. Journal of *Pain and Symptom Management, 41*(6), 1107-1110.

https://www.jpsmjournal.com/action/showPdf?pii=S0885-3924%2811%2900202-8

Bharadwaj, P & Ward, KT. (2008). Ethical considerations of patients with pacemakers. *American Family Physician*, 78(3), 398-399. https://www.aafp.org/afp/2008/0801/p398.html

Kramer, DB, Kesselheim, AS, Brock, DW, & Maisel, WH. (2010). Ethical and legal views of physicians regarding deactivation of cardiac implantable electrical devises: A quantitative assessment. Heart Rhythm, 7(11), 1537-1542. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3001282/pdf/nihms-243099.pdf

Continue reading:

Jonsen, Siegler & Winslade, *Clinical Ethics* 8th *Edition: A Practical Approach to Ethical Decisions in Clinical Medicine*, **Topic Four**

DUE: Chart note

Week 9 ((October 29): Nutrition/Feeding/PEGS (Maria Basile MD, MBA)

One of the complications of later-stage Alzheimer's Disease (AD) and other advanced dementias is the difficulty associated with adequate feeding and nutrition. Early in the course of the disease, this may manifest simply as irregular feeding patterns. As neurologic function becomes increasingly compromised, patients eventually suffer a lack of control over swallowing both solids and liquids. Family and friends are often faced with the unfortunate reality of watching a loved one suffer not only the drawn-out cognitive decline associated with these diseases, but also a terminal stage whereby achieving basic nutrition and hydration becomes an everyday challenge. Through the 1980's and mid-1990's, application of the PEG (percutaneous endoscopic gastronomy) tube (invented in 1979) procedure for patients with advanced dementia became commonplace and replaced the older practice of assisted oral feeding. The relatively simple procedure, which passes a feeding tube directly through the nearby skin and then directly into the stomach itself, was thought to present a humane method for keeping these patients adequately fed and hydrated by bypassing the compromised swallowing mechanism. It was also hoped that PEG tube placement would reduce associated complications such as bed sores from malnutrition and aspiration pneumonia from poor swallowing. However, by 2000 a number of key articles were published seriously questioning the value and the ethics of PEG use in individuals with end-stage AD. Since then, debate has raged over the PEG and its uses among deeply forgetful people.

<u>Readings: TBD</u>

Continue reading: Review text and choose a topic of interest for presentation (11/19 & 12/3) Jonsen, Siegler & Winslade, Clinical Ethics 8th Edition: A Practical Approach to Ethical Decisions in Clinical Medicine

Week 10 (November 5): Pain (Kevin Zacharoff, MD)

Pain is one of the most common reasons that people seek medical attention in the United States today, with an estimated 60 million people suffering from a pain-related condition at any given time. In the year 2000, pain was designated as the "fifth vital sign" giving people the right to have their pain assessed and treated by their healthcare providers. Several ethical dilemmas have surfaced since; including the increased/over-prescribing of opioid medications for patients with chronic pain, lack of oversight of suspicious dispensing of opioid analgesics by pharmaceutical companies and drug distributors, along with abuse, misuse, and addiction related to these medications. The "opioid overdose epidemic" has led to the dilemma of balancing the safe, compassionate, and effective treatment of chronic pain and negative outcomes (including overdose deaths) associated with the increased use of medications used to achieve these goals. Additionally, deadly illicit opioids such as fentanyl mixed with heroin and other illicit substances like xylazine have further blurred the lines between responsible parties for this increasingly fatal epidemic and possible solutions. The emergence of the Coronavirus pandemic in some ways magnified the societal impact of these phenomena with more people dying of opioid-related overdoses than ever before, especially people of color, low socioeconomic status, and other social determinants of health. This session along with reading materials will provide a forum for discussion and analysis of this important situation facing healthcare and society today.

<u>Readings: TBD</u>

After Class:

- Brief discussion after class about presentation of topic of interest from the text (PPT)
- Sign-up for either group 1 or group 2 (November 19 or December 3)
- Email the topic of interest of your discussion

Week 11(November 12): Ethical Issues in Hematology/Oncology (Michael Schuster MD)

Cancer medicine: the goal is always cure, or is it?

Sample questions to be discussed:

- 1. When is the right time to say, "there is no more treatment."
- 2. You're undocumented, have no insurance or resources, and you don't speak a word of English. How do I treat you?
- 3. I can cure the patient but you don't want treatment. Now what?
- 4. What chance for cure is enough of a chance?
- 5. Don't tell me anything. You're the doctor, just do what you think is best.
- 6. A patient is made DNR. Then, the daughter from California shows up and overturns everything.
- 7. Clinical trial issues
- 8. I disagree with almost everything you say. Can I still be your doctor?

<u>Readings:</u>

Northe, N., Palmer, A., Enck, G., Masciari, C.F., Neumann J., & Gallagher, C.M. (2024). Evolving landscape of ethics in oncology: A journey through the past, present, and future. *American Society of Clinical Oncology Education Book, 44*(3),e100043.

Week 12 (November 19): Discussion of topics of interest from Jonsen, Siegler, Winslade – Group 1

In class presentation of a topic of interest, $\sim 15-20$ minute presentation, and 5-10 minute discussion from your readings in the text. Explore the clinical ethical issue in depth and the key take-aways or learning points as the topic relates to ethical decision making.

Week 13 (November 26): Ethics of Reproductive Technology – Pre-Implantation Diagnosis and Selection, Designer Babies and Gene Editing (Devilie Migdel MD, MA)

(Phyllis Migdal, MD, MA)

In this section we will explore reproductive ethics of assisted reproductive technologies (ART), including preimplantation genetic testing (PGT), polygenic embryo screening, and a case involving the deaf culture.

Video:

Polygenic Embryo Screening: The Promise and Perils of Selecting Our Children's Traits. https://youtu.be/2DbkGWHTM9I?si=ycVINGU0TS51cRi5

<u>Readings:</u>

Practice Committee of the American Society for Reproductive Medicine. (2021). Guidance on the limits to the number of embryos to Ttansfer: A committee opinion. *Fertility and Sterility*, *116*(3), 651-654. <u>https://www.fertstert.org/action/showPdf?pii=S0015-0282%2821%2900563-X</u>

Spriggs, M., (2002). Lesbian couple create a child who is deaf like them. *Journal of* Medical *Ethics 28*(5), 283.

Fahmy, MS., (2011). On the supposed moral harm of selecting for deafness. *Bioethics* 25(3), 128-136.

Hladek, G., (2009). Cochlear implants, The Deaf culture, and ethics: A study of disability, informed – surrogate consent, and ethnocide. *The Institute for Applied and Professional ethics*, Ohio University.

Mand, C., Duncan, R. E., Gillam, L. Collins, V., & Delatycki, M. B. (2009). Genetic selection for deafness: The views of hearing children of deaf adults. *Journal of Medical Ethics*, *35*(12), 722-728.

Ethics Committee of the American Society for Reproductive Ethics. (2022). Use of reproductive technology for sex selection for nonmedical reasons: An Ethics Committee Opinion. *Fertility and Sterility*, *117*(4), 720-726.

Kaplan, A., & Quinn, GP. (2023). Bartering your eggs: A rotten deal. Posted in: *The Hastings Bioethics Forum*.

Kozlov, M. (2022). The controversial embryo tests that promise a healthier baby. *Nature, 609*, 668-671.

Optional:

Groce, N. E. (2016). Deafness on Martha's Vineyard. *Encyclopaedia Britannica*. https://www.britannica.com/science/deafness-on-Marthas-Vineyard

Furrer R.E., Barlevy, D., Pereira, S., Carmi, S., Lencz, T., & Lazaro-Munoz, G. ((2024). Public attitudes, interests and concerns regarding polygenic embryo screening. *JAMA Open Network* 7(5), e2410832.

Week 14 (December 3): Discussion of topics of interest from Jonsen, Siegler, Winslade – Group 2

In class presentation of a topic of interest, $\sim 15-20$ minute presentation, and 5-10 minute discussion from your readings in the text. Explore the clinical ethical issue in depth and the key take-aways or learning points as the topic relates to ethical decision making.

Week 15: (December 8): Position Paper due

GRADING

All papers must include:

- Name on title page
- Page number
- APA or MLA in-text and reference list citations

Absences:

- Must be excused prior to class
- If you miss more than one class or if absence was not excused a 3-5 page write-up is required about the topic of the week you missed.

Late assignments:

- Must have permission
- Grade deduction
- 1. Classic case-presentation 4-box approach, PowerPoint Presentation (20%)
 - a. Case analysis using a systematic process to identify and defend an ethical dilemma using ethical principles.
 - i. Cases to be distributed in class
 - b. Presentation using the Four Topics Chart described in Jonsen, et al.
 - i. Identify the Issue
 - 1. Provide an overview of the case

- 2. Outline the options
- 3. Construct ethical arguments
- 4. Evaluate the arguments provided in the classical case
- ii. Make a decision/recommendation
 - 1. Since cases are historical provide support for or against the decision
 - 2. Provide the ethical analysis that supports your decision
- iii. Form and discuss 2 reflective questions about the case
 - 1. To stimulate further discussion about the ethical dilemma
- 2. Students will be asked to turn in an **ethics chart note** following a specific template that we will discuss early in the course. (20%).
- 3. Students will **lead an in-class** ~15-20 minute discussion of a topic of interest from the *Clinical Ethics* text. (20%)
- 4. Students will turn in a ~7-page position paper on any topic covered in the course, drawing from the assigned readings and further research. You may use the topic as a springboard for your thoughts and positions that go beyond the discussion in class. Outside resources may be used to contribute to the strength of your position and should be cited in APA or MLA format. (20%)

Writing a Position Paper: (adapted from Xavier University guide, 2014)

- a.) The purpose of a position paper is to present one side of an arguable opinion to generate support on an issue. It describes a position on an issue and the rational for that position.
- b.) The position paper also presents the **counterargument** or the opposing position, but advocates for the side position that you take based on the evidence you present.
- c.) Choose an issue where there are clearly varying opinions that can be argued and substantiated.
- d.) Narrow your topic, define and limit your issue.
- e.) Format:
 - i. <u>Introduction</u>: (Identifies the issue and states your position) The first section begins with the selection of a topic that has multiple viewpoints and written to capture the reader's attention. The introductory paragraph includes a statement of your position (thesis), and how the paper will proceed in terms of arguments in favor of your position and the counterarguments that you will elaborate on in the body of your paper.
 - a. Introduction of the topic
 - b. Background information
 - c. State your thesis (your view on the issue)
 - ii. <u>*The main body:*</u> (Provides supporting evidence, discussion of both sides of the issue, arguments and counterarguments)

Develops the thesis discussed in the introduction. The body of your paper includes supporting information for your position from the class readings

or other sources. Further, this section includes why alternative positions are incorrect or not as strong as the position you support.

- *iii.* <u>Conclusion:</u> Summarizes the main strengths of your position and highlights a further question for a future discussion.
- 5. The remaining 20% will be class attendance, assigned readings and participation. It is important to be an active and vocal contributor to discussion.
 - a. Please note attendance requirements above.

Student Accessibility Support Center Statement

If you have a physical, psychological, medical, or learning disability that may impact your course work, please contact the Student Accessibility Support Center, Stony Brook Union Suite 107, (631) 632-6748, or at <u>sasc@stonybrook.edu</u>. They will determine with you what accommodations are necessary and appropriate. All information and documentation is confidential.

Students who require assistance during emergency evacuation are encouraged to discuss their needs with their professors and the Student Accessibility Support Center. For procedures and information go to the following website: <u>https://ehs.stonybrook.edu//programs/fire-safety/emergency-evacuation/evacuation-guide-disabilities</u> and search Fire Safety and Evacuation and Disabilities.

Academic Integrity Statement

Each student must pursue his or her academic goals honestly and be personally accountable for all submitted work. Representing another person's work as your own is always wrong. Faculty is required to report any suspected instances of academic dishonesty to the Academic Judiciary. Faculty in the Health Sciences Center (School of Health Professions, Nursing, Social Welfare, Dental Medicine) and School of Medicine are required to follow their school-specific procedures. For more comprehensive information on academic integrity, including categories of academic dishonesty please refer to the academic judiciary website at http://www.stonybrook.edu/commcms/academic integrity/index.html

Critical Incident Management

Stony Brook University expects students to respect the rights, privileges, and property of other people. Faculty are required to report to the Office of Student Conduct and Community Standards any disruptive behavior that interrupts their ability to teach, compromises the safety of the learning environment, or inhibits students' ability to learn. Faculty in the HSC Schools and the School of Medicine are required to follow their school-specific procedures. Further information about most academic matters can be found in the Undergraduate Bulletin, the Undergraduate Class Schedule, and the Faculty-Employee Handbook.