



**IFMSA**  
International Federation of  
Medical Students' Associations



**SCORP**  
Human Rights & Peace

# Ethics and Human Rights in Medicine and Medical Research

SCORP sessions MM 2019, Slovenia  
Juliette Matijssen & Anouk Nusselder

medical  
**students**  
worldwide

# What are medical ethics?



**IFMSA**  
International Federation of  
Medical Students' Associations

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?



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

# Ethics & Human Rights?



**IFMSA**  
International Federation of  
Medical Students' Associations

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.



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

# Medical ethics: very complex...



**IFMSA**  
International Federation of  
Medical Students' Associations

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



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

# Principlism



**IFMSA**  
International Federation of  
Medical Students' Associations

## Four principles

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

Specifying and balancing

Reflective equilibrium



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

ABCDEF



**IFMSA**  
International Federation of  
Medical Students' Associations

Principlism: as easy as ABCDEF?



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

# A - Autonomy



**IFMSA**  
International Federation of  
Medical Students' Associations

“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...



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

# B - Beneficence



**IFMSA**  
International Federation of  
Medical Students' Associations

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



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide



# C - Confidentiality



**IFMSA**  
International Federation of  
Medical Students' Associations

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



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

# D - Do No Harm



**IFMSA**  
International Federation of  
Medical Students' Associations

- 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)



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

# E - Equality/Equity



**IFMSA**  
International Federation of  
Medical Students' Associations

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.



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

# F - Fairness



**IFMSA**  
International Federation of  
Medical Students' Associations

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.



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

# ABCDE



**IFMSA**  
International Federation of  
Medical Students' Associations

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



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

ABCDEF



**IFMSA**  
International Federation of  
Medical Students' Associations

Medical ethics: *really* as easy as ABCDEF?



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

# Principlism



**IFMSA**  
International Federation of  
Medical Students' Associations

## Individualist approach

Focus on autonomy, privacy and confidentiality

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



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide



## 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



**IFMSA**  
International Federation of  
Medical Students' Associations

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?”



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide



## *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



**IFMSA**  
International Federation of  
Medical Students' Associations

## 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



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

# Ethics in medical research



**IFMSA**  
International Federation of  
Medical Students' Associations

video!



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

# Ethical medical research



**IFMSA**  
International Federation of  
Medical Students' Associations

## 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.*”



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

# Ethical medical research



**IFMSA**  
International Federation of  
Medical Students' Associations

- (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



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

**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



**IFMSA**  
International Federation of  
Medical Students' Associations

## → **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.



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide



# Ethical medical research



**IFMSA**  
International Federation of  
Medical Students' Associations

- 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)?



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

# Cases



**IFMSA**  
International Federation of  
Medical Students' Associations

- Values
- Virtues
- Process
- Outcome
- Reflection



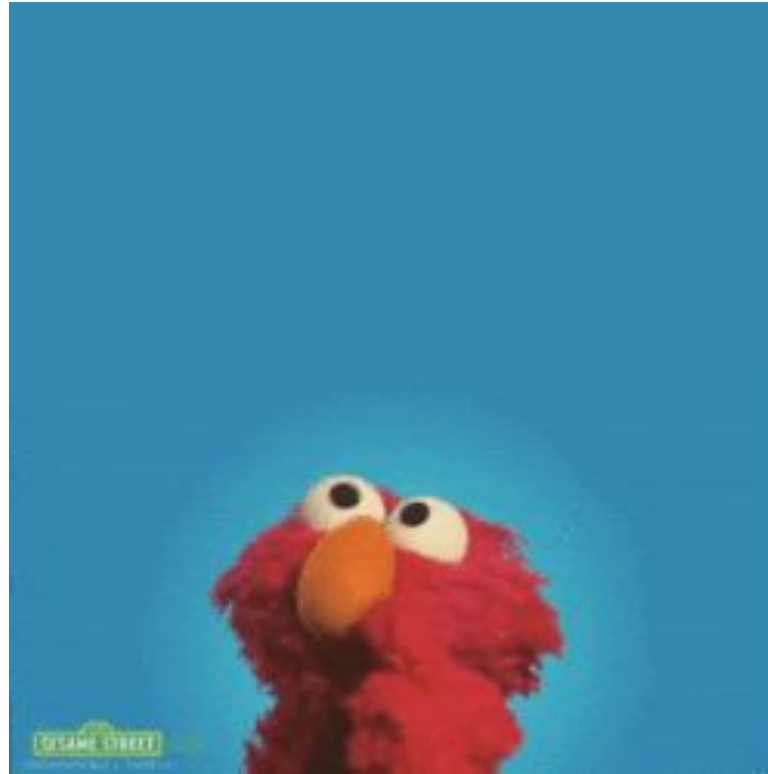
**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide

# Reflection



**IFMSA**  
International Federation of  
Medical Students' Associations



**SCORP**  
Human Rights & Peace

medical  
**students**  
worldwide