BIOL416
Bioethics of Genetics and Genomics

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Less Embarassing Choices

- I need to pass the exam ----- cheat or not ??
- I need the organs of this dying patient ---- Let him die fast ??
- I need the money of this Pharma company ---- Shall I change the results of my research on their drug??

ETHICS IS ABOUT MAKING DECISIONS

USUALLY HARD ONES!

What is an “ethical issue” or a “moral problem”?

- There is an ethical issue when:
  - …we encounter **conflicting values**, beliefs, goals, or responsibilities
  - …we are concerned that persons or their **rights are not being respected**
  - …we are concerned about **fairness and justice**
  - …we are **unsure** *what* we should do or *why* we should do it, morally speaking

Levels of moral response

- The **expressive** level (unanalyzed expressions or feeling that, by themselves, don't provide reasons or justification)
- The **pre-reflective** level (justification via law, religious tenets, social values, codes of ethics, etc.; accepted uncritically)
- The **reflective** level (reasoned ethical argument/ defense based on ethical principles, rules, virtues, values to which we consciously subscribe; justification provided)

Thomas J and Waluchow W, 1998

Introduction to Ethics

•The term ‘ethics’ broadly describes the way in which we look at and understand life, in terms of good and bad or right and wrong.

•Moral theories are the frameworks we use to justify or clarify our position when we ask ourselves “what should I do in this situation?” or “what is right or wrong for me

ETHICS / MORAL

- The oldest scientific and philosophical discipline
- ? Demarcation: science / subject

ethics

(gr. ethos = custom, practice)

moral

(lat. mos = character, nature)

- **Ethics – discipline about moral or philosophy on moral**
- **Moral** – system of norms or rules, written or not, about human behavior

Ethics is a philosophical discipline about moral problems, deals with art of living

SOME ETHICAL TERMINOLOGY

RIGHT/WRONG: Every action is either morally right or morally wrong.

Morally wrong = breaks a moral rule or precept.
Morally right =does not break a moral rule, not morally wrong).

Not breaking a moral rule or precept can be two things

performing an action that is morally demanded = **morally obligatory**

performing an action that it would be right to do and not wrong not to do = **morally permissible**

- Morally obligatory action: an action that it would be right to do and wrong not to do

- Performing an action neither morally demanded nor morally prohibited = **morally permissible**.

Aristotel

What is Ethics?

- The formal study of:
  - What is right and wrong.
  - The study of the bases or principles for deciding right and wrong.
  - The analyses of the processes by which we decide what is right and wrong.
  - The branch of knowledge that deals with moral principles

What is ethics?

- A system of moral principles or standards governing conduct.
- a system of principles by which human actions and proposals may be judged good or bad, right or wrong;
- A set of rules or a standard governing the conduct of a particular class of human action or profession;
- Any set of moral principles or values recognized by a particular religion, belief or philosophy;
- The principles of right conduct of an individual.
  (UNESCO/IUBS/Eubios Living Bioethics Dictionary version 1.4)

Ethics is not:

- Merely obeying the law
- Compliance

✓Although in many instances laws are statements of considered ethical positions and most of the time obeying the law is an element of ethical behavior.

There are many moral theories and there is no one right theory.

They converge and often borrow from one another.

Three theories will be described;

- Consequentialism
- Deontology
- Bioethics, a common morality theory, is a recent theory that dominates current thinking in health care settings.

1- Consequentialism

“The End Justifies the Means”

In consequentialism, the consequence of an action justifies the moral acceptability of the means taken to reach that end.

The results of actions outweigh any other consideration; in other words, ‘the end justifies the means.’

Consequentialism

"The End Justifies the Means"

Jeremy Bentham was an early and influential advocate of utilitarianism, the dominant consequentialist position.

A utilitarian believes in 'the greatest happiness for the greatest number.'

The more people who benefit from a particular action, the greater its good.

2-Deontology

Deontology or Kantianism is an obligation-based theory whose chief author was Immanuel Kant, who lived in the 18th century.

This theory emphasises the type of action rather than the consequences of that action.

Deontologists believe that moral decisions should be made based on one's duties and the rights of others.

According to Kant, morality is based on pure reason. As people have the innate ability to act rationally, they therefore must act morally, irrespective of personal desires.

Another way of stating Kant's theory is

"Act morally regardless of the consequences."

3-Bioethics

Common morality theories are usually based on principles that are used to guide ethical thinking, based on a shared moral belief.

One of these theories is Bioethics, the ethics of biology, biological research and the applications of that research.

It is an ethical theory that brings together **medicine**, the **law**, **social sciences**, **philosophy**, **theology**, **politics** and other disciplines to address questions related to clinical decision making and medical research.

- Bioethicists are concerned with the ethical questions that arise in the relationships among life sciences, biotechnology, medicine, politics, law, and philosophy.
- It includes the study of values relating to primary care and other branches of medicine.
- Bioethics also helps establish a common ground for different views, the democratic process being facilitated by the principle of giving equal and fair consideration to all sides or aspects of a given issue concerning human, animal or environmental rights.

Principles of Bioethics

Some of the early founders of bioethics put forth four principles which form this framework for moral reasoning.

These four principles are:

Autonomy – one should respect the right of individuals to make their own decisions

Nonmaleficence – one should avoid causing harm to reach a beneficial outcome

Beneficence – one should take positive steps to help others

Justice – benefits and risks should be fairly distributed

Principles

1. Autonomy: The rights of the individual to make decisions regarding their own health must be respected
2. Beneficence: Healthcare provides must strive to benefit their patients
3. Non-Malfeasance: Healthcare provides must not hurt their patients
4. Justice: Patients should share (more or less) equally in the costs and benefits of the healthcare system

Principles of Bioethics

Autonomy
Nonmaleficence
Beneficence
Justice

One commentator has said, "…the four principles should…be thought of as the four moral nucleotides that constitute moral DNA – capable, alone or in combination, of explaining and justifying all the substantive and universalisable moral norms of health care ethics…"

Scenario

Consider this scenario:

A woman goes to her doctor to receive the results of a genetic test. The results show she does have the condition for which she was tested and this allows her doctor to prescribe a treatment strategy that will reduce her symptoms and delay (and perhaps prevent) the progression of the condition. Her doctor knows from their discussions that the woman has an identical twin sister and he asks if she is going to tell her sister of the test results. The sister could then undergo genetic testing herself and perhaps enter treatment. The woman says she does not want her family to know about her condition; as well she will not talk to her sister as they are not on speaking terms. The doctor knows the woman's twin should be notified so that she can be helped also, but he has a duty of care to his patient. Which principles should be considered when trying to decide how to proceed?

Autonomy Nonmaleficence Beneficence Justice.

4 Principles

01

Autonomy

The rights of the individual to make decisions regarding their own health must be respected

02

Beneficence

Healthcare provides must strive to benefit their patients

03

Non-Malfeasance

Healthcare provides must not hurt their patients

04

Justice

Patients should share (more or less) equally in the costs and benefits of the healthcare system

In summary, ethics is how we look at and understand life, while moral theories are frameworks we use to decide how to act.

Consequentialism is a theory that emphasizes the results of actions, while

Deontology stresses the requirement to act morally, irrespective of the outcome.

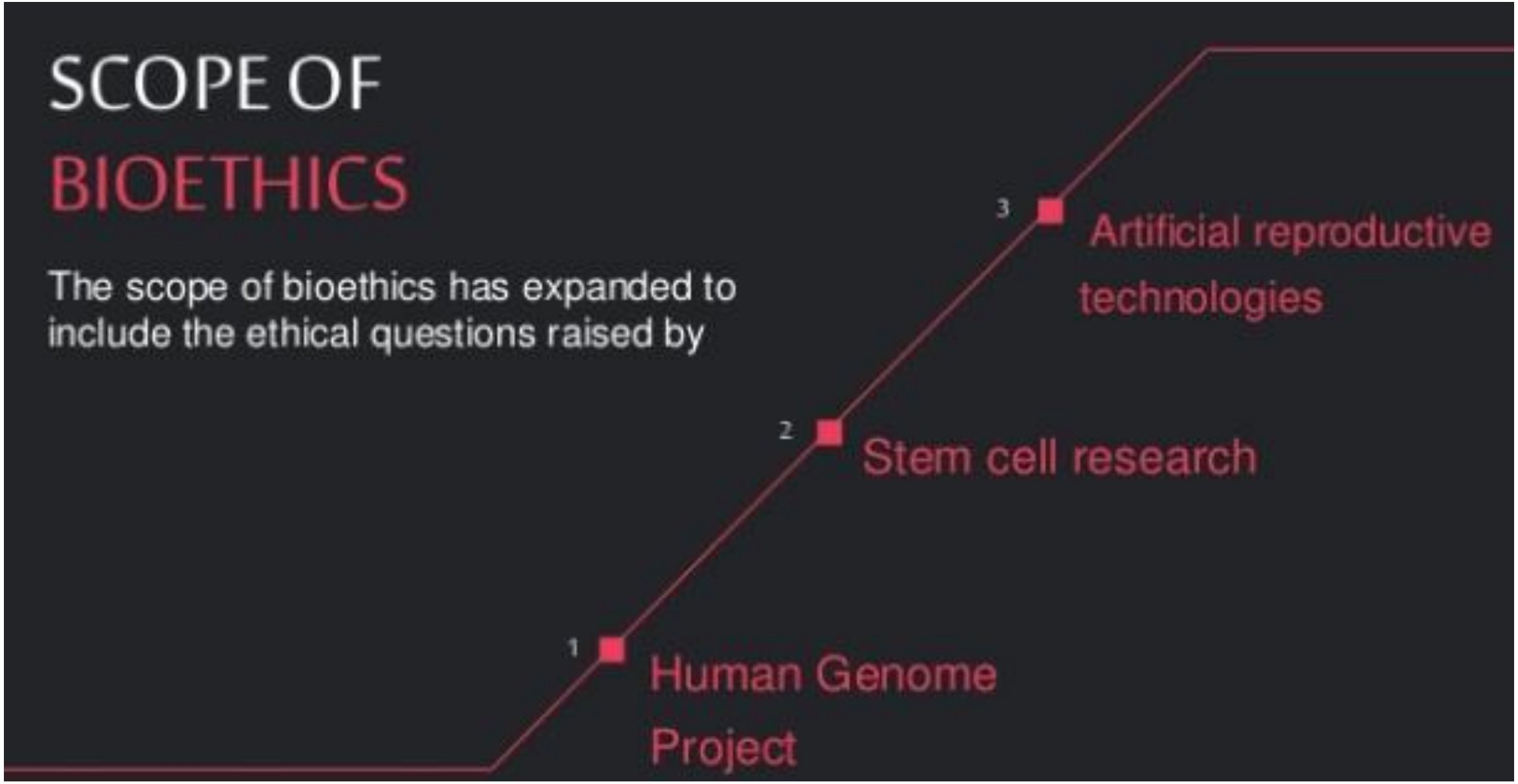
Bioethics is a principle-based theory that brings together the ethics of biology, biological research and their applications.

The four principles of Bioethics are autonomy, the right of individuals to make their own decisions; nonmaleficence, one should avoid causing harm; beneficence, positive steps should taken to help others; and justice, the benefits and risks should be fairly distributed.

While no one moral theory is correct, and there are many more to be considered, they provide a useful tool to guide ethical decision making.

SCOPE OF BIOETHICS

The scope of bioethics has expanded to include the ethical questions raised by



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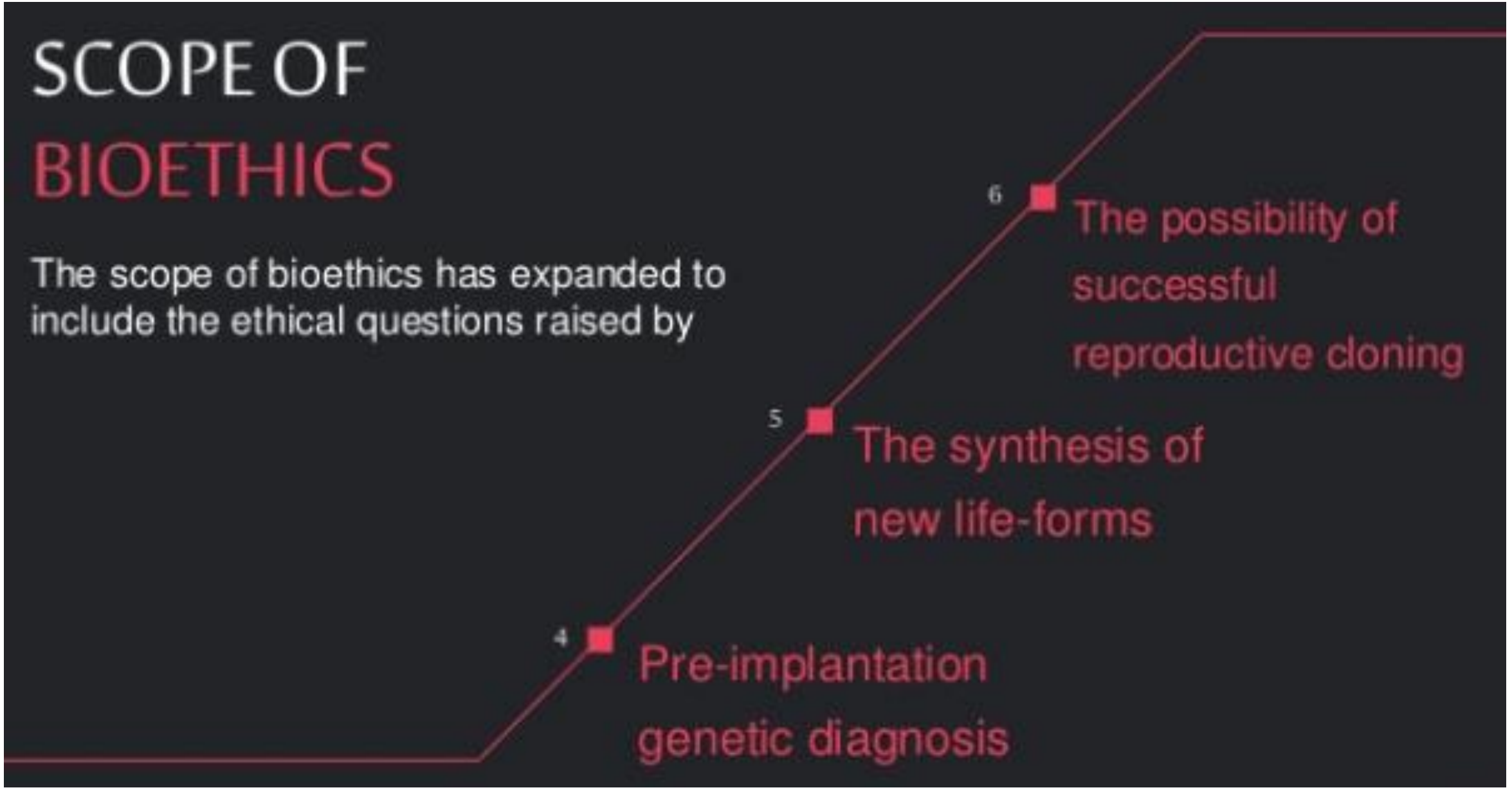

Three major ways of viewing Bioethics

1. Descriptive bioethics: the way people analyze life as affecting their responsibilities and moral actions.

- observations and descriptive interpretations of the way people view life, their moral interactions and responsibilities with living organisms in their life.

2. Perspective bioethics: telling people what is acceptable and unacceptable and the rights of others.

- to inform or try to tell others what is ethically good or bad, and what principles are most important in making such decisions.
- to say that someone or something has rights, and that others have duties to them.

3. Interactive bioethics: the debate and discussions involving people, societal groups and communities.

- discussion and debate about 1 and 2 above between people, groups within society, and communities.

History of Bioethics

- Started as concerns regarding research ethics
- Nuremberg Doctors' Trial -- 23 German physicians who either participated in the Nazi program to euthanize persons deemed "unworthy of life" or who conducted experiments on concentration camp prisoners without their consent were tried. The trial lasted 140 days. 85 witnesses testified and almost 1,500 documents were introduced. 16 of the doctors charged were found guilty. 7 were executed.

What Were Founding Bioethicists Studying?

- Normative ethics – formulation and defense of basic principles, values, virtues, and ideals governing moral behaviour
- Descriptive ethics – factual descriptions of moral behaviour and belief systems
- Analytic approach – discerning meanings of life, concepts of rights/justice/fairness, etc.
- Balancing ethical principles
- Shift from the greatest good to individual rights

Major Principles in Bioethics

- Tom Beauchamp and James Childress's Principles of Biomedical Ethics:
  - Non-maleficence and Beneficence
    - Utilitarian – harm-benefit analysis
    - do no harm
    - best interest standard
  - Autonomy
    - respect for one's rights and dignity
    - informed and voluntary consent
  - Justice
    - fairness
    - caring for the most vulnerable

Medical Ethics

- a field of applied ethics, the study of moral values and judgments as they apply to medicine.
- As a scholarly discipline, medical ethics encompasses its practical application in clinical settings as well as work on its history, philosophy, theology, sociology, and anthropology.

Why study medical ethics?

- ethics is and always has been an essential component of medical practice
- some ethical principles are basic to the physician-patient relationship, but application in specific situations is often problematic due to disagreement about what is the right way to act
- study of ethics prepares medical students to recognize difficult situations and to deal with them in a rational and principled manner

Why study medical ethics?

- integral part of medicine at least since the time of Hippocrates
  → concept of medicine as a **profession**

- in recent times - influence by developments in **human rights** (e.g., violations of human rights, such as forced migration and torture; whether healthcare is a human right)

- closely related to **law** (e.g., medical licensing and regulatory officials), *but*

  ethics prescribes higher standards; occasionally requires that physicians disobey laws that demand unethical behaviour; laws differ significantly from one country to another while ethics is applicable across national boundaries

Bioethics

- Medical ethics closely related to ***bioethics*** **(*biomedical ethics*)**, but

  not identical

- medical ethics focuses primarily on issues arising out of the practice of medicine

- bioethics: very broad subject, concerned with the moral issues raised by developments in the biological sciences

- bioethics does not require the acceptance of certain traditional values that are fundamental to medical ethics

Bioethics

- branch of applied ethics that studies the philosophical, social, and legal issues arising in medicine and the life sciences
- it is chiefly concerned with human life and well-being, though it sometimes also treats ethical questions relating to the nonhuman biological environment

Bioethics

- era of replacing human organs and their functions began with chronic dialysis and renal transplantation in the 1960s. → unprecedented problems (selection of patients; "God Committee“)

origin:

- Potter’s “Bioethics, the Science of Survival” (1970), which suggests viewing bioethics as a global movement;
- Callahan’s “Bioethics as a Discipline” (1973), in which he argues for the establishment of a new academic discipline; creation of institute in which researchers should examine and analyze medical dilemmas

Bioethics

- repeated story about the origin of the term bioethics is incorrect
- German theologian Fritz Jahr published articles (1927, 1928, 1934) using the German term “Bio-Ethik” (which translates as “Bio-Ethics”) and forcefully argued more civilized, ethical approach to issues concerning human beings and the environment
- his bioethical imperative: “Respect every living being, in principle, as an end in itself and treat it accordingly wherever it is possible.”

Questions answered by Bioethics

- deciding ***what*** **we should do** (what decisions are morally right or acceptable);
- explaining ***why*** **we should do it** (how do we justify our decision in moral terms); and
- describing ***how*** ***we should do it*** (the method or manner of our response when we act on our decision).

What is clinical/medical ethics?

- Clinical ethics is a practical discipline that provides a structured approach to assist physicians in identifying, analyzing and resolving ethical issues in clinical medicine.
- The practice of good clinical medicine requires some working knowledge about ethical issues such as informed consent, truth-telling, confidentiality, end-of-life care, pain relief, and patient rights

Process of making ethical decisions

- Awareness—Is there a moral issue here?
  - What is its nature? How important?
- What are the facts?
- What are the issues?
- What rules or values apply here?
- To whom or what do I owe a duty?
- How should they be applied?
- Who needs to decide and act? Who ought to?
- To what am I obligated because of role/position?
- What are the consequences?
- What are the options?!

Duties to whom or what?

- Individuals
  - Patients
  - Patients' families/guardians
  - Colleagues
  - Co-workers
  - Self
- Groups
  - Profession
  - Society
  - The weak
- Ideas/Principles
  - The Law
  - Truth
  - Justice
  - Individual value

Duties—Sources

- Legal Obligations
  - Health insurance
  - Emergency treatment
  - Reporting duties
- Institutional Obligations
  - Practices of hospital
- Professional norms and obligations
  - Inhere with being a physician

How do individuals decide what is ethical?

- Two different ways of approaching ethical issues:

1. Non-rational (irrational)

2. Rational

How do individuals decide what is ethical?

1. Non-rational (irrational) approaches:

- Obedience - following the rules or instructions of those in authority, whether or not you agree with them (common way: children and those who work with authorities)
- Imitation - following the example of the role model
- Feeling or desire (subjective approach)
- Intuition - location in the mind (rather than the will)
- Habit – there is no need to repeat a systematic process each time a moral issue arises similar to one that has been dealt with previously

How do individuals decide what is ethical?

2. Rational approaches:

- Deontology (search for well-founded rules)
- Consequentialism (the right action is the one that produces the best outcomes; the best known is utilitarianism uses “utility” as a measure: “the greatest good for the greatest number”)
- Principalism (often clash of principles)
- Virtue ethics (a type of moral excellence; important virtues: compassion, honesty, prudence, dedication)

Framework for ethical decision-making IN PRACTICE

- Four steps problem-solving process:

1. Problem identification (identify: technical facts, moral parameters, legal constraints, relevant human values)
2. Develop alternative curses action (identify: relevant ethical principles for each alternative, recognize ethical assumptions for each alternative, determine additional emerging ethical problems)

Framework for ethical decision-making IN PRACTICE

- Four steps problem-solving process:

3. Select one alternative course of action (justify the selection of your alternative, defend your selection upon ethical grounds)

4. Consider objections to alternative selected (objections arising from: factual errors, faulty reasoning, conflicting values)

Framework for ethical decision-making IN PRACTICE

1. Determine whether the issue at hand is an ethical one.
2. Consult authoritative sources to see how physicians generally deal with such issues.
3. Consider alternative solutions.
4. Discuss your proposed solution with those whom it will affect.
5. Make your decision and act on it.
6. Evaluate your decision and be prepared to act differently in future.

Factors in ethical decision-making in health-care

1. Ethical theories
2. Ethical principles
3. Ethical rules

ETHICAL MAXIM (principles)

General guidelines that site what is forbidden, desirable or permissible (often base for rules)

1. *Respecting autonomy*
2. *Doing no harm (nonmaleficence)*
3. *Benefiting others (beneficence)*
4. *Being just (justice)*

- Being faithful (fidelity)

ETHICAL RULES (codes)

manners developed by professional organizations

Structure of codes:

1. regulative
2. protective (for public opinion)
3. specific (regarding membership)
4. obligated

Why Ethics Become Important?

• Nowadays, conflicts of interests between the government and medical institutions, between medical institutions and medical personnel, between physicians and patients are getting more and more serious and complex.

• High technologies not only brought us hopes of cure but have also created a heavy economic burden.

• The ethical dilemmas of high technology medicine-brain death, organ transplantation, and concerns about quality of life-have become increasingly prominent

Why Ethics Become Important?

- A new and more specific code of ethics must be developed to meet the demands of social development and medical service.

- This new code integrates the traditional medical ethics with modern principles and values.

Some Bioethical Topics

Research issues:

- Should Scientists be held to some standard of integrity and honesty?
- Who should enforce this?
- Why is peer review so important?
- Should scientists be held responsible for creating or discoveint technology that can be used to harm others or have unforeseen side effects (chemical, nuclear warfare)

Some Bioethical Topics

Reproductive Technologies:

- In vitro fertilization, surrogacy, pre implantation, embryo screening, cloning.
- Is there as significant difference between cloning sheep for pharmaceutical production and cloning humans?

Some Bioethical Topics

Human Genome Project

Should employers be able to screen job applicants for specific genetic conditions? Who should have access to this informatoins: family members, lawyers, insurance agencies?

Some Bioethical Topics

Gene Therapy

What are the potential ramification of somaic and germ-line gene therapy? Should genes be tinkeed with and if so what limits should be placed on this technology?

Some Bioethical Topics

Abortion

Does a fetus have rights? If so, what are they and who is responsible for representing the interest of the fetus? Does a fetus have rights that supersede the mothers? Can government step in to ensure the heath of the fetus if the mother is not? What about embryos?

Abortion is the removal of a foetus or embryo from a woman's uterus resulting in the termination of a pregnancy. The controversy over abortion is actually a greater debate over when life truly begins. Pro-choice bioethicists place emphasis on the ability of a woman to have power over her own body while anti-choice supporters believe life begins at conception. As the public and political debates over abortion are overwhelmed by religious beliefs, pro- life bioethicists are generally secular in their reasons and merely view a fetus as a human life

Some Bioethical Topics

AIDS

issues involving disclosure, privacy, discrimination, insurance coverage

Some Bioethical Topics

Euthanasia

What is the right to die? How does withdraing or withholding treatments differ from physician assisted suicide? Who has the rigtht o decide when and how a person dies? Should doctors be held legally responsible if they assist a patient's death? What laws should be passed to protect doctors and patients?

Euthanasia refers to the act of purposefully ending a life to eliminate untreatable suffering. It brings up the question of what constitutes a life worth preserving and what lengths should be taken to preserve said life. Supporters of euthanasia view the course of action as a relief to unnecessary suffering if a patient it going to succumb to an incurable disease either way. However, opponents view life as sacred and fear a slippery slope into allowing treatable patients to die of their own well

Some Bioethical Topics

Eugenics

- Eugenics is a type of DNA manipulation that creates selective breeding to improve the human race. Bioethicists who support gene selection obviously want to see the advancement of the species along with the extinction of certain genetic diseases. However, critics are worried about the slippery slope that could occur. Since eugenics has been associated and discredited by the Nazis radical experiments to achieve an Aryan race, many opponents worry that one race will be deemed inferior and eradicated. This of course is the extreme argument, but opponents debate that eugenics could lead to discrimination against certain races, disabled individuals, or even hair color.

Some Bioethical Topics

Human cloning

Human cloning is the scientific production of an identical human cell, tissue, or entire body. Bioethicists that support human cloning see the benefits of regenerative medicine in terms of organ or tissue donation. This would eliminate the risk of a body rejecting a transplant and the issue of scarcity of organs and tissues to be donated. Critics fear that the process will produce an onslaught of severely disabled children since the cloning process has not been perfected. As well, they fear that cloning humans for their body parts will produce human farming and the killing of clones for their vital organs

Some Bioethical Topics

Stem Cell Research

- Stem cells are capable of multiplying themselves through mitotic cell division and embryonic stem cells even possess the ability to differentiate into a range of specialized cell types. This makes them incredibly valuable to disease research. The controversy surrounds the use of these embryonic cells. Supporters see the potential this research has in curing diseases such as Parkinson's Disease. As well, the majority of embryos used for research are left over from in- vitro fertility treatments and are on their way to being destroyed anyways. However, most of the opponents are also pro-life on abortion. They see the embryos as the potential for new life and destruction of such embryos as the destruction of life.

Some Bioethical Topics

Health Care Allocation

How do we decide who gets access to health care, particularly expensive equipment and therapies? How do we decide who gets access to transplanted organs? Should the government pay for the health care when a person cannot afford it?

Some Bioethical Topics

Environmental Issues

How do we decide between conservation and economic interest. How much land should be allocated to other species and to parks? Should industries be responsible fo the damage done to the environment by them (pollution)?

Some Bioethical Topics

Animal Right Issues

Is animal testing acceptable when it benefits humans? What animals should be tested and which should not? Does animal research be justified by its benefits to mankind?

Some Bioethical Topics

Population Control

Who has the right to decide who should have children and how many? What measures should be taken to control the population of the world?

Some Bioethical Topics

Minors and Medicines

What medical procedures shold minors have available to them withoug parental consent? Do doctors have an obligation to inform parents of conditions a teen has (pregnancy, AIDS) even if the teen does not wish it?

Some Bioethical Topics

Genetically Modified Crops

What rights do consumers have? What rights do farmers have to grow GM crops, who decides whether food is safe?