

Chapter 4: Truth telling and Confidentiality

Definitions

Arguments against full disclosure:

- Truth-telling can be injurious, evoking feelings of panic, hopelessness, fear and depression
 - **Counter:** many exaggerate the harm done by disclosure, underestimating the beneficial effects of truthfulness. They fail to recognize that lying can also cause damage
- Patients do not want to know the truth
 - Data from surveys suggest that most patients do prefer to be told
- Physicians have no duty to tell the truth because patients are incapable of understanding it
 - Even if communicating whole truth is impossible -> have an obligation to try to convey the essential and RELEVANT information
 - Conveying whole truth is unnecessary

Confidentiality: an obligation or pledge of physicians, nurses, and others to keep secret the personal health information of patients unless they consent to disclosure

- Without, physicians wouldn't be fulfilling duty of beneficence
- Without, trust would break
- Prima facie

Right to privacy: the authority of persons to control who may possess and use information about themselves

Readings

'Is it ever okay to lie to patients' by Shelley K. Schwartz

- Believes that trust is sacred in a doc-patient relationship
- Disclosure enables patients to plan -> improves their autonomy
 - Create a will, make wishes known to family, chance to 'life review'
- A case for Compassion ?
 - Most common argument against truth: impact it may have on a patient's physical or emotional state
 - Dana Farber Cancer Institute: found that patients who had end-of-life discussions were more likely to accept their illness and preferred comfort care over life-extending -> helped loved ones get closure
- What's your motive (for doc not to disclose) ?
 - Physician should examine motive for withholding info: compassion, fear of time, avoidance because it's hard to deliver news ?
- Way you deliver it
 - Dixon: learning how to read personalities (refine amount of detail disclosed based on person)
 - Younger patients seek more aggressive options
 - If patient is scared, break down convo or ask to continue next time
 - Give bad news with a positive spin
 - When people are prepared they're not afraid anymore

- a) What are some of the requirements entailed by the physician's duty of truth-telling?
- b) What are some reasons a physician might avoid truth-telling?

'Why privacy is important' by James Rachels

- Argues that “privacy is necessary to maintain social relationship” must have “control over who has access to us in order to control relationship”
- Why is privacy important to us?
 - Necessary to protect interests in competitive situations
 - Embarrassing for others to know
 - Medical records: consequences if they become public knowledge
 - Issue obtaining insurance
 - Application for credit shouldn't be influenced by private info

(The above is not very representative. Not normal situations (more when have something to hide)
- **Normal/Ordinary situations:** nothing embarrassing or shameful in the act and no threat in its disclosure
 - Maintain different sorts of social relationships with different people -> different conceptions of behavior depending on the role (husband, father, businessman, friend) and how appropriate to behave
 - Ability to control who has access to info about us allows us to maintain the variety of relationships
 - Doctor: their business to know health info
 - A fact about ourselves is someone's business if the specific relationship between them entitles them to know
- **Thomson's View:** suggests that the key to understanding right to privacy is to understand that there is nothing special about it
 - Right to privacy is a cluster of rights

- a) What are some other reasons for the importance of privacy?
- b) What role does privacy play in our relationships?

'Ethical Relativism in a multicultural society' by Ruth Macklin

- Investigates moral dilemmas due to clashes between cultural background of physicians/patients
- Macklin concludes: Western physicians should respect non-western cultural/religious beliefs but they shouldn't embrace it if results in detrimental practices
 - **Multiculturalism:** “social-intellectual movement that promotes the value of diversity as a core principle and insists that all cultural groups be treated with respect and as equals”
 - > produces dilemmas
 - Respect for autonomy is consistent with recognizing family's interests

- Culture shouldn't determine disclosure -> patient's wish is important (communicate directly with the physician, leave it to family ?)
 - Study done between elderly from different ethnicities:
(conclusion: physicians should ask patients if they want to receive info and make decisions - or family?
WHICH DOES SUPPORT PATIENT AUTONOMY because you don't assume)
 - Korean and Mexican Americans:
 1. **Less likely to believe that** patient told prognosis
 2. **Less likely to believe that** patient should make decisions
 3. **More likely to have** family-centered attitude
 4. Older subjects/lower socioeconomic status -> tend to oppose truth telling
 - Intolerance of another's beliefs: discourteous/prejudiced but not YET a failure to respect people (unless they deny their rights to exercise autonomy)
 - Belief of subculture: Navajo
 - Refuse negative info
 - It would be justifiable to withhold certain risks if the surgery is necessary and patient would deny it otherwise
 - Their meta-physical belief system = language has power to shape reality
 - Withholding info is ethically acceptable -> **BENEFICENCE and AUTONOMY**
 - **Navajos holding certain belief can act autonomously ONLY when they aren't thinking of negative risks**
 - How to respond when patient acts according to the values of their own country ?
 - Extreme 1: Obligated to follow local ethical practices and not comply with patient's
 - Extreme 2: Cultural sensitivity requires physicians to adhere to patient's beliefs
 - Should understand where the belief comes from before imposing western culture
 - ➔ Commentators:
 1. Worst choice: simply to tolerate the practice or to report them
 2. Doctor should discuss the risks of the practice and offer alternatives
 3. Tolerance ≠ Judgement
 4. Pediatricians have significant obligation: educate parents about their vulnerable patient and **SHOULD NOT CHANGE BASED ON CULTURAL BOUNDARIES**
- a) How could tolerance of the beliefs of other cultures lead physicians to harm patients?
- b) How can tolerance of other cultures cause physicians to violate patient autonomy?

Chapter 5: Informed Consent

Definitions

Competence: the ability to render decisions about medical interventions

Informed Consent: the action of an autonomous, informed person agreeing to submit to medical treatment or experimentation

- Ethical ideal
- Legal requirement
- Conditions of informed consent: DUCAC
 - Competent patient
 - Adequate disclosure given
 - Understands information
 - Decides about treatment voluntarily
 - Consents
- The disclosure
 - Nature of procedure
 - Risks
 - Alternatives (including option of no treatment)
 - Expected benefits of proposed treatment

Therapeutic privilege: the withholding of relevant information from a patient when the physician believes disclosure would likely do harm

Waiver: the patient's voluntary and deliberate giving up of the right to informed consent

Readings

'The concept of informed consent' by Ruth Faden and Tom Beauchamp

- Distinguish two common views and argue that only one reflects the true meaning
 1. Sense 1: Patient's autonomous action that authorizes a course of action (involve them in research or initiate medical plan) **authorized consent**
 - ❖ Given to patient with substantial understanding
 - ❖ In substantial absence of control by others
 - ❖ Intentional informed consent
 - ❖ Authorization to do procedure -> is key to actually giving informed consent
 - Assumes responsibility for what they authorized
 - Transfers to another authority to implement it
 - Needs to understand what they assume responsibility for
 2. Sense 2: Defined legally and doesn't refer to authorization **effective consent**
 - ❖ Policy-oriented based on institutional authorization
 - ❖ Effective because it follows procedure
 - ❖ Rules focusing on disclosure, comprehension, competence
 - ❖ Obtain consent through court's criteria -> does not follow that court's are using the right standards
 3. Relationship between Sense 1 and Sense 2
 - ❖ Sense 1 can fail to be informed consent in "sense 2" by a lack of conformity to specific applicable rules

- Faden and Beauchamp also believed that **informed consent** is confused with **shared decision-making**
 - ❖ Resist Katz's view that physician-patient should share decision-making or reason together -> may do it but only patient/subject AUTHORIZES AUTONOMOUSLY
- a) What is the difference between the first and second sense of informed consent?
- b) What is their criticism of equating informed consent with shared decision-making?

'Transparency: Informed consent in primary care' by Howard Brody

- Brody observes that theory/practice of informed consent are far apart -> legal standards send physicians wrong message
- Thinks that conversation standard (by Jay Katz) sends the right message but probably legally unworkable
 - Absence of any formal rules
 - Designed to encourage patient participation in medical interventions (to the extent that they want to be included)
 - Rely on intuition and communication skills -> doesn't translate to legal standard
 - Very subjective
 - Conversation one participates in ≠ how it's seen by an outsider
 - ➔ Reduced possibility for legal review
 - ➔ Take some of the points of the conversation model to another model
- Proposes "transparency standard" = disclosure is adequate when the physician's basic thinking is transparent to the patient
 - Brody thinks this operationalizes the best features of the conversation model
 - Reasonably informed:
 1. Physician discloses the basis on which the proposed treatment (or alt.) have been chosen
 2. The patient is allowed to ask questions suggested by the disclosure of the physician -> answered based on patient's satisfaction
 3. Disclosure is adequate when the physician's basic thinking has been rendered transparent to the patient (ex: if physician came to conclusion based on assessing risks and benefits then those should be rendered transparent to the patient)
 4. THINK OUT LOUD IN UNDERSTANDABLE LANGUAGE
 - Example: patient suffers harm from rare consequence of surgery and wants to sue
 - Based on transparency model: did physician think seriously consider the risks but failed to reveal it to the patient ? liable
 - Poor job of disclosing information
- Inability to inform patients correctly = lack essential medical skills
- Primary care SHOULD embrace patient autonomy and get informed consent
- Physicians usually document what they say instead of how the patient thought about it

- a) What are Brody's assessments of the 'conversation standard' and 'reasonable patient standard' of informed consent?
- b) What sets the 'transparency standard' apart from the rest?

'Informed consent: Some challenges to the universal validity of the western model' by Robert Levine

- Levine says that: different countries/cultures have different perspectives on the nature of persons thereby implying that it isn't possible to provide a universally applicable definition of informed consent (since informed consent is to show respect for people)
- The Nuremberg Code (4 attributes of consent): voluntary, legally competent, informed, comprehending
- A procedural resolution:
 1. All plans to conduct research (human subjects) should be reviewed and approved by a research ethics committee (REC) = **review/approval of protocol**
 2. Proposal to employ consent procedures that do not conform to the int. Standard -> should be justified by researcher and submitted for review (national level) = **specific modifications that do not conform to the international standard**
 3. Approvals by local ethical review committee = modifications that conform to int. Standard
 4. Externally sponsored research -> ethical review conducted in initiating country with advice to the host country

- a) How are the informed consent standards of the Declaration of Helsinki not universally valid?
- b) How do varying notions of *person* make applying the rules of informed consent problematic?

Chapter 7: Abortion

Definitions

Abortion: the ending of a pregnancy

Induced abortion: the intentional termination of a pregnancy through drugs or surgery

Quickening: at about 16-20 weeks of pregnancy, a pregnant woman's experience of fetal movement inside of her

Spontaneous abortion (miscarriage): an abortion due to natural causes such as a birth defect or maternal injury

Therapeutic abortion: abortion performed to preserve the life or health of the mother

Viability: the development stage when the fetus can survive outside the uterus

Fertilization: a sperm penetrates an egg, forming a single cell = zygote -> continually divides and moves towards uterus -> **blastocyst** (used in stem cell research and is pluripotent = create any type of tissue EXCEPT PLACENTA)

+50% of abortions are by women under 25 years of age

16-20 weeks: quickening

30-40 weeks: breathe on its own

Preterm babies: born <37 weeks (15 million worldwide and 29,000 in Canada)

- **Lung and brain most susceptible to morbidities**
- **When do they feel pain ?** BRCOG said can't before 24 weeks

Roe vs Wade:

- 1st trimester (1-12) : woman's right to end pregnancy cannot be influenced by state
- 2nd trimester (13-26): state may limit but not entirely prohibit
- After viability, state may regulate and even ban abortion except therapeutic

Canadian law doesn't ban abortion

Positions on Abortion:

1. **Conservative:** Abortion is never morally acceptable (except possibly to preserve the mother's life) because the unborn is a human being in the full sense.
2. **Liberal:** Abortion is acceptable whenever the woman wants it because the unborn is not a human being in the full sense.
3. **Moderate:** We must reject both views and take a stance somewhere between them.

All sides tend to accept that murder is wrong, that persons have a right to life, and that personal freedom should not be curtailed except for very important reasons.

Readings

'A defense of abortion' by Judith Thomson

- Argues that some abortions are morally permissible even if fetus as a 'right to life'
- A fetus may have a right to life but it does not guarantee having either a right to be given the use of or a right to be allowed continued use of another person's body- even if one needs it for life itself (violinist analogy)
- A woman has the right not to have her body used by someone else against her will
- Killing a fetus is not always wrong but killing it **unjustly** is always wrong
- **Argument is not centered around personhood**
 - 2 conditions for analogy:
 1. No consent given
 2. You will die if you remain attached for 9 months
- What does a 'right to life' mean ?
 - The right not to be killed by anybody unjustly
 - Bare minimum needed for continued life
 - Doesn't give you the right to use anyone else's body
 - Thomson: out of kindness (Good Samaritan) you can grant them usage
- Main Argument:
 - All persons have a right to life
 - The violinist is a person

- The violinist has a right to life
 - You have a right to your own body
 - Your right to your body is greater than the claim the violinist has to it
 - Unplugging therefore is not morally wrong because you are denying the claim
 - Counter Arguments:
 - Letting the mom die is better than killing an innocent person
 - Thomson: self-defense - It cannot seriously be thought to be murder if the mother performs an abortion on herself to save her life
 - Since mother's cannot safely perform abortions on themselves, third part invoked. Unfair to ask them to choose between mother and unborn child
 - Thomson: The mother OWNS the body. You have a right to say I CANNOT CHOOSE or I WONT ACT. You do not have the right to tell others HOW TO CHOOSE
 - Late-term abortions may be considered 'indecent' to have abortion but not UNJUST
- a) What is the violinist analogy and what point does Thomson make with it?
- b) What is her argument for abortion?

'Why abortion is immoral' by Don Marquis

- Identifies what it is that makes murder wrong, then applies this to the case of abortion
 - **Argument does not center around personhood**
 - Argues that:
 - Murdering someone is wrong because it robs him/her of their future (a loss of possible experiences, activities, projects and enjoyment)
 - Abortion is almost always wrong because it drives the fetus of all prospects of such future being
 - Main Argument 1:
 - The loss of life is one of the greatest losses one can suffer
 - Killing is wrong because it deprives someone of their future
 - Main Argument 2;
 - Fetus still has a future even though it doesn't understand it
 - Wrong to have abortion because we deprive fetus of its future
 - Counter Arguments:
 - The past experience does not determine the value in the future
 - Believes it is wrong to kill someone with no desire to live (unconscious, sleeping)
 - Just because someone doesn't value their life, doesn't mean it doesn't have value
 - Contraception prevents actualization of a possible future of value. No identifiable subject of that loss
- a) For Marquis, why is murder wrong?
- b) What is his argument against abortion and what exceptions does he allow?

Chapter 9: Stem Cells

Definitions

CANADIAN DISCOVERY IN 1960

- What is a stem cell ?
 - ‘Self-renew’ : replicate itself
 - ‘Differentiate’ : create different types of cells
 - Found everywhere
 - 2002 first legislation
 - CAN ONLY GROW TILL DAY 14 of development

Development:

- Growth or specialization of a tissue

Regeneration:






- Repair damaged or dead tissue

Ethical concepts:

- Moral status
- Personhood (individual not necessary human with higher order cog. capacities)
- Intrinsic Value
- Rights
- Sentience (capacity to feel pain/pleasure)

Adult Stem cells:

- Multipotent
 - Ability to differentiate into a limited number of cell types
- Undifferentiated cell found in tissues and organs

	Embryonic	Adult	
	Rapidly dividing	Slow division	
	Unlimited number of divisions	Limited divisions	
	Can differentiate into any tissue of the body (not placenta)	Can differentiate into specific tissues	
	Easy to maintain in culture	Difficult to maintain outside of the body	
	Potential to cure diseases of any organ	Can cure a limited number of diseases	

ES cells: moral standing (personhood, intrinsic value,..)

AS cells: informed consent

iPSC: gene editing

Readings

'What does "respect for embryos" mean in the context of Stem Cell Research?' by Bonnie Steinbock

- Argues that early embryos have less than full moral status
 - They are a form of life and are deserving of respect
- Shouldn't use embryos in frivolous ways
- Respect for embryos doesn't require refraining from research likely to have significant benefits (treating disease and prolonging life)
 - Daniel Callahan:
 - demonstrated that progress in scientific research depends on using human embryos
 - Argues that interests/goals to be accomplished by using embryos in research must be unreachable by other means
 - Richard M. Doerflinger:
 - Suggested that AS cells might be more clinically useful than ES because treatment would be based on patient's own cells (avoids tissue rejection)
 - To demand serious respect for ES cells, demands that other alternatives be explored first (should yield comparable results) -> possible that ES not necessary for therapeutic purposes
 - Unlikely = ES cells can differentiate
 - Conduct both types of research simultaneously
 - Derives from 'right-to-life' position
 - What does respect for embryos require ?
 - **Respect for persons (Kant) : treating them as ends in themselves**
 - We cannot do this with embryos as they do not have ends of their own (cannot be given the respect due to humans)
 - Embryos are potential human beings -> can develop which gives them significance and moral value
 - Respect doesn't require refraining from research that might have benefits
 - ES cells sourced from embryos remaining after infertility treatment (IVF)
 - Moral distinction: generating embryo for the sole purpose of procreation/child vs producing one without a goal other than research
 - If one takes the right-to-life view:
 - it is morally wrong to create embryos and then destroy them
 - Also wrong to create an excess of embryos
- Bonnie Steinbock concludes that in her opinion: it makes no moral difference whether one creates embryos for reproductive purposes then uses it for research VS creating for the sole purpose of research
 - States that respect for embryos is demonstrated by restricting their usage
- The acceptability of the latter based on **moral status of the embryo**
 - **If embryos are people:** moral difference between creating them for rep (benefits embryo) vs research (kills embryo)
 - **If you reject the idea that preimplantation embryos are kinds of beings:** no benefit or harm = no difference (position of the author)

- a) What is the distinction between respect for embryos and respect for persons
- b) How do embryos have a moral value that other bodily tissues lack?

'Declaration on the production and the scientific and therapeutic use of human embryonic stem cells' by Pontifical Academy for Life

- Official statement by Roman Catholic Church:
 - Morally impermissible to produce or use living human embryos to obtain ES cells
 - - - to produce then destroy cloned human embryos to acquire ES cells
 - - - to use ES cells that others have already derived

 - **First ethical problem:** Is it morally licit to produce and/or use living human embryos for the prep of ES cells ? **negative**
 - Believe that union of gametes signifies human identity
 - A **human subject** with a **well defined identity**, which from that point begins its own **coordinated, continuous and gradual development**, not just a mass of cells
 - Human individual has right to life -> every intervention not in favor of the embryo violates the right
 - A good end does not make right an action which in itself is wrong
 - **Second ethical problem:** Is it morally licit to engage in “therapeutic cloning” by producing cloned human embryos and then destroying them in order to obtain ES cells ? **negative**
 - **Third ethical problem:** Is it morally licit to use ES cells which are supplied by other researchers or are commercially obtained ? **negative**
 - AS cells: represent more reasonable and human method for making progress in the field
- a) What are some reasons for rejecting the use of human embryos for ES cells?
 - b) What critique of the use of ES stem cells is offered?
-