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Ethics and Human Rights in Medicine and Medical Research

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Juliette Matijssen & Anouk Nusselder

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What are medical ethics?



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What are medical ethics?

Why do we as future care professionals need medical ethics?

What ethical principles do you know of?

Where are ethical norms derived from?

How do ethics and human rights relate?



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Ethics & Human Rights?



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Ethics, from *ēthos*, "*practice, custom*"

Ethics is about doing the right thing.

Fundamental question: What is right and what is wrong?

Human rights and medical ethics are complementary (why?).

The use of the two together maximizes the protection available to vulnerable patients.



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Medical ethics: very complex...



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There are some easy guidelines and tools to tackle difficult ethical situations (e.g. ABCDEF)

But they are several different principles when it comes to medical ethics

- Principlism
- Hermeneutic ethics/dialogical ethics
- Care ethics
- Pragmatism
- Virtue ethics



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Principlism



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Four principles

- Respect for autonomy (A, C)
- Beneficence (B)
- Non-maleficence (D)
- Justice (E,F)

Specifying and balancing

Reflective equilibrium



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ABCDEF



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Principlism: as easy as ABCDEF?



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A - Autonomy



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“Self rule” - Competent, informed patients have the right to choose among treatment options and refuse any unwanted medical interventions.

- Self-determination
- Informed consent
- No treatment without consent, unless...
- No participation in medical research without consent, unless...



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B - Beneficence



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Physicians must act in the best interests of their patients.

- Maximize health
- Prolong life
- Weigh and balance possible benefits against possible risks of an action.
- Beneficence can also include protecting and defending the rights



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C - Confidentiality



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- Confidentiality respects patient autonomy.
- Encourages patients to be candid.
- Can confidentiality be overridden?



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D - Do No Harm



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- The principle of nonmaleficence directs physicians to “do no harm” to patients.
- Physicians must refrain from providing ineffective treatments or acting with malice toward patients.
- The pertinent ethical issue is whether the benefits outweigh the burdens. (B, D)
- The patient decides (A, B, D)



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E - Equality/Equity



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The principle of **distributive justice** deals with issues of treating patients equally.

- Economic Justice – Fair share of resources
- Physicians should treat similarly situated patients similarly and allocate resources justly.
- Limited health care resources → practice cost-effective medicine.



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F - Fairness



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The principle of **procedural justice** requires that the process for making decisions for patients be fair and just.

- Fair treatment of individuals by institutions
- Set guidelines → Unbiased decisions
- More likely that patients accept outcomes they don't like.



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ABCDE



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- A - Autonomy
- B - Beneficence
- C - Confidentiality
- D - Do no harm
- E - Equality/equity
- F - Fairness



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ABCDEF



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Medical ethics: *really* as easy as ABCDEF?



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Principlism



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Individualist approach

Focus on autonomy, privacy and confidentiality

- Patients are seen as individuals
- Self-determination
- Privacy
- Support decision-making of patients
- Informed consent



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Relational approach

Context and interpretation, sharing and negotiation of responsibilities

- Patients are seen as part of a relational context
- Self-realization
- Commitments
- Support people to live a life with dependencies and responsibilities towards others
- Deliberation on values



Care ethics



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Origin: feminist critique in the 1980's

Basic ideas:

- All individuals are **interdependent** for achieving their interests.
- The vulnerable need to be cared for.
- Contexts and individual situations are of fundamental importance in deciding what is wrong or right.
- Importance of lived experience

“How can I meet my caring responsibility?”



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hermēneuein: to interpret

- Meaning is related to lived experience
- Understanding is always partial and dialogue is needed
- Reciprocity between dialogue partners
- Deliberative model
- Negotiated consent rather than informed consent (autonomy is not regarded as the right to choose without interference, but as a process of moral development).
- Interpretation is not a matter of theoretical insight, but of practical moral experience.





- Principles, values and virtues



To summarize



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ABCDEF: easy tool to medical ethics

But in practice: way more complex and many different ethical models/principles

- **Principlism**
- **Hermeneutic ethics/dialogical ethics**
- **Care ethics**
- Pragmatisme
- Virtue ethics



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Ethics in medical research



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video!



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Ethical medical research



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The Helsinki declaration (2013)

ETHICAL PRINCIPLES FOR MEDICAL RESEARCH INVOLVING HUMAN SUBJECTS

Article 16 “In medical practice and in medical research, most interventions involve risks and burdens. Medical research *involving human subjects may only be conducted if the importance of the objective outweighs the risks and burdens to the research subjects.*”



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Ethical medical research



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- (1) value
- (2) scientific validity
- (3) fair subject selection
- (4) favorable risk-benefit ratio—
- (5) independent review
- (6) informed consent
- (7) respect for enrolled subjects



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What Makes Clinical Research Ethical? Ezekiel J. Emanuel, MD, PhD; David Wendler, PhD;
Christine Grady, PhD JAMA. 2000;283(20):2701-2711

Ethical medical research



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→ **Exploitation**

- Community exploitation vs. individual exploitation
- **Exploitation:** unfairness in distribution of benefits and burdens involved in specific transactions.
- **Coercion** is the use of threats, in that sense that consent would be invalid as participants were or thought they were being threatened.



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Ethical medical research



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- Are the risks/benefits fair for both sides? Individual benefits =/ community benefits
- Why has the company chosen to conduct study X on this community?
- Is there a possibility for coercion (using vulnerability as an opportunity)?



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Cases



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- Values
- Virtues
- Process
- Outcome
- Reflection



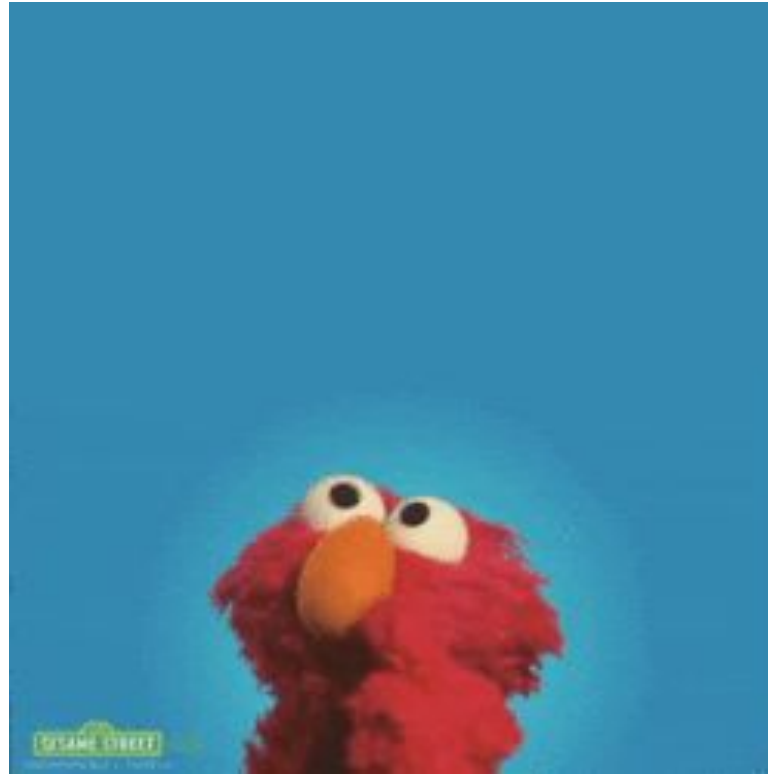
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Reflection



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