

(Updated August 2019)
HCB 521 Clinical Ethics Practicum

Course Director Phyllis Migdal MD, MA will attend sessions throughout
Core Supplemental Faculty Robyn McKeefrey RN, MA
Session Faculty Jean Callaghan RN, Laureen Diot ANP-C, WCC, ACHPN, Jill
Genua MD, Gabrielle Gerber MSN, Rina Meyer MD, Kathleen Scotto DiMaso RN,
James Tychnowitz RT, Kevin Zacharoff, MD

Semester: Fall 2019
Schedule: Thursday, 6-8:30 pm
Room 067, Preventive Medicine 3rd Floor

Clinical ethics is an interdisciplinary activity to identify, analyze, and resolve ethical problems that arise in the care of particular 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 factors, psychological conditions, familial circumstances, “stakeholders,” time constraints, heightened emotions, communication barriers, and a host of other dimensions make clinical ethics a matter of getting to plausibly “good” outcomes.

Readings – required text (can be purchased on Amazon, AbeBooks, or ebooks)

AR Jonson, M Siegler, WJ Winslade, *Clinical Ethics, 8th Edition: A Practical Approach to Ethical Decisions in Clinical Medicine* (New York: McGraw-Hill, 2015).

This is “the” classic manual that is commonly used by clinician and the most successful “how to” book in the field.

Otherwise, articles will be forwarded to you weekly via e-mail.

Course Structure

The first several weeks of the course are introductory with regard to the nature and function of ethics committees and clinical ethical consultations, including background and essential documents. The course will then turn to an array of clinical areas and cases.

In addition to the lectures on Thursday evenings, students are required to attend one additional lecture or meeting outside of the usual class and write a 2-3 page reflection essay. Choices include Schwartz Rounds sessions, Grand Rounds from the Center as well as a meeting of the Hospital Ethics Committee. Event dates will be posted as available.

Week 1 (August 29): Introduction
(Migdal)

In this week we will discuss the historical development of clinical ethics committees, their composition, and their primary roles (policy, advisory case review, education). 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?

Readings

Hoffmann DE, Tarzian AJ. “The Role and Legal Status of Health Care Ethics Committees in the United States.”

Diane Ranieri, “Training in Ethics Consultation: A Model for Physician Assistant Programs,” *J of Physician Assistant Education*, Vol. 26 (no. 2), 2015, pp. 212-214.

Stony Brook Med “Ethics Consultation”

Who’s Who in the Hospital Setting

American Medical Association Opinion 9.11 Ethics Committees in Health Care Institutions

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

Week 2 (September 5): Introduction to the Healthcare Setting, the Law of Healthcare Decisions, Informed Consent, Healthcare Agents, and Surrogacy
(McKeefrey)

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
(McKeefrey)

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

Stony Brook Med - Steps in Practical Judgement

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

The MOLST Form - Frequently Asked Questions (McKeefrey)

What is a MOLST Form?

New York State Health Care Proxy

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

Week 3 (September 12): Introduction to Case Analysis and Some Approaches to Ethical Reasoning

(Migdal)

We will introduce students to the basics of clinical case write-ups and clinical case analysis. 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. You will also be provided with a template to model your assignments on. We will discuss approaches to ethics case analysis (inductive details, ethical principles involved, casuistical dimensions, the Jonsen rubric, who decides, framing goals, shared decision making and its basis/limits, etc.).

Readings

Courtenay R. Bruce, et al., "Practical Guidance for Charting Ethics Consultation." *HEC Forum*. Vol. 26, 2014, pp. 79-93.

Ethics Case Consultation Toolkit Summary Template

Exemplary Clinical Ethics Chart Note

Stony Brook Medicine, Moral Values Important in Clinical Decision Making

John H. Schumann and David Alfandre, "Clinical Ethical Decision Making: The Four Topics Approach," *Seminars in Medical Practice*, Vol. 11, 2008, pp. 36-42.

Timothy E. Quill and Howard Brody, "Physician Recommendations and Patient Autonomy: Finding a Balance between Physician Power and Patients Choice," *Annals of Internal Medicine*. Vol. 125, 1996, pp. 763-769.

Tarzian, A.J., "Health Care Ethics Consultation: An Update on Core Competencies and Emerging Standards from the American Society for Bioethics and Humanities' Core Competencies Task Force," *The American Journal of Bioethics*, Vol.13(2), 2013, pp.3-13.

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

Week 4 (September 19): Ethical Issues in Clinical Pediatrics

(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.

Readings

TBD

Cases

Week 5 (September 26): Oncology

(Jean Callaghan RN, Gabrielle Gerber RN)

We will examine the ramifications of ethics in the clinical setting. Our readings and discussions will realistically demonstrate the interrelationship between compassionate care, empathy, professional obligations, and the ethical struggles encountered while addressing the desires of patients, families and the requirements of the hospital and government regulations.

Readings

Helft P, Daugherty C. "Are We Taking Without Giving in Return? The Ethics of Research-Related Biopsies and the Benefits of Clinical Trial Participation (editorial),"

Journal of Clinical Oncology. Vol. 24 (no. 30), 2006..
<<http://ascopubs.org/doi/pdf/10.1200/JCO.2006.05.7125>>.

Kodish E, Post SG. "Oncology and Hope," *Journal of Clinical Oncology*. Vol. 13 (no. 7), 1995, pp. 1817-1922.
<<http://ascopubs.org/doi/abs/10.1200/jco.1995.13.7.1817?journalCode=jco>>.

Peppercorn J. "Ethics of Ongoing Cancer Care for Patients Making Risky Decisions," *Journal of Oncology Practice*. Vol. 8 (no. 5), 2012, pp. 111-113.
<<http://ascopubs.org/doi/abs/10.1200/jop.2012.000622>>

Phelps A, Jaciejewski PK, Nilsson M, et al. "Religious Coping and Use of Intensive Life-Prolonging Care Near Death in Patients With Advanced Cancer," *JAMA*, Vol. 301, 2009, pp. 140-147. <<http://jamanetwork.com/journals/jama/fullarticle/183578>>.

Sahm S, Will S. "Attitudes Towards and Barriers in Writing Advance Directives Amongst Cancer Patients, Healthy Controls, and Medical Staff," *Journal of Medical Ethics*, Vol. 31 (no. 8), 2005. <<http://jme.bmj.com/content/31/8/437.short>>.

Schneiderman L, Gilmer T, Teetzel H et al. "Effect of Ethics Consultations on Nonbeneficial Life-Sustaining Treatments in the Intensive Care Setting: A Randomized Controlled Trial," *JAMA* Vol. 290 (no. 9), 2003, pp. 1166-1172.
<<http://jamanetwork.com/journals/jama/fullarticle/197212>>.

Smith AK, McCarty EP, Paulk E, et al. "Racial and Ethnic Differences in Advance Care Planning Among Patients With Cancer: Impact of Terminal Illness, Acknowledgment, Religiousness, and Treatment Preferences," *Journal of Clinical Oncology* Vol. 26, 2008, pp. 4131-4137. <<http://ascopubs.org/doi/abs/10.1200/JCO.2007.14.8452>>.

Sulmasy, DP. "Cancer Care, Money and the Value of Life: Whose Justice? Which Rationality?" *Journal of Clinical Oncology*, Vol. 25, 2007, pp. 217-222.
<<http://ascopubs.org/doi/abs/10.1200/jco.2006.08.0481>>.

Cases

Week 6 (October 3): Reproduction (McKeefrey)

Reproductive ethics assures that the basic rights of all people to decide freely concerning whether or not to reproduce is independent of discrimination, coercion or violence. In making those choices, the framework of human rights and basic medical ethics principles of autonomy, self-determination, justice, liberty, individual freedom and equitable access to services all apply. In this section we will explore within the field of reproductive ethics the topics of preimplantation genetic diagnosis (PGD), the deaf

culture, and assisted reproductive technology with applicable case studies sure to result in an interesting paradigm of discussion.

Readings:

American Society for Reproductive Medicine. "Criteria for Number of Embryos to Transfer," *Fertility and Sterility*, 2013.

Bronson R. "In Memoriam," *Human Reproduction*, 1997

Edwards RG, Beard HK. "Destruction of Cryopreserved Embryos," *Human Reproduction*, 1997.

Fahmy, M. S. "On the Supposed Moral Harm of Selecting for Deafness," *Bioethics*
<https://pdfs.semanticscholar.org/fe98/dd5de7274edcb2cc74e92a407a17d4dad626.pdf>

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

Hladek, G. "Cochlear Implants, The Deaf Culture, and Ethics," The Institute for Applied and Professional Ethics, Ohio University, July 27, 2009.
<https://www.ohio.edu/ethics/2001-conferences/cochlear-implants-the-deaf-culture-and-ethics/index.html>

Levy, N. "Deafness, Culture, and Choice," *Journal of Medical Ethics*, Vol 28, 2002, 284-285. <https://jme.bmj.com/content/28/5/284>

Mand, C., Duncan, R. E., Gillam, L. Collins, V., & Delatycki, M. B. "Genetic Selection For Deafness: The Views of Hearing Children of Deaf Adults," *Journal of Medical Ethics*, 35, 2009, 722-728.

Shaw, G. "Breaking News: The Ethics of Designing a Deaf Baby," *The Hearing Journal*, Vol. 65(5), 2012, 22.

https://journals.lww.com/thehearingjournal/Fulltext/2012/05000/Breaking_News_The_Ethics_of_Designing_a_Deaf.2.aspx

Cases

DUE: Chart Note 1 from cases from week 4 & 5

Week 7 (October 10): Respiratory/Extubation
(James Tychnowitz)

We will discuss withdrawal of mechanical ventilation from patients who are not expected to sustain independent respirations without it. We will discuss withdrawal of life sustaining treatment and the ethical issues surrounding it, including ethical justification, legal issues, conflicts which may arise between medical teams and families.

Readings
TBD

Week 8 (October 17): Palliative Care
(Laureen Diot ANP-C, WCC, ACHPN)

Palliative care medicine encompasses the care of patients and families during serious, possibly life-threatening illnesses. The goals of ensuring that patient preferences are met along with providing the relief of pain and suffering are important aspects of palliative care. The differences with hospice care will be discussed and how ethical guidelines can be used to help the patient and family make decisions about their care.

Readings
TBD

DUE: Position Paper 1 based on topics from weeks 1 - 7

Week 9 (October 25): 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 60-100 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. A number of 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 have further blurred the lines between responsible parties for this increasing epidemic. This session along with reading materials will provide a forum for discussion and analysis of this important situation facing healthcare and society today.

Readings

Achenbach, J., Bernstein, L., Harrow Jr, R., and Boburg, S. An Onslaught of Pills, Hundreds of Thousands of Deaths: Who is Accountable? *The Washington Post*. July 20, 2019.

Aviv, R. "Prescription for Disaster: The Heartland's Pain-pill Problem," *The New Yorker*, May 5, 2014.

Cheatle, M. D., Gallagher, R. M., & O'Brien, C. P. "Low Risk of Producing Opioid Use Disorder in Primary Care by Prescribing Opioids to Prescreened Patients with Chronic Noncancer Pain," *Pain Medicine*, 19, 2018, 764-773.

Chen, J. H. "The Patient You Least Want to See," *JAMA*, 315(16), 2016, 1701-1702.

Executive Office of the President of the United States. "Epidemic: Responding to America's Prescription Drug Abuse Crisis," 2011. Retrieved from: <http://publications.iowa.gov/12965/1/NationalRxAbusePlan2011.pdf>

Feke, T. "I Am a Doctor, But I Didn't Cause the Opioid Epidemic," *KevinMD.com*. May 26, 2016. Retrieved from: <https://www.kevinmd.com/blog/2016/05/doctor-didnt-cause-opioid-epidemic.html>

Institute of Medicine. "Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research," Retrieved from: <https://www.nap.edu/resource/13172/reportbrief.pdf>

Kroenke, K. "Management of Chronic Pain in the Aftermath of the Opioid Backlash," *JAMA*, 317(23), 2017, 2365-2366.

Wamsley, L. Fentanyl Surpasses Heroin as Drug Most Often Involved In Deadly Overdoses. *NPR*. December 12, 2018.

Week 10 (October 31): Feeding PEGS (Genua)

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 toward 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.

Our session will focus on the clinical ethical literature around this topic, which we will discuss in detail. We will also examine a number of clinical cases where PEG use is considered.

Readings

Gillick MR, "Rethinking the Role of Tube Feeding in Patients with Advanced Dementia," *NEJM*, Vol. 342, No. 3, 2000, pp. 206-210.

Casarett D, et al., "Appropriate Use of Artificial Nutrition and Hydration – Fundamental Principles and Recommendations," *NEJM*, Vol 353 (no. 24), 2005, pp. 2607-2612.

Teno JM, Mitchell SL, Gozalo PL, et al., "Hospital Characteristics Associated with Feeding Tube Placement in Nursing Home Residents with Advanced Cognitive Impairment," *JAMA*, Vol. 33, No. 6, 2010, pp. 544-550.

Post SG. "Tube Feeding and Advanced Progressive Dementia," *Hastings Center Report*, Vol. 31, No. 1, 2001, pp. 36-42.

Mendiratta P, Tilford JM, Prodhan P, "Trends in Percutaneous Endoscopic Gastrostomy Placement in the Elderly from 1993 to 2003," *American Journal of Alzheimer's Disease & Other Dementias*," Vol. 27, No. 8, 2012, pp. 609-613.

Schultze J, et al., "Incidence of Tube Feeding in 7174 Newly Admitted Nursing Home Residents With and Without Dementia," *American Journal of Alzheimer's Disease & Other Dementias*," Vol. 31, No. 3, 2016, pp. 27-33.

Rosler A, et al. "Dysphagia in Dementia," *JAMDA*, Vol. 16, 2015, pp. 697-701.

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

Cases

Week 11 (November 7): Bone Marrow Transplant
(Kathleen Scotto-DiMaso)

Bone marrow transplant raises many clinical ethical issues. For example, does a young brother or sister really want to become a donor, or is it really just family pressure and expectation that is at work? What about parents who bring a child into the world with the intent of using it as a donor?

Readings

HJ Deeg, "Treatment Ethics, Quality of Life and Health Economics in the Management of Hematopoietic Malignancies in Older Patients," *Bone Marrow Transplantation*, Vol. 50, 2015, pp. 1145-1149.

<http://www.nature.com/bmt/journal/v50/n9/full/bmt2015130a.html?foxtrotcallback=true>

Sigrid Droste et al., "Ethics Issues in Autologous Stem Cell Transplantation (ASCT) in Advanced Breast Cancer: A Systematic Review," *BMC Medical Ethics*, Vol. 12 (no. 6), 2011, pp. 1-16.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3103481/>

Winnie S. Wang et al., "Advance Care Planning and Palliative Care Integration for Patients Undergoing Hematopoietic Stem-Cell Transplantation," *J of Oncology Practice*, on-line June 2017.

American Academy of pediatrics, "Policy Statement – Children as Hematopoietic Stem Cell Donors," *Pediatrics*, Vol. 125(2), 2010, pp. 392-404.

cedures

Due: Chart note 2 from cases from week 10

Week 12 (November 14): Full Discussion of Jonsen, Siegler, Winslade
(Migdal)

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

Week 13 (November 21) Student Presentations on Position Papers
(Migdal)

In class discussion of a topic of interest to each student. Please select a topic and prepare a "Big Question" from one of the areas of interest in the Jonsen, Siegler, and Winslade text. You should be able to lead ~10 minute discussion about this topic that explores your Big Question in-depth. Consider if you would like to show a video or other information to add to the discussion.

Week 14 (December 6) Student Presentations on Position Papers

DUE: Position Paper 2 based on a topic from week 8 - 12

GRADING

1. Students will write up a two/three-page reflection after attending an activity sponsored by the Center for Medical Humanities, Compassionate Care and Bioethics such as a Schwartz Rounds, a Center Grand Rounds or Ethics Committee meeting. Dates will be made available in class. **The reflection is due one week after the meeting or lecture**, after that the assignment will not be accepted. (10%)
 - a. Institutional Ethics Committee (IEC) held every 3rd Wednesday of the month, (confidentiality form needs to be completed prior to attending meeting). Email me if interested in attending
 - b. Grand Rounds Tuesday October 22: Vincent de Luise, MD – *Slow Looking: Art and Observation in the Toolkit of Clinical Diagnosis Skills*
 - c. Other lectures to be announced as available
2. Students will be asked to turn in **2** ethics chart notes following a specific template that we will discuss early in the course. Each chart note will be worth 15 points (30%).
3. Students will lead an in-class ~10 minute discussion of a topic of interest from the *Clinical Ethics* text. (10%)
4. Students will turn in two 5-page “position” papers on any topic covered in the course, drawing only on assigned readings from a single week. The topic for Position Paper #1 will be chosen from lectures 1-7 and from lectures 8-12 for Position Paper #2. Students should select a topic from the week that engages them. The first paragraph should begin with a relevant Big Question, followed by some explanation of why the question is important. The second paragraph should pose an answer (thesis) to the Big Question that takes a clear position, followed by some explanation of how you will elaborate on it in the main body of the paper. The main body of the paper should begin with a section that develops your thesis, and one that takes on any arguments against it and rebuts them. The final section should be a conclusion that points toward a further question that you will not address at this time. So:

BIG QUESTION and significance
THESIS (ANSWER) and how you will proceed
THESIS DEVELOPMENT
COUNTERPOSITIONS AND THEIR REBUTTAL
CONCLUSION

You do not need to go beyond the assigned readings, and any weekly topic of the course will do. Re-read the readings for the week, think about some question that floats your boat, and try to respond to it in depth.

Each will contribute 15% of their grade. (30%)

5. In class presentation of one of your positions based on either the first or second position paper. (5%)
6. The remaining 15% will be class attendance, assigned readings and participation. It is important to be an active and vocal contributor to discussion.

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