Extensive and detailed notes have been typed out and placed in the notes section of the PowerPoints for Chapters 4 and 6 (most extensively for Chapter 4 but also sufficiently long for Chapter 6); please be sure to check them all out!

Midterm 2 Material

[Chapter 3 – The Birth of Bioethics]

[The Emergent Patient Consciousness]

- Doctor's Group published the momentous book "*Our Bodies, Ourselves"*
    - Validated women's embodied experiences as a resource for challenging medical dogmas (principles that people believed were true) about women's bodies; strategy for personal and collective empowerment
    - In a rather conflicting time in the USA, the 1960s was a time where weaker and minority groups demanded more equality and individual rights – particularly in healthcare
        - Began the uprising for patient autonomy and rejection of medical paternalism (authority always restricting the subordinate's freedom for their best interest)

[Bioethics across Cultures – ""The Sanitary Revolution"]

- What many regard as the most important medical milestone: providing clean water and sewages disposal; but millions of people worldwide this was not the case in the 19th century
    - **Edwin Chadwick** the lawyer introduced piped water to people's homes and rinsed sewers
    - **John Snow** the doctor discovered cholera was spread by water, cholera now rare in developed countries
    - **Joseph Bazalgetteto** established the provision of municipal sanitation
- **1.5 million** deaths in 2001 accounted for by unsafe water, sanitation, and poor hygiene
    - Incidence of cholera 16 600 times greater in Africa than Latin America
- Is there a moral responsibility for ensuring everyone around the world has the basic rights for water and sanitation? (Kant – universal)
    - Developed countries like USA prioritize their own development first.

[The New Frontier of Medicine]

Technology and Treatments

- Invention **of kidney dialysis machine** (1945) and shunt (1962) made it possible for patients suffering from chronic kidney disease to receive ongoing hemodialysis treatments
- **Heart – lung machine** (1953)
- Issue: *Is death better than being supported by a machine?*
- First human kidney and heart transplants performed
    - *Was modern medicine selling false hope? When does life end? Does quantity of quality of life matter more?*
- Religious and medical tradition was that death equated to when blood stopped circulating – taking out a heart violated this

→ Advances in Reproductive Technologies

1. **Amniocentesis:** process of removing a pregnant woman's uterus a sample of amniotic fluid; analyzed for genetic defects – *should abnormal fetuses be ended or carried to term?*

2. In Vitro Fertilization: fertilizing egg outside womb and then transferring to uterus. *If human beings exist from or at conception, is it proper to destroy fertilized eggs? Does this equate to murder?*

3. Surrogacy: Woman carries pregnancy and gives birth to a baby for another woman.

4. Cloning: Making genetically identical copies of a cell or individual. Healthy superior gene pools vs the question 'is a clone a human, could it be bred for parts, impact on traditional Judeo-Christian understanding of the link between personal union and procreation in marriage?"

→ Scientific Research

- **Positive**
  - Extended knowledge base
- **Negative**
  - Involved too much non-consensual experimentation on vulnerable populations
  - Refer to **Tuskegee Study** on slide 4 and page 69.

*Overall, what defined life; what defined parenting, the responsibilities of researchers and their methods and goals were all new issues (in the early- mid 20th century)

[Globalization of Clinical Research]

- The poor, under informed, and/or powerless were the subjects of many clinical trials as pharmaceutical companies tried to make medical advances
- Many experiments conducted in India, Latin America, and Africa
- Americans don't want to take placebos but plenty of test subjects in underdeveloped countries do; however, they receive little medical attention
- The drug being evaluated wasn't even readily available in the country tested for after the drug is approved

[Challenges: Birth and Death] – Refer to Slide

[The Pioneers and their Mind-Set]

The Theologians

- **Were students of the nature of God and religious truth**; took interest in the new technologies implications for understanding fundamental matters as human nature and destiny, value of life, meaning of illness and suffering
- Differed themselves in many ways of how the thought of an issue
  - **Catholic theologians** draw on centuries of theory and explicit teaching about reproduction, end-of-life and other issues
  - **Protestant** thinkers favoured Enlightenment liberty of individual conscience in the interpretation of moral doctrine and conduct
  - **Neo-orthodox theologians** depicted a transcendent God working through humanity to establish justice on Earth

The Philosophers

- Reason rather than faith as basis of morality
- **Hans Jonas:** 1967 essay "Philosophic Reflections on Experimenting with Human Subjects" anticipated moral implications of biomedical research
- **Daniel Callahan:** helped establish bioethics as an academic discipline, why we have this course, nice. Founded The Hastings Center, an internationally acclaimed institute for bioethics.

Points of Difference

- Both share an interest in first principles and reality.
    - **Theologians** trust in faith and a fixed universal truth; found their final truth. Divine.
    - **Philosophers** trust in reason and only what can be rationally demonstrated; still looking for truth. Secular.

[Common Ground: Philosophy + Theology]

- Both agreed that the ultimate goal of medicine was health and that medical science is beneficial for life; agreed on the dignity and worth of human beings; therefore, how we treated human subjects was a concern
- Both desired to balance utility and autonomy, shared faith in rationality, and their inheritance of a national religious identity

Utility and Autonomy

- Framed moral dilemmas in terms of risk and benefits; utilitarian fashion to balance risks and benefits while also respecting individual autonomy and rights – giving patients a voice

Faith in Rationality

- Theologians didn't share the philosopher's supreme faith in rationality, but their own traditions recognized its importance and value
- Reasoning together, they could find common morality to frame bioethics for everyone

[The Jeffersonian Compromise]

- Attempt to alleviate the tension between religion and democracy
- Religious liberty was to be protected, but had to be submitted to the scrutiny of common sense and reason. However, it should only be practiced in a church or temple, and kept separate from government and law aka the public square. Was not to be a factor in determining public policy, and if it was – it would be in secular terms
    - Religious contributions and ideas would have to be translated into secular terms acceptable to as much as the public as possible
- Only publicly acceptable reasons would provide the desired conceptual framework of universal appeal

[Belmont Report – 1979] – Slide is good.

Conclusion: the private/public separation was reasonable and necessary. It allowed the founders of bioethics to define common ideals and values that though had religious context; did not favour any one in particular. Privatization allowed everyone to speak the same language and advance the thoughts that came about Post-Enlightenment.

[Chapter 4: The Basic Principles of Bioethics]

[Hippocratic Paternalism]

- Ruled Western medical ethics until 1960s; issue of physician's power arose; choice of medical treatment became the patient's not the physicians
- Belmont Principles: range of patient rights

[Belmont Principles]

Core of *Belmont Report* were three principles – respect for persons, beneficence, and justice. Extensions of two responsibilities:

1) The time-honored primary and overriding duty of physicians to patients

2) The state's responsibility to protect its members

- **Principalism** became the new and dominant method for doing bioethics; autonomy, **nonmaleficence (the 4th)**, beneficence, and justice

[Autonomy]

- Should the social good to which the results of biomedical experimentation contributed overrule the freedom, wishes, and choices of individuals?
    - Autonomy won
- Like Kant believed, autonomy; respect for humans was an ends in itself
- Autonomy came to mean "persons should be free to perform whatever action he wishes – even if it involves serious risk for the agent and even if others consider it to be foolish"
    - Treated children and mentally incompetent paternalistically
- Autonomy was about not just freedom, but protection
    - Acknowledge the freedom of choice of the mentally able patient
    - Protect those with diminished mental ability by acting in their best medical interests
- Aristotle, Aquinas, and Kant believed autonomy was to be directed toward some ultimate good; immorality was the product of misdirected autonomy
- Belmont Report gave guidelines for autonomy with **moral limits**

Moral Limits

- Autonomy was to function as a constraint on certain actions, like medically treating people against their express wishes
    - Person with contagious disease can't refuse therapy
    - The health, welfare, or rights of others are natural limits
- The function of autonomy was to liberate the patient from the oppression of a physician; no forcing life-prolonging technology, withholding bad news or treating with no consent
- Most bioethical questions today are along the lines of putting freedom of choice against the nature of the choice, regarding its social and religious implications

Secular and Religious Appeal

- Principle of autonomy played a vital role in the development of secular ethics and political theory
    - Undermined the theological doctrine about the sacredness of the individual
- Self-govern and self-rule made autonomy the heart of the liberal and democratic state

    - Secular perspective: autonomy is fundamental to democracy
    - Religious perspective: autonomy is fundamental to freedom of conscience and expression

[Nonmaleficence]

- Requires physicians that they not intentionally create a needless harm or injury to the patient by acts of omission or commission
    - Don't harm patients by what you do or don't do
- Related to 2 legal concepts:
    - **Medical negligence**: involves a violation of nonmaleficence that results in serious harm to the patient
    - **Due care**: care or quality of care that a reasonable person would exercise under circumstances

[Beneficence]

"Strive to help." Maximize possible benefits, while minimizing possible harms to patients and the larger society.

- Negative obligation to avoid harm on one end, and positive duty to do good on the other; in the middle is the duty of preventing and eliminating harm
    - First avoid, prevent, then eliminate harm, then comes positive duties to maximize possible benefits and minimize possible harms
    - Doing good by doing happy things; similar to principle of utility
- Mirrored the historical significance of good moral character and technical skill as the criteria of the ideal physician
- Supports acts of kindness that go beyond obligation to erase harm (duty prevails); don't be just a doctor of the body, but a doctor of the mind - aim to alleviate pain and suffering
- Autonomy exists within autonomy by saying autonomy exists in the patient's desire to accept appropriate clinical management

[Justice]

"Who is to get what when there isn't enough for all?" – The basis of questions medical schools may ask during interview.

- Patients should get what they deserve or its unfair, and that patients should be treated equally – in the absence of some criteria like age, merit or distinction – like is treated alike

1) To each person an equal share

2) To each person according to individual need

3) To each person according to individual effort

4) To each person according to societal contribution

5) To each person according to merit

- Today, we have huge concerns regarding *scarcity* and *allocation* which deals with the most efficient distribution of resources, or from an ethical standpoint, the most fair. Allocation problems exist in 2 levels.

L1) Macroallocation: amount that a society should **expend** for medical resources and how it is distributed. Do we spend more on primary care, intensive care units, transplants, etc?

L2) Microallocation: Who will have access to the available resources and how will that be determined? Will the resources be distributed to each patient equally? Or according to some criteria like merit, and position? Questions of resource accessibility.

- Ultimately, macro decisions affect micro-circumstances.

[Transcultural Human Rights] (Page 76 – slide is pretty good)

"The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being."

- Transcultural Nursing Society aiming to make this happen by providing culturally competent nurses and health care providers to people of diverse and similar cultures.

Is this a charity or obligation to meet the world wide crisis in health and health care?

- My thought: it is an obligation – everyone is equal – it is our duty (according to Kant) to act on what is universally accepted. Only because of how few acts of this scale exists, and how rare and sacred it is, do we even consider it charity. We have undermined obligation to the point where supposedly once acts considered strict duty are now considered as charity.

[Conclusion]

- Amongst autonomy, beneficence, nonmaleficence, and justice, autonomy gained priority.
- Patients have the right to define their visions of a good life, and healthcare workers should respect those individual assessments.
- **Principalism** became self-governance, liberty, rights, individual choice, and following one's will. Led to arguments about many topics we deal with today: cloning, abortion, euthanasia, etc.

[Chapter 5 – Applications]

[Canada Health Act, 1984]

Healthcare became a provincial responsibility, and aimed to ensure that all residents of Canada have access to necessary hospital and physician services on a prepaid basis.

- Established uniform level of service – more equal service to all, previously governments didn't quite match up their sources of revenue (fiscal capacity) correctly with their spending (fiscal spending).
- Certain criteria the provinces and territories must meet to be allowed federal transfer payments
- **Healthcare should be based on need, not one's ability to pay.** (In the USA, it'd be more like the other way around)

[East Asian Autonomy]

Autonomy to Asians was family oriented. Was influenced by Confucian tradition. An individual's suffering was the whole fam's suffering. Information was disclosed to all; final authority of medical affairs rests with the family, and not solely the individual.

- Medical information in East Asia is offered to family, and they decide whether to tell the patient.
    - Especially with severe and fatal diagnoses
- The only exception in the West when a patient isn't the only one entitled to all information, choices and actions regarding his illness was when the truth will severely harm the patient or they don't want to know.

[Truth Telling – Autonomy] – more of the physician's duty

If patients had autonomy, they would need to know everything about their medical condition to make their self-proclaimed best choice. For this autonomy to exist, physicians are obligated to be truthful and disclose the necessary information.

- When it isn't advisable to tell the patient, someone appropriate should be informed.
- Deception, refusing to reveal information, evasion, denial or "half-assing" it is common amongst physicians
    - Even when death is inevitable, physicians are falsely optimistic and avoid telling the truth
    - Picture yourself as a physician in this scenario; it is a lot harder for them than it sounds, but they need to do the right thing
        - In one study of 5000 of cases of adults with 6 months to live, only 15% of patients given clear *prognoses* (course of ailment)
        - Patients may have a more painful end of life experience; no chance to see distant loved ones, draft wills, no choice on what medical care to receive
        - Many patient's aren't competent in literacy, or illiterate from 15% in some cases up to 55%
            - 52% more likely to die than those who are literate
- All physicians should assume their patients don't know medical concepts and explain things in a way so they fully comprehend the situation (like lab report write ups that a stranger who knows no chemistry will read; they should be able to understand the experiment and even replicate it)

[Informed Consent – Autonomy]

Means that a patient freely agrees to a medical treatment provided they had a correct understanding of everything involved, particularly risks.

- No consent = Yes prosecution

Did you know in Ontario there is no minimal age of consent? Consent need not even be in writing, even though it is preferred. It can be implied or expressed (obviously that could lead to problems) and it can be withdrawn.

- **To be informed requires deliberation. To give consent requires voluntariness.**

**Good case scenario on slides.*

[Deliberation]

To deliberate, patients need significant, truthful and understandable information. Other than emergencies it involves knowing:

1) The specific procedure/treatment, risks involved, duration of incapacitation

2) Alternatives for treatment

3) Name of the person responsible for procedures and treatment

4) Time to consider choices, and choose deliberately

- *Informed refusal* is when physician does not wish to carry out a treatment, but must inform the patient about it to see their choice
- Refusal of treatment raises issues like sanctity of life versus the quality, and resource usage

[Voluntariness]

Consent is only valid if the patient is not only informed, but it must also be voluntary. Patients must willingly agree or refuse treatment.

- Patient must be competent to make a decision; **competence is key**
    - Anyone at age or majority or above is assumed competent

    Competence

    - There are degrees of competence
    - Incompetence in one area is not always related to incompetence in deciding medical treatment (a does not imply b)
    - Incompetence is easier to determine than competence

If a patient is determined to be incompetent, *substituted judgement* (like next of kin) aka a **surrogate** may be designated to speak on the patient's behalf. If not found, doctors must make what they think is the best decision until a surrogate is found.

[Kinds of Informed Consent] – Slide 8

Physician Based Standard: physicians must inform the patient everything we mentioned above based on what they thought was caring/necessary

- Doesn't happen. Autonomy should be about the patient.

Patient Based Standard: physicians provide all information listed above so patient can make informed choice

- Reliance on the patient based standard may result in the patient being denied the amount of information required to give informed consent

Shared Medical Decision-Making: physician shares all risks and benefits, alternatives, and patient shares all relevant personal information that might make one treatment more preferential; mutual decision is made

- Sounds great; improves autonomy but it is impractical. Puts more strain on physicians, and patients may not even want or understand the information.

[Advance Directives]

- Permits another individual (representative) to make judgement on behalf of a patient who may not be autonomous
- Living wills used by patients to formally declare how they would like their treatment should illness render them incapable of self-representation
    - Tend to be too general, patient's change their mind when actually in deathbed situations; living will only matches up with current wishes 2/3 of time

[Participation in Medical Research]

Consent of human subjects in medical subjects to participate in research must be based on clear understanding of the experiment including risks and benefits.

- Must know that being in a control group = no benefits.
- Even today, the minority, the poor, the politically powerless are test subjects.
- Patients in need of emergency medical treatment may be subjects of experimentation assuming standard treatment is not good enough – issue because it is like taking advantage of those who aren't capable of giving consent even if it turns out beneficial for society

[Privacy and Confidentiality]

Privacy is a right to be let alone – control of information about oneself and who can see it, physically or psychologically.

Confidentiality specifically addresses how participant and patient data will be handled and to whom it is disclosed to.

- The value of privacy itself, has been somewhat forgotten because of how hard we try to control information

Autonomy is impossible without understanding oneself as autonomous and privacy plays a huge role in this. Without privacy, we can't be the most autonomous person we can be, and make decisions from our very core. We are vulnerable without privacy, everything can be scrutinized, manipulated, etc.

Oath of Hippocrates: what I may see or hear in the course of the treatment or even outside the treatment in regard to the life of men I will keep to myself.

- Privacy is at the very root of a sound patient-physician relationship

DNA: The Genetic Footprint

- The greatest threat to our privacy may be others opportunities to learn about our DNA and construct our identities out of it
    - So much information can be derived from DNA: family, diseases, etc
        - If DNA is stored, there is the possibility of unauthorized access to it

***Relate the core principles of the *Belmont Report* to how ethical standards were many decades later. Autonomy overrides physician power. But today as more issues arise, is autonomy enough to justify everything?**

[Chapter 6 – Beyond Principalism I: Autonomy under Attack]

[Feeling betrayed by Principalism]

- The patient may be highly religious/ other factors, and not always know what is best for them.
- In 80's and 90's there has been tort reform, but not so many of these cases anymore; *the principle of autonomy really broke through after the Belmont's Report in 1979 – however law has not caught up.*
    - Usually we follow the patient's autonomy, but the physicians will like to have some autonomy as well – refusing treatment **but** the patients are seen to having more legal rights b/c the healthcare system are supposed to provide an even level of care to the general public.
    - In Canada, after 14, your parents don't have the legal right to your medical records.

[The Critique of Autonomy]

- Autonomy says there is only one value: individual capacity for self-determination; nothing else really matters
    - Social goods, interest of society in general may be interfering with the individual's best interest
- For an individual to be completely autonomous, there needs to be a social structure that helps you that away.
    - Common good is everyone's own defined vision
- In a hospital; you are not autonomous, you are dependent on healthcare system, the nurses and the orderly
- Informed consent is not always the highest and best standard to be followed; sometimes a situation is just a burden.
- Autonomy comes from our bonds and dependencies on others. The person who is ignorant in medicine has the final say. In terms of best help practice; this seems contradictory.
- Now we see the doctor as another part of the service industry
- Utilitarianism only cares about the tangible, sensible results. Produce the best possible world to live in, where sensible life takes place. It will be permissible for them to use placebos.
- Kant (deontology) will not support, CI says that lying is one of the things we should do EVER. If I lie right now, everyone else will lie. Then, my lie isn't a lie anymore, because everything else is a lie now. Doesn't matter what the result is, just follow the right in itself.

[Suggested Offsetting Principles]

- Euthanasia undermines the value of life.
- Challenge autonomy because you believe that another principle is just as important.
- Too much freedom of choice can corrupt the background culture, and detract from a social good.

*Skip offsetting principles.