

BIOETHICS

CORE

CURRICULUM



**SECTION 1: SYLLABUS**  
**ETHICS EDUCATION PROGRAMME**  
Sector for Social and Human Sciences

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# BIOETHICS CORE CURRICULUM



## **SECTION 1: SYLLABUS** **ETHICS EDUCATION PROGRAMME** Sector for Social and Human Sciences

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# INTRODUCTION

**Background** On 19 October 2005, the 33rd Session of the General Conference of UNESCO adopted the *Universal Declaration on Bioethics and Human Rights* (hereafter referred to as the Declaration). The Declaration embodies a set of bioethical principles that has been agreed upon by 191 Member States of UNESCO after an intense elaboration and consultation process involving independent and governmental experts from all regions of the world. This set of bioethical principles provides a common global platform by which bioethics can be introduced and strengthened within each Member State, and UNESCO is mandated to promote, disseminate and elaborate these principles for practical purposes.

The core curriculum consists of two sections. Section 1 (this document) provides the core contents with objectives, syllabus and teacher manual for each unit of the curriculum. Section 2 contains the proposed study materials for each unit of the curriculum.

The content of this curriculum should be shared and used in accordance with the specific teaching context in which it is being implemented. Teachers are advised to consider the unique circumstances and setting in which the curriculum is being used.

**Justification** The UNESCO Bioethics Core Curriculum sets out to introduce the bioethical principles of the *Universal Declaration on Bioethics and Human Rights* to university students. Bioethics teaching has not been introduced in many universities in many countries. This UNESCO Bioethics Core Curriculum can provide an incentive to start introducing such teaching. Its contents are based on the principles adopted in UNESCO. It therefore does not impose a particular model or specific view of bioethics, but articulates ethical principles that are shared by scientific experts, policy-makers and health professionals from various countries with different cultural, historical and religious backgrounds.

The UNESCO Bioethics Core Curriculum furthermore presents a core: it defines what should be regarded as the minimum (in terms of teaching hours and contents) for appropriate bioethics teaching. It allows flexible application. It also invites teachers and students to expand its contents and approaches in diverse directions.

**Objectives** The core curriculum is built upon learning objectives. Each unit starts with specific objectives. The focus on objectives not only serves to demarcate the contents for each unit. It also is the basis of the assessment of the program as well as the evaluation of the students.

**Target groups** The primary target group of the core curriculum is medical students. The teaching can be implemented before the end of the clinical phase of their medical education. Although the core curriculum can be introduced in the pre-clinical phase of medical studies, it will probably be more effective for students who are in the clinical phase. These students have experienced the need for ethical reflection and they will also more easily recognize the ethical dimension of cases and problems. Another option is to use the curriculum early on in the medical education depending on how the education is structured in the university.

Nowadays, bioethics teaching is also introduced in other educational programs such as nursing education, health care sciences, dentistry and public health. Furthermore, bioethics teaching is provided to law, philosophy and social sciences students. The core curriculum can be used for teaching to these other categories of students. It provides a basic training on the fundamentals and major issues of present-day bioethics. It is up to the teacher to select appropriate examples and cases for the students.

Students engaged in research with human beings should partake in additional training beyond the core curriculum.

When bioethics teaching is lacking at all levels of education, the core curriculum can also be used as the first introduction into bioethics for health care professionals (medical doctors and nurses in particular). It is therefore useful for post-academic training and continuing education. The curriculum may also be applied in educational programs for members of ethics committees.

## Structure of the curriculum and possible uses

### △ Units based on principles

The first thing a teacher will notice about the syllabus is its innovative and unconventional structure. Typically, ethics courses in medical schools are organized around specific medical dilemmas such as beginning of life and end of life issues. The core curriculum, however, is designed around the bioethical principles of the Declaration, with each unit of the syllabus (except for the first two units) elaborating one of the principles. The primary rationale for this design is firmly rooted in the fact that Member States have achieved consensus on these bioethical principles, thus establishing an uncontroversial core curriculum for the teaching of bioethics in all Member States.

### △ Not a complete course but source of inspiration

However, the core curriculum should not be treated as a comprehensive curriculum in bioethics. It is recognized that the content of the core curriculum does not necessarily cover all aspects of bioethics. Traditional issues that have not been included could be incorporated as examples that are pertinent to one or several of the Declaration's principles within the curriculum's framework. Furthermore, the number of hours proposed for each unit should be considered as the minimum amount of time to be dedicated to the material. It is preferred that teachers do not deem the proposed time allotment as sufficient, and they should strive to build more hours into their teaching. Although UNESCO has taken measures to ensure that the curriculum is sensitive to various social, cultural and economic contexts, it is emphasized that teachers using the curriculum must still exercise discretion on the methods employed to convey the content of the curriculum, selecting contextually relevant materials provided or sourcing other available materials. Therefore, the core curriculum is intended to be a minimum teaching programme in bioethics with the possibility of further innovation, expansion and flexible application in different contexts. It is not intended to impose a particular model of teaching but rather is a source of ideas and suggestions on how to approach bioethics teaching.

### △ Flexibility

Teachers are encouraged to build additional modules focusing on traditional and other relevant issues around the units of the syllabus, bearing in mind that all units should be covered, dedicating at least the minimum recommended time. The proposed order of units could and should be adjusted according to the teaching style of the teacher. However, it should also be noted that the following units should be taught in conjunction to maintain a logical flow of the syllabus: Units 1 and 2; Units 5, 6 and 7; Units 13, 14 and 15; and Units 16 and 17. Depending on the structure of university education, this can imply that some units of the core curriculum will be taught in earlier phases of the university program, and other units in later stages. Implementation of the core curriculum may have many varieties, as long as the appropriate connection between the units and the coherence among the units is maintained. It is up to individual schools and universities to design additional hours into the implementation of the core curriculum, as well as decide how and at what level the core curriculum should be integrated into the university program.

### △ Wider scope of bioethics

Teachers should keep in mind that the core curriculum is meant to provide them a way of getting students to reflect upon the ethical dimensions and human rights considerations of medicine, health care and science, and that the Declaration approaches bioethics by going beyond the usual individualistic perspective of ethics, widening the scope to include social and community issues. Finally, it is stressed that although a bioethics course is important and a prerequisite, ethics needs to be taught as much as possible throughout the entire university curriculum.

## Methods of assessment

As with other courses in university education, bioethics teaching should be evaluated. Two types of evaluation will be necessary.

### △ Course evaluation

After completion of the core curriculum the teaching should be evaluated. Students as well as teachers are invited to provide feedback on the implementation of the curriculum. The purpose of this evaluation is to identify how the course and the teaching can be improved. In order to obtain comparable data about the implementation, UNESCO will develop a standardized questionnaire for the evaluation of the course.

### △ Student evaluation

The purpose of this evaluation is to assess whether the teaching of the course has resulted in the accomplishment of the objectives in each student. This evaluation is therefore focused on assessing the impact of the course in individual students. Various methods can be used: a written test, a multiple choice test, paper assignments, case analyses, presentations, essays, oral examinations.

In the future, on the basis of the outcome of the evaluation of the core curriculum, other assessment methods can be suggested.



## Feedback

As they adapt the curriculum to their teaching styles and contexts, teachers are invited to submit additional modules they have developed around the core units of the syllabus as well as additional study materials that are deemed useful. Teachers are also encouraged to provide feedback on the core curriculum to enable UNESCO to improve the product.

Please submit all feedback and materials to:

Bioethics and Ethics of Science Section,  
Sector for Social and Human Science  
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7 place de Fontenoy  
75352 Paris 07 SP  
France  
Email: [bioethics@unesco.org](mailto:bioethics@unesco.org)

# CORE CURRICULUM CONTENT

UNIT 1	What is ethics?*	2 hours
UNIT 2	What is bioethics?*	2 hours
UNIT 3	Human dignity and human rights (Article 3)	2 hours
UNIT 4	Benefit and harm (Article 4)	2 hours
UNIT 5	Autonomy and individual responsibility (Article 5)**	1 hour
UNIT 6	Consent (Article 6)**	2 hours
UNIT 7	Persons without the capacity to consent (Article 7)**	2 hours
UNIT 8	Respect for human vulnerability and personal integrity (Article 8)	1 hour
UNIT 9	Privacy and confidentiality (Article 9)	2 hours
UNIT 10	Equality, justice and equity (Article 10)	2 hours
UNIT 11	Non-discrimination and non-stigmatization (Article 11)	2 hours
UNIT 12	Respect for cultural diversity and pluralism (Article 12)	2 hours
UNIT 13	Solidarity and cooperation (Article 13)***	2 hours
UNIT 14	Social responsibility and health (Article 14)***	2 hours
UNIT 15	Sharing of benefits (Article 15)***	2 hours
UNIT 16	Protecting future generations (Article 16)****	2 hours
UNIT 17	Protection of the environment, the biosphere and biodiversity (Article 17)****	2 hours
UNIT 18	Gender and Bioethics	2 hours

Content Note

\* Units 1 and 2 are tied together.

\*\* Units 5, 6, and 7 are tied together.

\*\*\* Units 13, 14, and 15 are tied together.

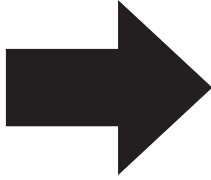
\*\*\*\* Units 16 and 17 are tied together.

Total (MINIMUM): 34

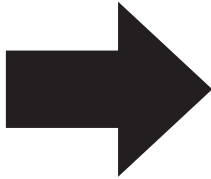
(1 hour = 60 minutes)

# COURSE LEARNING OBJECTIVES

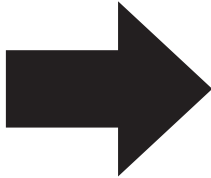
## General Objectives



Students should be able to identify ethical issues in medicine, health care and life sciences



Students should be able to provide rational justification for ethical decisions



Students should be able to apply the ethical principles of the *Universal Declaration on Bioethics and Human Rights*

UNIT 1

# What is ethics?

## Unit Learning Objectives



Students should be able to recognize and distinguish an ethical issue from other issues



Students should be able to reason about ethical issues

## Outline of the Syllabus

1

### The moral point of view

- a What is ethics?
- b The world of ethics
- c The universal experience of duty
- d Moral experience is universal, but some moral perceptions and judgements vary
- e Universality and variability of human morality
- f Moral statements

2

### The nature of moral judgements

- a Three types of sentences
- b Surface grammar and depth grammar
- c Moral criteria and moral judgements

3

### An ethical method of reasoning

- a First step: Fact deliberation
  - i The case
  - ii Deliberation about the facts
- b Second step: Value deliberation
  - i Identification of the moral problems
  - ii Choice of the main problem
  - iii The values at stake
- c Third step: Duty deliberation
  - i Reflecting on the most challenging cases
  - ii Reflecting on other cases
- d Fourth step: Testing consistency
- e Fifth step: Conclusion

## Teacher Manual

1

## The moral point of view

**a** What is ethics?

Morality is a unique feature of the life of human beings. It is deeply influenced by several cultural factors, such as history, traditions, education, religious beliefs, etc. The intellectual analysis of this human dimension in all of its complexity is the goal of the discipline called Ethics. Ethics does not create morality or moral behaviour. The goal of ethics is much more modest: to explore the nature of moral experience, its universality and its diversity. Ethics and morality are generally taken as synonyms, because they originally had the same meaning: the study of the disposition, character, or attitude of a specific person, group of people or culture, and ways of promoting or perfecting it.

**b** The world of ethics

In its development through history, the discipline called Ethics has known different approaches. None of them have obtained, to this moment, a general agreement. There are ethical systems ordered around the ideas of human rights, law, duty, obligation, virtue, happiness, principles, consequences, etc. In an effort to capture the valuable insights of each of these approaches it will be useful to begin by analyzing the universal moral experience of human beings. Proceeding this way, two concepts emerge as basic: one is 'value' and the other is 'duty'. Values can be identified amongst all peoples and societies and they often provide unique identifiers of those cultures. Values therefore predate the discipline called ethics, being promoted by religions, cultural traditions, history, etc. Values are the background of many other moral concepts derived from them, like principles, norms, laws, virtues, etc. One of the most important goals of ethics is the intellectual analysis of values and value conflicts, in order to define our duties. And duties always involve the values at stake in each specific situation, promoting them as much as possible.

**c** The universal experience of duty

We all consider that some things ought to be done and others avoided. We have a duty to act in certain ways rather than others. The experience of duty is one of the most universal characteristics of human life. There is no human language without the so-called 'duty-verbs', such as 'must', 'ought', 'shall', or without imperative moods, in order to express commands, like: 'do no harm!', 'fulfil your promises!', 'do not steal!', 'do not lie!'. Similarly, there is no human society without some rules of conduct, either 'prohibitions' or 'obligations'.

**d** Moral experience is universal, but some moral perceptions and judgements vary

For instance, morality has been changing all over human history. Moral values are different depending on the place in which one is living, the language one speaks, the culture, the religions practised. Ask the students to provide examples.

**e** Universality and variability of human morality

It follows from the previous statements that there are some universal and unchangeable elements in human morality, but others are historically conditioned and particular. Structurally, morality is always the same, but the contents are, at least to some extent, variable. In fact, moral values are constantly evolving. But at the same time, some moral duties remain unchanged, reflecting the logical limits of what counts as part of moral discourse. For instance, do not harm others, or tell the truth.

**f** Moral statements

Human beings express, communicate, and exchange human experiences through language. Statements are judgements, propositions or assertions that attribute some predicates to subjects.

## The nature of moral judgements

### a Three types of sentences

- i Mahatma Gandhi was 1.5 metres tall.
- ii Mahatma Gandhi was nice.
- iii Mahatma Gandhi was good.

### b Surface grammar and depth grammar

The words surface grammar refers to the construction of the sentences in terms of subject, verb and complement. The sentences are identical in this respect. As the first sentence ascribes a property to a subject we might expect the others to do the same. However when we look at the way we handle the sentences in the case of apparent disagreements about their truth we see that they behave very differently. This shows that the depth grammar or the logical character of the sentences varies.

- i How do we resolve a disagreement about the first sentence? It is a matter of measurement. Though we might not be in a position to make the measurement we certainly know what it would be like to make it. Our understanding the sentence depends on such knowledge. If two people disagree about the claim made by the sentence one of them must be wrong. It is a question of objective fact, an empirical claim.
- ii How do we resolve an apparent disagreement about the truth of this sentence? Each speaker might be able to give a reason for their statement. But they do not have to be able to do so and might simply say that they just like him. There is no logical limit to what people may like or dislike. The lesson is that the sentence is not in fact about Gandhi at all but about the speaker who is simply expressing a feeling he has about Gandhi. This is not therefore a statement at all but an expression of feeling. The speaker might be trying to deceive us but he cannot be mistaken.
- iii How do we resolve a disagreement about the truth of the final sentence? No-one can say that they have no reason for the claim as it is not a matter of whim. Further there are limits to the kind of consideration which can count as a proper reason. It has to be a moral reason. Thus the fact that Gandhi was a man of peace who supported non-violent protest would be a justification of the claim. But another observer might consider that opting for non-violent protest is a sign of weakness which hinders the quest for justice. This would be a reason for disagreeing with the claim. Thus the same consideration can count either for or against the judgement. It follows that relevant criteria are called for but they might not guarantee agreement.

### c Moral criteria and moral judgements

In the history of ethics we can find two groups of thinkers who have taken different views of moral statements depending on which of sentence i or ii most resembles sentence iii.

One group have seen passions or emotions as the key element of moral sentences which makes them much like sentence ii. This takes seriously the possibility of no agreement being reachable by the application of reason. However it ignores the fact that there are logical limits to the feelings relevant to moral statements. It has been pointed out that we cannot simply experience feelings like pride by just trying hard. Rather we have to remember some achievement or relation to the object of pride in order to experience pride. Similarly we cannot experience the moral feeling of shame without recalling some unworthy event in our lives.

It has also been pointed out that no rule of behaviour can count as a moral principle except it is related to a family of concepts like respect, truthfulness, pride, ostentation, harm, benefit and so on. These logical limits make moral statements appear to be akin to sentence i. But to overemphasise this similarity suggests that all moral disagreements can be resolved by appeal to these principles and criteria. But if it were not for moral values there would be no moral problems for these are created by tensions between those values in specific situations. Nevertheless reason has its role to play in moral deliberation for the logical limits we have referred to have to be respected. In many cases reasonable reflection will facilitate agreement but it simply cannot be guaranteed to do so.

## An ethical method of reasoning

### Decision-making and ethics

Ethics is both a theoretical and a practical discipline. The language of ethics refers to rights, duties and values. One goal of ethics is to determine right decisions, and in order to do that, it is necessary to go step by step, analyzing, first, the facts of the case, second, the values at stake, and third, the duties.

#### a First step: Fact deliberation

##### i The case

The deliberation process begins always in the same way, with the presentation of a problem or a case, which is often difficult from the moral point of view. This difficulty is perceived as a conflict, generally called 'moral conflict'. Conflicts appear when a decision should be taken, and it is difficult to identify the best course of action, because in all possible actions important values are at stake, and selecting one implies the infringement of other compelling values. The goal of the ethical method of reasoning is always the same, to help people to resolve these kinds of problems, taking wise or decisions.

##### ii Deliberation about the facts

In order to resolve a moral conflict, the first thing we must do is to make a careful analysis of the facts of the case, lowering the uncertainty in this field as much as possible and also correcting misperceptions. This is not an easy task, and it usually takes a lot of time. But at this point, the careful analysis of facts is basic if we want to do things well. For instance, a careful analysis of medical facts is essential in medicine in order to know the situation of the patient, the diagnosis, prognosis, and treatment. This is a very difficult task. We must reduce uncertainties as much as possible, through the process of individual or collective deliberation. Nobody knows all possible facts involved in a situation. Our perception of facts is influenced by our education, cultural background, personal expertise and experience. We might have been trained to perceive some facts, for instance, the medical ones, but we might not have the same sensitivity to perceive others, such as the patient's socio-economic situation, which other people, with other training, perceive more readily. Therefore, we should analyze facts carefully, considering the advice of other people when things are difficult. For instance, in medicine so-called 'clinical rounds' often take place, in which members of the health care team discuss the facts of a clinical case, in order to reduce their uncertainty about its diagnosis, prognosis, and treatment. However their considerations should range more widely than the medical facts and should take account of the patient as a whole.

#### b Second step: Value deliberation

##### i Identification of the moral problems

The analysis of a case starts when somebody thinks that he or she has a problem and thinks it is a moral problem. Such cases are often more complex than they at first appear. People ask about a problem, but this does not mean that this is the only problem the case presents. It is necessary, therefore, to identify and describe the different moral problems we are able to find in the case, to enable full and unambiguous discussion.

##### ii Choice of the main problem

After the identification of all ethical problems at stake in the case, we must choose one among them, which is to be discussed in the next steps of the analysis. Problems should be discussed one by one. Only after the discussion of one can we begin the debate about another, and so on. If we mix different problems, reaching a conclusion will be impossible. In any case, we consider that the problem to be discussed first is, of course, that conveyed by the person who presented the case in step 1. This is the main problem, at least for him or her, and our duty now is to help him or her to reach a wise decision. The problem identified by the questioner might be insignificant compared to other moral problems the case involves. The solution of the major problems might remove the original problem from the scene altogether. For example a doctor might perceive the problem of whether to choose a more expensive form of treatment for a patient or not when the major problem might be that he has not enquired whether the patient wants to be treated at all. Therefore, we should analyse the problem conveyed by the person who presented the case, and the problems on which it is dependent, if they exist.

##### iii The values at stake

We have been talking until now of 'problems', and 'moral problems'. We have not given a precise definition of this expression. 'Moral problems' are always concrete, specific. They are not abstract. When someone has a moral problem, it is because he or she does not know which moral value should be respected in the situation. We say that the person has a 'conflict of values'. Therefore, the specific language of 'moral problems' can be translated into the abstract and universal language of 'values' and 'conflict of values'. Values are special qualities. For instance, justice and truthfulness are values. Values are qualities that human beings think important. If we think of a world without justice, or truthfulness, we can realize that these are important or positive values. There are, of course, opposite values to them, as injustice. Our duty is always and necessarily to implement positive values, promoting them in our world. And moral conflicts appear when the attempt to implement a specific value infringes the fulfilment of another. In order to solve this conflict, the first thing to do is to identify the different values at stake; that is, to translate 'moral problems' into the language of values and 'conflict of values'.

### **c** Third step: Duty deliberation

A conflict of values can be solved in different ways, and our duty is to identify and choose the best one, that is, that which promotes best the fulfilment of positive values, or that infringes least upon the values at stake. Therefore, we must identify the different possible courses of action of the case. And the easiest way of doing that is identifying first the extreme courses of action.

#### i Reflecting on the most challenging cases

It is important for the doctor to be sensitive to the whole range of ethical values in dealing with clinical cases. Such sensitivity, however, will often present challenges which would otherwise not occur. These challenges are ethical in nature in that it is the tensions between respect for various values which make it difficult to decide what should be done. There will be more and less demanding challenges of this kind. The most problematic for the doctor to deal with will be those where it seems that whichever alternative course of action is taken he will be doing wrong by failing to respect an important value. These situations are called dilemmas and are rarer than might at first appear. More often than not careful consideration of all aspects of the case will show that the dilemma is only apparent. The following example is such a case.

A Jehovah Witness refuses a blood transfusion for himself in line with his sincere religious beliefs but at the same time asks for help in saving his life. The two main values at stake here are respect for his spiritual wellbeing on the one hand, and respect for his physical wellbeing on the other. We might at first think that we cannot maintain respect for both of these values in this situation. If we are correct then we shall have to choose between the extremes and sacrifice one value for the other believing that we are doing wrong whichever option we take. This would constitute a moral dilemma. Our view might be that the best outcome of the treatment is the survival of the patient whereas his view might be that surviving at the cost of being damned forever would be the greatest possible personal disaster.

Our first moral duty is to endeavour to respect all values at stake as much as possible. Ideally we need to find a way of saving the life of the patient without ignoring his religious beliefs. That is, we need to carefully examine our initial belief that we have a genuine dilemma on our hands. There are numerous possible ways of respecting both values in such cases. For example, around 12% of Jehovah's Witnesses do not fully agree with the Watchtower's blood doctrine. One intermediate course of action is, therefore, to evaluate individual beliefs in respect to blood among Jehovah's Witnesses patients. Some of them accept some form of blood or blood products. If we find that our patient is firmly opposed to this option there are other possibilities. One is the use of bloodless surgery techniques. Another is the use of transfusion alternatives, like volume expanders, and oxygen therapeutics (Perftec, Hemopure, Oxygent, PolyHeme, Perfloran). And yet another course of action is avoiding the use of blood or any substitute unless the need really arises. Thus in the case under discussion the apparently contradictory ethical demands on the clinician can both be satisfied. Failure to reflect on these matters could result in serious harms to the patient whichever of the two apparent options is taken.

#### ii Reflecting on other cases

Most moral problems which face doctors in treatment decisions are less dramatic than the apparent dilemmas such as the case cited above. They usually take the form of numbers of ethical values calling for attention and making demands on practitioners. These call for careful

consideration but do not suggest that the practitioner is presented with an impossible task to find an acceptable solution. We might call these moral problems rather than dilemmas. Nevertheless considerable harms can be caused if the doctor fails to take the various issues into account. The reflection should involve weighing the various values against each other in the specific situation to facilitate the wisest decision. That decision will be the one which is least morally objectionable, or, to put it another way, involves least disrespect for the values which figure in the case. These reflections can be complex and different cases might involve details which tip the balance one way or the other to give priority to a particular value. Sadly neat solutions are not always available but there are a number of possible outcomes. There are those where each value is compromised somewhat but at no great moral cost, and others where one value or set of values will be seen to outweigh the others in the specific set of circumstances. In the latter cases that value or set of values will win out over the other at no moral cost for the duty to act in that situation becomes clear.

#### **d** Fourth step: Testing consistency

It is important that moral reflection is consistent. Special pleading involves giving undue weight to one or more consideration because it is in the interest of the decision maker so to do. This will always prejudice the decision and undermine the proper role of reason in ethical reflection. We can use a number of techniques to guard against such inconsistency.

- i We can avoid such bad practice by referring to some external measures such as the Law. Though the law does not solve ethical problems it does usually reflect the moral values of citizens. On some occasion laws might be unjust and not serve us in this way.
- ii We can also ask ourselves the question: Would I behave in this way if it was to become generally known that I had done so? An honest appraisal in these terms would draw our attention to our disregard for the principle which has been extremely important in the history of ethics, namely to act in such a way as to be able to wish that mode of behaviour be a universal law.
- iii We should not be hasty in drawing conclusions in moral reflection. Once presented with moral problems in practice doctors experience a considerable injection of emotions. Such feelings are not unimportant but they might cloud any immediate judgement and stimulate rash decisions. Using the time that is available, which might also involve consulting with colleagues, allows these emotional rushes to recede somewhat and facilitate wiser decisions.

#### **e** Fifth step: Conclusion

The desired outcome of all these reflective activities is to arrive at wise decisions. Practical wisdom, the art of making well-thought decisions is the moral virtue par excellence. Well-thought decisions are not necessarily universally agreed decisions. Serious and responsible people can disagree on ethical matters. However it has been said that the unexamined life is not worth living and in medicine it is certainly true that the morally unreflective life is to be deplored.

UNIT 2

# What is bioethics?

## Unit Learning Objectives



Students should be able to explain the difference between medical ethics and bioethics



Students should be able to identify the principles of bioethics and to understand that these principles may conflict with each other

## Outline of the Syllabus

1

### The birth of bioethics

- a The birth of the concept of 'bioethics'
- b Bioethics as bridge between facts and values
- c Bioethics versus medical ethics
- d The idea of Potter
- e Bioethics as global ethics

2

### Health and disease as values

- a Health and disease are facts as well as values
- b Health identified with wellbeing

3

### Principles of bioethics

- a Health care decisions include facts and values
- b The principles of *the Universal Declaration on Bioethics and Human Rights*
- c Many principles have not been respected throughout history
- d Paternalism and 'informed consent'
- e Conflicts between bioethical principles. Limits to the autonomy of patients
- f Limits of justice and resource allocation
- g Limits to paternalism

4

## Ethics committees

- a Previously, moral conflicts were scarce
- b Nowadays, many principles need to be respected and they are often in conflict
- c The occurrence of conflicts is not negative
- d The main goal of bioethics is to manage moral conflicts
- e To accomplish this goal, bioethics uses deliberation
- f 'Bioethics committees' are platforms for deliberation
- g Different types of committees
- h Ethics committees are not legal tribunals

5

## Medical professionalism

- a Professional ethics
- b Changes in medical ethics
- c The unchanging goal of professional ethics
- d Professionals strive for excellence

## Teacher Manual

1

## The birth of bioethics

- a Bioethics is a relatively new concept coined by a biochemist, Van Rensselaer Potter, in 1970 in an endeavour to draw attention to the fact that the rapid advances in science had proceeded without due attention being paid to values. For some time the word referred to the attempt to link scientific facts and values in the area of environmental concerns. Nowadays it has taken on a more general meaning which includes medical, or more generally, health care ethics. Though there are examples of reflection on ethics in medicine through the ages the subject of bioethics has led to several sub-disciplines in the past decades. This growth was stimulated both by abuses of human beings in the course of medical research, especially during the Second World War, and by the emergence of medical technologies which have challenged various widely held public values.
- b Potter conceived this new discipline, bioethics, as a 'bridge' between 'facts' and 'values'. During the second half of the twentieth century, he said that biological sciences had been increasing their knowledge and technical power continuously, but reflection about the values at stake has not progressed in the same proportion. Potter said that he coined the word bioethics using two Greek words, *bíos*, life, representing the facts of life and life sciences, and *éthos*, morals, referring to values and duties.
- c One profession dealing with life during centuries and millennia, especially with human life, has been medicine. But today there are many sciences and professions working in this field. Therefore, bioethics should not be mistaken with medical ethics or medical deontology, which is only one of its branches. The field of bioethics is as wide as the facts of life, and its study is divided in many branches, each one with its specificity: environmental, medical, clinical, research, etc.
- d The idea of Potter, and in general of bioethics, is that not all that is technically possible is morally right, and that some control of our intervention in nature and the environment, on animals and on human beings, is needed. The future of life and of humankind is at stake.

**e** Bioethics is the first attempt of thinking 'globally' in ethics. In fact, one of the books written by Potter is titled *Global Bioethics* (1988). Throughout its history, ethics has not had a global dimension. The widest criterion introduced in ethics was the Kantian principle of 'universality': 'Act only according to that maxim whereby you can at the same time will that it should become a universal law'. But the German philosopher Immanuel Kant (1724-1804) probably understood 'universal' in a narrow way, as comprising only all rational beings. On the contrary, the idea of 'globalization' includes not only all rational beings, but also future generations (called 'virtual' human beings), all other living organisms, and also nature, the environment.

**f** Global bioethics includes, therefore:

- i All actual human beings (see Units 5–15)
- ii Future human beings (see Unit 16)
- iii All living organisms and the environment (see Unit 17)

## 2 Health and disease as values

**a** Health and disease, like life and death, are not bare facts, but also embody values. Usually health and life are valued and disease and death disvalued. It is also true that values can determine what counts as health itself. Many physicians, especially in the West, think that health and disease can only be understood as bare facts. Diseases, they say, are due to the alteration of some tissues or parts of the human body, which can be determined scientifically. Therefore they conclude that disease is a scientific fact, the same as the usual facts in physics or in chemistry.

**b** We think of health as positive as a good and disease as negative, as an evil. Nowadays it is usual to identify health with wellbeing. This is the core idea of the definition of health stated by the World Health Organization (see Unit 4). People think today that they are ill when they feel some lack of wellbeing, even without any biological alteration. Because of this new conception of health values are important in the concepts of health and disease.

## 3 Principles of bioethics

**a** Physicians and other health care professionals have to make health care decisions. Many of the facts they consider have values built into them, for example that a given condition causes suffering or threatens a patient's life or detracts from their wellbeing in some other way.

**b** Our duties are always the promotion and implementation of values. The duty of promoting values is the origin of norms. When these norms are wide and general, they are called principles. The UNESCO *Universal Declaration on Bioethics and Human Rights* identifies fifteen bioethical principles:

- i Human dignity and human rights
- ii Benefit and harm
- iii Autonomy and individual responsibility
- iv Consent
- v Persons without the capacity to consent
- vi Respect for human vulnerability and personal integrity
- vii Privacy and confidentiality
- viii Equality, justice and equity
- ix Non-discrimination and non-stigmatization
- x Respect for cultural diversity and pluralism
- xi Solidarity and cooperation
- xii Social responsibility and health
- xiii Sharing of benefits
- xiv Protecting future generations
- xv Protection of the environment, the biosphere and biodiversity

**c** Many of these principles have not been respected through history. For instance, physicians have traditionally applied their own values and neglected those of patients in making clinical decisions. Doctors as experts have considered that they know best what is good for their patients as fathers know what is best for their children. This historical approach has been called 'paternalism' and is now seen as inadequate.

**d** Paternalism is a behaviour that might be taken as morally when societies are homogeneous from the point of view of values. This was the case in the past, and might be thought so today in many parts of the world. People in traditional societies shared the same values. When physicians, therefore, made medical decisions taking into account only their own values, they could suppose they were respecting also the values of their patients. But this situation has changed drastically during the last centuries. One of the reasons for this change has been the continuous mobility of people and the mix of different values, beliefs, and traditions in modern societies. There may yet be some societies where physicians can assume that patients share their values but they would be very few. Doctors must therefore take patients' values into account. This is the origin of the doctrine of 'informed consent', which counters the traditional paternalism of the medical profession. The moral principles here involved are the following of the previous list: i, iii, iv, vi, vii, and x.

**e** Professionals must respect the values of patients. But in some cases the values of patients cannot be honoured by physicians, because they are in conflict with other bioethical principles. One very important duty of health care professionals is expressed by the traditional saying: 'do no harm'. Medical interventions are risky, with important side effects, and many times they hurt people. The balance between benefits and risks is essential in order to determine when medical procedures are harmful or not. A limit to the autonomy of patients is set by the moral principles listed with the numbers ii, ix, and xv.

**f** Another limit to the values of patients is fairness in the access to health care and the distribution of resources. The growing technological development of medicine is increasing the price of health care to such an extent that most individuals are incapable of paying their own bills. This has opened another set of moral problems, all of them related to justice, the right to have health care, and the fair distribution of scarce resources. The moral principles to deal with these problems are the following: viii, ix, x, xi, xii, xiv and xv.

**g** Our moral duty is not only not to harm others, but to help and benefit them. This is especially important for health care professionals since their goal is to do the best for people in need. This has always been the main principle of medical ethics but today what is beneficial for patients and what is not cannot be determined only by health care professionals; it is also, and primarily, determined by patients. Ignoring this situation leads to paternalism. To act in the best possible non-paternalistic way: this is the new interpretation of the moral principles listed with the numbers ii, v, and xiii.

## 4

## Ethics committees

**a** The situation of present day health care is much more conflict laden than ever before. Traditional medical ethics used to work with the moral principle of beneficence and non-maleficence, understood in a paternalistic way. The only decision maker was the professional, and the only moral principle to be taken into account was beneficence and non-maleficence. Therefore, the possibility of moral conflict was very remote.

**b** On the contrary, there are different moral principles and values to be respected in each specific situation. Often, these principles conflict with each other. There are potential conflicts between all of them.

**c** The number of conflicts is not related to the morality of a society, or of a profession. In fact, conflicts arise when people are entitled to decide and take part in decision-making processes. When only one person has the power to decide and the unique moral duty of all others is obedience, conflicts are quite impossible. Conflicts are part of human life, and they are more frequent as respect for human freedom and moral diversity increases.

**d** The problem is not the existence of conflicts; the problem is the will to respect and resolve them. This is the main goal of bioethics, to train people in the management of moral conflicts, in order to take wise decisions and, in this way, improve the quality of health care.

**e** In order to reach this goal, bioethics uses deliberation as the way of approaching and thinking about moral conflicts. People can work individually with this procedure, especially when problems are not very complex. But when conflicts are difficult, or when they involve many people, deliberation should be done collectively.

**f** There are some areas outside specific treatment decision making where special bioethics bodies have been created to build respect for values into health care provision. This is the origin of so-called 'bioethics committees'. They are platforms for deliberations in order to take wise decisions and to make policy recommendations. There are different types of ethics committees, as described in the UNESCO Guides *Establishing Bioethics Committees* and *Bioethics Committees at Work: Procedures and Policies*:

- i Policy-Making and Advisory Committees (PMAs)
- ii Health-Professional Association (HPA) Bioethics Committees
- iii Health Care Ethics Committees (HECs)
- iv Research Ethics Committees (RECs)

**g** Each of these committees has its own characteristics, as described in the UNESCO documents. For instance, HEC committees do important work in clinical bioethics. They consist of physicians, nurses, social workers, and lay members, both men and women. Different backgrounds, expertise and experiences allow a better understanding of cases, enriching all the individual perspectives and facilitating decision-making.

**h** HEC committees are not judicial bodies with the responsibility of sanctioning wrong conduct and imposing disciplinary measures. This is one of the biggest differences between ethics committees and legal tribunals. The goal of ethics is not to compete with law, but to promote wise decisions among people and professional excellence. Bioethics does not look for what is legally right but for what is humanly best. The goal of bioethics is to promote the best possible action.

5

## Medical professionalism

**a** Professionalism refers to the conduct, aims, or qualities that characterize or mark a profession or a professional person. The project 'Medical Professionalism in the New Millennium: A Physician Charter' defines professionalism as the basis of medicine's contract with society. 'It demands placing the interests of patients above those of the physician, setting and maintaining standards of competence and integrity, and providing expert advice to society on matters of health. The principles and responsibilities of medical professionalism must be clearly understood by both the profession and society. Essential to this contract is public trust in physicians, which depends on the integrity of both individual physicians and the whole profession.' (*Annals of Internal Medicine* 2002; see <http://www.annals.org/cgi/content/full/136/3/243>) Professionalism is, therefore, directly related with ethics. Its ethical expression is called Professional Ethics. Some of its formulations are the Codes of Professional Ethics.

**b** Throughout the history of medicine, many changes have occurred in medical ethics. The influence of paternalism has decreased, to the same extent as respect for autonomy has increased. There have also been important changes related to access to health care services and the distribution of scarce resources.

**c** But there is one thing that has remained unchanged in professional ethics all over its history, which is the moral duty of professionals not only not to do harm but to do the best for their patients. This is a primary goal of professional codes of conduct which each professional is obliged to observe.

**d** Professionals must strive for excellence. They have in their hands the most valued things people have: life and health, and their duty is to do the best for them.

At the beginning of the *Nicomachean Ethics* Aristotle wrote: 'There is some end of the things we pursue in our actions which we wish for because of itself, and because of which we wish for the other things; [...] clearly this end will be the good, i.e. the best. Then surely knowledge of this good is also of great importance for the conduct of our lives, and if, like archers, we have a target to aim at, we are more likely to hit the right mark.' (*Nicomachean Ethics* I 1: 1094 a 18–26)

## UNIT 3

## Human dignity and human rights (Article 3)

## Unit Learning Objectives



Students should be able to explain and apply the concepts of human dignity and human rights



Students should understand the relevance of these concepts in the context of bioethics

## Outline of the Syllabus

- 1 Concepts of dignity in the history of ideas
  - a Classical antiquity
  - b World religions traditions
  - c Modern philosophy
  - d Contemporary humanitarian law
    - i *The Universal Declaration of Human Rights*
    - ii *The European Convention on Human Rights and Biomedicine*
- 2 Human dignity as an intrinsic value of the person capable (at least potentially or as a member of natural kind) of reflection, sensitivity, verbal communication, free choice, self-determination in conduct and creativity
  - a Human dignity is an end in itself
  - b Equality in dignity of all human beings
  - c Respect and care
  - d The interests and welfare of the individual are prior to the sole interest of society
  - e Human dignity as a foundational concept
- 3 The diverse understandings of human dignity in different cultural and moral traditions (Buddhist, Confucian, Judeo-Christian, Muslim, communitarian, liberal) and different types of societies
- 4 A person's dignity and rights entail others' obligation to treat a person respectfully
- 5 Ethical aspects of health care provider-patient relations in regard to human dignity and human rights
  - a The problem of paternalism
  - b In treatment of children, elderly persons, and mentally handicapped individuals
  - c In palliative treatment of terminal patients and patients in 'vegetative state'
  - d In treatment of embryos and fetuses

1

## There are several concepts of dignity in the history of ideas:

- a Classical antiquity. Common understanding of dignity as deserving of honour and esteem according to personal merit, inherited or achieved. In ancient Greek philosophy, particularly of Aristotle and the Stoics, dignity was associated with human abilities of deliberation, self-awareness, and free decision-making.
- b In many world religions human dignity is considered to be predetermined by the creation of human beings in the image of God; those who are weak in body and soul have dignity equal to those who are robust and sturdy.
- c Modern philosophy proposed secular understanding of human dignity and progressively associated this concept with the idea of human rights. In different teachings human dignity was presented as an aspect of personal freedom (Giovanni Pico della Mirandola) or an embodiment of one's public worth (Thomas Hobbes), or as universal virtue, unconditional and incomparable worth determined by one's autonomy rather than origin, wealth, or social status (Immanuel Kant). One of Kant's basic principles of ethics – to treat any other person always at the same time as an end, never merely as a means (categorical imperative) – has been accepted by moral and political philosophy as the actual basis for the conception of human rights and in this sense it is a foundational concept.
- d In contemporary international law, national constitutions, and other normative documents, human dignity is strongly connected with human rights.
  - i According to Art. 1 of the *Universal Declaration of Human Rights* (1948), 'all human beings are born free and equal in dignity and rights.' The Declaration establishes human rights (like freedom from repression, freedom of expression and association) on the inherent dignity of every human being.
  - ii The *European Convention on Human Rights and Biomedicine* in Art. 1 declares protection of 'the dignity and identity of all human beings and guarantees everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine' as its main purpose.

2

## The notion of human dignity expresses the intrinsic value of the person capable (at least potentially or as a member of natural kind) of reflection, sensitivity, verbal communication, free choice, self-determination in conduct, and creativity.

- a Unlike material values, or financial prices, human dignity has no external equivalent; it is an end in itself. Unlike merit as an embodiment of publicly recognized personal achievements, a person is dignified as a human being as such.
- b All human beings are equal in dignity irrespective of gender, age, social status or ethnicity.
- c Recognition of a person's dignity presupposes active respect for her human rights, self-esteem and self-determination, as well as care for her privacy, protecting her from illegitimate intrusions and preserving her valid public space.
- d A society or a community should respect each of its members as a person or a moral agent on the basis of the notion of human dignity. This notion also requires that the interests and welfare of the individual are considered as prior to the sole interest of society, community, or any particular kind of publicly wholesome activity. The emphasis on 'the sole interest of science or society' is important. It implies that because of his/her human dignity, the individual should never be sacrificed for the sake of science (as has happened in medical experiments during the Second World War) or for the sake of society (as has happened in totalitarian regimes). But 'sole' also implies that there might be exceptional circumstances in which the interest of others or the community as a whole are so important that infringing upon the interests of individuals is unavoidable in order to save others or the community. An example is the threat of a deadly pandemic.

**e** Human dignity is a foundational concept and it is theoretically and normatively inappropriate to reduce it to functional characteristics of person's activity, ability to decision-making or to taking into account her autonomy. Respect for dignity means recognition of other's intrinsic worth as a human being.

**3** In a comparative view, human dignity has diverse forms in different cultural and ethical traditions (for example, Confucian, Judeo-Christian, Muslim) and is respected in various ways in different types of societies (traditional, modern, totalitarian, democratic). It is less respected in totalitarian societies and more respected in modern and democratic societies. Regardless cultural, confessional, and political varieties human dignity is universally based on the person's self-awareness and appropriate respectful treatment towards her. As it is emphasized in Declaration, the regard to cultural diversity is 'not to be invoked to infringe upon human dignity, human rights and fundamental freedoms' (See Article 12).

**4** From the point of view of ethics, the person's dignity and rights are proved by others' obligation to treat a person respectfully, that is to cause no harm, not to abuse, to be fair, not to impose unwelcome models of personal good and happiness, not to treat her merely as a means, and not to consider the interests and welfare of the individual as subordinate to others' interests and welfare, to 'the sole interest of science and society'.

**5** **Health care provider-patient relations are just one kind of human relations, presupposing all ethical requirements.**

**a** However, historically these relations used to be considered as unequal. A physician was associated with an active role of decision-maker, providing medical care, taking responsibility. Hence, he or she was higher in status. A patient was associated with a passive role of recipient, being in need, not responsible for his or her condition and, hence, lower in status. In this paternalistic model of health care provider and patient relationship the patient used to be in a dependent position.

**b** Inequality in the status of the health care provider and the patient may be aggravated in special cases when patients are children, handicapped individuals, and elderly persons. Particularly risky are cases of patients who are mentally handicapped.

**c** Special attention in regard to human dignity and human rights is required in palliative treatment of terminal patients and patients in 'vegetative state'.

**d** Though there is no consensus either in public or in the expert community concerning the ethical and legal status of embryos and fetuses, the latter should be treated with respect and care.

The principles manifested in articles 4–15 of the *Universal Declaration on Bioethics and Human Rights* give a proper framework to respect patients' dignity and rights and clarify the specific context of human rights in bioethics.

UNIT 4

# Benefit and harm (Article 4)

## Unit Learning Objectives



Students should be able to identify harms and benefits in health care settings



Students should be able to evaluate harms and benefit in health care settings



Students should be able to justify decisions taking harms and benefits into account

## Outline of the Syllabus

1

### What is a health benefit?

- a Problems in determining what is a health benefit; this is not always related to disease states
- b A narrow concept of health
- c The WHO definition of health as a possible solution of these problems

2

### What is harm?

- a Similar problems of identifying what is harm
- b Ancient notion: 'above all do no harm'
- c Different types of harm

3

### How do we evaluate benefits and harms in practice?

- a Dimensions of comparing harms and benefits in individual patients
- b Significance of these dimensions for making treatment choices

## Teacher Manual

1

### What is a health benefit?

- a Begin by analyzing the various interpretations of 'health benefit' proposed by the students. Various possibilities can be mentioned:
  - i relief of suffering
  - ii care
  - iii prevention of disease, illness, disability
  - iv health
  - v enhancement
  - vi psychological benefit

At first glance it does not seem to be problematic to identify health needs. We are all only too familiar with the common reasons we have for going to see our doctor. Perhaps we have an unexplained pain or we are short of breath or we simply feel dreadful and find we have no energy to do anything. We expect the doctor to diagnose some kind of problem associated with disease, either trivial or serious. We are told that we have an infection, or that our condition demands further investigations which will involve sophisticated investigative work to determine whether we are developing a malignant tumour, or rheumatic joints or a stomach ulcer or whatever. There is a standard classification of diseases to which doctors refer when conducting these investigations. It is tempting therefore to conclude that to be healthy is to be free from any of the diseases detailed in that list and being unhealthy is to suffer from one or more of them.

Once we have determined the disease state of a person then, it seems, we have also identified their health needs. Absence of disease means no health needs and therefore no possibility of health benefits; disease means there is a need for treatment and the possibility of treatment leading to either a cure or the palliation of the effects of the disease, each of which counts as a health benefit.

### **b** A narrow concept of health

Attractive though the above story is, it is only part of the truth. A cursory glance at the practice of medicine will show that health benefits are available to people who do not presently suffer from any disease. These are provided by prophylactic treatments or disease prevention programmes such as vaccination against whooping cough. To be protected from the onset of a disease clearly constitutes a health benefit. Indeed it has been argued by health economists that these are the cheapest forms of health benefits to achieve. Most people would also prefer that their health practitioners enable them to avoid suffering diseases rather than have to treat those diseases when they occur. However, conceding this point does not move us far from the disease model of health in that the range of health benefits is still exhausted by either the treatment or the avoidance of disease.

If we look more closely at health care delivery we will see that non-disease conditions are also part of the remit of medicine and surgery. The most obvious treatments which go beyond the disease related conditions are bodily dysfunctions arising from traumas, such as broken legs and brain injuries. Restoring proper physical functioning by treating the results of non-disease events are clearly part of the remit of health care provision. But the practice of health care professionals might go far beyond restoring normal bodily functions in the face of such events. When such restoration is impossible, health care professionals might still have a role in providing health benefits to those who suffer impairments of function. For example, the provision of prostheses to people who have suffered the loss of arms or legs in accidents is doing nothing to restore normal bodily functioning nor to treat or ameliorate the effects of disease. It is to treat a social dysfunction insofar as the new limb enables its wearer to engage in a wider range of social activity and the affairs of life than would otherwise be possible. No-one would hold that this was not to provide a health benefit. Such an extension of the definition of health benefits demonstrates that simply widening the disease model of health to one related to physiological function is also inadequate. Here the social context of a physical condition becomes significant.

Further reflection will soon bring us to a consideration of mental health problems. Only a very few people would assert that such problems always originate from or are explicable in terms of physiological functioning. Even though there has been vigorous debate amongst psychiatrists and philosophers about the application of terms like 'illness' to mental conditions, it is generally accepted that many behaviours and psychological phenomena fall under the umbrella of health. Indeed mental health is a major segment of health care delivery. Whilst there are some advocates for physiological explanations of mental problems, including genetic determinists, most practitioners disagree. If, for example, an apparent psychopathy can be explained by the existence of a brain lesion, a physiological explanation, then it is described as a 'pseudo-psychopathy'.

- c** Discuss the WHO definition of 'health': 'a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity'
- i examples of a wider range of proper clinical activities can be used to demonstrate the narrowness of any disease oriented definition of health benefits
  - ii the example of infertility constituting a health need can be employed to explore the evolution of the character of health intervention
  - iii at the same time, the WHO definition is often criticized for being too wide; it is encompassing many situations that are not disease related and that can expand the area of work of medical doctors

Given the apparently limitless extension of the boundaries of health and consequently of needs and benefits indicated above, can we find some kind of general description which would secure a manageable range of benefits for which health care should aim?

The WHO, fully aware of the dangers of imposing narrow limits on the notion of health, has provided a definition which has been influential for many years. This definition certainly takes account of the extensions of health beyond the boundaries imposed by disease related and physiological dysfunction related conceptions. It takes the psychological and social dimensions of people's conditions seriously. Insofar as this is the case the definition is valuable. However it is limited in its usefulness by the sheer immensity of the range of circumstances and conditions for which, by implication, health authorities should be regarded as responsible. These would include the benefits of the provision of adequate defence capabilities to provide for the security of the population of a country and for the benefits of the provision of education to a population. A later amendment includes 'the ability to lead a socially and economically productive life'. However the amended definition remains open to the same criticism. In addition the amended definition might tempt us to consider that there are universal objective measures of health and consequently of health benefits. This would oversimplify the task of identifying and measuring health benefits.

So how do we proceed when we want to identify a health benefit? General definitions of health tend to be either too wide or too narrow to fit all cases to be of much assistance. It might therefore be helpful to look at the arguments that have been made for and against the identification of a particular condition as a candidate for being a health need and for the identification of the relevant concomitant health benefits attaching to the treatment of that condition.

## 2

### What is harm?

**a** It will not be surprising to learn that the task of identifying harms in health care delivery suffers from the same difficulties as the identification of benefits. It is not necessary to labour this point and one example of this relationship should be sufficient. Let us imagine that a surgical procedure to remove an ovarian cyst is carried out successfully on a patient. In the course of the procedure one of her fallopian tubes is inadvertently damaged and scarred. This damage results in infertility. Has a harm been visited upon that patient? The answer to this question is that it all depends on the patient. If the patient considers that she has completed her family and that she will not want any further children, then the inability to conceive will not constitute a harm for her. Of course it might turn out that she will change her mind about this, given the possible circumstances which could develop in her life. In such an event she would come to consider that the surgical error did harm her. In other words we are obliged to consider the context of the surgical mistake in the life of the patient before we can determine whether it was harmful or not. The harm that is established in relevant cases, however, cannot be divorced from the kind of benefit which the provision or protection of fertility would constitute for the woman concerned.

Proceed with analyzing the various interpretations of 'harm'; ask the students to identify what can be harm in the health care setting, for example:

- i physical harm
- ii psychological harm
- iii moral harm (harm to interests, harm as unfairness, harm as disrespect)
- iv social/economic harm (consequences for social role, stigmatization)

**b** But there remain some interesting issues to consider around the question of identifying and avoiding harms in health care. If the ancient notion which asserts the *primum non nocere* (above all do no harm) principle is to be adhered to in practice, how can any surgical procedure be attempted, or indeed any medication be prescribed, when we can never know with certainty what the effects in total of that intervention will be in a given patient? In another context the wound inflicted by the surgeon in an abdominal operation would constitute a grievous bodily harm. Similarly the administration of cytotoxic drugs in other situations than in treatments of malignant disease would constitute poisoning. What justifies them in surgery and chemotherapy is the net balance of benefit over the harm which the treatments inevitably involve. Indeed any clinical intervention has to be undertaken only after the completion of a risk of harm/likelihood of benefit calculation. If a patient does not stand the chance of benefiting overall from an intervention, then that intervention is not indicated for him/her. That is, where the risk of harm outweighs possible benefit, then the treatment is not indicated.

These calculations are often very difficult to make for not only will the variety of perceptions of harm and benefit mentioned earlier come into play, but the empirical and conceptual uncertainties of the possible outcomes will confound the procedure. With respect to the former uncertainty it has been said that every administration of a drug is an experiment. How one patient will react will not always be a reliable guide to how another will react. One patient with the same disease as another might respond well to a drug whereas the other might not be helped. Or one might suffer unpleasant adverse events whereas the other will tolerate the medication well. Whilst there is hope that the new technology of pharmacogenomics will increase our levels of confidence in matching medicines to patients and remove much of the trial and error element of prescribing, it will never eliminate uncertainty.

With respect to conceptual uncertainty we might consider the difficulties of making risk of harm/likelihood of benefit calculations in withdrawing or continuing intensive care treatments. In such circumstances is it the same to ask whether it can be of benefit to a patient to withdraw life prolonging treatment as to ask whether it can be harmful to continue life support where it precludes the possibility of a dignified death? We might well find that we cannot easily determine what can count as a harm or benefit in such cases.

**c** In ancient medical ethics, an important moral principle is 'above all do no harm'. This notion continues to be used as an important ethical principle in contemporary health care. Discuss this principle and answer the following questions:

- i Can a physician avoid harm?
- ii What is the distinction between expected and unexpected harm?
- iii What is positive and negative harm?
- iv Who determines what counts as harm?

3

### In health care practice it is important to evaluate benefits and harms

**a** Explore the difficulties of measuring harms and benefits in individual patients, involving

- i the assessment of degrees of harm and benefit
- ii the incommensurability of harms and benefits
- iii the social context of physical and mental suffering
- iv the subjective nature of suffering

**b** Treatment choices also have to be made among patients; here an assessment has to be made between risk of harms and potential benefits for different patients. This will be particularly important for resource allocation; when time or material resources are scarce, different priorities can be selected; focusing on patients who are most in need because of the harm they are suffering or on patients for whom treatment will produce the greatest benefit.

UNIT 5

# Autonomy and individual responsibility (Article 5)

## Unit Learning Objectives



Students should be able to explain the concepts of autonomy and individual responsibility and to understand their significance for the health care provider-patient relationship



Students should understand the relationship between autonomy and individual responsibility

## Outline of the Syllabus

1

### The concepts of autonomy and responsibility

a

#### Autonomy:

- i Different levels and notions of autonomy
- ii Different theoretical approaches to autonomy

b

#### Responsibility: its different aspects and dual nature

c

#### Mutual correlation of autonomy and responsibility in ethics

2

### Decision making in medicine

a

#### Autonomy and patient's right to self-determination in treatment

- i Autonomy and paternalism
- ii Autonomy as a right and an obligation

b

#### Patient autonomy should be respected by physicians

c

#### The patient's right to refuse a health care provider's recommendation

d

#### Special measures for protecting the rights and interests of socially and mentally disabled patients

3

### Patient autonomy and responsibilities in health care. The range of patient responsibilities

4

### Evaluation of patient's abilities to self-motivation and self-control

## Teacher Manual

1

## The concepts of autonomy and responsibility

- a** Autonomy – as individual capacity for self-determination, independent decisions, actions, and evaluations.
- i Different levels and notions of autonomy
    - Δ freedom from paternalistic interference, all the more so, from authoritarian dictates from any agent, including the state and especially transnational corporations; one's capability to self-determination;
    - Δ capability to act on the basis of rational principles and rules accepted as adequate to one's understanding of good, personal dignity, and happiness;
    - Δ capability to reflect upon these principles and rules, to influence their formation and transformation through public discourse.
  - ii In the Kantian approach, autonomy is an ability of deliberated self legislation; in the utilitarian approach, autonomy is associated with one's ability to follow one's preferences
- b** Responsibility is one's awareness of one's obligation to make decisions and to act appropriately on the basis of certain commitments (for example, towards an external authority, oneself, one's status, engagements, or agreements, respected others, accepted principles and rules).
- i Different aspects of responsibility
    - Δ spontaneously obtained status or commitments (for example, responsibility of parents);
    - Δ consciously accepted status or commitments (responsibility of an officer, professional, self-committed person);
    - Δ legal responsibility.
  - ii Dual nature of responsibility
    - Δ responsibility as accountability,
    - Δ responsibility as personal and universalizable duty.
- c** In ethics, the notions of autonomy and responsibility are mutually related. Responsibility manifests autonomy; there is no autonomy without responsibility; beyond responsibility autonomy turns to arbitrariness, which means that the person in his/her decisions does not take into consideration the interests of others.

2

## Decision making in medicine

- a** In medical practice the principle of autonomy underlies the patient's right to self-determination. As such the principle of autonomy has been recognized in opposition to paternalism, which has been essential for a traditional type of health care provider-patient relationship. As a condition for the patient's final decision, autonomy is not merely a right but also a responsibility. The patient is autonomous to make responsible decisions.
- b** So far most patients feel dependent on physicians, the respect for patients' autonomy by physicians is crucial; so a discretionary space should be secured for patients to make their own decisions with respect to their own dignity.
- c** A health care provider is an expert in medicine; a patient is an expert in her/his preferences, beliefs, and values. A patient may refuse a health care provider's recommendation, but she/he is not entitled to treatment beyond the present medical standards and the availability of treatment. In other words, patients have a right to refuse treatment but they cannot claim all treatments.
- d** Special measures are needed for protecting the rights and interests of persons who are not capable of exercising autonomy and making responsible decisions concerning medical care and treatment (see Unit 7).

3

### Patient autonomy and responsibilities in health care

Patient responsibility has the following range:

**a** Responsibility for consequences of freely taken decisions

If individuals are really autonomous and if they decide in all freedom, they have to take responsibility for the consequences of these decisions. An example is engagement in risky behaviours.

**b** Responsibility to avoid infringement of another person's autonomy

A limit to the autonomy of an individual is the autonomy of other individuals. We cannot argue that as autonomous persons we have the right to limit the autonomy of other persons. If we want our free choices, and thus our values, to be respected, we are obliged to give the same respect to the free choices, and thus values, of others. An example is the debate on smoking; we are free to decide to smoke and endanger our own health, but we cannot endanger the health of others.

4

**In cases when a patient's ability to make autonomous and responsible decisions is not clear, special steps should be taken to evaluate her/his abilities to self-motivate and self-control, to keep commitments and loyalties, to make decisions while taking into account the given situation, the goals, and the results, and to choose on the basis of reflective preferences and principles.**

## UNIT 6

## Consent (Article 6)

## Unit Learning Objectives



Students should be able to explain the meaning of 'consent', 'informed', and 'informed consent'; they should be able to define the principle of 'informed consent'



Students should be able to explain what the process of informed consent requires



Students should be able to explain how the principle of consent is applied in different interventions, research, and teaching



Students should be able to explain how exceptions to the principle can be justified

## Outline of the Syllabus

1

## Interconnection of principles

- a The principle of consent is based on the principle of human dignity and human rights
- b The principle of consent is a practical specification of the principle of autonomy and individual responsibility
- c If the principle of consent cannot be applied, the provisions of Article 7 ('Persons without the capacity to consent') are applicable

2

## What is the purpose of the principle of consent?

- a The principle of consent aims to achieve several objectives:
  - i it asserts the patient's autonomy
  - ii it protects his/her status as a human being
  - iii it prevents coercion and deception
  - iv it encourages the doctor's self-criticism
  - v it supports the process of rational decision-making
  - vi it educates the public at large
- b Consent expresses respect for the dignity and rights of each human being

3

## Interrelation between consent and autonomy

4

## Explanation of the principle

- a The article applies to all medical interventions
- b What is prior, free and informed consent?
- c Consent requires adequate information

5

- d** What is express consent?
- e** Withdrawal of consent
- f** The patient's right to refuse and right not to know
- g** Consent of subjects of scientific research. Compare the provisions for consent in scientific research with those for medical interventions
- h** Consent by individual, group and community

### Exceptional circumstances for the application of the principle of consent

- a** Emergency situations
- b** Minors
- c** Mental patients
- d** Jehovah's Witnesses

## Teacher Manual

1

### Introduction

Explain how the principle of consent is connected to other principles of the Declaration

- a** **Article 3**  
A person's basic rights are established on the recognition of his/her human status, the inviolability of his/her life, and the fact that he/she was born and will always be free. Because human dignity and human rights are to be respected, the person concerned needs to give consent for medical interventions and for participation in scientific research.
- b** **Article 5**  
Since the autonomy of every person is accepted as an important value, participation in decisions concerning one's own body or health must be recognised as a right.
- c** A decision to treat should be determined by co-operation between the person who treats and the person who is treated, both parties being linked together by mutual trust and reciprocity.
- d** Article 6 of the Declaration states that any medical intervention is only to be carried out with the prior free and informed consent of the person concerned based on adequate information. The Article also applies to scientific research.
- e** If the provisions of Article 6 cannot be applied (because consent is not possible), Article 7 applies with special provisions for persons not able to consent (see Unit 7).

2

## The principle of consent has several objectives

- a The purpose of the informed consent principle is to achieve several objectives. It asserts the patient's autonomy; it protects his/her status as a human being; it prevents coercion and deception; it encourages the doctor's self-criticism; it supports the process of rational decision-making; it educates the public at large.
- b The principle of consent is also important even if it does not achieve any objective. Article 1 of the *Universal Declaration of Human Rights* 1948 holds that all human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood. Consent therefore expresses respect for the dignity and rights of each human being.

3

## Explain the relation between autonomy and consent

- a Autonomy may be defined as self rule and refers to the right of persons to make authentic choices about what they should do and what shall be done to them (see Unit 5).
- b Autonomous persons can only make decisions and take responsibility for these decisions if they can consent to interventions that affect their lives.

4

## The provisions of Article 6 are subsequently explained

- a The article applies to all medical interventions. Medical intervention includes diagnosis, treatment, prevention, rehabilitation and palliation.
- b Being informed implies cognition, understanding, willingness, intention, and consideration. Consenting implies freedom (no coercion).
- c Consent requires adequate information. The requested information content should concern diagnosis, prognosis, treatment, alternative treatment, risks, benefits, according to relevant circumstances. The information process should specify: by whom; when (in advance); how (oral, writing, expressed); and to whom (patients, relatives, guardians, others).
- d The patient's consent may be given explicitly or implied. The term *implied consent* reflects the readiness of a patient to be treated even if verbal or written agreement has not been explicitly given by him. Consent to medical treatment may be implied from the words or conduct of the patient. Implied consent may exist when immediate treatment is required in order to save a patient's life, and it is impossible to obtain his explicit response. Consent can be implied also in various nonemergency cases.
- e A patient has the right to withdraw consent to treatment in any stage unless he or she is not capable of making such a decision.
- f A patient has the right to refuse treatment, unless he or she is not capable of making such a decision. A patient has the right to be treated without being informed if he or she is aware of the implications of such a decision.
- g Consent of subjects of medical research:
  - i The nature of the consent
  - ii The adequate information
  - iii The withdrawal of consent
  - iv The role of domestic and international human rights law
- h Consent by the individual and by the community in appropriate cases of research carried out on a group of persons or a community may require additional agreement of the legal representatives of the group or community concerned.

## Exceptional circumstances

**a** There are some circumstances in which the application of the principle is difficult or even impossible.

**b** For difficult circumstances special care needs to be given to the application of the principle, but it still does apply, even if difficult.

**c** If consent is impossible for various reasons, the provisions of Article 7 do apply (see Unit 7).

**d** Examples of exceptional circumstances:

**i Emergency situations**

There are certain circumstances in which acting out of necessity without informed consent is justified. For example, when an unconscious patient is involved and there is no known objection to treatment which is essential for the patient's survival.

**ii Minors**

The traditional concept put forward the claim of legal incapacity due to minority, and did not allow minors to consent to medical treatment. That concept has undergone modification. Various jurisdictions authorize minors to consent to certain types of care. Minors may be deemed legally capable for some purposes but not others. Whether the consent of a child is valid or not depends, *inter alia* on the extent of the child's ability to understand the issues involved and to exercise sufficient judgment.

**iii Patients who are mentally or emotionally incapable of rational decision making**

A patient is expected to have sufficient mental and emotional abilities in order to be engaged in the informed consent process. Otherwise, the consent must be obtained from a legally authorized substitute decision-maker. The mere fact that a person is mentally ill does not *per se* imply that he is unable to consent. However, if he/she is affected mentally, he/she lacks the capacity to understand in a reasonable manner the nature and effect of the medical information that is vital to the informed consent process.

**iv Jehovah's Witnesses**

Generally, the refusal of Jehovah's Witnesses to be treated need to be respected. However, the application of informed consent is difficult in cases of parents who refuse treatment on behalf of their children. If the child may die or suffer if not treated, treatment should be offered without the parents' consent and regardless of the refusal. Concerning pregnant mothers, a life-saving blood-transfusion for a Jehovah's Witness whose death would amount to abandonment of foetus may be allowed in light of the understanding that the need for its protection prevails over the mother's interest in freedom of religion. The above is based on the principle that the foetus or the infant has not yet reached a state in life in which they have assumed the religious or cultural values of the parents/community, so it cannot be assumed that the refusal of treatment/transfusion is in its/his/her best interest.

## UNIT 7

# Persons without the capacity to consent (Article 7)

## Unit Learning Objectives



Students should be able to explain the meaning of 'capacity to consent'



Students should be able to explain the criteria of capacity to consent



Students should be able to explain how the criteria for consent are applied in different circumstances of treatment and research

## Outline of the Syllabus

1

### Criteria for capacity to consent

- a Definition of incapacity
- b Criteria to determine capacity to consent
- c Article 7: special protection is to be given to persons who do not have the capacity to consent
- d Give examples of persons who cannot satisfy the criteria; distinguish different categories of persons not able to consent

2

### Categories of persons without the capacity to consent

- a Different distinctions can be made
- b Examples of persons who cannot satisfy the criteria

3

### Procedures

- a Explain Article 7.a.
- b How to obtain consent in health care practice?
- c Special procedures in ethics to construct consent
  - i Determination of appropriate substitute decision-makers
  - ii Best interest criterion

4

### The context of research involving human subjects

- a Explain Article 7.b.
- b Should research been done with persons not able to consent?
- c Research for direct health benefit
- d Research without potential direct health benefit

1

## Define incapacity and the criteria for capacity to consent

- a** Incapacity can be defined as lacking the freedom to make authentic decisions because of an inability to make such decisions even when given the opportunity. Various groups of people have been traditionally labelled in this way. They include people with learning difficulties, the mentally ill, children, confused elderly and unconscious people. A more systematic distinction between categories will be made later in this unit.
- b** Define the criteria for capacity to consent
  - i The ability to understand given information
  - ii The ability to appreciate the nature of the situation
  - iii The ability to assess the relevant facts
  - iv The ability to exercise choice
  - v The ability to use understood information for realistic and reasonable decisions
  - vi The ability to appreciate the consequences of giving or refusing consent
- c** Why is it important to make special arrangements for persons without the capacity to consent, as stated in the first sentence of Article 7?
- d** Give examples of persons who cannot satisfy the criteria; distinguish different categories of persons not able to consent

2

## Categories of persons not able to consent

- a** Different distinctions
 

Capacity to consent can be compromised due to various circumstances. Distinctions should be made between:

  - i categories of practices
    - △ clinical treatment and research
    - △ epidemiological research (e.g. use of previously collected data)
    - △ public health (e.g. vaccination)
    - △ emergency conditions (e.g. resuscitation)
  - ii categories of subjects
    - △ persons not yet able to make their own decisions (e.g. minors)
    - △ persons no longer able to make their own decisions (e.g. demented persons)
    - △ persons temporarily unable to make their own decisions (e.g. unconscious persons)
    - △ person permanently unable to make their own decisions (e.g. severely intellectually impaired persons)
  - iii categories of contexts
    - △ disadvantaged economical conditions
    - △ illiteracy
    - △ socio-cultural circumstances
    - △ captive audiences (e.g. prisoners, laboratory assistants)
- b** Examples
  - i Neonates
 

Neonates cannot think like adults. It is therefore impossible for them to be able to make decisions, to understand information, to process information rationally or to desire reasonable outcomes. As decisions have to be made about them, the best candidates for this role are the parents, on the

assumption that above all people they will have the best interests of their child at heart. However, in some cases parents do not make decisions in the best interests of their children. In those cases it is possible for the state to step in and remove the decision making role from them. This is done by making the child a ward of the court.

#### ii Children

It might appear that children cannot think like adults. Whilst this is certainly true of very young children, as children develop they show marked differences from each other. The *United Nations Convention on the Rights of the Child* (UNROC) asserts that children have the right to say what they think should happen when adults make decisions that affect them and to have their opinions taken into account (Article 12), have the right to get and share information (Article 13), have the right to think and believe what they want and practice their religion as long as they do not stop other people enjoying their rights (Article 14), and have the right to privacy (Article 16). Research activities involving children are carried out to learn more about the nature of paediatric development, disease and potential treatments. An important safeguard required to minimize loss of respect for autonomy is the general rule that where the research can be carried out by employing adults then children should not be used.

#### iii Confused elderly patients

Various forms of neurological deterioration including Alzheimer's disease rob people of the powers to make decisions. Relatives or true friends who knew them when well should be asked to help to build a picture of the patient's life, the preferences, the values and the wishes in which one can locate the decision that should be made. A hypothetical consent is a consent which would likely be in accord with the feelings of the patient when well.

#### iv Patients with learning difficulties

It is important not to confuse intellectual impairment with mental illness. Patients with learning difficulties represent a wide range of intellectual ability and no simple standard of capacity can be assumed between them. In each case an assessment according to the criteria outlined above is called for in combination with an awareness of the nature of the decision to be made. Only in extremely serious cases will a person with this problem be unable to make a decision about anything. In those cases where either the impairment is so severe that the decision is too onerous or complex to be grasped by the person, a best interest judgement on their behalf should be made.

#### v Mentally ill patients

A person who is termed incapable is one whose mental deficiency deprives him/her of the ability to safeguard his/her own interests. As with intellectual impairment so with mental illness, one cannot assume that all persons possess equal capacity or otherwise. On the one extreme, demented people cannot make coherent choices. On the other hand when not in florid state a person with schizophrenia might be quite clear about how he feels about matters of life and how he would wish to address them.

#### vi Unconscious patients

Such documents as Advance Directives or Living Wills might be valuable guides but have inherent weaknesses that should be taken into account. They might be old and out of date, they express hypothetical wishes, and there is always the need to know under what circumstances the documents were produced. The documents should be in accordance with domestic law.

3

## Procedures:

### a Explain Article 7.a.

- i. Authorization for research and medical treatment should be obtained in accordance with the best interest of the person concerned. This person should be involved to the greatest extent possible in the decision-making process of consent, as well as that of withdrawing consent.

### b Obtaining consent in health care practice

- i. The concept of informed consent consists of two ingredients: the consent should be free, and it must be based on adequate information and explanation. Patients and research subjects should be advised, inter alia, about the contents and process of the research and the treatment, the foreseeable injuries, risks and benefits, and their right to discontinue their participation at any time and without any sanctions. Consent should be obtained from research subjects or their legally authorized representatives. The research should not involve more than minimal risk for the subjects.

### c Special procedures in ethics to construct consent

- i. Determination of appropriate substitute decision-makers
  - Δ If a patient is placed under a guardianship, usually the legal capacity to consent to care is taken away.
- ii. Best interest criterion
  - Δ Medical treatment and research should only be carried out for the direct health benefit of the subject, and according to the authorization and protective legal conditions.

4

## The context of research with persons

### a Explain Article 7.b.

- i. Research should only be carried out if there is no research alternative of comparable effectiveness with research participants able to consent.

### b Should research be done with persons not able to consent?

- i. For a potential research subject who is incompetent, the researcher must seek informed consent from the legally authorized representative.

### c Research for potential direct health benefit

- i. Medical research involving human subjects may only be conducted if the importance of the objectives outweighs the inherent risks and burdens to the research subjects. Incompetent subjects must not be included in a research study that has no likelihood of benefit for them unless it is intended to promote the health of the population represented by the potential subject. Medical research involving a disadvantaged or vulnerable population is only justified if the research is responsive to the health needs and priorities of this population and if there is a reasonable likelihood that this population stands to benefit from the results of the research.

### d Research without potential direct health benefit

- i. In certain situations harms and benefits to the society may justify the use of medical research. Research that does not have potential direct health benefit should only be undertaken by way of exception, with the utmost restraint, exposing the person only to a minimal risk and minimal burden, and if the research is expected to contribute to the health benefit of other persons in the same category.

## UNIT 8

# Respect for human vulnerability and personal integrity (Article 8)

## Unit Learning Objectives



Students should be able to explain the principle of respect for human vulnerability



Students should be able to analyse the interrelationship between present-day scientific medicine and human vulnerability and to illustrate the difficulties in this relationship with examples



Students should be able to specify the connections of the principle of respect for human vulnerability with the notion of personal integrity and with care ethics

## Outline of the Syllabus

1

### The notion of 'human vulnerability'

- a Respect for human vulnerability
- b Different aspects of vulnerability
  - i biological
  - ii social
  - iii cultural
- c Implications of the principle: care

2

### The powers of medicine

- a The fight against vulnerability
- b Successes and failures
- c Problems with the basic assumption that vulnerability should be eliminated
- d Towards sustainable medicine

3

### The dilemmas of vulnerability

4

### Care ethics

- a New approaches in bioethics
- b Solidarity
- c The duty to care

5

## The notion of personal integrity

- a Relation between vulnerability and personal integrity
- b Personal integrity does not refer to a virtue
- c Personal integrity refers to respect for the patient's understanding of his or her own life and illness, but also for his/her interests and free will

## Teacher Manual

1

### Explain the notion of 'vulnerability'

- a The principle of respect for human vulnerability expresses a concern for the fragility of human beings. As whole and integrated entities their functioning can easily be disturbed and deranged so that their health and even existence can come under threat. The principle is related to the principle of personal integrity.
- b Several aspects of vulnerability need to be distinguished:
  - i biological or corporeal vulnerability; this concerns the fragility of the human organism originating from:
    - △ natural threats are coming from our biology: ageing, susceptibility to illness and disease, and death
    - △ environmental and other natural and man-made threats: famine, earthquake, hurricanes, pollution and environmental disasters
  - ii social vulnerability; this concerns the fragility of the human capacity for creating coherence in one's life and for sharing goods and services.
    - △ social threats stemming from war and crime, prejudice and discrimination, cruelty and indifference
    - △ persons also become vulnerable due to hospitalization and institutionalization
    - △ social circumstances and conditions
  - iii cultural vulnerability; this concerns the fragility of particular traditions and conceptions of values that are typical for a community or local cultures.
- c In ethics, the notion of vulnerability is not just a neutral description of the human condition but instead a normative prescription to take care of the vulnerability that is characteristic for human beings. Ethics is more than respecting individual choices and decisions; it aims at care for the other. For example, the human face can show the vulnerability of the human person and at the same time appeal for help and assistance.

2

### The powers of medicine

#### The fight against vulnerability

- a A common idea is that the vulnerability of the human condition should be eliminated or reduced. Science and technological innovations should be used to overcome the natural threats. Medical research should be focused on eliminating the biological threats to the human body. The basic assumption behind this fight is that many vulnerabilities of the human condition are contingent, not inherent.
- b This fight has been successful but at the same time has failures. Life expectancy and health have improved, poverty and starvation reduced, but at the same time many people die from common diseases, life expectancy is decreasing in many countries, and poverty is still widespread.

- c** The basic assumption that vulnerability should be eliminated has in itself created problems:
- i if vulnerability is regarded as an evil to be eradicated, it cannot be given any positive meaning; we cannot understand human vulnerability and thus human suffering
  - ii religion, alternative medicine and traditional knowledge present different ways of knowing and valuing; because they are open to different perspectives, they can give meaning to vulnerability, but their views are generally not accepted by mainstream science or bioethics
  - iii economic problems; the success of science and technology has created financial difficulties in almost all countries in achieving decent levels of health care for the population. Because of its continuous fight against vulnerability, medicine often is not 'sustainable'
  - iv medical progress itself has created new forms of vulnerability, i.e. chronic illness. This presents continuing vulnerability for a growing population
- d** An unrestrained fight against human vulnerability generates its own problems. Not the struggle against human vulnerability is a mistake but the struggle to rid the human condition of all vulnerability. For a sustainable medicine it is necessary to accept some vulnerability as a permanent part of the human condition.

## 3

**The dilemmas of vulnerability**

- a** 'Taking into account human vulnerability', as stated in Article 8, requires a balance between eliminating and accepting human vulnerability. This balance is manifest in some dilemmas:
- i disability
- Disability is viewed as abnormal and the disabled therefore are by definition vulnerable; at the same time the disabled should not be stigmatized by being treated as abnormal.
- ii death
- In medicine the place of death in human life is ambivalent; in palliative care, death is understood as being part of life; in some other sectors of medicine death is still treated as the enemy.
- iii depression
- Prozac is widely used as an anti-depressant drug, when there are clear clinical symptoms of depression; at the same time it is regarded as medication for unhappiness and sadness.

- b** Human suffering and misery express human vulnerability. They also pose a challenge. We must at the same time struggle to keep suffering to a minimum and also accept it as part of life. Human vulnerability cannot be merely regarded as an enemy to be eliminated. Too much emphasis on eradication has led to evils in the name of some supposed good: the eugenics movement, Nazism to eliminate the socially and ethnically unfit, and totalitarian regimes to eliminate social injustice.

## 4

**Care ethics**

- a** The challenge of human vulnerability is that it can never be entirely eliminated from human life. Instead, it should inspire new approaches in bioethics
- b** The human condition requires solidarity; human beings all share common vulnerabilities
- c** Human vulnerability also leads to an ethics of care. Because it is a shared characteristic, it is also a source of concern for others as well as awareness that we rely on others. It is the basis for the duty to care for those threatened by biological, social and cultural threats as well as by the power of medicine itself.

## The notion of personal integrity

- a The principle of respect for human vulnerability is related to the notion of personal integrity; this is mentioned in the last part of Article 8.
- b Integrity concerns the wholeness of an individual. In ethical discourse, integrity is often considered as a virtue, related to the honesty of somebody's character for example. But respect for personal integrity in this Article does not refer to somebody's moral character or his/her good behaviour. It refers to fundamental aspects of a human life that should be respected.
- c Personal integrity refers here to respect for the patient's understanding of his or her own life and illness, but also for his/her interests and free will. Each person's life has a coherence, a narrative whole based on important events in his/her life and by his/her interpretations and values. What is most valuable to a person is grounded in this narrative whole. It is this personal integrity of human beings that must be protected.

## UNIT 9

## Privacy and confidentiality (Article 9)

## Unit Learning Objectives



Students should be able to explain why patient privacy and confidentiality should be respected



Students should be able to recognise legitimate exceptions to confidentiality

## Outline of the Syllabus

1

Definitions of 'privacy' and 'confidentiality'

2

Reasons for respecting privacy and confidentiality

3

Duty of health care providers to protect the privacy of patients

4

Duty of health care providers to maintain confidentiality (also known as 'professional secrecy')

5

Confidentiality extends to all personal health information, including genetic data

6

Justified breaches of confidentiality include:

- a Sharing information for patient care
- b Using interpreters
- c Teaching medical students
- d Mandatory reporting
- e Serious danger to others
- f Genetic information
- g Patient or guardian consent

7

Special circumstances of research

## Teacher Manual

### 1 Definitions of 'privacy' and 'confidentiality'

Privacy is the right of an individual or a group to be free from intrusion from others, and includes the right to determine which information about them should be disclosed to others (see Units 5 and 6). Confidentiality is an attribute of personal information requiring that it not be disclosed to others without sufficient reason.

### 2 Reasons for respecting privacy and confidentiality:

- a Individuals 'own' their information: it is essential to their personal integrity.
- b For many people privacy is an essential aspect of their dignity (see Unit 4); invading their privacy against their will is a violation of their dignity.
- c Respect for others requires protecting their privacy and the confidentiality of information about them.
- d Patients are less likely to trust health care providers and confide in them if they think that the health care providers will not keep the information confidential. This can have serious consequences for the patients' health and well-being and sometimes for the health of others (e.g. family members).

### 3 Duty of health care providers to protect the privacy of patients

Health care providers have an ethical obligation to protect patient privacy to the greatest extent possible in the circumstances. For example, they should interview patients where they cannot be overheard; they should ask the patient's permission to examine him or her unclothed; and they should ensure that an unclothed patient cannot be viewed by passers-by.

### 4 Duty of health care providers to maintain confidentiality

The duty of maintaining confidentiality (also known as 'professional secrecy') has been part of Western medical ethics since Hippocrates (5<sup>th</sup> century B.C.E.). The Hippocratic Oath states, 'Whatever I see or hear, professionally or privately, which ought not to be divulged, I will keep secret and tell no one.' Ethics courses in non-Western countries should discuss the source of medical confidentiality in their cultures.

### 5 Confidentiality extends to all personal health information, including genetic data

UNESCO *International Declaration on Human Genetic Data*: '...all medical data, including genetic data and proteomic data, regardless of their apparent information content, should be treated with the same high standards of confidentiality.'

### 6 Justified breaches of confidentiality include:

- a **Sharing information for patient care**  
In the hospital setting, many individuals need access to the patient's chart in order to provide care; however, each of these individuals is bound to maintain confidentiality to the greatest extent possible; outside the hospital setting, family members may need patient information in order to provide care and/or to protect themselves.

**b Using interpreters**

Where the health care provider does not speak the patient's language, an interpreter will be needed who will then have access to information about the patient; interpreters should be bound to observe confidentiality.

**c Teaching medical students**

Observation and discussion of patients is a necessary part of medical education; students should be informed of their obligation to maintain confidentiality.

**d Mandatory reporting**

Health care providers should be familiar with the laws about mandatory reporting of infectious diseases, suspected child abuse and other conditions in the country where they practise; normally patients should be informed that their information has to be reported to the appropriate authorities.

**e Serious danger to others**

For example, in exceptional circumstances and generally as a last resort, health care providers may need to inform other persons that the patient has threatened to harm them, whether by violence or by sexual contact when the patient has a transmissible disease such as HIV.

**f Genetic information**

There is controversy regarding whether other individuals with the same genetic makeup (usually close family members) have a right to a patient's genetic information. Physicians should consult their national regulations or guidelines when faced with this situation.

**g With patient or guardian consent**

This should generally be obtained for all breaches of confidentiality and renders the breach acceptable ethically.

## 7

**Special circumstances of research**

**a** Disclosure of personal health information obtained in the course of a research study requires the prior consent of the research subject.

**b** There is a great controversy regarding whether anonymized patient information requires consent for disclosure; researchers should consult their national regulations or guidelines if such exist, otherwise international guidelines such as the *Declaration of Helsinki*.

**c** In research, communities as well as individuals have a right to privacy, and information about them should be kept confidential, especially when its disclosure may be harmful to the community.

**d** Scientific publication should respect confidentiality to the greatest extent possible. Consent is always required when an individual research subject can be identified in a publication.

UNIT 10

# Equality, justice and equity (Article 10)

## Unit Learning Objectives



Students should be able to identify and deal with the ethical issues involved in allocating scarce health care resources



Students should be able to recognize conflicts between the health care professional's obligations to patients and to society and identify the reasons for the conflicts

## Outline of the Syllabus

1

Definitions of 'equality', 'justice' and 'equity'

2

The different types of justice

- a Distributive
- b Procedural
- c Retributive
- d Social

3

The different concepts of distributive justice (the most important types for health care)

- a Authoritarian
- b Libertarian
- c Utilitarian
- d Egalitarian
- e Restorative

4

How these different concepts of justice are reflected in the different health care systems found around the world

5

The right to health care

6

**Disparities in health status**

- a Local disparities
- b National disparities
- c Global disparities

7

**Roles of health care professionals in establishing health care priorities and allocating scarce health care resources**

- a As government policy makers and officials
- b As hospital authorities
- c As direct health care providers

**Teacher Manual**

1

**Definitions of 'equality', 'justice' and 'equity'**

'Equality' means sameness in some respect such as human dignity; 'justice' has different meanings (there are different types of justice – see below) but generally it signifies fairness; 'equity' is the application of fairness, which may require unequal treatment.

2

**The different types of justice:**

- a Distributive (ensuring that each person receives a fair share of public resources); this is the most important type for health care
- b Procedural (ensuring a fair process for making decisions and settling disputes)
- c Retributive (ensures punishment of wrongdoers)
- d Social (combination of the previous types as applied to a society in which individuals and groups receive fair treatment and an equitable share of the benefits of society).

3

**The different concepts of distributive justice:**

- a Authoritarian (what the highest authority decrees is just)
- b Libertarian (what an individual decides to do with his or her own property is just)
- c Utilitarian (what most contributes to the greatest good of the greatest number is just)
- d Egalitarian (justice is achieved when everybody has equal access to the societal resources that they need)
- e Restorative or transformative (justice requires favouring previously disadvantaged individuals or groups)

#### 4 — How these different concepts of justice are reflected in the different health care systems found around the world

The Libertarian one is strong in the U.S.A. The Egalitarian one is predominant in many European countries where the value of social solidarity is recognized. South Africa is attempting to implement a restorative approach. Most economists lean towards the Utilitarian approach. Which predominates in your country?

#### 5 — The right to health care

The Constitution of the World Health Organization states that the 'enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being...' International statements on human rights, such as the *International Covenant on Economic, Social and Cultural Rights* and the *Convention on the Rights of the Child*, support the right to health and require signatory nations to secure its observance. What does this right to health mean in practice?

#### 6 — Disparities in health status

Health care professionals are faced with many disparities in health status, generally associated with disparities in wealth/income or with discrimination against women, minorities or other disadvantaged groups

- a Local disparities
- b National disparities
- c Global disparities

What can/should health care professionals do about these disparities?

#### 7 — Roles of health care professionals in establishing health care priorities and allocating scarce health care resources

Health care professionals play several roles in establishing health care priorities and allocating scarce health care resources

- a As government policy makers and officials
- b As hospital authorities
- c As direct health care providers
- d As researchers

What concept of distributive justice is most appropriate for each of these roles? How should health care professionals deal with conflicts between roles (e.g., between providing expensive curative measures for individual patients in need and vaccination programs for the population)?

## UNIT 11

# Non-discrimination and non-stigmatization (Article 11)

## Unit Learning Objectives



Students should be able to explain the concepts of discrimination and stigmatization in the context of bioethics



Students should be able to identify different contexts and bases of discrimination and stigmatization and their implications



Students should be able to identify and deal with situations where exceptions to the principle can be justified

## Outline of the Syllabus

1

### What is discrimination and stigmatization?

- a The notion 'discrimination'
- b The notion 'stigmatization'

2

### What is positive or reverse discrimination?

3

### Grounds of discrimination and stigmatization

- a Advances in medical technology may create disproportionate disadvantages for some social groups
- b The unfair use of genetic testing
- c Genetic discrimination

4

### Context and background

- a Explanation of Article 11
- b Background for the Article

5

### Limitations of the principle:

- a Each principle of the Declaration relates to the other principles (Article 26)
- b Limiting the application of the principles is regulated in Article 27
- c The protection of public health can be a limiting factor

## Teacher Manual

1

### Definition of the notions 'discrimination' and 'stigmatization'

- a The word 'discrimination' comes from the Latin *discriminare*, which means to 'distinguish between'. Thus, to discriminate socially is to make a distinction between people on the basis of class or category without regard to individual merit, which is an infringement of the ethical theory of egalitarianism based on social equality (see Unit 10). Distinctions between people which are based just on individual merit (such as personal achievement, skill or ability) are generally not considered socially discriminatory, contrary to distinctions based on race, social class or caste, nationality, religion, sex, sexual orientation, disability, ethnicity, height, age or any other ground in violation of human dignity, human rights and fundamental freedoms.
- b According to the *Encyclopaedia Britannica* 'stigmatization' is a discrediting process which strikes an individual who is considered as 'abnormal' or 'deviant'. He or she is reduced to this single characteristic in other people's eyes or opinions for whom this 'label' justifies a range of social discriminations and even exclusion. The social impact of stigmatization shows a number of negative behaviours toward stigmatized people that can end in real discrimination as regards, for example, access to social services such as health care and education, employment and professional advancement, income level and domestic life.

2

### Positive or reverse discrimination

- a Discriminatory policies or acts that benefit a historically and socio-politically non dominant group (typically women and minorities but sometimes majorities), at the expense of a historically and socio-politically dominant group (typically men and majority races) are called 'positive or reverse discrimination' or 'affirmative action policies'.
- b However, whether a given example of discrimination is positive or negative is often a subjective judgement.
- c In the field of health care and bioethics, some groups need more protection such as infants and elderly people, AIDS patients, psychiatric patients and depressed patients.

3

### Grounds of discrimination and stigmatization

- a Advances in medical technology have the potential to create disproportionate disadvantages for some social groups, either by being applied in ways that harm members of these groups directly or by encouraging the adoption of social policies that discriminate unfairly against them with significant individual, social and legal consequences. For instance, reproductive medicine has developed techniques that enable parents to choose the sex of their child which raises the concern of discrimination against girls and women in societies where male children are valued more highly than female children. Similar concerns have been raised about the increasing use of abortion as a method of birth control in overpopulated countries where there is considerable social and legal pressure to limit family size and where the vast majority of the parents who use it choose to have a boy rather than a girl.
- b In the field of genetics, the use of relatively simple tests for determining a patient's susceptibility to certain genetically transmitted diseases has led to concerns that the results of such tests, if not properly safeguarded, could be used in unfair ways by health-insurance companies, employers, and government agencies. In addition, through genetic counselling prospective parents can be informed about the chances that their offspring will inherit a certain genetic disease or disorder; this will enable them to make more informed decisions about reproduction. This is viewed by some bioethicists and some NGOs as contributing to a social atmosphere considerably less tolerant of disability than it ought to be. The same criticism has been levelled against the practice of diagnosing, and in some cases treating, congenital defects in unborn children.

**c** Research on the genetic bases of behaviour, though still in its infancy, is controversial, because of its potential to encourage the adoption of crude models of genetic determinism in the development of social policies, especially in the areas of education and crime prevention. Such policies, it is claimed, could result in unfair discrimination against large numbers of people judged to be genetically disposed to 'undesirable' forms of behaviour, such as aggression or violence.

**d** The advent of genetics has provided a powerful tool to analyse and describe differences between people. Great care is called for in the investigation of cultural differences by such means else the harms already endured by minorities might be intensified. Consider the example of the 'warrior gene'. The so-called warrior gene was not identified by a New Zealand researcher but was internationally known before it was measured in Maori people. It is, in fact, not a gene as such but rather a variant of the gene monoamine oxidase-A which was originally found in monkeys and then found to exist in most humans. It has been suggested that the 2R variant of the gene correlates with the likelihood of committing crimes or violence. This variation was found to be over-represented in a small Maori population by a ratio of 2 to 1 over white/non-hispanic groups in a study on the incidence of tobacco smoking amongst Maori. The press soon caught on to the possibility that this gene might indicate, for example, why Maori were also over-represented in New Zealand prisons and caused something of a national scandal. The number of Maori respondents made trenchant criticisms of this kind of 'discovery' which stigmatised Maori people as being anti-social and having criminal tendencies when there were perfectly proper social explanations of the demographic features wrongly attributed to genetic make-up.

4

## Context and background

**a** Explanation of Article 11, as a theoretical and practical continuation of Articles 3 and 10, and continued in discussion of Articles 13, 14, and 15

**b** Background for the Article:

- i Articles 1 and 2 of the *Universal Declaration of Human Rights*
- ii Article 7 of the *International Declaration on Human Genetic Data*

5

## Limitations of the principle:

**a** Article 26 of the Declaration states that the principles should be understood as complementary and interrelated; the Declaration is to be understood as a whole. This implies that if a bioethical issue or problem emerges, it is usually the case that several principles are relevant to the issue or problem and need to be balanced in order to reach a justified conclusion about what to do.

**b** Article 27 specifies the limitations on the application of the principles. It mentions several conditions in which application may be limited:

- i by law
  - △ laws in the interests of public safety
  - △ laws for the investigation, detection and prosecution of criminal offences
  - △ laws for the protection of public health
  - △ laws for the protection of the rights and freedoms of others
- ii such law need to be consistent with international human rights law

**c** When therefore public health is at risk, exceptions or restrictions to the non discrimination principle can be *necessary* either by affirmative actions in favour of some key persons or groups, or by 'negative' actions that may infringe upon individual rights. These exceptions must be publicly discussed and applied with transparency and according to the national law. They also must be subject to revision according to developments of the situation and scientific knowledge.

UNIT 12

# Respect for cultural diversity and pluralism (Article 12)

## Unit Learning Objectives



Students should be able to explain the meaning of 'culture' and why it is important to respect cultural diversity



Students should be able to explain the meaning of pluralism and why it is important in the field of bioethics



Students should be able to deal with cultural diversity and take into consideration cultural specificities (appropriate approach, positive inputs and limits) with respect to the fundamental principles of bioethics and human rights

## Outline of the Syllabus

1

### Background

- a Definition of culture and cultural diversity
- b Value of respect for cultural diversity
- c Definition and value of pluralism

2

### Explanation of Article 12

- a As a theoretical and practical continuation of other articles
- b The principle will raise questions concerning:
  - i Discrimination
  - ii Infringement of the autonomy principle
  - iii Infringement of national laws

3

### Limits to the consideration for cultural specificities

- a Human dignity, human rights and fundamental freedoms
- b Domestic law, national regulations and international human rights laws
- c Indigenous knowledge and practices
- d Principles set out in the Declaration

1

## Definitions and background

### a Definition of culture and cultural diversity

- i According to the UNESCO *Universal Declaration on Cultural Diversity*: 'Culture should be regarded as the set of distinctive spiritual, material, intellectual and emotional features of society or a social group, and it encompasses, in addition to art and literature, lifestyles, ways of living together, value systems, traditions and beliefs.'
- ii As stated in Article 1 of the above Declaration: 'Culture takes diverse forms across time and space. This diversity is embodied in the uniqueness and plurality of the identities of the groups and societies making up humankind.'

### b Value of respect for cultural diversity

- i UNESCO considers cultural diversity as the common heritage of humanity and therefore it should be recognized and safeguarded for the benefit of present and future generations.
- ii As a source of exchange, innovation and creativity, cultural diversity is as necessary for humankind as biodiversity is for nature and it is essential to ensure harmonious interaction among people and groups with plural, varied and dynamic cultural identities as well as their willingness to live together.
- iii Thus, policies for the inclusion and participation of all cultural groups and citizens are guarantees of vitality, social cohesion and peace.

### c Definition and value of pluralism

- i Pluralism is, in a general sense, the affirmation and acceptance of diversity. The concept is used in a wide range of issues: politics, science, medicine and medical practices, religion, philosophy and ethics.
- ii Value-pluralism means that there are several values which may be equally correct and fundamental, and yet in conflict with each other. These various values and ideals have no common character apart from the fact that they are ideals (see Unit 1).

2

## Explanation of Article 12

### a As a theoretical and practical continuation of Articles 3 and 10, and to be continued in discussion of Articles 13, 14, and 15

### b The principle will raise questions concerning:

- i Discrimination
- ii Infringement of the autonomy principle
- iii Infringement of national laws

3

## Limits to the consideration for cultural specificities

### a Human dignity, human rights and fundamental freedoms.

- i Respect for cultural diversity can never be invoked when it infringes upon human dignity, human rights and fundamental freedoms.
- ii Cultural value pluralism thus cannot be used as a way of justifying discrimination and stigmatization. Value-pluralism is an alternative to moral absolutism and differs also from value-relativism in that pluralism imposes limits to differences, such as when vital human needs or rights are violated. The value of cultural

diversity may be in conflict with other human rights values. In this case, it is necessary to analyze and balance wisely the values in conflict.

**b Domestic law, national regulations and international human rights laws**

i Legal limits

Example: blood transfusion for children in the case of Jehovah's Witnesses.

ii Moral and legal limits

Example: sex selection by the use of prenatal and preimplantation genetic diagnosis without any concomitant medical reason but for 'family balancing' in some societies. Usually used to select male embryos or foetuses, this is considered discrimination (see Unit 11).

**c Risks/benefits of indigenous knowledge and practices**

For example practices of traditional healing should be promoted or nationally authorized as long as they are effective and there is no scientific evidence of toxicity or harm. They should be evaluated by the concerned societies and groups although there are disputes about the criteria for evaluation.

**d Using international declarations/instruments**

- i Article 4 of the UNESCO *Universal Declaration on Cultural Diversity* stipulates 'Human rights as guarantees of cultural diversity. The defence of cultural diversity is an ethical imperative, inseparable from respect for human dignity. It implies a commitment to human rights and fundamental freedoms, in particular the rights of persons belonging to minorities and those of indigenous peoples. No one may invoke cultural diversity to infringe upon human rights guaranteed by international law, nor to limit their scope.'
- ii Article 4 of the *International Declaration on Human Genetic Data*: human genetic data have a special status because: (Paragraph iv) they may have cultural significance for persons or groups. Due consideration should be given to the sensitivity of human genetic data and an appropriate level of protection for these data and biological samples should be established.

## UNIT 13

## Solidarity and cooperation (Article 13)

## Unit Learning Objectives



Students should be able to explain the development of the notion of solidarity in different societies



Students should be able to describe the difference between solidarity as an instrumental and a moral value



Students should be able to give examples of solidarity in the context of health care and research

## Outline of the Syllabus

1

## The notion of solidarity

- a Discuss the notion of solidarity: first associations
- b Solidarity in health care
- c Opposition to individualism
- d Evolution of solidarity in society
  - i mechanical solidarity
  - ii organic solidarity
  - iii organized solidarity
- e Ethical perspective
  - i Solidarity as instrumental value
  - ii Solidarity as moral value

2

## Threats to solidarity in present-day societies

3

## Relationship of solidarity, autonomy, and justice

4

## International cooperation

5

## Health insurance – provision of health care to the general population as an end, health insurance as a means

## The notion of 'solidarity'

### a Discuss the notion of 'solidarity'

Ask students with what do they associate this notion, for example:

- i mutual respect
- ii support of the weak and vulnerable
- iii commitment to a common cause or the common good
- iv belonging together
- v mutual understanding
- vi shared responsibility

**b** Solidarity is applicable in the context of health care systems. In Europe for example, everyone is obliged to make a fair financial contribution to a collectively organised insurance system that guarantees equal access to health and social care for all members of society.

**c** Solidarity is often considered to be opposed to individualistic behaviour and contrasted with self-centred individualism, as a personal and social concern for vulnerable groups in modern societies, in particular the chronically ill, the handicapped, political refugees, immigrants and the homeless.

**d** Sociological analysis shows that solidarity can have different expressions in the evolution of societies:

- i In traditional societies (homogeneous and without much differentiation in social functions) solidarity rests on the social uniformity of beliefs, practices and sentiments ('mechanical solidarity', 'group solidarity' or 'associative solidarity');
- ii During the transition from traditional to modern societies, the form and contents of social ties between individuals are transformed and hence the nature of social solidarity. Differentiation and diversification of functions and tasks create relations of interdependence between individuals. Division of labour and structural interdependence require new rules of cooperation ('organic solidarity', 'contractual solidarity');
- iii In post-industrial, globalised societies, solidarity takes the form of 'organised solidarity'. Building new forms of solidarity is an ongoing project. In many cases, common interests, interdependencies and personal relations no longer exist. Still 'solidarity of strangers' is possible. Modern solidarity functions between non-related and impersonal members of a society.

**e** From an ethical perspective, solidarity is first and foremost a moral value focused on providing support to those who need it. Among members of a community mutual obligations exist. This also implies that a fundamental difference should be made between two forms of solidarity:

- i Solidarity as instrumental value

Solidarity as self-interest, reciprocal solidarity. The enlightened self-interest of rationally calculating individuals motivates them to cooperate.

- ii Solidarity as moral value

Group oriented responsibility to care for the weaker and more vulnerable members of the community. Real solidarity implies that we take care of vulnerable persons even if it would not be in our interest or even if there is no specific purpose. Human beings share identity as members of the same collectivity and therefore feel a mutual sense of belonging and responsibility. Solidarity in this sense is 'humanitarian solidarity'; it is the expression of an ethics of commitment, a sense of responsibility towards the most vulnerable in society. Not self-interest but the interest of others motivates cooperation.

2

## Threats to solidarity

- a** Solidarity in present-day societies is under threat due to various factors.
- i Globalisation; more anonymous approach; less connectedness with other human beings;
  - ii Increasing demands for expensive treatments, for instance due to the ageing of populations; the range of options for individuals has enlarged;
  - iii Changing and more demanding attitudes of clients, related to increasing individualisation of societies with increasing stress on the moral significance of individual autonomy;
  - iv Shift towards more private financial responsibility and increasing pressure of market ideology;
  - v Erosion of local communities and extended family networks changing personal and social relationships;

- b** In present-day societies there is a tension between solidarity, personal autonomy and responsibility. The example of unhealthy lifestyles illustrates this tension. Individuals are free to choose the lifestyles they prefer but if these are notoriously risky for their health, can they still expect the solidarity of citizens if they fall ill?

3

## Relationship of solidarity, autonomy, and justice

Solidarity goes beyond justice. Justice is a matter of obligation from one free individual to another; it is based on the shared interest of preserving the requisite amount of freedom for all citizens. Solidarity is not necessarily a legal obligation. Solidarity does not necessarily restrict autonomy.

4

## International cooperation

- a** What do solidarity and cooperation imply?
- b** Relationship with benefit sharing (see Unit 15)

5

## Health insurance

Provision of health care to the general population as an end, health insurance as a means

UNIT 14

# Social responsibility and health (Article 14)

## Unit Learning Objectives



Students should become acquainted with the shared responsibilities of the state and various sectors of society in regard to health and social development



Students should understand the requirements of global justice and the notion of the highest attainable standard of health care as a right



Students should be able to explain that health status is a function of social and living conditions and that the attainment of the highest attainable standard of health care depends upon the attainment of minimum levels of social and living conditions



Students should be able to appreciate the urgent need to ensure that progress in science and technology facilitates access to quality health care and essential medicines as well as the improvement of living conditions and the environment, especially for marginalized segments of the population



Students should be able to analyze potentially exploitative social practices or arrangements affecting public health and recommend possible solutions

## Outline of the Syllabus

1

Highest attainable standard of health as a fundamental human right

a *Universal Declaration of Human Rights*

b WHO Constitution

2

Health and the impact of social and overall living conditions

a The need for health care initiatives to take into account the broad development context

b The ethical significance of public and population health initiatives

3

Duty, obligation and responsibility and how these are acquired by individuals, groups or institutions

4

Responsibilities for governments and various sectors of society

a Responsibilities of governments

b Social responsibilities of the health sector and the medical profession

c Social responsibilities of the private sector and industry

5

## Health and contemporary challenges to global justice

- a Access to essential drugs and health services
- b Poverty and the HIV/AIDS pandemic
- c Standard of care in international health research
- d The protection of vulnerable populations
- e Research prioritization
- f Providing health care services across national boundaries
- g Organ transplantation and medical tourism

### Teacher Manual

1

#### Highest attainable standard of health as a fundamental human right

- a Section 1, Article 25 of the *Universal Declaration of Human Rights* states that 'everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services . . .' (1948).  
  
Moreover, the WHO Constitution provides that 'the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition' (1946). The recognition of the highest attainable standard of health as a fundamental human right establishes a heavy ethical burden on health care and related sectors, especially because of the broad definition of health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (1946). See also Units 2 and 4.
- b

2

#### Health and the impact of social and overall living conditions

- a Ethically-minded players in the health sector appreciate the need for health care initiatives to take into account the broad development context that includes the reduction of poverty, stewardship of the environment, and assurance of human rights, gender equity and global security. Such ethical initiatives reaffirm the definition of health as expressed in WHO's Constitution, and the recognition of health as both a means to other development goals and as an end in itself.
- b This section also highlights the ethical significance of public and population health initiatives, as they constitute a dynamic instrument for achieving social and economic development, justice and security. Whereas health has been conventionally viewed as an end in itself, the discussion examines the synergistic relationship between health and other aspects of development.
  - i Poverty defined as the undermining of a whole range of key human capabilities, including health. Ill-health disproportionately afflicts poor people, and sudden health problems push people into greater poverty (the 'medical poverty trap').
  - ii The need to reduce the burden of excess mortality and morbidity suffered by the poor populations in both poor and rich countries.
  - iii The sensitivity of health to the social environment and to 'the social determinants of health'.
  - iv Inequalities between men and women, regions, ethnic groups, rural and urban areas, and in legal status.

3

### Duty, obligation and responsibility and how these are acquired by individuals, groups or institutions

- a Individuals, groups or institutions may be ascribed duties, responsibilities or obligations in a number of ways. In the case of governments, these may be defined constitutionally, or by the instrument that established the state. These may also be determined by agreements entered into with other governments, international organizations, or other bodies. In the case of individuals, these may be defined by state laws or by rules and regulations governing membership of a particular group (e.g., professional, religious, interest, or advocacy group). The same applies to groups or agencies established within the context of national laws or statutes.
- b Responsibility may be acquired also in respect of roles that individuals, groups or institutions assume in a particular social-political-economic context. Moreover, in light of conditions characterized by wide disparities in economic, social and political power, protection of the fundamental right to the highest attainable level of health puts a burden on individuals, groups and institutions to provide assistance that is within their means. This notion of responsibility has been specifically referred to as social responsibility.

4

### Responsibilities for governments and various sectors of society

This section examines the context within which governments and other stakeholders have to operate when they try to provide health care and other needs to the population. The conditions characterizing that context have implications for the specific responsibilities that may be ascribed to the different stakeholders. Ordinarily, the degree of responsibility increases as one's amount of control over a given situation rises. It is useful to analyze different situations in order to consider the extent to which stakeholders may be adjudged to have a responsibility, and to identify the specific initiatives that may be identified as falling within the sphere of their ethical obligations.

- a **Responsibilities of governments**  
The government or the state has the primary duty to uphold and protect the rights of its citizens. It is also charged with the responsibility to provide the environment that could maximize the contributions of other sectors to the promotion of fundamental rights.
- b **Social responsibilities of the health sector and the medical profession**  
The Physician's Oath contained in the *Declaration of Geneva* (1948, 1968, 1983, 1994, 2006) and the *WMA International Code of Medical Ethics* (1949, 1968, 1983, 2006) enumerate the duties of medical practitioners. Nurses, dentists, caregivers and other workers in the health care community have similar or corresponding responsibilities. This section examines the responsibilities that arise in relation to professional roles as well as to the gaps in health service that cannot be sufficiently filled by referring to such roles.
- c **Social responsibilities of the private sector and industry**  
Regardless of the nature of the products they produce or services they offer, industries have an ethical responsibility to promote the interests of society. The responsibility ought to be shared in accordance with relevant principles of justice and fairness. In many countries, the pharmaceutical industry observes codified regulations that include provisions for social responsibility. A study of the regulations could reveal certain gaps that need to be filled.

5

### Health and contemporary challenges to global justice.

The wide disparities in the provision of health care experienced globally give rise to questions of equality and global justice.

**a Access to essential drugs and health services**

More than 33% of the global population has no access to essential drugs and more than half of this deprived population lives in the poorest regions of Africa and Asia. The development of drugs for tropical diseases has progressed very little and even when drugs are available, they are often inaccessible to those who need them the most.

**b Poverty and the HIV/AIDS pandemic**

HIV/AIDS spreads more quickly in poor countries and amongst poor people. This highly visible and paradigmatic example illustrates the inevitable connection between poverty and disease in general. Poverty itself is one reason for such an exacerbated effect; thus, the fight against HIV/AIDS (and disease in general) requires progress in the elimination of poverty.

**c Standard of care in international health research**

Developing countries attract researchers from the affluent parts of the world. Many pharmaceutical companies are testing their drugs in developing countries. While these countries urgently need research to help address the enormous burden of disease they carry, the inequalities in resources pose a real risk of exploitation in the context of externally-sponsored research. It is of great importance to develop local expertise in the provision of health care and come up with research hosting protocols. Researchers on the other hand should follow an ethical framework guided by duties to (1) alleviate suffering, (2) show respect for persons, (3) be sensitive to cultural differences, and (4) not exploit the vulnerable.

**d The protection of vulnerable populations**

The 2005 World Summit Outcome adopted by the United Nations General Assembly expresses the resolve of UN member states to 'continue making progress in the advancement of human rights of the world's indigenous peoples' (Sec. 127), to 'pay special attention to the human rights of women and children and undertake to advance them in every possible way' (Sec. 128), and to recognize the need for persons with disabilities to be guaranteed full enjoyment of their rights without discrimination (Sec. 129). Member states also noted that the promotion and protection of the rights of persons belonging to national or ethnic, religious and linguistic minorities contribute to political and social stability and peace and enrich the cultural diversity and heritage of society (Sec. 130). Persons without capacity to consent, prisoners and refugees also deserve special attention as vulnerable populations. These and similar groups ought to receive special consideration for a number of important ethical and historical reasons, specifically those give rise to various forms of exploitation (See also Unit 8).

**e Research prioritization**

Global health research funding has been heavily tilted in support of the needs of the affluent minority, leaving a mere 10% of research resources to address the needs of the developing world. It is important to promote responsive, fair and equitable initiatives in this area. Research projects carried out in poor countries should be relevant to their needs. Participants should also be considered as major stakeholders in the research projects. This section looks at illustrations and case studies in developing countries.

**f Providing health care services across national boundaries**

The migration of medical doctors and other health care workers has reached alarming proportions. Developing countries are continuously losing their health care workers to developed countries that provide higher remuneration and benefit packages. This section examines the experience from a global perspective and traces responsibility to the various institutions involved, including the highly developed countries that draw valuable health care personnel away from the environments where they are most needed.

**g Organ transplantation and medical tourism**

The global income disparity is also manifest in the ongoing practice of transplanting organs from the poor to the rich. The medical tourism industry has provided a smokescreen that serves to disguise the injustices associated with transnational exploitation. This section examines the ethical issues involved and some of the measures that have been offered to curb unethical and illegal practices.

UNIT 15

# Sharing of benefits (Article 15)

## Unit Learning Objectives



Students should be able to understand the need for ensuring that scientific knowledge contributes to a more equitable, prosperous and sustainable world



Students should be able to explain that scientific knowledge has become a crucial factor in the production of wealth, but at the same time has perpetuated its inequitable distribution



Students should be able to explain the reality that most of the benefits of science are unevenly distributed among countries, regions and social groups, and between the sexes



Students should be able to analyse efforts that have been undertaken at various levels to promote the sharing of the benefits of scientific knowledge and research and to explore novel initiatives that may be undertaken



Students should be able to identify and assess potentially undue or improper inducements in different research settings/situations

## Outline of the Syllabus

1

Global justice as basis for sharing the benefits of science and scientific research

2

International instruments on benefit sharing

- a *International Declaration on Human Genetic Data (2003)*
- b *Bonn Guidelines on Access to Genetic Resources and Fair and Equitable Sharing of the Benefits Arising out of their Utilization (2002)*
- c *Doha Declaration on the TRIPs Agreement and Public Health (2001)*
- d Human Genome Organization (HUGO) Committee Statement on Benefit Sharing (2000)
- e *Universal Declaration on the Human Genome and Human Rights (1997)*

3

Models of benefit-sharing agreements

- a Fair and equitable options for research subjects
- b Biopiracy and fair sharing of benefits of genetic resources
- c Patents and intellectual property
- d Valid options for promoting fair and equitable access to new diagnostic and therapeutic modalities or to products stemming from them

4

**Integration of capacity-building components to externally funded research and other initiatives**

5

**Prohibition of using improper inducements to participate in research**

## Teacher Manual

1

**Global justice as basis for sharing the benefits of science and scientific research**

Many benefits of science are unevenly distributed, as a result of structural asymmetries among countries, regions and social groups, and between the sexes. As scientific knowledge has become a crucial factor in the production of wealth, so its distribution has become more inequitable. Principles of global justice should take central place in scientific endeavours. This can be actualized through the long-term commitment of all stakeholders, public and private, through greater investment, the appropriate review of investment priorities, and the sharing of scientific knowledge.

2

**International instruments on benefit sharing**

International agreements and other documents have been drafted under the auspices of international bodies committed to enhancing opportunities to share the benefits of scientific advances and research. Article 19 of the *International Declaration on Human Genetic Data* (2003); the *Bonn Guidelines on Access to Genetic Resources and Fair and Equitable Sharing of the Benefits Arising out of their Utilization* (2002); the *Doha Declaration on the TRIPs Agreement and Public Health* (2001); the Human Genome Organization (HUGO) Committee Statement on Benefit Sharing (2000); and the *Universal Declaration on the Human Genome and Human Rights* (1997) are just a few examples.

3

**Models of benefit-sharing agreements**

This section examines different models for benefit-sharing agreements and the lessons that may be learned from successful and unsuccessful initiatives. Proper assessment should reveal which measures governments could take in order to ensure that the benefits of science and research are made available to the poor.

**a Fair and equitable options for research subjects**

Agreements for sharing the medical and scientific benefits arising from the involvement of human subjects in health research projects.

**b Biopiracy and fair sharing of benefits of genetic resources**

The human genome is part of the common heritage of humanity. It is incumbent upon scientists, governments and industry to find ways for the achievements in scientific and technological research to contribute to economic and social progress to developing countries and not only to developed ones.

**c Patents and intellectual property**

There is a need to create ways of protecting intellectual property rights and at the same time making discoveries and innovations available and accessible to the public, particularly to those populations who need them the most. The Doha Declaration, for example, affirms that the WTO

TRIPS Agreement can and should be interpreted and implemented in a manner supportive of WTO members' right to protect public health and, in particular, to promote access to medicines for all.

**d Valid options for promoting fair and equitable access to new diagnostic and therapeutic modalities or to products stemming from them**

To ensure the availability of new products and innovations, continuous, time-specified or needs-based supply, local version manufacturing, patent and licensing agreements are just some of the ways that can be explored.

**4 Integration of capacity-building components to externally funded research and other initiatives**

Apart from access to material results of research, efforts should be dedicated to improving health systems by strengthening local health research capacities. Higher levels of skills and ability to perform research will prove useful in addressing local needs and concerns.

**5 Prohibition of using improper inducements to participate in research**

While participants should benefit from the research, there is a strong case for the prohibition of inducements that may unduly compromise informed consent or erode autonomy.

## UNIT 16

## Protecting future generations (Article 16)

## Unit Learning Objectives



Students should be able to explain the principle of protecting future generations



Students should be able to evaluate the possibilities and difficulties in the application of the principle in practical settings

## Outline of the Syllabus

1

## Why care about the future?

- a Contexts of concern
- b Contemporary sensibility towards future generations

2

## The scope and limits of future related responsibilities

- a Intergenerational; distant generations, all unborn generations?
- b Human or non-human species?

3

## Do we have obligations to the possible people of the future?

4

## How to represent the future in present decision-making?

5

## Biotechnology, health care and future generations

- a Prescription of medication without any rationale (e.g. antibiotics, etc.) is a threat to future generations – long-term effects of medicine
- b Xenotransplantation
- c Genetically modified food
- d Germ-line genetic interventions

6

## Precautionary Principle

1

## Why care about the future?

- a** Start by exploring in what contexts the concern for future generations has emerged
- i Many countries are rapidly developing. At the same time, economic growth has consequences such as increasing inequity or environmental degradation. Economic growth is often based on natural resources (such as oil or wood) that are diminished, destroyed or consumed. If present trends continue, the world will be more crowded, more polluted, less stable ecologically and more vulnerable to disruption. In this context, the notion of 'sustainable development' (see Unit 17) or 'development without destruction' has been introduced.
  - ii The 1987 Report of the World Commission on Environment and Development (with the title *Our Common Future*) defines sustainable development as 'development that meets the needs of the present without compromising the ability of future generations to meet their own needs'. The key idea is that the needs of present and future generations must be taken into account.
  - iii Responsibility for future generations has been endorsed in many international documents. An example is the 1992 *Rio Declaration on Environment and Development*.
  - iv The ethical context of the principle is articulated in the *Declaration on the Responsibilities of the Present Generations towards Future Generations*, adopted by UNESCO in 1997. Article 4 of this Declaration states that 'The present generations have the responsibility to bequeath to future generations an Earth that will not one day be irreversibly damaged by human activity'.
- b** It is argued (see, for example, Agius, 2006) that three factors are responsible for the contemporary sensibility towards future generations:
- i technology has altered the nature of human activity which is now impacting on not only the lives of people living now but of those who will live in the future;
  - ii present-day reality is interdependent and interrelated; for example, environmental disasters in one region will affect other regions and other generations;
  - iii the increasing awareness of the finitude and fragility of our existence and 'our one and only Earth', as the UN Secretary General said in 1998.

2

## The concept of moral responsibilities towards future generations is also related to the concept of intergenerational justice

It implies that the activities of present generations are limited by the obligation to take into account and safeguard the development and needs of future generations. Traditionally, justice has been defined as 'giving to everyone his or her due'. By promoting obligations to future generations as a matter of justice, a new discourse of intergenerational justice has been introduced.

3

## Arguing that we have responsibilities to posterity or obligations of justice towards future generations is, however, problematic

Does it make sense to claim that we have responsibilities towards persons who do not yet exist? What exactly do we mean if we speak about 'future generations': our children or grandchildren who have just been born, human beings who are not yet born and who we cannot even consider as individual persons, or all distant generations, human and non-human, who will inherit the earth from us? Two positions are usually defended:

**a We only have a moral relationship with generations of the immediate future**

Our obligations only extend to the succeeding one or two generations. Crucial here is the view that it makes only sense to talk about moral responsibility if there are moral relationships;

**b All future generations can claim that we take them into account**

We therefore have responsibilities to even far-distant future generations. Central here is the concept of 'common heritage'; that which belongs to all humanity cannot be considered simply as unexplored and unclaimed territories suitable for expropriation and exploitation on a first-come, first-served basis. Earth's resources belong to all generations.

**4****How do we represent the future in present decision-making?**

**a** Even if we agree that moral concern for future generations is necessary, what kind of obligations do we have to people who do not yet exist or who might even not ever exist? We do not know what will be the needs of future generations since their identity is dependent or contingent on many factors. Future generations can, by definition, not have any claims upon us because they are not present to make them.

**b** A solution to this last problem is to have others who act on their behalf. Some have proposed the establishment of an office of guardian to represent future generations at national, regional and international levels. It is a matter of justice to give voice to the voiceless. Institutional mechanisms should therefore be created to make our responsibilities towards future generations a reality. Discuss this option. Take the example of the Commission for Future Generations, created in one Member State of UNESCO. Discuss whether and how a similar approach could be realised at international level, for example by creating a UN Commission. Analyse the advantages and disadvantages.

**5****In health care, there are several examples of technological and scientific progress that have serious impact on future generations**

One example is the use of medication without rationale; antibiotics are widely used in agriculture as well as the bio-industry so that the production of meat for human consumption will be more profitable. Also human viral infections like flu are increasingly 'treated' with antibiotics. This practice however will increase the probability that micro-organisms will become more and more resistant to antibiotics. In the *E. coli* outbreak in Northern Europe in the summer of 2011, thousands of cases were reported and tens of people died. The bacteria were difficult to treat. Various vegetables have been incriminated as the source of the epidemic. Discuss the application of the principle of protecting future generations in the case of (a) xenotransplantation, (b) genetically modified food and (c) germ-line genetic interventions.

**6****One principle that is often used in this context is the Precautionary Principle**

Where a threat to health or the environment is serious and imminent, we cannot afford to wait for a high degree of proof before acting to prevent damage. If we wait too long, especially the interests of future generations will be irreversibly damaged. Examine this principle, its definitions and applications.

UNIT 17

# Protection of the environment, the biosphere and biodiversity (Article 17)

## Unit Learning Objectives



Students should be able to explain how bioethics is related to environmental issues



Students should be able to analyse environmental issues from anthropocentric, biocentric and ecocentric ethical perspectives



Students should be able to describe sustainable development

## Outline of the Syllabus

1

### Ethics and the environment: views of nature

- a The relation of bioethics and environmental issues
- b Background

2

### Ethical perspectives

- a Anthropocentric environmental ethics: human centred ethics
- b Non-anthropocentric environmental ethics
  - i Biocentric: other living organisms have intrinsic value
  - ii Ecocentric: ecosystems have intrinsic value as well
- c Basic principles of environmental ethics
  - i respect for nature
  - ii environmental justice
  - iii intergenerational justice

3

### Notion of sustainability

- a A new ethics of conservation and stewardship
- b What is sustainable development?

## Teacher Manual

1

### Ethics and the environment: views of nature

- a Ethical concerns with the environment
  - i Characteristics of such concerns:
    - Δ extend the scope of ethical concerns beyond one's community and nation to include also animals and the whole of nature

- △ interdisciplinary
- △ plural: different approaches
- △ global: the ecological crisis is a global issue
- △ revolutionary: challenge to the anthropocentrism of modern ethics

## b Background

- i Ecological crisis first noticed in 1960s and 1970s
- ii Report of the Club of Rome (*Limits to Growth*) in 1972
- iii First United Nations environmental conference in Stockholm in 1972
- iv Birth of environmental ethics in 1970s
- v 1992 Rio Earth Summit Conference
- vi 2000 *UN Millennium Declaration*: the core of our environmental concerns has to do with 'the threat of living on a planet... irredeemably spoilt by human activities, and whose resources would no longer be sufficient' for the needs of all humanity, and above all, 'the needs of our children and grandchildren'
- vii *UN Millennium Declaration*: clearly indicates the object of environmental concern: 'current unsustainable patterns of production and consumption'

## 2

## Ethical perspectives

There are different schools of environmental ethics. They differ as regards (1) the scope of human duties towards others, (2) ethical methodologies, and (3) cultural context

### a Anthropocentric environmental ethics: human centred ethics

- i Human beings have moral duties only towards one another
- ii Human interests prevail over the interests of other species
- iii Ethical methodologies: utilitarianism and deontology
- iv More related to Western culture (in which nature often has an economic value)

### b Non-anthropocentric environmental ethics

- i Biocentric: other living organisms have intrinsic value
  - △ all life forms are 'moral patients', i.e. subjects that are entitled to moral consideration
  - △ it is therefore an ethical imperative to respect all life forms
  - △ all organisms have intrinsic value
  - △ more related to non-western cultural traditions
- ii Ecocentric: ecosystems have intrinsic value as well
  - △ nature as a whole is a 'moral patient'
  - △ all organisms and entities in the ecosphere, as parts of the interrelated whole, are equal in intrinsic value
  - △ holistic methodology

### c Basic principles of environmental ethics

- i respect for nature

the prosperity of human beings depends on the prosperity of nature. Human beings are part of nature. They have therefore the duty to conserve and protect the integrity of the ecosystem and its biodiversity

- ii environmental justice

- △ environmental benefits and burdens should be equally distributed
- △ opportunities to participate in decision-making concerning environmental issues should be equally provided

iii intergenerational justice

every generation should leave the following generation an equal opportunity to live a happy life, and should therefore bequeath a healthy earth (see Unit 16)

3

## Notion of sustainability

### a 2002 Johannesburg Declaration on Sustainable Development

A new ethic of conservation and stewardship should be adopted, focussing on:

- i measures to curb global climate change (reduction of emissions of greenhouse gases)
- ii conservation and management of all types of forests
- iii better use of water resources
- iv intensified cooperation to reduce the number and effects of natural and man-made disasters
- v fundamental change in the lives of the affluent
- vi equitable access to resources

### b What is sustainable development?

- i Original definition given in report of World Commission on Environment and Development (1987): sustainable development is development that meets the needs of present generations without compromising the ability of future generations to meet their needs.
- ii Two important qualifications:

#### **△ the needs of the poor are central in sustainable development**

The UN Millennium Declaration for example points out that sustainable development is a prerequisite to bringing Africa into the mainstream of the world economy. It also links the challenges of poverty eradication and sustainable development. The World Commission on Environment and Development considers poverty as the main cause and effect of environmental degradation.

#### **△ the only constraint on sustainable development is the state of technology and social organization in society**

The Commission is also convinced that our ability to deal with problems has never been greater. But then social institutions need to be remodelled. Human attitudes need to be changed radically. And technologies need to be developed for conservation of environmental resources.

- iii Different views of sustainable development

#### **△ Weak notion of sustainability**

Classic view: integration of economic, socio-political and ecological spheres: three components of sustainable development but interdependent and mutually reinforcing; problem is that they are often viewed as separate spheres with their own logic and values; often also 'trade-offs' between human and social development and ecological concerns; economic growth and social development often have priority. This notion of sustainability is also strongly anthropocentric; human beings and their needs are the point of departure; everything in nature has instrumental value, contributing to achieving human purposes.

#### **△ Strong notion of sustainability**

In order to prevent a continuing decline of natural resources over time, a drastic change in patterns of production and consumption is necessary; the way we are using natural resources need to be transformed. It is necessary to emphasise the intrinsic value of nature; nature has a value in and of itself, regardless of any benefits for humans. It is therefore more helpful to regard sustainable development as three embedded spheres; the spheres are intertwined from the outset.

## UNIT 18

## Gender and Bioethics

## Unit Learning Objectives



Students should be able to explain the concepts of sex and gender, and understand the significance of these concepts in areas such as healthcare, public policy and research to avoid discrimination and stigmatization;



Students should understand the relationship between gender and both structural and interpersonal power within the health system (including clinical care, sexual and reproductive care, and public health);



Students should be able to reflect on the link between gender, bioethics and feminism

## Outline of the Syllabus

1

## Sex and gender bias

- a Definitions
- b Relevance to health care providers
- c Gender and health

2

## Gender bias in health care, public health and emerging technologies

- a Health care ethics
- b Public health ethics
- c Research ethics
- d Emerging technologies

3

## Contextualizing gender bias

- a Policy solutions and efforts
- b Intersectionality
- c Feminist bioethics

## Teacher Manual

1

## Sex and gender bias

- a Definitions
  - i. **Sex** refers to the biological characteristics that distinguish women and men (such as male or female genitalia, hormones and chromosomes).
  - ii. **Gender** refers to the socially constructed roles and relationships, personality traits,

attitudes, behaviors, values, relative power and influence that society ascribes to women and men on a differential basis.

iii. **Gender bias** is a systematic issue that can impact healthcare and research in two ways: first, by assuming that women's and men's health determinants are the same when they are not, and secondly, by presuming differences where there are, in fact, similarities.

**b** It is often assumed there are only two separate and distinct genders: that of women and men. According to the Yogyakarta Principles, a universal guide to human rights, there are not only two genders, they even suggest that there are as many genders as persons. It is evident that there are alternative ways for people to identify themselves outside the binary distinction between women and men. For example, someone can identify as trans or non-binary. Similarly, it is often assumed that there are only two separate and distinct sexes, namely women and men. However, someone can be intersex that can lead to people with sex characteristics that do not fit the typical average for male or female bodies.

### **c** Relevance to healthcare providers

Gender biases affect healthcare providers in three ways:

- i. Gender bias can affect the care that healthcare professionals provide in a negative way. On the one hand, they might overlook certain symptoms or factors when it is important to consider them. On the other hand, gender biases can wrongly exaggerate factors that cause healthcare professionals to treat patients differently when it is not justified.
- ii. Gender biases likely affect the relationship between patients and their healthcare providers. Gender-based differences occur in communication, treatment decisions and outcomes.
- iii. Gender bias likely affects providers' professional careers in terms of their specialty, pay, and access to leadership opportunities.

### **d** Gender and health

Acknowledging gender bias is critical in understanding the differential health burden for men, women, trans gender, intersex and gender diverse people and their health-related choices and behaviors. While some health differences can be explained in terms of genetic, epigenetic and endocrine factors, others are related to gender differences in behavior. Examples that can be discussed: maternal morbidity, mental health illnesses in trans people, the effect of men's reluctance to visit a health provider on their health.

## 2

## Gender bias in health care, public health, and emerging technologies

### **a** Health care ethics

- i. **Access to safe and effective reproductive care**  
Quality reproductive care is essential for the health of women, people of child-bearing potential and children. Reproductive care should encompass sexual health education, including strategies for pregnancy and disease prevention. Many people of child-bearing potential, mostly women, still lack access to basic reproductive, sexual health and prenatal information and services. These structural and social barriers prevent them from exercising their reproductive rights. Many persons, especially women, have little if any control over their bodies in respect to their reproductive rights. Examples that could be discussed are access to contraception and abortion.
- ii. **Infertility and reproductive services and technologies**  
There is a growing global market in reproductive services (i.e. selling sperm, eggs and/or commercial surrogacy) and cross-border reproductive care. This growing global market in reproductive services is primarily driven by great pressure on women and couples to conceive children, particularly those who are genetically related to them. Assisted reproductive

technologies and services can both positively and negatively affect women, trans and gender diverse people. On the one hand, certain assisted reproductive technologies and services have the capacity to promote reproductive freedom and reproductive autonomy for women and people of non-childbearing potential. On the other hand, assisted reproductive technologies and services can involve harm to the people providing these services, caused by lack of autonomy, unjust conditions of poverty, commodification, and invalid consent. Examples of commercial reproductive services such as commercial surrogacy could be discussed.

### iii. Home and community care/work

Within traditional family structures, women provide a disproportionate amount of unpaid care for children and older persons, both within the family and within the community more broadly. An aging global population, in many countries have resulted in increasing demand for in-home care (both paid and non-paid). This globalization of domestic care raises questions of gender equity, intergenerational justice, global justice, and the appropriate balance between societal versus family responsibility for the provision of care. It also leads to an unequal burden for women regarding their mental and physical health.

## b Public health ethics

### i. Gender-based violence

Worldwide, one in three women experience physical and/or sexual violence in their lifetime, mostly by an intimate partner. This gender-based violence is a complex and multidimensional problem that is a cause and a result of gender inequities. Patriarchal and sexist structures with rigid notions of manhood often legitimize gender-based violence to ensure the domination of men stays intact. Gender-based violence can lead to severe and permanent consequences on human health and is therefore a major public health problem. There are still many countries which do not have laws preventing and sanctioning gender-based violence.

### ii. Covid-19 pandemic

The Covid-19 pandemic has aggravated pre-existing care deficits, health inequalities and inequities, economic crises, and gender-based violence with disproportionate impacts on women. Sex and gender were important drivers of risk of Covid-19. During this pandemic, another pandemic was also exposed: the violence against women. Restrictions regarding not leaving the house to stop the spread of Covid-19 potentially locked women up with their abusers, creating dangerous situations. Trans and gender diverse people were also more negatively affected due to the Covid-19 pandemic including higher rates of unemployment, limited access to gender-affirming health services, increased risk of mental health issues.

### iii. Climate change

There are various ways in which gender and environmental issues intersect. We know the effects of climate change will be disproportionately felt by women and girls. Climate change will exacerbate food insecurity which will further harm women and girls, who are more likely to experience hunger due to gender inequality and cultural norms. Furthermore, gender discrimination can act as a barrier to women's access to aid during disasters, including those linked to climate change.

## c Research ethics

Historically, biomedical research has ignored sex-specific biological differences and mainly focused on male experimental models, such as the overrepresentation of male mice, and male participants. In clinical research, women and people of child-bearing potential have been systematically excluded from research participation. This was in part to protect women (who may fall accidentally pregnant and thereby expose the developing fetus to teratogens), to reduce the costs of research, and to protect the researchers from liability for fetal anomalies. Traditional clinical research simply assumed the results of research on male participants could be safely and effectively extrapolated to women. However, there is growing evidence challenging this assumption. A range of diseases, including arthritis, depression, heart disease, and tropical and infectious diseases show important differences between men and women in incidence, treatment responses, and/or prognosis. The unjustified or unnecessary exclusion of female experimental models and women (or any group) amounts to an individual harm to those who wish to participate in the research and group harm, because that entire cohort of patients will lack information about safe and effective treatment options.

**d Emerging technologies: artificial intelligence**

Artificial intelligence (AI) is becoming increasingly important in healthcare systems. AI is trained on datasets that are compiled or designed by humans and that track health, genetic and biometric data, as well as data on human behavior. These datasets therefore typically reflect biases, stereotypes and inequalities that are present in human social systems. These issues can be generated by simple statistical error or through human subjectivity, such as implicit or explicit assumptions (institutional racism and sexism) that programmers make about race, gender, other social identities and social stereotypes. There is a risk that AI can reinforce and entrench existing discrimination, stigmatization and inequality in healthcare. Examples of gender biases in AI include natural language processing in medical chatbots and human-robot relations and wrong medical diagnostics.

**3**

**Contextualizing gender bias**

**a Policy solutions and efforts**

To solve these gender-related issues, changes need to be made on multiple structural levels. For instance, specific policies that address bias should be installed. Health research funders could encourage or require researchers to recruit appropriate proportions of male and female research participants. Moreover, the editors of scientific journals could encourage scientists to include sex and gender in their research.

**b Intersectionality**

It is important to acknowledge that there is more to people than their gender. People identify themselves on several levels, such as race, ethnicity, ability and social class. These are referred to as social identities. These social identities interact with each other and affect our lives in terms of opportunities, inequities and inequalities which is referred to as intersectionality. For example, women are not a homogenous group and women with particular social identities (such as ethnicity or age) can have a significant (dis)advantage over some other women in terms of health, education and career development.

**c Feminist bioethics**

Feminist bioethics is the study of ethical issues relating to human health, health care, science and technology from a feminist perspective. It provides a valuable methodological approach for understanding how gender norms affect the health and wellbeing of people of all genders, and for analyzing and combating oppression and injustice across diverse social systems. It also has reconceptualized autonomy, care and dependency, and highlighted concerns about social justice. Feminist bioethics is:

- i. A systematic critique of how power and injustice generate inequalities in health, wellbeing and liberty.
- ii. Practically orientated, with strong links to activism to overcome oppression and domination.
- iii. Focusing on empirical epistemology and attention to the role of social, political or epistemic power and biases in bioethics debates.

# Further reading

## Gender and Bioethics

### Objectives

#### After completion of the course students:

- 1) should be able to explain the concepts of sex and gender, and understand the significance of these concepts in areas such as healthcare, public policy and research to avoid discrimination and stigmatization;
- 2) should understand the relationship between gender and both structural and interpersonal power within the health system (including clinical care, sexual and reproductive care, and public health);
- 3) should be able to reflect on the link between gender, bioethics and feminism

### UNESCO Universal Declaration on Bioethics and Human Rights 2005

This chapter provides core curriculum in bioethics relating to the following Articles:

- Article 5 – *Autonomy and individual responsibility*. The autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, is to be respected. For persons who are not capable of exercising autonomy, special measures are to be taken to protect their rights and interests.
- Article 8 – *Respect for human vulnerability and personal integrity*. In applying and advancing scientific knowledge, medical practice and associated technologies, human vulnerability should be taken into account. Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected.
- Article 10 – *Equality, justice and equity*. The fundamental equality of all human beings in dignity and rights is to be respected so that they are treated justly and equitably.
- Article 11 – *Non-discrimination and non-stigmatization*. No individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms.
- Article 13 – *Solidarity and cooperation*. Solidarity among human beings and international cooperation towards that end are to be encouraged.
- Article 14 – *Social responsibility and health*
  1. The promotion of health and social development for their people is a central purpose of governments that all sectors of society share.
  2. Taking into account that the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition, progress in science and technology should advance:
    - a) access to quality health care and essential medicines, especially for the health of women and children, because health is essential to life itself and must be considered to be a social and human good;
    - b) access to adequate nutrition and water;
    - c) improvement of living conditions and the environment;
    - d) elimination of the marginalization and the exclusion of persons on the basis of any grounds;
    - e) reduction of poverty and illiteracy.

## Background

Gender is at the center of our social world and therefore affects people's lives in very concrete ways. Gender plays a critical role in how individuals experience and navigate the world. While gender is intrinsically tied to human existence, it also leads to inequalities and inequities in social systems. These disparities stem from gender norms that shape our lives in undesirable ways. Gender inequality is one of the oldest and most pervasive forms of inequality, affecting nearly half of the global population throughout history, primarily women. This is the reason why women fight and continue to fight for their rights to put an end to this form of discrimination.

Unfortunately, gender inequality and discrimination are still a worldwide and common problem. Large gender gaps still exist in all areas of life, including health care and education, despite the progress that has been made. Acknowledging differences between women and men, whether assumed or actual, is crucial for comprehending and ethically assessing any social practice, including healthcare. This attention exposes unjust disparities in the distribution of rights and resources and brings to light oppressive relationships and social structures. Considering gender enriches our understanding and evaluation of bioethics by directing our attention to power structures that exist within healthcare institutions and practices and highlighting the impact of social marginalization on health-related issues.

Bioethics, as a field, has made significant and key progress in addressing various ethical issues related to healthcare, research and advancements in the life sciences. However, it is important to acknowledge that for a considerable period of time, bioethics did not adequately incorporate a gender perspective in mainstream writings (Crosthwaite, 2009). Important attempts have been made to reflect on gender and bioethics and they have led to an academic activist path (like feminist bioethics), yet these reflections are not always fully taken into account in bioethical theorizing. Having a gender sensitive approach compels bioethicists to pay more attention to the political and social contexts of the moral issues they analyze and bioethics as a discipline.

In this core curriculum, important topics and concepts will be addressed to show and evaluate gender inequalities and inequities and demonstrate how power structures contribute to the partiality within healthcare systems. A nuanced understanding of gender and its intersection with bioeth-

ics is essential for identifying and addressing issues of equity, justice and power within healthcare systems, as well as promoting the well-being and autonomy of all individuals, regardless of their gender identity.

Importantly, not only women face gender-related inequalities and inequities. In fact, men also face gender-specific injustices such as rigid gender norms that may for instance lead to bad health (WHO, 2021). For example, the influence of masculinity on boys and men can promote behaviors such as smoking, engaging in sexual and other health risks, misusing alcohol and avoiding seeking help or healthcare (WHO, 2021). These gender norms can also be linked to men perpetrating violence against women and girls, as well as violence committed against other men (WHO, 2021). Correspondingly, both women and men will benefit from a more equal society.

Gender equality is an important global priority at UNESCO. UNESCO sees all forms of gender-based discrimination as violations of human rights, as well as a significant barrier to the achievement of the 2030 Agenda for Sustainable Development and the 17 Sustainable Development Goals.

It is important to recognize that the gender identity of people may not necessarily fall under the traditional gender binary (male versus female). There is an ongoing societal and political debate on inclusive language and using the right terms to address differences in gender identities. For example, inclusive language acknowledges that not all people who can get pregnant and have children identify as women, and not all women can get pregnant and give birth. In these cases, we will respectively use 'woman/women' and terms such as 'people of child-bearing potential' or 'pregnant people'. These categories will be used throughout this curriculum as they make the additional health burdens of these people visible. However, sometimes we refer to a study or report that only involves women and/or men, in which case gender-specific language such as 'woman/women' or 'man/men' is the most accurate to reference that study's or report's findings.

The following paragraphs will cover several topics. Firstly, an explanation of the concepts of sex and gender, as well as related concepts, will be provided. Secondly, we will examine the contexts where gender bias has an impact and we will offer insights into the issue. Finally, we delve deeper into the topic of gender bias by discussing potential policy solutions, introducing an intersectionality approach and reflecting on feminist bioethics.

# Part 1: Sex and gender bias

## Definitions

There is ongoing debate about how to define gender, and to what degree gender is different from sex. Traditionally, sex is distinguished from gender as follows: “sex refers to the biological characteristics that distinguish women and men (such as male or female genitalia, hormones and chromosomes), whereas gender refers to the socially constructed roles and relationships, personality traits, attitudes, behaviors, values, relative power and influence that society ascribes to women and men on a differential basis” (UNESCO, 2022). However, this traditional distinction has been challenged since Judith Butler critiqued it in 1990 which opened up a new path of understanding this debates among various authors. Butler argued that these definitions might be the result of dominant ideas about gender and that sex and gender therefore cannot be simply distinguished. She argues that sex is a cultural construct that has been collectively created by scientists (Butler, 1990). The concept of sex is the preliminary result of a historical process and viewpoints about sex changed over time. How we defined sex 1500 years ago, by just looking at differences between genitals, changed over time. We now understand that biological sex is also determined by factors such as chromosomes, gametes and testosterone levels. At a certain point, we collectively decided what counts as biological sex. This means that the strict and unchangeable binary of sex is a social construct. This also means that our definition of biological sex can change in the future, by for example new scientific discoveries. Biological sex is a result

of how we perceive and categorize bodies in society rather than a natural outcome of having a fixed physical body. This concept is used as a classification and it is up to society to determine how we label and categorize individuals. Butler, therefore, concludes that sex has the same status as gender (as socially constructed), which means that the distinction is redundant. Sex falls under the scope of gender. This does not mean that biological differences between men and women are denied. Both sex and gender are partly based on biological data and are at the same time social and political constructs.

As stated above, it is often assumed there are only two separate and distinct genders: that of women and men. According to the Yogyakarta Principles (2006), a universal guide to human rights, there are not only two genders, they even suggest that there are as many genders as persons. It is evident that there are alternative ways for people to identify themselves outside the binary distinction between women and men. For example, someone can identify as trans or non-binary. Similarly, it is often assumed that there are only two separate and distinct sexes, namely women and men. However, someone can be intersex that can lead to people with sex characteristics that do not fit the typical average for male or female bodies. The way people identify themselves in terms of gender is called gender identity. According to the Yogyakarta Principles gender identity is understood as each person’s deeply felt internal and individual experience of gender, which may or may not correspond with the sex assigned at birth (UN Women, n.d.).

It is also important to note that gender identity is different and independent from sexual orientation because this refers to whom someone is attracted to. Examples are gay and lesbian people that are attracted to people of their own gender. Both gender identity and sexual orientation can diverge from the dominant (cis)heteronormative discourse.

Term	Definition
<b>Gender identity</b>	Gender identity is understood as each person’s deeply felt internal and individual experience of gender, which may or may not correspond with the sex assigned at birth, including the personal sense of the body (which may involve, if freely chosen, modification of bodily appearance or function by medical, surgical or other means) and other expressions of gender, including dress, speech and mannerisms (UN Women, n.d.).
<b>Trans(gender)</b>	Transgender (sometimes shortened to “trans”) is an umbrella term used to describe a wide range of identities whose appearance and characteristics are perceived as gender atypical — including transsexual people, cross-dressers (sometimes referred to as “transvestites”), and people who identify as third gender (UN Free & Equal, n.d.).
<b>Non-binary</b>	Non-binary is describing people whose gender identity falls outside the male-female binary (UNHCR, 2021).
<b>Cisgender</b>	Cisgender is a term used to describe people whose gender identity is aligned with the biological sex they were assigned at birth (UN Free & Equal, n.d.).
<b>Intersex</b>	Intersex people are born with sex characteristics, including genitals, gonads and chromosome patterns, which do not fit the typical binary notions of male or female bodies (UN Free & Equal, 2017).
<b>Sexual orientation</b>	Sexual orientation is understood to refer to each person’s capacity for profound emotional, affectional and sexual attraction to, and intimate and sexual relations with, individuals of a different gender or the same gender or more than one gender (UN Women, n.d.).
<b>Heteronormativity</b>	Heteronormativity refers to a social norm relating to standardized heterosexual behavior as women or men, whereby this standard is only socially valid form of behavior and anyone who does not follow this social and cultural posture is disadvantaged in relation to the rest of society (UN Women, n.d.).

## Discrimination

Gender inequality can lead to gender discrimination. Gender discrimination is defined as: “Any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on the basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field” (UN Women, n.d.). Gender discrimination often stems from gender biases. Gender bias is a systematic issue that can impact healthcare and research in two ways: first, by assuming that women’s and men’s health determinants are the same when they are not, and secondly, by presuming differences where there are, in fact, similarities (Ruiz & Verbrugge, 1997). As will be explained in what follows, gender bias can be explicit or implicit.

### Explicit bias

Explicit bias refers to the prejudices and attitudes of an individual towards a certain group or person on a conscious level. In some countries, explicit biases are justified by society. Historically, women have often been prevented from owning property in their own name. In some countries, women may be required to have permission from a male guardian – their father, husband, brother or son – to enroll in higher education, seek employment, travel, marry and receive health care. Based on cultural norms, women have been subjected to health risks due to female genital mutilation or inaccessibility of contraception and sex education. Also, the other way around, dominant views about the man’s role in their family affect their way of life on many levels. For example, parental leave policies dramatically differ between countries. In many cases, these policies only grant leave to women and pregnant persons who physically carried the child, which poses a disadvantage for partners who want to care for their baby and for the overall well-being of both the child and the women or people who have carried the child.

### Implicit bias

Implicit biases are unconscious preferences or prejudices that inform our reasoning, decision-making and behavior. Angela Ballantyne is one of the authors that regularly discusses this type of bias. Implicit bias is a sort of mental shortcut. The human brain must filter and process huge amounts of information very quickly. One way it does this is to recognize patterns and develop schemas that help to organize and interpret information and make predictions. For example, the majority of Heads of State or Heads of Government are male (UN Women, 2023). A child might also observe that and conclude that being male correlates with authority and leadership ability. These schemas about the apparently ‘normal’ roles of men and women can act as powerful drivers of gender inequality and discrimination. These implicit biases can be deeply rooted in our culture and society and often individuals and institutions do not see them.

Our preferences and prejudices are always situated and necessary to understand the world around us, but also have profound negative effects. It can result in discrimination, and this can breach Articles 10, 11, and 14 of the UNESCO Universal Declaration on Bioethics and Human Rights. When such discrimination is the result of implicit bias, it can moreover be particularly difficult to identify, evaluate and debate on this type of bias because it operates under the radar. As such, it can even undermine the progressive agenda of organizations or individuals that have an explicit commitment to gender equity and diversity.

### Relevance to health care providers

Both explicit and implicit gender biases cut across the whole spectrum of social interactions. For example, these biases influence health care providers. First, gender biases can affect the care that healthcare professionals provide in a negative way. On the one hand, they might overlook certain symptoms or factors when it is important to consider these. On the other hand, gender biases can wrongly exaggerate factors that cause healthcare professionals to treat patients differently when it is not justified. For example, research showed that women wearing a hijab are presumed ignorant and were at times refused care (Padela & Zaidi, 2018).

Second, gender biases likely affect the relationship between patients and their healthcare providers. Research shows gender-based differences for patients regarding communication, treatment decisions and outcomes (Tsugawa et al., 2017; Bertakis, 2009). For instance, in the study of Schieber et al. (2014), the concordance or discordance of gender between patients and physicians is linked to agreement or disagreement on advice during consultations. Female concordant dyads demonstrated better agreement on advice related to exercise and nutrition (Schieber et al., 2014). In surgery, the quality of the communication between patient and surgeon and their gender has an influence on patients who undergo surgical treatment (Hutchison & Rogers, 2017). For example, various studies conducted in the United States of America have shown that female surgeons are more eager to engage in communication skills which facilitate better patient outcomes than male surgeons (Hutchison & Rogers, 2017). This gets even more complicated since there are fewer women surgeons than male which in the end affects all patients (Hutchison, 2019; Hutchison & Rogers, 2017). For example, only 10% of active practicing surgeons in Australia are women (Hutchison, 2019; Hutchison & Rogers, 2017). Another example is about gender bias that occurs when cultural demands are not met in health care. Patients, both men and women, from Muslim communities have a strong preference for same-sex healthcare professionals (Padela & Zaidi, 2018). If these needs are not met it may delay diagnosis and treatments and future health care-seeking behavior (Padela & Zaidi, 2018). It is important to find a balance between these preferences, the perception of these demands by health care providers, and the organizational capacities of a hospital and health services. While acknowledging that gender biases can affect the patient-healthcare provider relationship, it is essential to recognize

that these examples may not be universally applicable and could reinforce stereotypes. Nevertheless, healthcare providers must be aware that their demographic characteristics and perceptions may influence their treatment and advice to patients (Schieber et al., 2014).

Third, gender bias likely affects providers' professional careers in terms of their specialty, pay, and access to leadership opportunities. For example, 70% of the workforce in global health and social care is comprised of women, but women only hold 25% of leadership roles in healthcare (WHO, 2021b). Moreover, women on average earn 24 percent less than men (WHO, 2022). This gender pay gap is larger in the healthcare sector than in other economic sectors (WHO, 2022). Additionally, gender pay gaps tend to be wider in higher pay categories, where men are overrepresented, while women are overrepresented in the lower pay categories. Gender equality matters in health and social sector leadership because it will, among other things, positively affect health outcomes. Overall, companies with diverse executive teams perform better than companies run solely by men. Also, enabling nurses (of which are 90 percent women) to lead health services has led to better health outcomes, retention and greater innovation (WHO, 2021b). Also, more women leaders will increase the number of women role models and mentors for everyone, breaking stereotypes of men as 'natural' leaders (WHO, 2021b).

## Gender and health

Acknowledging gender bias is critical in understanding the differential health burden for men, women, trans gender, intersex and gender diverse people and their health-related choices and behaviors. The examples below highlight gender as a crucial determinant of health. While some health differences can be explained in terms of genetic, epigenetic and endocrine factors, others are related to gender differences in behavior.

Gender-related health burdens for women and girls have multiple sources, including reduced access to nutrition and healthcare, reproductive risk, as well as exposure to house and workplace environmental hazards. Women and girls face various challenges, such as the risk of unintended pregnancies and a higher susceptibility to sexually transmitted infections, including HIV (WHO, 2021). Additionally, they have a greater vulnerability to cervical cancer and an increased likelihood of experiencing mental health issues, including depression, among other concerns (WHO, 2021). Gender discrimination poses barriers for women and girls to access educational opportunities, health care information and health care. As a result, gender discrimination leads to higher rates of illiteracy and poorer health outcomes (WHO, 2021). Maternal morbidity remains high in the Global South, due to limited health infrastructure, a lack of trained health care professionals, and unsafe abortions (WHO, 2023). Persistent 'son preference' in parts of Asia, Middle East and North Africa results in sex-selective abortions of female fetuses and the neglect of the health and nutrition needs of young girls or even infanticide (OHCHR, 2011). Women are more likely to live in poverty than men and – due in part to the gender pay gap described above – are less able to afford health care (Oxfam,

2018). Counting both paid and unpaid work, women work more than men, averaging an additional four years of work over a lifetime (Oxfam, 2018). The global value of women's unpaid work (typically childcare and housework) is estimated at \$10.8 trillion annually (Oxfam, 2018). For example, reliance on burning unclean fuels can have devastating impacts on the health of women and girls, who often spend more time at home. The lack of safe water in many parts of the world increases the risks for girls and women, who are generally responsible for carrying water from wells and other sources and are therefore more frequently exposed to accidents (e.g. animal attacks) and to sexual harassment and rape (GWTF, 2005-2015). Neglected Tropical Diseases affect over 1,7 billion people a year, 40% of these are in the continent of Africa. Women and girls are disproportionately affected (UCNTD, 2017). These diseases affect poor and vulnerable communities living in remote or urban slums leading to health issues, nutritional deficiencies and social and economic consequences (UCNTD, 2017).

Trans people also face multiple health burdens. Mental health illness is more prevalent in trans people which is linked to the discrimination, stigmatization, bullying, and lack of acceptance they experience from society and in healthcare settings (Blondeel et al., 2018). Due to stigmatization and discrimination, trans people experience more stress and distress. This increases their risk of several diseases such as developing heart disease and circulatory disease. Evidence exists that trans people have a higher risk of heart attacks compared to cisgender people (Alzahrani et al., 2019). Stress also increases the risk of unhealthy behaviors like smoking and drug abuse. Trans people have a 13 times higher chance to be HIV-positive than other adults of reproductive age (WHO, n.d.). In general, trans people have less access to health services. When individuals or groups, such as trans people, do not conform to established gender norms they are likely to experience stigma, discrimination, social exclusion and barriers to access health resources – all of which adversely affect health. Trans people have significant unmet physical and psychological health needs, including higher rates of depression, anxiety, suicidal ideation and attempts, self-harm, violence and homelessness. These problems address the relationship between discrimination, disadvantage and ill health.

When compared to women, trans and gender diverse people, men have more opportunities, and privileges. Nonetheless, these advantages do not always translate into better health outcomes. Stereotypes about masculinity and gender norms can also adversely affect men's health. Gender-related health burden for men is driven by occupational exposure to physical and chemical hazards, more risk-taking, and reluctance to visit a health provider, combined with a greater reticence to report symptoms of disease or illness (WHO, 2014). For example, in Europe 95% of fatal accidents and 76% of non-fatal accidents at the workplace are experienced by men (European Commission, 2011). Globally, men's health seeking behavior (avoiding or delaying seeking medical care) is likely to be linked to views of masculinity that emphasize self-reliance, strength and invulnerability. These views are shared by many other non-European and occidental societies.

## Part 2: Gender bias in health care, public health, and emerging technologies

The following topics will be discussed in the next paragraphs: gender bias in health care, public health and emerging technologies. The work cited focuses on structural and interpersonal power differentials and how these affect the delivery of health services to certain groups of people. Many of these topics will be focused on women. However, trans, intersex and gender diverse people will also be mentioned when relevant, and when the knowledge about these groups is available.

### Health care ethics

#### **Access to safe and effective reproductive care**

Quality reproductive care is essential for the health of women, people of child-bearing potential and children. Reproductive care should encompass sexual health education, including strategies for pregnancy and disease prevention. Many people of child-bearing potential, mostly women, still lack access to basic reproductive, sexual health and prenatal information and services. These structural and social barriers prevent them from exercising their reproductive rights. Many persons, especially women, have little if any control over their bodies in respect to their reproductive rights (IBC, 2019).

Current cis-heteronormative views and ideals of reproduction that inextricably link femininity to childbearing causes the experiences of trans and gender diverse people to become invisible. Although, there are often additional reproductive care barriers for lesbian, gay, trans and gender diverse people. They may be explicitly denied access to reproductive services or may avoid seeking care due to previous experiences of discrimination and stigmatization. Also, trans people and gender diverse people report feeling pressure to present themselves as women to conform to the expectations of the healthcare providers (Fischer, 2021).

An important reproductive topic that needs to be addressed is access to contraception. According to estimates from 2017, 214 million women of reproductive age in developing regions who wish to prevent pregnancy do not have access to modern contraceptive methods (WHO, 2019). Several factors contribute to this situation, including limited availability of contraception, particularly among young individuals, marginalized populations, rural communities, those affected by humanitarian crises, and unmarried individuals (WHO, 2019). Other reasons include limited options for contraceptive methods, concerns or past experiences of side effects, cultural or religious opposition, substandard quality of available services, and gender-based barriers.

However, it is crucial to ensure access to preferred contraceptive methods for women, girls and couples, and to promote family planning in general. Doing so is essential to secure the well-being and autonomy of women while supporting the health and development of communities. Access to contraceptives offers a wide range of potential benefits that encompass economic development, maternal and child health, education and women's empowerment (WHO, 2019). For instance, by preventing unintended pregnancies, contraception plays a significant role in reducing maternal morbidity and mortality (WHO, 2019). It also helps to prevent pregnancies and births that are closely spaced or ill-timed, which contribute to infant mortality around the world (WHO, 2019). Family planning and contraception empower individuals to make informed decisions about their sexual and reproductive health (WHO, 2019). Furthermore, it could create opportunities for women to pursue education and gaining employment (WHO, 2019).

A second important reproductive topic that needs to be addressed is abortion. Almost half of all abortions globally are unsafe which equates to 25 million unsafe abortions per year (WHO, 2017; Ganatra et al., 2017). This results in approximately 39,000 deaths every year and millions more women hospitalized with complications. The vast majority (97%) of unsafe abortions occurs in the Global South and abortions are an important cause (4.6-13.2%) of global maternal mortality (Kim et al., 2016; WHO, 2021c). Abortion is a controversial topic leading to ethical debates. Views on abortion are shaped by core beliefs, including moral, emotional, religious, political and ethical perspectives, making it a deeply personal issue. Abortion involves balancing the right to bodily autonomy and health of the pregnant person with the right to life of the embryo or fetus, creating a conflict between two fundamental rights. This complexity leads to varying abortion laws among nations and states. Abortion is generally permitted in most countries, especially when the woman's life is threatened (WHO, 2015). Additionally, many national laws permit abortion when the woman's physical or mental health is at risk, and some allow it in cases of rape, incest or fetal abnormalities. Socio-economic reasons and the woman's request are also recognized as valid grounds for abortion in some legal systems (WHO, 2015). However, laws on abortion are continuously changing. While certain countries, like Argentina, are taking steps to legalize abortion, and others, like Chile, are beginning to decriminalize it, there are also countries moving in the opposite direction. For example, the legislation in the US underwent a significant change in 2022, resulting in the banning of most abortions in 13 states. This change has also led to an increase in the number of people seeking unsafe abortions (OHCHR, 2022). Evidence indicates that imposing restrictions on access to abortions does not effectively reduce the overall number of abortions (WHO, 2021c). It is even the case that abortion rates are similar in countries where abortion is restricted and those where the procedure is broadly legal (Guttmacher Institute, 2022). However, it does have a profound impact on the safety and dignity of the abortions sought by women and girls. As such, in countries with highly restrictive abortion laws, the proportion of

unsafe abortions is considerably higher compared to countries with less restrictive laws (WHO, 2021c).

### ***Infertility and reproductive services and technologies***

There is a growing global market in reproductive services (i.e. selling sperm, eggs and/or commercial surrogacy) and cross-border reproductive care (i.e. individuals or couples traveling across borders or overseas to purchase reproductive services that are unavailable or too expensive at home). The global in vitro fertilization (IVF) industry alone is worth approximately \$15 billion.

This growing global market in reproductive services is primarily driven by great pressure on women and couples to conceive children, particularly those who are genetically related to them. However, infertility is a worldwide growing problem (IBC, 2019). Such reproductive health problems can also induce mental health problems (IBC, 2019). A possible solution for reproductive health problems such as infertility is the development of assisted reproductive technologies. At the same time, the failure of such technologies can even add more specific psychological and emotional problems (IBC, 2019). For example, multiple unsuccessful attempts of assisted reproduction cycles may lead to lower self-esteem and feelings of sadness and incompleteness in both men and women (IBC, 2019). Moreover, the intended parents can be negatively affected by social prejudices about infertility and the need to secrecy or to mimic a natural pregnancy (IBC, 2019). While it is important that research considers the psychological and social aspects of infertility and assisted reproductive technologies treatment in both women and men, current research is mostly focused on women (IBC, 2019). There is a widespread tendency to put the responsibility for infertility on women. Clinical protocols primarily focus on the female body, even in cases of male infertility, and unsuccessful attempts can degrade the woman's social or family status (IBC, 2019).

Assisted reproductive technologies and services can pose certain ethical challenges. At the same time, these technologies and services can positively affect the social status of women, trans and gender diverse people.

On the one hand, certain assisted reproductive technologies can have the capacity to promote reproductive freedom and reproductive autonomy for women and people of non-childbearing potential, such as male gay couples or trans people. Such technologies pave the way for other forms of parenthood like co-parenting, bi-motherhood, bi-fatherhood, or mono-parenthood (single parenting). By expanding the range of who can have biological children and with whom, these technologies open up new ways of starting a family.

On the other hand, assisted reproductive services can involve harm to the people providing these services, caused by lack of autonomy, unjust conditions of poverty, commodification, and invalid consent. There is great variability in regulatory systems, oversight and enforcement, prohibitions on reproductive services, as well as costs. The extent of poverty and other vulnerabilities varies among individuals engaged in these services. These variabilities do contribute

to the rise of cross-border reproductive care, but also pose challenges in drawing general conclusions about consent, harm and exploitation.

An important example of assisted reproductive services is surrogacy. A surrogacy procedure requires the involvement of at least two parties: the intended parent(s) who initiate the procedure with the intention of being the child's legal and social parent(s) and the surrogate, who carries the child and gives birth with the intention of giving the child to the intended parent(s) (IBC, 2019). Surrogacy is being used as means of becoming parents for people with different medical and/or social reasons. For example, to become a genetic mother for women who were born without a uterus or who had their uterus removed during medical treatment (IBC, 2019). There are multiple forms of surrogacy such as altruistic and commercial surrogacy. Within altruistic surrogacy the woman or person of child-bearing potential deliberately chooses to carry a child for someone else without remuneration (IBC, 2019). Within commercial surrogacy the woman or person of child-bearing potential will get reimbursed for this service. Although, these types of surrogacies are not necessarily problematic, each of these forms do raise unique ethical questions. For instance, in the context of altruistic surrogacy, one must take into account the unique dynamics that may arise post-birth, for example the complex role of being both the surrogate and related to the child after birth (as their grandmother or aunt) and the potential psychological effects this may have on all parties involved. Commercial surrogacy also raises ethical challenges. Commercial surrogacy sometimes involves an arrangement between surrogates from emerging economies and wealthy parents. This is problematic because often it involves an inherent power imbalance that could lead to forms of exploitation of both surrogate and child (UNHCR, 2018). Surrogates are often women who are vulnerable, live in poor environments and in need of financial resources. It can be said that most surrogates make decisions under pressure (IBC, 2019). It can be questioned if they can give voluntary consent because financial incentives to support their family and children can interfere with their voluntariness (IBC, 2019). For both types of surrogacy, it remains crucial to carefully consider the psychological impacts of this procedure, such as the considerable physical and emotional effort required of the surrogate throughout the gestational, birthing and relinquishing process.

### ***Home and community care/work***

Within traditional family structures, women provide a disproportionate amount of unpaid care for children and older persons, both within the family and within the community more broadly. An aging global population, combined with increasing participation of women in paid work and, in many countries, cutbacks in public health and welfare services, have resulted in increasing demand for in-home care (both paid and non-paid). Throughout the Covid-19 pandemic, there has been a global increase in the time dedicated to care and domestic work for both women and men, but the increase and intensity of this workload have disproportionately affected women (Seedat & Rondon,

2021). Moreover, wealthy countries are increasingly reliant on international migrant workers (predominantly women) to provide in-home care for their children, elders and people with chronic conditions. In 2015, there were 11.5 million migrant domestic workers in the world (representing 17% of domestic workers globally) (Galotti, 2015). This globalization of domestic care raises questions of gender equity, intergenerational justice, global justice, and the appropriate balance between societal versus family responsibility for the provision of care (Reid, 2013; Yeates, 2009). It also leads to an unequal burden for women regarding their mental and physical health (Seedat & Rondon, 2021).

## Public health ethics

### **Gender-based violence**

Gender-based violence is a global public health emergency that has inflicted harm upon girls and women throughout history (UN Foundation, 2022). It is defined as harmful interventions or acts directed at an individual based on their gender (UN Foundation, 2022). Any harmful intervention or act on a person's body (excluding urgent interventions aimed at survival) without their explicit and voluntary consent, is ethically problematic.

Gender-based violence can have many forms, encompassing physical, psychological, and economical domains. Physical violence is often recognized as the most familiar form of violence. Worldwide, one in three women experience physical and/or sexual violence in their lifetime, mostly by an intimate partner (WHO, 2021a). However, men can also disrespect, insult and degrade women and girls without physically inflicting harm on them, which is called psychological violence. Moreover, if men do not allow women to work, or to use the money they earn, it can be called economical violence. This gender-based violence is a complex and multidimensional problem that is a cause and a result of gender inequities. Patriarchal and sexist structures with rigid notions of manhood often legitimize gender-based violence to ensure the dominance and superiority of men.

All forms of gender-based violence can lead to severe and permanent consequences on human health and is therefore a major public health problem. Examples of such permanent damage are acute and chronic physical injuries and disabilities, fatal outcomes, mental health problems, gynecological disorders, unwanted pregnancies, obstetric complications, and HIV/AIDS. There are still many countries which do not have laws preventing and sanctioning gender-based violence. In these countries, violent acts are often not recognized as violence based on deeply ingrained gender biases. Some of these violent acts are even justified.

An important example of gender-based violence is female genital mutilation. This refers to partial or total removal of the external female genitalia or other injury to the female genital organs. This procedure has no health benefits and can do great harm to women and girls including infections, urinary and vaginal problems, sexual problems, mental health problems and even death. It is internationally recognized as a violation of the human rights (bodily autonomy

and integrity) of girls and women (WHO, 2023a). More than 200 million girls and women have been affected by female genital mutilation and annually, approximately 3 million women and girls are at risk. It is mainly performed in Western, Eastern and North-Eastern regions of Africa and some countries in the Middle East and Asia. Cultural and social factors play an important role in the performance of female genital mutilation. For example, as part of entering adulthood and marriage, or to ensure premarital virginity and marital fidelity (WHO, 2023a).

Besides violence against women and girls, violence against trans people, intersex people and gender diverse people is also a worldwide problem. Gender diverse people are more likely to experience violence and coercion, stigmatization and discrimination, including from health workers (WHO, 2021). Behind this violence are often preconceived ideas about the gender identity of the victim from a binary view of what it is to be a woman or man (OHCHR, n.d). These acts of violence stem from deep-rooted stigma and prejudice, with hatred and violence serving as punishment for these individuals who challenge binary gender norms (OHCHR, n.d.).

### **Covid-19 pandemic**

During the Covid-19 pandemic, another pandemic was also exposed: the violence against women. Restrictions regarding not leaving the house to stop the spread of Covid-19 potentially locked women up with their abusers, creating dangerous situations. Globally, 245 million women and girls (15 years or older) have been subjected to sexual and/or physical violence perpetrated by an intimate partner in the first year of the pandemic (UN Women, 2021a). Younger women (aged 18-49) were the most vulnerable group. Approximately 45% of women surveyed across 12 countries worldwide, either themselves or someone they know, have encountered a form of violence amidst the pandemic (UN Women, 2021a).

The Covid-19 pandemic has aggravated pre-existing care deficits, health inequalities and inequities, economic crises, and gender-based violence with disproportionate impacts on women (UN Women, 2021). Sex and gender were important drivers of risk of Covid-19. On the one hand, men were more likely to die from the disease. On the other hand, women had a higher risk of infection. This is because they make up for 70 percent of the health and social work force and are more often front-line health workers, such as nurses, midwives and community health workers (UN Women, 2020). Women faced more difficulty accessing health services, including reproductive care (UN Women, 2020). Furthermore, women were less likely to have access to water while they are more in need of water and a hygienic environment during menstruation, pregnancy and child-rearing (UN Women, 2020). In most countries, more women than men reported their mental health being impaired (UN Women 2020).

Trans and gender diverse people were also more negatively affected due to the Covid-19 pandemic including higher rates of unemployment and limited access to gender-affirming health services (Burgess et al, 2021). For example, in

most countries non-emergent surgeries were canceled and therefore medically necessary procedures for trans people were delayed (Burgess et al, 2021). Access to the most basic needs was hindered. Mental health disparities were aggravated as precautions against spreading Covid-19 limited access to social support (Burgess et al, 2021). For example, due to closed schools, many LGBTI+ students were forced to stay at home in unsupportive homes, increasing their risk of developing mental health issues, being victims of domestic violence, or even becoming homeless (UNESCO, 2020a).

### **Climate change**

There are various ways in which gender and environmental issues intersect. We know the effects of climate change will be disproportionately felt by women and girls. Climate change will result in, for example, rising sea levels, drops in farming yields and flooding. The greatest impact will be within poor communities. Women are more likely to live in poverty than men and have less access to resources (such as improved seeds, fertilizers and equipment) (UNFCCC, 2018). Climate change will exacerbate food insecurity which will further harm women and girls, who are more likely to experience hunger due to gender inequality and cultural norms (in some countries tradition dictates that women eat only after men, and research shows that women will often sacrifice their food consumption so that other family members can eat) (WFP, 2018). In addition, gender discrimination can act as a barrier to women's access to aid during disasters, including those linked to climate change. The United Nations has committed to gender equality and women's empowerment as core tenants in climate change discourse and actions (UN Women, 2017).

### **Research ethics**

Historically, biomedical research has ignored sex-specific biological differences and mainly focused on male experimental models and male participants. In cell culture studies, researchers often ignore the sex of the individual from which the cells are obtained (NIH, 2014). In preclinical (animal) research male mice are overrepresented compared to female mice (Cirillo et al., 2020). In clinical research, women and people of child-bearing potential have been systematically excluded from research participation. This was in part to protect women (who may fall accidentally pregnant and thereby expose the developing fetus to teratogens), to reduce the costs of research, and to protect the researchers from liability for fetal anomalies. Traditional clinical research simply assumed the results of research on male participants could be safely and effectively extrapolated to women.

However, there is growing evidence challenging this assumption. A range of diseases, including arthritis, depression, heart disease, and tropical and infectious diseases show important differences between men and women in incidence, treatment responses, and/or prognosis. For example, research suggests that adverse effects of antihistamines, antibiotics, antiarrhythmic, and antipsychotics are more common and/or more severe in women than in men (Rogers et al., 2008). Moreover, clinicians sometimes do not recognize female

symptoms and only look for male symptoms. For instance, cardiovascular disease has been defined primarily in terms of men's typical presentation of symptoms and has therefore been under-recognized and under-treated in women. This leads to men being more likely than women to receive appropriate interventions for cardiovascular disease and experience positive outcomes (Rogers, 2017). This focus on men's typical presentation of symptoms is due to the underrepresentation of women in clinical trials which reduces the ability to measure the safety and efficacy of therapies in women and the potential for identifying sex-specific differences in important outcomes (Vogel et al., 2021). Most healthcare providers tend to underestimate the cardiovascular risk in women and physicians are often not sufficiently trained to address cardiovascular risk and educate women about their individual risk (Vogel et al., 2021). To identify, track and address these differences, gender analysis needs to be systematically integrated into clinical research and reporting.

The unjustified or unnecessary exclusion of women (or any group) amounts to an individual harm to those who wish to participate in the research and group harm, because that entire cohort of patients will lack information about safe and effective treatment options. Furthermore, women's health issues may receive comparatively less research funding; and research into areas such as women's reproductive health that are well-funded, may not measure outcomes that are important to women (as opposed to outcomes important to health care providers or researchers).

While there have been recent successful efforts to increase the participation of women in research, pregnant people remain systematically excluded from the research agenda. This results in harm to pregnant people and their fetuses, because pregnant people often end up taking medication off-label, under the supervision of an individual doctor, without the benefit of specialist clinical oversight (Lyerly et al., 2008). The 2016 revision of the International Ethical Guidelines for Health-related Research Involving Humans produced by the Council for International Organizations of Medical Sciences recognizes this and advocates for greater inclusion of pregnant women in medical research (CIOMS, 2016).

### **Emerging technologies**

#### **Artificial intelligence (AI)**

Artificial intelligence (AI) is becoming increasingly important in the provision of services in both the private and public sector, including within health systems. AI are 'technological systems which have the capacity to process information in a way that resembles intelligent behavior, and typically includes aspects of reasoning, learning, perception, prediction, planning and control' (UNESCO, 2020). AI is trained on datasets that were originally compiled or designed by humans and that track health, genetic and biometric data, as well as data on human behavior (such as hospital admissions, prescribing and service utilization). These datasets therefore typically reflect biases, stereotypes and inequalities that are present in human social systems. These issues can be generated by simple statisti-

cal error or through human subjectivity, such as implicit or explicit assumptions (institutional racism and sexism) that programmers make about race, gender, other social identities and social stereotypes (UN Women, 2022). Moreover, if the training data does not represent the population, AI becomes prone to reinforcing bias (UN Women, 2022). For instance, in a study on digital biomarkers for Parkinson's disease only 18,6% of the study population were women. When such datasets, in which the majority of the study population is male, are used to train an algorithm, it may lead to less accurate detection of symptoms that are prevalent in female patients compared to those symptoms that are more prevalent in male patients (Cirillo et al., 2020).

Another example of the use of AI in healthcare is when natural language processing is used in medical chatbots. Natural language processing refers to the field in which AI is used to give computers the ability to understand spoken or written human language the same way human beings can. These medical chatbots are used for real-time symptom assessment and recommendation to improve the user's wellbeing. For example, Woebot is an app that helps people with mental health problems, such as anxiety and depression. Available data is used as input for a dialogue and makes it possible for the chatbot to adapt to the characteristics of the user in terms of gender, age, mood (Cirillo et al., 2020). Although this chatbot is approved to be effective, certain risks are not well addressed and researched. For example, possible important factors such as sex and gender differences in non-verbal communication are not considered and can lead to the oversimplification of mental conditions and therapeutic approaches (Cirillo et al., 2020).

Another example of AI in healthcare is of robotics technology that provides care for ageing adults and young children. Care robots are being used in homes and healthcare systems around the world. For example, Kasper, a friendly childlike robot, helps children with autism spectrum to develop social skills. Sex and gender differences need to be considered in human-robots relations (COMEST, 2017). The World Commission on the Ethics of Scientific Knowledge and Technology (COMEST) report on robotics ethics suggests a greater sensitivity to cultural and gender issues as drivers for research and innovation in robotics. For example, robotic engineers should be sensitive to the reproduction of gender bias and sexual stereotypes in robots (COMEST, 2017). Research shows that female robots are preferred in healthcare settings over male robots (Nomura, 2017). There are also gender differences between how men and women perceive robots (Nomura, 2017). Men think that female robots are more credible and trustworthy than male robots, while women think the exact opposite (Nomura, 2017). Gendered robots address certain gender stereotypes. It is even suggested that naïve gendering of robots might provoke users to display abusive behavior toward robots that follows gender stereotypes (Nomura, 2017). For example, most voice assistants are female and this sends a signal that

women are obliging and eager to please. The voice assistant holds no power of agency beyond what the user asks of it. It will respond to questions regardless of the user's tone or hostility. In turn, this may reinforce commonly held gender biases that women are subservient and tolerant of poor treatment even when they are being harassed or bullied (UNESCO, 2019). This means that the development of gendered care robots and voice assistants in accordance with the perceived gender role could emphasize social constructs and gender stereotypes.

These examples show that there is a risk that AI can reinforce and entrench existing discrimination, stigmatization and inequality in healthcare. Furthermore, the complexity and opacity of AI can create a barrier to interrogating and challenging this bias. For this reason, algorithmic transparency (making algorithms open to external critique and testing) is important, as is the right to challenge AI decisions (IBC, 2017).

Current attempts to address and resolve harmful effects of AI bias remain mostly focused on computational factors such as statistical errors (UN Women, 2022). At the same time, human, systemic institutional and societal factors are being overlooked. While possible solutions can emerge from AI technologies themselves, more profoundly solutions can emerge from fundamental cultural changes. For example, prioritizing diversity, equity and inclusion in teams that are involved in training and deploying AI systems is needed (UN Women, 2022).

Having diverse and inclusive teams within AI is not easy to achieve. For example, there is a low representation of women/girls in Science, Technology, Engineering and Mathematics (STEM) subjects, including computer science. Research shows that in most countries (with limited available data on this topic) the majority are men/boys that take advanced-level STEM courses (UNESCO, 2019). Research by the World Economic Forum shows that the percentage of men graduates in Information and Communication Technologies is 400% higher than women graduates (UN Women, 2022). Gender stereotypes and a lack of role models affect girls' interest in STEM from an early age (UN Women, 2022).

UNESCO's Recommendation on the ethics of AI devoted several policies on gender and AI. The primary focus is on utilizing AI to diminish the gender gap, maximize gender equality, to stop violence against women in the digital world, foster female entrepreneurship, enhance participation and involvement of women at all stages of an AI system's lifecycle, including decision-making, and allocate resources to encourage their active engagement in the realm of AI (UNESCO, 2020a).

## Part 3: Contextualizing gender bias

In the following paragraphs, firstly attempts to solve gender biases are discussed such as policy solutions and efforts. Secondly, intersectionality is introduced to broaden the scope of this curriculum and to show the effects of multiple social identities on health inequalities and inequities. Finally, feminist bioethics is discussed to show why and how feminism shaped the bioethics field further.

### **Policy solutions and efforts**

In this curriculum, many gender biases are addressed. Globally, there are many initiatives that try to address and solve these problems. It is evident that changes need to be made on multiple structural levels.

In some cases, specific policies have been introduced to address bias. Many health research funders encourage or require researchers to recruit appropriate proportions of male and female research participants in order to address gaps in medical knowledge. For example, CIOMS research ethics guidelines address that special effort is needed to include members of populations that are underrepresented to overcome health disparities and to achieve equity (CIOMS, 2016). The European Commission announced in 2020 that research-grant recipients need to include sex and gender specific analyses in their study design. Moreover, the editors of scientific journals have a responsibility to encourage scientists to include sex and gender in their research. Some journal policies have changed over the past few years. For example, *Nature*, the world's leading multidisciplinary science journal, is now prompting researchers who submit a paper to state whether and how sex and gender were included in their study design or to indicate that no sex and gender analyses were carried out and why. Also, researchers need to mention if findings apply to only one sex or gender in their title and/or abstract.

Some organizations, such as the United Nations, have adopted a policy of 'gender mainstreaming' which is the process of systematically assessing the implications for women and men of any planned action, including legislation, policies or programs, in all areas and at all levels; with the ultimate goal of achieving gender equality (UN Women, 2018). UNESCO has also implemented a policy mandating that gender equality needs to be included into the budget allocation for every program, and that publications be thoroughly examined through a gender lens to ensure that language is gender inclusive, and gender dimensions are adequately addressed.

### **Intersectionality**

The focus of this core curriculum was mainly on how sex and gender can play a role in health care, policies and research. However, it is important to acknowledge that there is more to people than their gender. People identify themselves on several levels, such as race, ethnicity, ability and social

class. These are referred to as social identities. These social identities interact with each other and affect our lives in terms of opportunities, inequities and inequalities which is referred to as intersectionality. Intersectionality was developed in the late 20<sup>th</sup> century by black feminists, particularly by Kimberly Crenshaw, and seeks to highlight the unique experiences of individuals who belong to multiple marginalized groups and to challenge the idea that social identities can be considered in isolation from one another.

Women are not a homogenous group and women with particular social identities (such as ethnicity or age) can have a significant (dis)advantage over some other women in terms of health, education and career development. For example, women who come from lower socioeconomic backgrounds are often concentrated in lower-status roles within the healthcare workforce (WHO, 2021b). Similarly, a study conducted in the United States revealed that Black and Latina women in the healthcare workforce earn less than white women in equivalent positions (WHO, 2021b).

In the Arab region, gender also intersects with various identities increasing women's hardship (UNESCWA, 2018). For example, women with disabilities, both in rural and urban areas, tend to have lower literacy rates than men with disabilities (UNESCWA, 2018). Additionally, women with disabilities face greater challenges in participating in public spheres compared to men with disabilities, with even fewer available opportunities for rural women (UNESCWA, 2018). Unpacking the multiple layers of intersecting inequalities is a complicated endeavor because related research and literature reflect many methodological gaps. Besides, sex-disaggregated data on healthcare topics are often not available and data that is disaggregated further by other social identities is even harder to find.

### **Feminist bioethics**

As mentioned in the background section, bioethics began to slowly recognize the effect of gender differences on bioethical issues. Feminist bioethics raised awareness for these effects and made us sensitive towards the previously discussed topics and issues by introducing new ways of thinking about bioethics.

Feminist bioethics is the study of ethical issues relating to human health, health care, science and technology from a feminist perspective. As with feminist scholarship more generally, there are divergent views between conservative<sup>1</sup>, radical, socialist and liberal feminists within bioethics (McAfee et al., 2018). Here, we focus on some of the common themes of feminist bioethics.

Feminist bioethics adds notions to the field of bioethics on three levels. First, feminist bioethics involves a systematic critique of how power and injustice generate inequalities in health, wellbeing and liberty. These inequalities relate

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1 There is for example a feminist group who oppose abortion called Feminists For Life, <https://www.feministsforlife.org/>

not just to gender, but also to power relationships driven by race, class and disability, and the intersection of these factors (i.e. intersectionality). Attending to structural factors such as social norms, economic structures and decision-making processes is crucial for understanding domination and oppression. Second, feminist bioethics is practically orientated, with strong links to activism to overcome oppression and domination. Third, feminist bioethics methodology is distinctive due to its focus on empirical epistemology and attention to the role of social, political or epistemic power and biases in bioethics debates (Stanford Encyclopaedia of Philosophy, 2015a). In other words, feminist bioethics pays attention not just to ‘what’ is said in bioethics, but also ‘whose’ and how voices (i.e. the voices of women) contribute to shaping debate.

Feminist bioethics has reconceptualized autonomy, care and dependency, and highlighted concerns about social justice (Rogers, 2017; Scully et al., 2010). Feminist bioethics provides a valuable methodological approach for understanding how gender norms affect the health and wellbeing of people of all genders, and for analyzing and combating oppression and injustice across diverse social systems.

In the following sections we highlight some of the major methodological and theoretical contributions of feminist bioethics and demonstrate that gender is a morally relevant category for analyzing ethical issues arising in health, technology and science.

### **Autonomy**

Autonomy is a central concept to bioethics, as it refers to the capacity for self-government or self-determination. To be self-governing, a person must be informed by reasons that are “their own”. However, dominant gender norms and social conditions can affect the way a person perceives themselves, their responsibilities and the reasonable choices available to them (Stanford Encyclopaedia of Philosophy, 2015a). Some feminists have argued in favor of a relational account of autonomy, in part, as an explanation for how social norms can affect an agent’s capacity for autonomy (Mackenzie & Stoljar, 2000). On this view, persons are members of communities and genuine autonomy emerges from nurturing and empowering relationships. “Persons come after and before other persons” (Baier, 1985). There are two elements to these accounts of autonomy –

first, the adoption of a non-individualist conception of the person (as embedded in social networks and relationships), and second, the view that a person’s autonomy depends strongly on social relations (Stanford Encyclopaedia of Philosophy, 2015a; Oshana, 2006). Relational conceptions of autonomy have been used particularly to develop more nuanced ways of thinking about professional respect for patients’ autonomy in clinical practice (Entwistle et al., 2010; Ells et al., 2011). The principle of respect for individual consent is not given away but understood in the context of the individual.

### **Vulnerability**

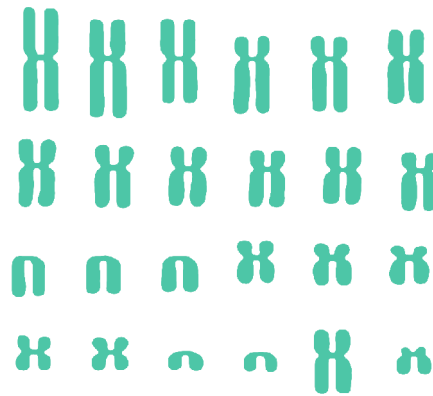
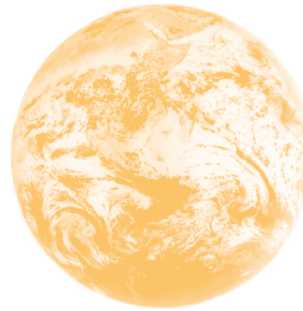
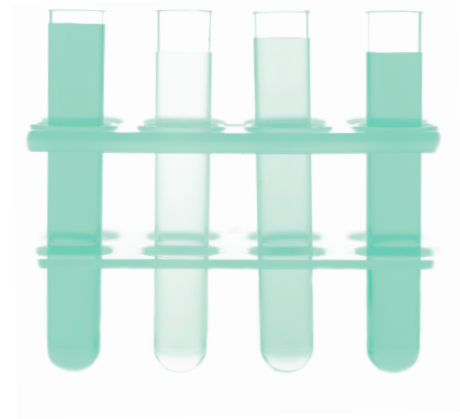
Recent work in bioethics and especially feminist bioethics has focused on elucidating concept of vulnerability. In earlier works in bioethics, the dominant group protection approach causes problems of labelling, stereotyping and discrimination. Feminist bioethicists such as Florencia Luna have criticized this approach. According to Luna, vulnerability must not be understood as a fixed attribute of a certain group, but as a result of compounding layers of risk associated with, for example, gender, age, health, capacity, wealthy, education and social status (Luna & Vanderpoel, 2013; Luna, 2018). This is a relational account of understanding vulnerability because it refers to the relation between a person or group and their context or circumstances (Rogers et al., 2022). However, there is an ongoing debate within feminist bioethics, if vulnerability must be understood as a relational or ontological (as fundamental condition of human life) concept. Recent theoretical work in feminist bioethics have proposed a reconciliation between the idea of vulnerability as inherent to the human condition with vulnerability as a result of external situational conditions. Therefore, Mackenzie, Rogers and Dodds (2014) developed the taxonomy account of vulnerability. This account elaborates on three different sources of vulnerability: inherent (sources of vulnerability inherent to the human condition); situational (arising from a specific contexts such as illness, divorce, natural disasters or political coups); and pathogenic (a subset of situational vulnerabilities that arise from or are exacerbated by unjust social, political and economic institutions or interpersonal relationships such as slavery, patriarchy or abusive relationships) (Mackenzie et al., 2014).

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