Morality & Ethics - Fisher

- 3 Branches of Ethical Theory:
    - **Meta-ethics:** (Meta=Beyond) identification, explanation, critical evaluation of morality as a concept
        - I.e. is there a god, are there moral facts?
    - **Normative ethics**: statements often in the form of principles or rules
        - 1. **Consequentialism**
            - John Stuart Mill, based on the consequences of the action, we must weigh the outcome
                - **Utilitarianism (Mill, Bentham)**
                    - "Actions are right in proportion as they tend to promote happiness, wrong as they tend to produce the reverse of happiness. By happiness is intended pleasure, and the absence of pain."
                    - Many accept because theory is impartial but has does not take the minority into account
                        - **Act Utilitarianism**
                            - Each case evaluated via the principle of utility
                        - **Rule Utilitarianism**
                            - Find the general rules that will promote the most happiness in society
                                - Rule of thumb when it is impossible to go through the full calculation
                        - RU collapses into AU as rules should be broken when the outcomes are better
        - 2. **Deontology** (non-consequentialism)

- Immanuel Kant, based on duty, we ought to do this because it is the right thing to do
    - We don't see eye to eye because we mistakenly let reason fall under influences such as emotion or error
    - Moistic approaches: single universal principal
    - Pluralistic approaches: several equally basic principals
- **Categorical imperative:** a binding, unconditional, or moral requirement
    - **CI1 Law of Nature Formula:** Act in such a way that you can at the same time desire that the principal of your action to become a universal law of nature
        - I.e. should I lie? This very practice of believing each other would disappear if lying became the universal law, thus lying is wrong
    - **CI2 Practical Imperative Formula:** Act so that you treat humanity, whether in yourself or in another, as an end and never a means, "treat other humans as ends in themselves, and never merely as means"
        - Lying is wrong as we would be treating people as a way to get things rather than an end
    - **Perfect Duty**: one we must always do
    - **Imperfect duty:** one we have to do some of the time, "beneficence" (helping others) is an imperfect duty, because its opposite could be a universal law but it could not be desired as a universal law
    - Too strict as sometimes we must lie, or not keep promises
- **Hypothetical Imperative:** if you want to Y, then you must do X

        - **Prima Facie Duties, Pluralistic Deontology:** WD Ross, believed ethics is a set of prima facie duties (duties that are binding unless they are overridden by some other important considerations), the most pressing duties need to be respected
            - Duties are: fidelity, reparation, gratitude, justice, beneficence (helping others), self-improvement, nonmaleficence (not harming others)
    - 3. **Virtue theory**
        - Aristotle, based on what figuring out what kind of person one should be, to discover highest virtues or character traits (honesty must be cultivated whereas vanity should be avoided
        - We become virtuous by developing stable character traits
        - A virtuous health-care professional is surely one that we would most "trust" as they are not trying to calculate some formula
    - 4. **Ethics of Care**
        - Feminist roots (Carol Gilligan, Nel Noddings, Susan Sherwin, Eva Feder Kittay, Virginia Held), points to ways the other theries are seen through a masculine view
        - Argues that the other theories are not a fair, or inclusive, way of understanding
        - We must see the world through moral categories of care or relationships, we owe our mother a different level of duty than a stranger
- **Applied (practical) Ethics**: the study of the theoretical and practical moral issues involved in specific contexts, Tackles controversial or urgent questions such as business, environmental, biomedical
    - Do animals have rights?, what obligation does a company have to its employees?

- Ethics and law don't work together, breaking moral rules don't equate to crimes
- Ethics and religion, appealing to authority

- We can not insist that there is one way of seeing the world, thus no one moral code is correct

- Meta ethical positions
    - **Ethical Subjectivism**: commitment to protecting the integrity of an individual's right for autonomy
        - Ties into autonomy
        - There are “no moral facts’ in the universe, no reason is needed
        - X is wrong means I disapprove of X to a subjectivist, your opinion can be right if it is honesty
        - Ties right and wrong to an “opinion”
        - Just because we don’t have a scientific or mathematical proof does not mean that we must accept subjectivism
            - Fails to allow genuine debate and the role of reason in evaluation
    - **Ethical Relativism:**
        - Ethical statements are true or false but only relative to the speaker’s culture
        - We must use culture to choose what is correct i.e. if my cuture says abortion is wrong, then it is wrong and thus my opinion is right or wrong based off that
        - Conforming our behavior
        - I.e. if slavery is acceptable to a specific culture, a relativist would say that relative to this culture, slavery is not wrong.
        - We can never be fully excluded from all cultures, thus there can’t be an unbiased moral code relative to culture
            - Women voting is simply a change in the culture and oppression doesn’t exist within this realm
            - Two cultures can have a respect for life but view abortion differently
            - Reminds us that we are the products of our environments

        - Fails to allow for moral judgement between groups, fails to account for progress and customs may mask shared values

- **Objectivism:**
    - It doesn't matter what your beliefs are, X is objectively wrong
    - Sure, it was allowed to own slaves then but *what about now?*
    - UDHR is based off objective guidelines for human rights
    - There are some moral standards to which all people should be held to the "right" ethical code has yet to be established
- **Soft Objectivism?:**
    - Commitment to ongoing meaningful discussion of morality, the recognition that reasons can be given for comparisons between cultures or time and an open attitude that respects differences and that final answers may not be found

Principles of Biomedical ethics:

1. **Respect for autonomy**
2. **Beneficence**
3. **Nonmaleficence**
4. **Justice**

Codes

- **The Hippocratic Oath**
    - "Above all, do no harm"
    - Modernised in 1964 by Louis Lasagna

Principles of Biomedical Ethics:

1. **Principal of Autonomy and Respect for Persons:** "persons ought to be able to determine their own destiny, so long as they do not do so at the cost of others"
2. **Principle of Nonmaleficence:** do no harm upon others, "prima facie duty to prevent harm to others, but not at the risk of significant harm to myself"
3. **Principle of Beneficence**: advance the good of others if it is possible to do so without undue risk to oneself "beneficence is not required in each possible occurrence, and it remains a prima facie duty that can be overwritten by other competing concerns."
4. **Principle of Justice/Equality:** All persons, insofar as they are persons, are equal and should be treated the same

Paternalism:

- Pater: latin for father, refers to decision making and autonomy in regards to beneficently
- Doctor takes the father role
- Contradicts patient autonomy
- "The intentional overriding of one person's preferences or actions by another person, where the person who overrides justifies this action by appeal to the goal of benefiting or of preventing or mitigating harm to the person whose preferences or actions are overridden" Beauchamp and Childress
    - **Soft Paternalism**: avoid harm that might arise from substantially non-voluntary action (action that arises due to causes that undermine the person's autonomy)
    - **Hard Paternalism:** suspension of autonomy in order to prevent harm or in order to benefit a patient even though the risky behavior or decision is indeed a result of informed, voluntary, and autonomous deliberation
        - I.e. 1. A patient is at risk of a significant, preventable harm. 2. The paternalistic action will probably prevent the harm. 3. The projected benefits to the patient of the paternalistic action outweigh its risks to the patient. 4. There is no reasonable alternative to the

limitation of autonomy. 5. The least autonomy-restrictive alternative that will secure the benefits and reduce the risks is adopted. [6.] … a paternalistic action would not damage substantial autonomy interests.

Morally Relevant Characteristics of HCP-Patient Relationship

- Medical care monopoly
- Physician has highly technical expertise
- Patient often in distress
- Patient claims rights, Physician recognizes obligations
- Exchange of Information shapes the course of decision making

- **HCP-Patient Models**
  - **The Paternalistic Model**
    - Physician holds final decision making power
    - Making decision for the patient rather than with
  - **The Agency Model**
    - Physician acts as a "Technical Consultant", Patient makes decisions
    - Too much authority given to patient rather than HCP
  - **The Contractual Model**
    - Contract entered into freely by both parties
    - Limited to the terms that are agreed upon, only providing care within those confines
    - Pull between what they can do and what they feel obligated to do
  - **The Friendship Model**
    - HCP acts as a friend, even arguing with them
    - Patient ultimately has the choice
    - Are friends too invested?
  - **The Fiduciary Model**

- Relationship of trust, for honest communication and belief that the HCP is working towards the best interest of the patient
- Autonomy of patient is key

Autonomy

- Auto = self, nomos= governance
  - Liberty: freedom from external limitations
  - Agency: ability to perform intentional actions
- Autonomous Action
  - Intentional, performed with understanding, free of external influence
- Respect for Autonomy
  - Rational, mentally mature individual's right to make decisions regarding his or her own life obligates HCP to allow patients to direct their own care
- Competence
  - Going beyond any minimal form of autonomy and asking about the quality of the decision making process, arriving at the decision
  - Surrogate decision makers can step in

Unit 2

- **Informed Consent**
  1. Disclosure: the patient must receive thorough disclosure of relevant information.
  2. Comprehension: the patient must understand the information being given.
  3. Voluntariness: the patient must not be coerced into giving consent or refusing treatment.
  4. Competence: the patient must be competent to consent or refuse treatment.
  5. Consent: the patient must actively give consent or refuse treatment.

- • Ethics of Care // Relational Ethics ideal vs. practice in obtaining informed consent... • assumptions about the patient in the "informed consent" approach are not necessarily neutral... and many patients do not fit the "paradigm" rational adult male deciding base-upon individualistic goals. • socialization and the influence of internalized oppression... • Relational "alternative" and the requirements for broad social change...

Competency

- Ability to perform a task, can be incompetant in a situation but not overall

- **Standards of competence (Allen Buchanan, Dan Brock)**
    a. Minimal standard of competence (focus on autonomy, more subjective)
    b. Outcome standard of competence (focus on beneficence, more objective)
    c. Process standard of decision-making competence (balancing autonomy and beneficence)
    - Expected benefit/harm assessment changes the required level of competence
        - Accepting a benefitting procedure requires minimal competence
        - Refusing a benefitting procedure requires maximal competence
            - HCP needs to assess whether the decision is well-made or not, Soft-Paternalism

Involving Children in Medical Decisions (Christine Harrison, et al)

- Children have different levels of voluntariness, abilities, psychological capacities
    - Competent adults can even refuse life-saving treatment
        - Typically the developing capacities:
            - Infants and young children (no capacity)
            - Primary school children (capacity to assent)
            - Teens (sometimes reaching full capacity to consent)
    - Informed Consent
        - Physician has duty to disclose all information
            - General questions to keep in mind:

- 1. Is the patient competent? 2. Is the consent voluntary? 3. Has the relevant information been proper disclosed? 4. Has the recommendation been clearly and neutrally presented? 5. Has the patient fully understood the recommendation, the information, and the related risks/benefits?

- **Faden & Beauchamp "The Concept of Informed Consent"**
    - Sense-1: Autonomous authorization (individual)
        - informed consent requires that the individual understands the situation and authorizes the physician to proceed.
        - "Informed consent in sense-1 is given if a patient or subject with (i) substantial understanding and (ii) in substantial absence of control by others (iii) intentionally (iv) authorizes a HCP to perform procedure X" (44).
    - Sense-2" Social practice (viewed by institution/practice)
        - consent will be considered "effective," or "valid," not because of autonomous authorization, but because it has been "obtained through procedures that satisfy the rules and requirements" set out by the policies or institutional practices
        - Sense-2 informed consent is "effective" or "valid" when a consent has been obtained through procedures that are the accepted policies or institutional practices (45).

Limits to autonomy

- One must take the HCP into account, i.e. racism towards the HCP
- **Ruth Macklin "Ethical Relativism in a multicultural Society"**

        - We must take culture into account and HPC should explicitly ask patients how information should be distributed (i.e. family involvement) as a respect for patient's rights (66)
            - Eg. scattering a toxic compound to ward off bad spirits
                - Intervention may be seen as imposing values but "public education and extensive efforts at gaining an understanding within the community being regulated need to be of the highest priority"
        - We must avoid deciding for the patient as it will result in paternalism
    - Intolerance (practices are refused due to lack or respect) vs Overtolorance (HCP allows a custom to override patient autonomy)
        - Only accommodate when a practice or request poses no threat to others
- **Hardwig "What About The Family"?**
    - "to what extent can the patient's family legitimately be asked or required to sacrifice their interests so that the patient can have the treatment he or she wants" (73).
        - Patient autonomy may fail to take other aspects (emotional, psychological, financial, social) on the family (family as people who are close to the patient)
            - I.e. patient wants drug A (90% effective) vs B (605 effective) even though the family can't afford it, puts the rest of the family in danger
            - Hardwig wants to find "What is best for all concerned" (75)
            - "The right course of action for me to take will not always be the one that promotes my interests" (77)
            - patient autonomy should be understood as the practice of a "responsible use of freedom, not simply the right to choose the treatment one wants" (78)

Case Study : Navajo

- Western Bioethics and Navajo patients believe in life and health but differ on beliefs about world

    - Navajo patients believe talking about what bad can happen, will make the bad happen
    - How can a HCP respect informed consent? Removes the informed part (69)
- This is to say, ethical principles need to be flexible
- "Macklin concludes that cultural sensitivity is important, but not to the extent that all cultural beliefs and rituals must be allowed and supported"
    - where no good reasons can be given, such as for procedures that "are manifestly harmful and have no compensating benefits except for the cultural belief that they are beneficial" can be rejected while still remaining open to being sensitive to cultural diversity
    - "Anything goes" is as bad as hard paternalism, try to find middle between autonomy and beneficence

Privacy and truth

- Right to privacy
    - A right to the access and viewing and touching intimate aspects of their bodies
    - The revelation of intimate, personal information according to their own discretion
        - Confidentiality is not absolute as safety exists lol
- Fisher, forms of Privacy
    - Bodily privacy
    - Information privacy
    - Communication privacy
        - Patients need to have control over the disclosure of their diagnosis
- Technology makes privacy less secure as privacy is being shared everywhere
    - Is confidentiality outdated?
- Mark Siegler
    - Believes confidentiality traditionally does not exist
        - Studied a case of a man in hospital, 25-100 have access to his chart

        - But the best medical care requires this
        - Better care might be at the expense of the diminishment of confidentiality
            - Suggests “need to know” protocol as confidentiality is evolving
            - Patients more worried about other non HCP finding out things
- Mack Lipkin
    - When can truth telling be suspended?
        - Fragile patients, non competent patients,
- David Tomasma
    - Soft paternalism, we must tell the truth
        - Telling the truth is default but facts are secondary
        - But if the patient is not in a good rational state, we must protect the from harm (119)

Health

- Health and diseases as social constructs
    - Homosecuality was considered a disease until the 1970s
    - Something that is normal in one place isn’t always in other places
    - Health relates to wellbeing
- “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” (WHO)

Allocation and the Right to Health Care in Canada and Beyond

- Allocation: distribution of resources when there is some limited set of resources and various alternative or competing ways they could be allocated
    - Macroallocation
    - Mesoallocation
    - Microallocation
- The right to healthcare - Allen Buchanan

    - Everyone has a right to a decent minimum of healthcare but what is decent?
    - Medicare only became a reality in 1984
- Canada Health Act

    (1) **public administration**, in that the system be run by public officials and on a non-profit basis

    (2) **comprehensiveness**, in that all necessary services be provided

    (3) **universality**, in that all residents are entitled to equal coverage

    (4) **portability**, in that residents moving within Canada or traveling within our outside of Canada remain entitled to coverage

    (5) **accessibility**, in that all insured persons have reasonable access to necessary services.
- Pat Armstrong -Managing Care the Canadian Way
    - "Managed care"
        - Competition, financial incentives, new strategies used to cut cost
    - Believes canada has developed an equitable system
- Edmund Pellegrino - The Commodification of Medical and Health Care
    - Is healthcare a commodity?
        - Healers or money makers
        - Argues that economic incentives are encouraging students
        - Believes healthcare is NOT a commodity and that commodification is bad
- Fisher - Microallocation
    - Limits to medication, hospital beds, etc
    - HCP need to make allocation decisions based on needs and costs or organs (extreme) but are not always black and white
    - We can not easily ration

Unit 3

Abortion

- "Deliberate and intentional termination of a human pregnancy resulting in the death of the fetus"
    - Important debate, even in Hippocratic Oath
        - St Thomas Aquinas and Saint Augustine idetified a difference between early and late abortions
            - Abortion can not occur in unformed body (prior to sensation or mental activity) so early= not murder
                - Contemporary catholic views believe it begins at conception
                - Other religions are less strict
- Legal status of abortion
    - Abortion is not "illegal" in canada
        - Some argue a fetus is a living being
            - We must as what is a person?
    - Canada had a law against abortion in 1892,
    - changed in late 1969 (Trudeau) to reasons not health related
    - 1988 law decides it violates women's rights
        - Supreme Court decides legal status of personhood only is granted at birth
- What is the moral status of the fetus?
    - Debate is framed as s competition of rights (woman vs baby)
- Why Abortion is Immoral - Don Marquis
    - Argues abortion is in the same moral category as murder because of the Loss Of Future, would only allow rare cases
- On The Moral and Legal Status of Abortion - Mary Anne Warren
    - How should we define the moral community, the set of beings with full and equal moral rights?

        - Opposite from above, all biologically human entities should be accorded human rights, and that all "potentially" human beings in the sense of "full persons" should be accorded human rights **we need to know what personhood means**
        - **Argues personhood exists after the moment of birth, you can lose personhood by losing the characteristics**
        - Characteristics of a "person"
            - Conscious, reasoning, self-motivated action, communication, self-awareness
- A Defense of Abortion - Judith Jarvis Thomson
    - Believes personhood is probably before birth but it does not always outweigh right to bodily integrity
        - Is it your duty ?
        - **Even if the right to life is acknowledged, the right to one's bodily integrity is not necessarily overridden**
    - Positive and negative rights
        - Right to life is a negative right
    - Moral Decency
        - One hour of pain vs one month, we must be able to say you have a duty to save a life without saying you owe them that
- Virtue Ethics and Abortion - Rosalind Hursthouse
    - argues that Virtue Ethics does offer plenty of action-guiding principles and it doesn't assume that solving ethical dilemmas should be as simple as applying a straightforward principle or doing a simple calculation
        - We must know the context of Abortion
        - Each situation needs to be evaluated

        - "is this abortion in these circumstances for this woman and her decision-making partners (father, family, etc.) a virtuous, a vicious, or a neutral action"?

- Abortion Through a Feminist Ethics Lense - Susan Sherwin
    - We should not mistake feminist and liberal as the same thing
        - Liberals focus on justice, feminist focus on rights (they can have the same views)
    - Will focus on the safety of women, analysis begins by assuming women take the decision seriously
    - Abortion is essential if there is no escape from the economical and social opression
    - Believes it is a case by case, the woman must be able to decide for herself
- Enforced treatment (eg. if the mom is harmful in her behavior)
    - Slippery slope of control, people will be scared of imposed treatment, is a question of autonomy

Euthanasia, Futility, and the Double-Effect

- Eu (well/good) +thanatos (death)
    - euthanasia: an intentional killing, either through act or omission, for the good (or supposed good) of the patient
    - physician assisted suicide: a killing enacted by the patient herself or himself via means provided by a physician, such as a prescription for a lethal dose of drug
- Suicide is not a crime but helping someone is
    - Sue Rodriguez
        - ALS, wanted assistance to end her unbearable life, SC said no
        - Gloria Taylor, argued law is unjust, won
            - Disrupted how to interpret charter of rights, Federal gov, when to court, own in overturning the case until a law changes
            - Quebec Dying with Dignity wants to pass law to facilitate euthanasia
    - Question of autonomy,

- Fear for the manipulation of vulnerable patients, slippery slope
    - We must assess the slipperiness, that the slope may have dangerous consequences

- Medical Futility(pointlessness, not objective) - Mark R Wicclair
    1. Physiological futility
        a. If there is no “reasonable chance” something will reach its goal
    2. Patient Goal Futility
        a. If a procedure has no chance is reaching the patient's goals
    3. Professional Standards
        a. Physician has responsibilities (i.e. ensure proper use of resources)

- Medical Ethics and Double Effect: Terminal Sedation - Joseph M Boyle
    - Terminal sedation: active euthinasia
        - Doctrine of double effect
            - Actions have more than one effect, the “actor” can intend one outcome but accept the side effects - dates back to Thomas Aquinas
                - I.e. you intend to save your life but the side effect is killing the attacker
                - Requires accepted side effects to not be wanted, thus does not justifu euthanasia
        - Is There a Right to Die - Leon Kass
            - Argues against the notion of the right to die as it is problematic and groundless, may require others to act in specific ways (not interfering or actively helping)
            - A right to die is incoherent since we all die regardless
        - Is There a Duty to Die? - John Hardwig

- Medicine enables us to outlive out illnesses past what we can even know to do with ourselves, do we want quantity or quality of life?
    - Illness can destroy out humanhood and the people around us
- We sometimes feel a technological imperative
    - That is to say , If we have the technology we should use it
    - He argues that just because we can keep people alive, does not mean we always should
- Our lives are interwoven with those whom we are close
    - We need to evaluate burden past ourselves
        - I.e. 55 yr old taking care of sick 89 yr old mother, goes with aggressive treatment to have her live 2 more years but loses savings, home, career
        - Sometimes death is not the largest burden
    - If there is a duty to die, it is contextual
        - Larger burden/older patient/fuller life/greater illness greater duty to die

Killing and Letting Die, Slippery Slopes, More Options as Harms, and Considerations of Oppression

- Voluntary Active Euthanasia - Dan Brock
    - This sensationalized coverage can distract from the detail and nuance in this debate...
    - voluntary active euthanasia vs physician assisted suicide (voluntary)
        - Is there a moral difference?
    - The principle of autonomy and self-determination
        - This extends to deciding the manner and timing of death (life becoming a burden vs ex. depression)
    - The principle of beneficence

- Promotes the patient's well-being if their life is a burden
- If the physician is not willing, the patient should be transferred

- Voluntary Active - Dan Brock
  - 1) euthanasia is wrong in all cases despite prima facie values of self-determination and well-being;
  - 2) euthanasia is wrong because of the broader consequences of permitting the practice
    - Is euthanasia murder?
      - Brock rejects the argument as he says there is no moral difference between killing and allowing to die
    - Is the role of a physician a healer or killer?
      - A murder is wrong because fo the removal of a valued future, but this isn't the case with euthinasia
      - A slippery slope
- Against the right to die - J. David Velleman
  - moral entitlement to being allowed or helped to die is mistakenly sought in the notion of "autonomy."
  - Argues this comes from benevolence, you are ending their suffering
  - A "right to die" would give patients the option
    - Believes allowing the patient to choose should be avoided and that the decision be placed on qualified people
    - Believes more options, more danger
  - Believes it will deny them the possibility of staying alive by default
    - The vulnerable patient has now another burden, the burden of justifying their own continued existence

        - entitlement to die, should come from the physician through beneficence... not autonomy

- Active and Passive euthanasia - James rachels
    - Letting die but not killing vs “killing”
        - Ending treatment results in worse suffering
        - Passive euthanasia can be cruel
            - no moral difference between killing and letting die
- When Self-determination runs amok - Daniel Callahan
    - Argues that euthanasia would be require a great change of moral values
    - Argues that euthanasia would require a shift from the healing priority of medicine
- Gender, Feminism, and Death - Susan Wolf
    - Every patient is socially and culturally situated, but the euthanasia debate talks in abstract terms, as if the patient in question has no geneder, race, or class... • these factors are essential to recognize, since euthanasia is a contextualized and incredibly serious decision... • key cases very often involve female patients... • might gender shape how patients might respond to the option of euthanasia. Are women more vulnerable to “self-sacrifice”?Are women more likely to feel devalued/a burden when they fall ill? • “we had better determine whether tacit assumptions about gender are influencing the enthusiasm for legalization [of physician assisted suicide and euthanasia]” (227-228).

The Dark History of Genetics and Contemporary Issues in Genetic research

- Medical experimentation “Trial-by-error”
- Nuremberg Code became the Declaration of Helsinki
    - Came from looking into the unethical practices and experiments
- Medical research questions

- Is informed consent always necessary, and what counts as informed consent? Is the experiment genuinely necessary, and by what criteria? • What is to be done when scientific method requires one thing, but ethics demands something else? • Should subjects be paid for their participation, or does this result in a form of coercion with regard to economically underprivileged potential research subjects? • What about oppressed groups, children, or persons with diminished capacity? • Can researchers deny access to an experimental treatment that might help a patient when that patient does not fit the "enrollment criteria"? • If the funding for the research is external, will this unconsciously bias the results or lead to mistreatment of patients?

- Medical research
    - Double blind: subjects and researchers are not given information until the experiment is over
    - Placebo-control group
        - Necessary so they are not compromised experiments
    - Gregory Pence - The Tuskegee Study
        - US health service study on the "Untreated course" of Syphilis
            - Participants freely entered the study, but were not given the choice to quit when a cure became available, nor were they even informed of the possibility of venereal and congenital transmission of syphilis
            - Pence: that the experimenters in Tuskegee "regarded their subjects as less than human," and this influenced the continuation of the study past 1947
    - Colin A Ross "Dr. Ewen Cameron"
        - Cameron developed brainwashing techniques without informed consent
            - At the time, the brainwashing and re-programing possibilities were actually hailed not as torture, but as a great step forward for psychiatry

        - Clearly violated Nuremberg Code and the Helsinki Declaration
            - Funding from CIA
- Arthur Schafer - Biomedical Conflict of Interest
    - Nancy Olivieri and David Healy revealed unfavorable results and potential dangers to patients related to the drugs being tested
        - Later found that the funding for studies came from the drug companies
        - Physicians who spoke out were fired or discredited
- Steven Lewis et al "Dancing with the Porcupine: Rules for Governing the University Industry Relationship"
    - Analogy of dancing with a porcupine and how dangerous it is
        - Universities must be careful in accepting invitations from drug companies as the motivations of pharma vs academics is very different
            - University has a goal of furthering education while pharma wants to create profits
                - The goals may conflict but both must stick to their fundamental goals, resulting in conflict
        - Rules needed to protect: public interest, academic freedom, and patient safety
        - sometimes this influence leads universities or individuals away from the university's mission (truth and safety) • intimidation, altered or suspended regulations, and shifts in researcher behaviour, and a "positive skew?"

Unit 10

Research without Consent: Children and Incompetent Research Subjects

- Therapeutic: persons are both patients (being treated for disease X) and research subjects (enrolled in a trial testing disease X)

    - both patient and humanity in general stand to benefit...

- Non-Therapeutic: persons are otherwise healthy
    - benefit of research only to “humanity in general” • different burden of justification, and different levels of requirements to count as informed consent...