

VI International Workshop
*The future of bioethics in the fight
against exclusion and poverty*

**Dimension and scope of human
vulnerability in bioethics**

**Article 8º: “Respect for Human Vulnerability and
Personal Integrity”**



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Dimension and scope of human vulnerability in bioethics

Due to the double nature of this principle, it is, indeed, human vulnerability that in a more accomplish way leads bioethics from its traditional biomedical domain and individual perspective to the social domain and to a societal perspective, along with its globalization process.

1. The concept of Vulnerability in Bioethics: its wide dimension

1.1. The major dimensions of Vulnerability in Bioethics

1.2. The concept of Vulnerability in the Declaration

2. The role of Vulnerability in Bioethics: its broad scope

2.1. The moral requirements the principle of Vulnerability entails

2.2. The application of the principle of Vulnerability

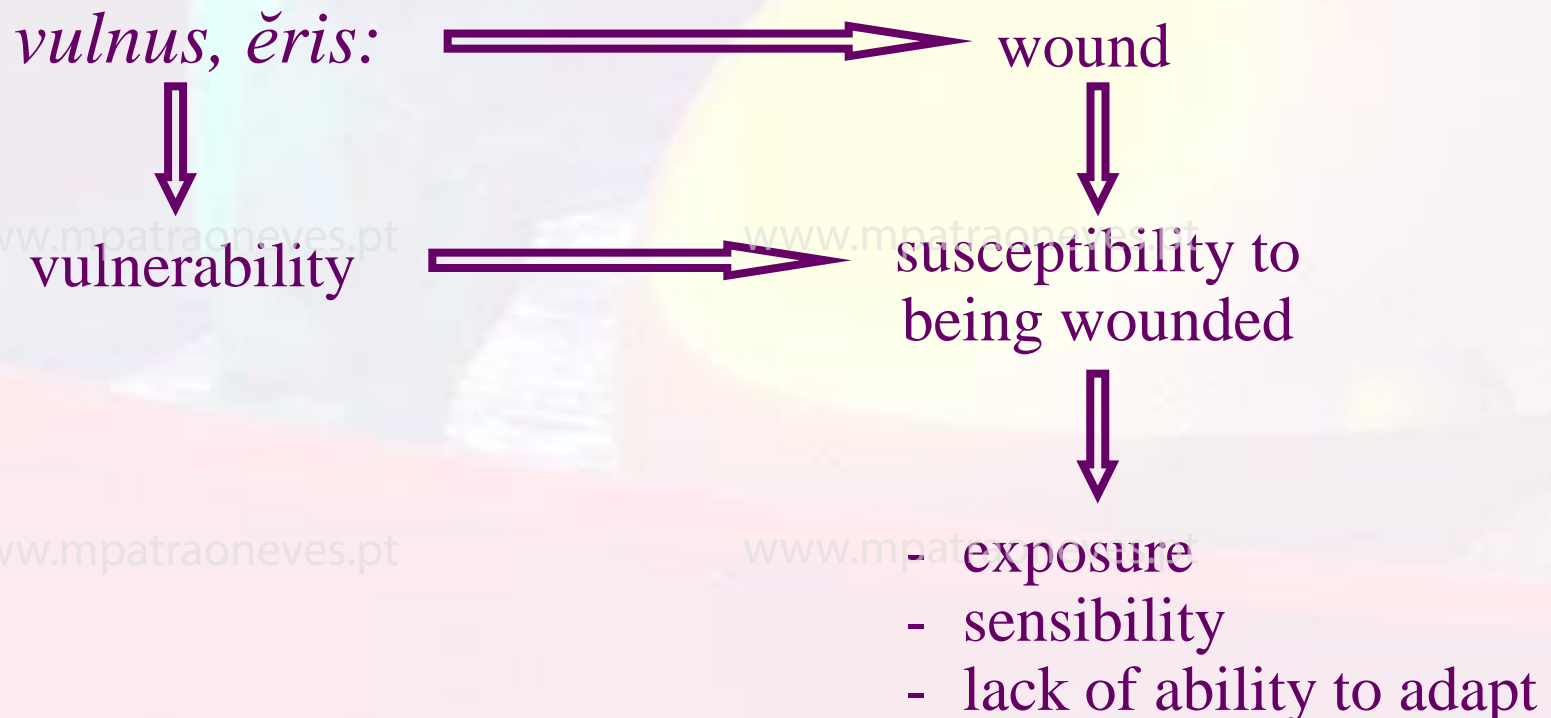
2.3. The principle of Vulnerability in the fight against exclusion and poverty

1. The concept of Vulnerability: its wide dimension

etymological approach

Vulnerability is a common word in a daily language, also applied in a technical meaning in many different fields, that range from the military to environment sciences.

The more the same concept is used in different contexts the easier it is to lose the accuracy of its definition.



1.1. The major dimensions of Vulnerability

conceptual approach before the UNESCO Declaration

1978, The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *Belmont Report: ethical principles and guidelines for the protection of human subjects of research*

1993, CIOMS/WHO, *International Ethical Guidelines for Biomedical Research Involving Human Subjects* (1982, 1993, 2002)

1996, WMA, *Declaration of Helsinki: ethical principles for medical research involving human subjects* (1964, 1975, 1983, 1989, 1996, 2000, 2004)

1997, UNESCO, *Universal Declaration on the Human Genome and Human Rights*

1.1. The major dimensions of Vulnerability

conceptual approach before the UNESCO Declaration

particular and relative classification



adjective
contingent
provisional



of persons and populations
to defend and protect



human
experimentation

to overcome through strengthening the
respect for persons (autonomy) and
consent

1.1. The major dimensions of Vulnerability

conceptual approach before the UNESCO Declaration

1998, *The Barcelona Declaration*

1972, Emmanuel Levinas, *L'Humanisme de l'autre Homme*

1979, Hans Jonas, *Das Prinzip Verantwortung*

1991, Jürgen Habermas, *Erläuterungen zur Diskursethik*

1.1. The major dimensions of Vulnerability

conceptual approach before the UNESCO Declaration

common and uniform designation



noun

universal

indelible

of persons (and living beings)
to acknowledge and respect



Human experimentation
Clinical assistance
Health care policies

to accept through deepening of the
principle of human dignity (and the
respect for the integrity of life)

1.1. The major dimensions of Vulnerability

conceptual approach before the UNESCO Declaration

characteristic

(anglo-american; bioethics)

adjective

(persons and groups)

contingent and provisional
(situation)

differentiation factor

human experimentation

autonomy and consent

a instrumental concept

condition/identity

(european continental; philosophy)

noun

(humanity)

universal and indelible

equalising factor

human experimentation

clinical assistance

health policies

human dignity, integrity
responsibility and solidarity

a theme in itself

The recovery of the history of the concept leaves us with two different meanings: both legitimate and apparently irreconcilable

1.2. The concept of Vulnerability in the Declaration

The principle of “Respect for human vulnerability and personal integrity” was introduced in the Declaration during the second and final “Intergovernmental Meeting of Experts aimed at finalizing a draft Declaration on Universal Norms on Bioethics”, in June 2005, on a proposal by the Portuguese delegation.

It never appeared in any of the earlier drafts of the Declaration.

1.2. The concept of Vulnerability in the Declaration

Last draft
(April, 2005)

Declaration
(June, 2006)

1. Human Dignity and Human Rights

2. Equality, Justice and Equity

3. Benefit and Harm

4. Respect for Cultural Diversity and Pluralism

5. Non-Discrimination and Non-Stigmatization

6. Autonomy and Individual Responsibility

7. Informed Consent

..... 5. Person without capacity to consent

..... 6. Respect for human vulnerability and personal integrity

8. Privacy and Confidentiality

9. Solidarity and Cooperation

10. Social responsibility

11. Sharing Benefits

..... 14. Protecting future Generations

12. Responsibility towards the Biosphere 15. Protection of the Environment, the Biosphere, and Biodiversity

1.2. The concept of Vulnerability in the Declaration

Principle's proposal: justification

- nearly exhaustive character of the “Principles” section
the absence of the principle of vulnerability, after having been stated as such in the Barcelona Declaration and in the context of a nearly exhaustive section on “Principles”, would be equivalent to its deliberate rejection;
- high level of specification of the principles of “Consent”
the significant development of “Consent” in two articles intended to cover all vulnerable situations, what needed to be shown as impossible.

Principle's proposal: goal

Acceptation of vulnerability as a noun or a human condition, broadening its dimension from a derivative principle or rule of

- the principle of (individual) autonomy
- to the principle of (universal) human dignity

1.2. The concept of Vulnerability in the Declaration

Double interpretation:

- western countries understand vulnerability only in a narrow sense, as adjective / situation, applied to human experimentation / clinical trials; vulnerability is to be overcome by the persons empowerment, strengthening autonomy;
- the so-called developing countries were sensible to its broad sense, as noun / condition, applied to every field of human activity; vulnerability is to be acknowledged and respected.

1.2. The concept of Vulnerability in the Declaration

In the Declaration, “vulnerability” came to express both senses :

“In applying and advancing scientific knowledge, medical practice and associated technologies, human vulnerability should be taken into account [“vulnerability” as expressing the universal human condition].

Individuals and groups of special vulnerability should be protected [“vulnerability” as expressing a specific and contingent situation]

and the personal integrity of such individuals respected”

Previous wording:

*In applying and advancing scientific knowledge, medical practice and associated technologies, human vulnerability should be taken into account **by** protecting vulnerable individuals and groups [...]*

2. The role of Vulnerability in Bioethics: its broad scope

Criticism to the principle started to appear even before the 2005 Declaration, and mainly after the Barcelona Declaration, as the notion of vulnerability became more and more decisive in the bioethics discourse.

The critiques share:

the willingness to maintain the notion of vulnerability in the bioethics discourse (and to, eventually, reinforce it), but to review its concept and, mostly, its statute as principle;

the willingness to unfold the notion of vulnerability in several others so as to better specify its sense and/or more rigorously define its statute.

2.1. Moral requirements from principle of Vulnerability

The most pertinent critique on theoretical grounds, for it questions the very principle and the way of its application, is that vulnerability cannot be considered a principle, due to the absence of a prescriptive sense.

On a philosophical point of view, “principles” are general statements, formal, abstract, and descriptive, at a meta-ethical level; they can gain content by losing abstraction, becoming like rules and being of a prescriptive nature. It is, in fact, in this latter sense that “principle”, as mid-level principles, have been understood in the bioethical realm.

Indeed, in the Declaration not all principles have the same prescriptive strength, but none is neutral from an axiological point of view.

2.1. Moral requirements from principle of Vulnerability

Declaration on Bioethics and Human Rights: Principles

1. (respect) Human Dignity and (comply with) Human Rights
2. Benefit and (do not) Harm
3. (respect) Autonomy and (acknowledge) Individual Responsibility
4. (promote) Consent
5. Person without capacity to consent
6. **Respect for human vulnerability and personal integrity**
7. (respect) Privacy and (promote) Confidentiality
8. (promote) Equality, Justice and Equity
9. (promote) Non-Discrimination and Non-Stigmatization
10. Respect for Cultural Diversity and Pluralism
11. (promote) Solidarity and Cooperation
12. (promote) Social responsibility and health
13. Sharing Benefits
14. Protecting future Generations
15. Protection of the Environment, the Biosphere, and Biodiversity

2.1. Moral requirements from principle of Vulnerability

The principle of “*human vulnerability*” states

- (1) the obligation of taking “into account” the vulnerability inherent to all human beings, which entails some important consequences:
 - awareness that all persons are exposed to be “wounded” by “*scientific knowledge, medical practice and associated technologies*”, they are all sensitive to their advances, and might lack the capacity to adapt to the imposed novelties which implies that they should be recognized and respected as such;
 - requires precaution and care in order to prevent any abuse of one’s own vulnerability and to protect the person from a negative impact of these advances;
 - establishes an egalitarian factor among all persons (all vulnerable);
 - implicitly reviews the nature of autonomy that cannot be considered as a compact, homogeneous and static substance but, on the contrary, a plastic, heterogeneous and dynamic reality (people are autonomous for specific decisions in given situations);

2.1. Moral requirements from principle of Vulnerability

The principle of “*human vulnerability*” states

- (1) the obligation of taking “into account” the vulnerability inherent to all human beings, which entails some important consequences:
 - widens the ethical reasoning from an individual (focused in autonomy) to a universal perspective (acknowledging vulnerability). The point of view of vulnerability, as a universal feature, leads to the consideration of the whole humanity, together with the principle of human dignity;
 - “*In applying and advancing scientific knowledge, medical practice and associated technologies*”, centers the reflection in the social context where the techno-scientific innovations are applied, and raises the issue of justice;
- (2) gives priority to individuals and groups classified as vulnerable, for whom it demands not only protection against being “wounded”.

2.2. Application of the principle of Vulnerability

Briefly, even the principles of a more descriptive nature express not only the fundamentals for action – all action has to take into consideration that all persons, in different degrees, are vulnerable –, but also its orientation or obligation:

- a negative obligation – one's vulnerability should not be abused (should be respected, awareness of the validity of the statement and the duty to comply with);
- and a positive one – protection should be given to those who are more exposed, more sensitive and lack capacity to adapt.

This principle, owing to its broader sense of vulnerability, was intended to be applied, pertinently and indispensably, in situations already covered by the principles of autonomy or consent, but in which, nevertheless, human dignity and human rights were being threaten, at the three levels in which bioethics operates today:

- (human experimentation) biomedical research;
- (clinical assistance) medical practice;
- health care and biomedical research public policies

2.2. Application of the principle of Vulnerability human experimentation

Vulnerability, intrinsic or inherent to every human being, can be, in a subtle and even non-deliberate way, exploited in the realm of human experimentation, for example through:

- a self reliant presentation of the clinical trials for which volunteers are being recruited, underestimating that information is never neutral;
- healthcare benefits for volunteers, frequently a mandatory requirement for their participation;
- the neglect of the psychological structure of the individuals and of their life experiences what, sometimes, may induce them to feel the obligation to volunteer;

2.2. Application of the principle of Vulnerability

human experimentation

Application of the principle of vulnerability at this level of human experimentation does not make autonomy secondary, nor renders consent less important, but brings to light that these principles not only fail to protect the individuals from every expression of vulnerability but also can be used as “deresponsibilizers” by those who, in this relationship, detain more power, violating the respect for human dignity.

2.2. Application of the principle of Vulnerability

medical practice

Vulnerability, intrinsic or inherent to every human being, can be, in a subtle and even non-deliberate way, exploited in the realm of medical practice, for example through:

- the neglect of the psychological structure of the individuals and of their life experiences what, sometimes, may induce them to feel the obligation to volunteer as organ donors for members of their own families;
- the medicalization of society, what contributes to create the illusion that medicine holds the solution for everything (this aspect questions the very concept of “disease”);
- the publicity of medication and procedures, creating unrealistic expectations in the patient and in society in general, also aggravating the process of medicalization of the society.

2.2. Application of the principle of Vulnerability

medical practice

Application of the principle of vulnerability at this level of medical practice does not diminish the responsibility of the individuals in their autonomous choices, but brings to light that the principle of autonomy is not abstract but situated in a context, and that the circumstances surrounding the decision do influence it, thus obligating those who hold more power (society, institutions, state) to protect the individuals from potential abuse by the system requiring that they are respected as persons, in their dignity.

2.2. Application of the principle of Vulnerability

public policies



2.2. Application of the principle of Vulnerability

public policies

Vulnerability, intrinsic or inherent to every human being, can be, in a subtle and even non-deliberate way, exploited in the realm of health and research policies, for example through:

- the action of lobbies, namely patients' lobbies, whose benefits are obtained through their power to reivindicate, thus weakening others;
- the progress of genetics, which has identified new defects, thus broadening the spectrum of the diseases;
- the progress of biotechnologies in general, what can be a factor aggravating injustice and discrimination.

2.2. Application of the principle of Vulnerability

public policies

Application of the principle of vulnerability at this level of health care and research policies requires institutions and states to be aware that not always biomedical progress and/or the reinforcement of the power of those so-called vulnerable result in diminishing and/or suppressing vulnerability but, on the contrary, they can create and/or aggravate vulnerabilities.

2.3. The principle of Vulnerability in the fight against exclusion and poverty

Bioethics unfolded as

Vulnerability
pivotal principle

biomedical
ecological
social

demands:

- reinforcement of autonomy (vulnerability covers situations that autonomy does not protect)
- respect for dignity (vulnerability enhances human dignity claiming that the most vulnerable are equals in dignity)
- promotion of justice (vulnerability requires justice to prevent abuse)

2.2. Application of the principle of Vulnerability

public policies



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Thank you