

Respect for Human Vulnerability and Personal Integrity:

**theoretical challenges
and
practical achievements**



M. Patrão Neves

Respect for Human Vulnerability and Personal Integrity: theoretical challenges and practical achievements

1. Theoretical challenges (how it should be read)

1.1. The history of the formulation of the concept in the framework of bioethics

1.2. The story of the inclusion of the principle in the Declaration

1.3. The interpretation of the principle within the Declaration

- the criticism

- “what kind of principle is it?”

2. Practical achievements (how it should be applied)

2.1. Human experimentation

2.2. Medical practice

2.3. Health care and biomedical research policies

2.4. Respect: human vulnerability and personal integrity

1.1. History of the concept

vulnerability

Ethymology

vulnus, ěris:



vulnerability



wound



susceptibility to being wounded

Bioethics

becomes morally relevant
in the bioethical
normatives

adjective
contingent
provisional

Philosophy

conceptual foundation is sought in
those philosophers who attributed
it moral significance

noun
universal
indelible

1.1. History of the concept in bioethics documents

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. History of the concept

in bioethics documents

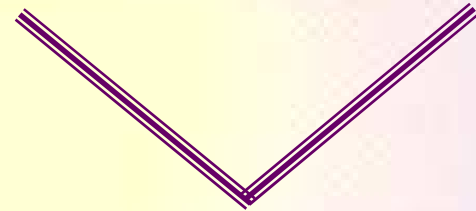
particular and relative classification



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. History of the concept in contemporary philosophy

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*

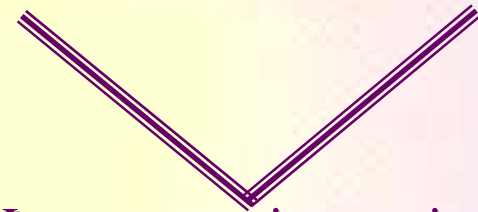
1.1. History of the concept in contemporary philosophy

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. History of the concept

characteristic
(anglo-american; bioethics)

adjective
(persons and groups)

contingent and provisional
(situation)

differentiation factor

human experimentation

autonomy and consent,
justice

condition
(european continental; philosophy)

noun
(humanity)

universal and indelible

equalising factor

human experimentation

clinical assistance

health policies

human dignity, integrity
responsibility and solidarity

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

1.2. Story of the principle

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. Story of the principle

Last draft
(April, 2005)

Declaration
(June, 2006)

- | | |
|---|--|
| 1. Human Dignity and Human Rights | 1. Human Dignity and Human Rights |
| 2. Equality, Justice and Equity | 8. Equality, Justice and Equity |
| 3. Benefit and Harm | 2. Benefit and Harm |
| 4. Respect for Cultural Diversity and Pluralism | 10. Respect for Cultural Diversity and Pluralism |
| 5. Non-Discrimination and Non-Stigmatization | 9. Non-Discrimination and Non-Stigmatization |
| 6. Autonomy and Individual Responsibility | 3. Autonomy and Individual Responsibility |
| 7. Informed Consent | 4. Consent |
| | 5. Person without capacity to consent |
| | 6. Respect for human vulnerability and personal integrity |
| 8. Privacy and Confidentiality | 7. Privacy and Confidentiality |
| 9. Solidarity and Cooperation | 11. Solidarity and Cooperation |
| 10. Social responsibility | 12. Social responsibility and health |
| 11. Sharing Benefits | 13. Sharing Benefits |
| | 14. Protecting future Generations |
| 12. Responsibility towards the Biosphere | 15. Protection of the Environment, the Biosphere, and Biodiversity |

1.2. Story of the principle

Vulnerability

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.

1.2. Story of the principle

Vulnerability

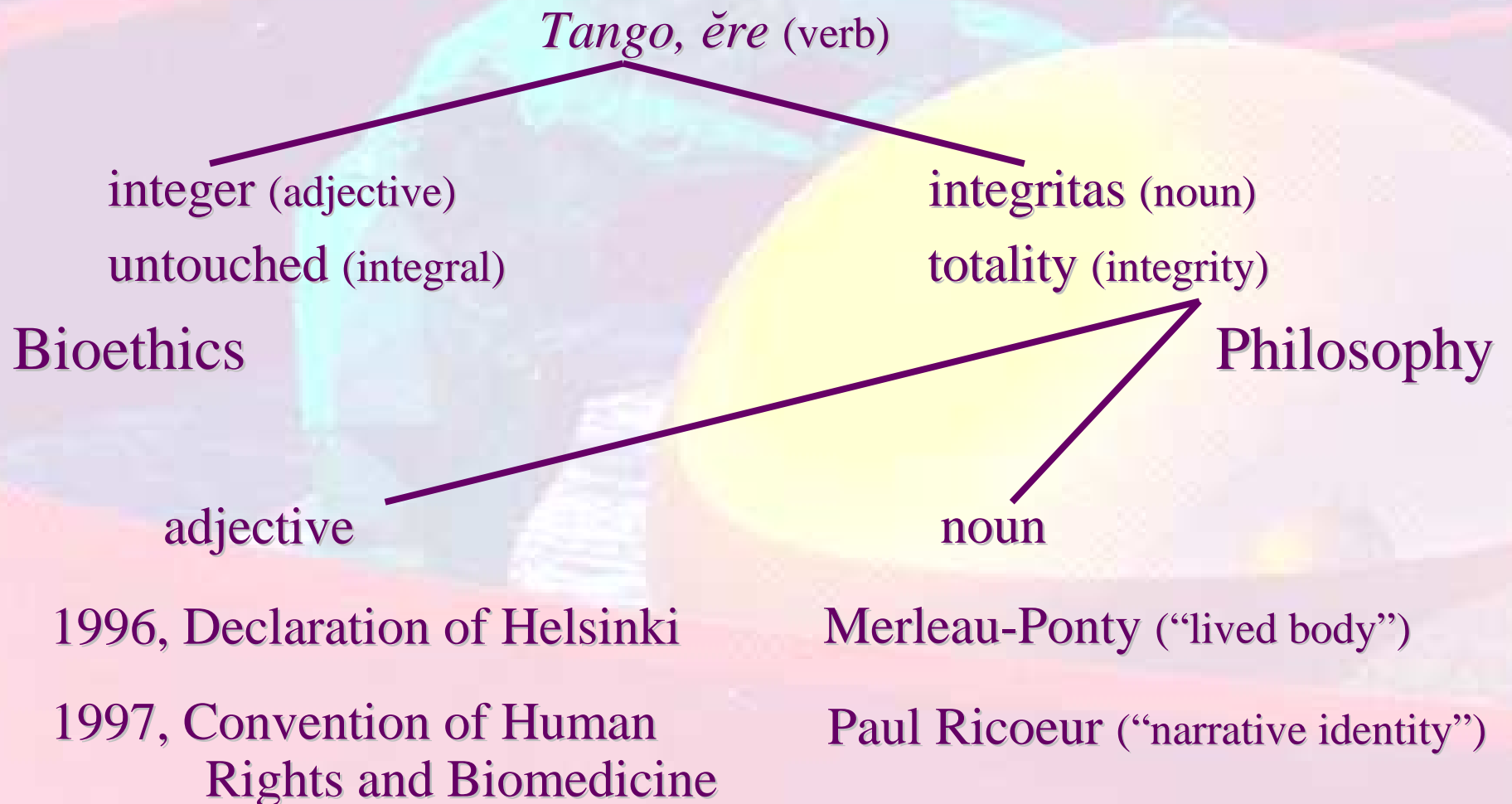
Double interpretation:

- western countries tended to understand it 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 tended to understand it in a broad sense, as noun/condition, applied to every field of human activity; vulnerability is to be acknowledged and respected.

1.2. Story of the principle

Integrity

The reference to “personal integrity” was never perceived as problematic. Nevertheless, it involves some duality, too:



1.2. Story of the principle

Integrity

Principle's intended meaning

The primordial objective was to privilege the broader, philosophical sense, expressed through the noun and translated by the notion of “totality”.

In any case, even for etymological reasons, the distance between the two senses – “integrity” evokes both, the state in which all the parts are maintained (totality) and the quality of that which is unaltered (untouched) – is not at all significant, nor does it invoke any contradiction, so their coexistence is possible.

1.3. The principle within the Declaration

In the Declaration, “vulnerability” came to express both senses and “integrity” was (nevertheless) understood mainly in its narrower sense, in its dependence to the narrow sense of vulnerability. Thus:

“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 [“integrity” refers to the inviolable character of the individual, to the right to not be “touched” physically or psychologically].”

1.3. The principle within the Declaration

the criticism

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.

1.3. The principle within the Declaration

the criticism

It is possible to systematize the most relevant criticism in two main streams, well represented by *Michael Kottow* and *Carol Levine*:

Michael Kottow (“*The vulnerable and the susceptible*”, 2002; “*Vulnerability: What kind of principle is it?*”, 2004)

He suggests a distinction between:

- “vulnerability” that applies to everyone, as “human fragility” (anthropological feature)
- “susceptibility” being “injured and predisposed” (ethical principle)

Fermin Shramm (2008), following Kottow’s reasoning and even taking it to the extreme, proposes three types of vulnerability to designate different situations:

- primary vulnerability, understood as the ontological condition of any living being (universal);
- secondary vulnerability or susceptibility;
- vulnerability proper, vulneration (vulnerated, that is, directly affected).

1.3. The principle within the Declaration

the criticism

Carol Levine

(*“The limitations of ‘vulnerability’ as a protection for human research participants”*, 2004)

She points out that, at the same time, that the concept is:

- too broad (“if everyone is vulnerable, then the concept becomes too nebulous to be meaningful”)
- and too narrow (“an almost exclusive emphasis on group characteristics that ostensibly undermine or eliminate the capacity to give consent can divert attention from features of the research itself.”)

Florentia Luna (2008), following Levine’s reasoning when it becomes restricted to the consideration of vulnerability as adjective, proposes the understanding of vulnerability through the metaphor of layers. Instead of having “a solid and unique vulnerability that exhausts the category, there might be different vulnerabilities, different layers operating.”

1.3. The principle within the Declaration

“what kind of principle is it?”

The most pertinent critique on theoretical grounds, for it questions the very principle and the way of its application, is that neither vulnerability nor integrity are principles, due to the absence of a prescriptive sense.

On a philosophical point of view, “principles” are general statements that can be seen as formal, abstract, and descriptive, at a meta-ethical level, or as gaining content but losing abstraction, becoming like rules or mid-level principles and being of a prescriptive nature. It is, in fact, in this latter sense that “principle” has 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.

1.3. The principle within the Declaration

“what kind of principle is it?”

The principle of “*respect for human vulnerability and personal integrity*” first states the obligation of taking into consideration the vulnerability inherent to all human beings. That is to say, it is important to gain awareness of the fact that a person is vulnerable, is exposed to being “wounded” by the other, subject to diverse and often subtle forms of exploitation or abuse, irrespective of his level of autonomy.

Secondly, it gives priority to individuals and groups classified as vulnerable, for whom it demands not only protection against being “touched” but also respect for their integrity, so that they are not altered in their ownness.

2. Practical Achievements (how it should be applied)

I will proceed to show how this principle can be applied and, along the process, answer the criticism. That is:

- showing that it expresses an obligation to act (in a negative and in an affirmative way) in situations not covered by the principles of autonomy, consent and justice;
- and that it can be applied, advantageously, beyond the labeling of persons and groups in the restricted realm of human experimentation.

This principle, owing to its broader sense of vulnerability, was intended to be applied, pertinently and indispensably, as a safeguard of human dignity at the three levels in which bioethics operates today:

- human experimentation;
- medical practice;
- health care and biomedical research policies

2.1. Practical Achievements (how it should be applied) 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;
- the hyperbolization, by the media, of the biomedical achievements, what can create the illusion that biomedicine is a rigorous science and that its studies invariably lead to success.

2.1. Practical Achievements (how it should be applied) 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.

2.2. Practical Achievements (how it should be applied) 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;
- the narrowing of the concept of “normality”.

2.2. Practical Achievements (how it should be applied) 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.

2.3. Practical Achievements (how it should be applied) health care and biomedical research 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.

2.3. Practical Achievements (how it should be applied) health care and biomedical research 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.

2.4. Practical Achievements (how it should be applied)

Respect: human vulnerability and personal integrity

At the three realms herein considered, the application of the **principle of integrity** demands recognition that the person is more than the summation of its objectivable parts, being, in its essence, an indissoluble lived unit. To slash one of the dimensions of the person and to disengage it from the others is to distort the essence of the human.

This is what, in the wording of the principle, is applicable to the specially vulnerable, but that, in the spirit of the principle, is applicable to every person without exception.

2.4. Practical Achievements (how it should be applied)

Respect: human vulnerability and personal integrity

On that concerning specifically the application of the **principle of vulnerability** understood, in its broader sense, as a condition intrinsic to every human being, it is expressed in two ways:

- initially as (aspect to take into consideration) demand for pondering in the decision making of the ethical action (what some critics would designate by element of a “check list” what, in any case, results effectively);
- then also as demand for respect or action reserve, of non-exploitation or abuse.

It is only the latter aspect that is contemplated in the narrow acceptance of vulnerability.

Respect: Human Vulnerability and Personal Integrity

theoretical challenges and practical achievements

Respect for human vulnerability and personal integrity requires, at the three levels of ethical analyses, that we remain constantly aware of human vulnerability and that we take it into consideration in all our actions, as an obligation not to take advantage of others' fragilities (negative action) and to reinforce the social and institutional safeguards against them (affirmative action).

For those who are more vulnerable, due to different situations, an affirmative action of protection is always required, preventing that the self, in its unity, be compromised.

This principle expresses a commitment to morality.

Respect: Human Vulnerability and Personal Integrity theoretical challenges and practical achievements

In brief, regardless of the rigor of the ethical analysis, what is truly fundamental is to recognize that the principle of vulnerability moves morality away from a *rights-based* orientation and expresses a *duties-based* orientation.

The principle leads to a logic of action of care, of solicitude, of solidarity, of responsibility, alternative and complementary to a logic of freedom, of self-determination, of power.

The principle is worth for the shift of orientation it proposes.



Thank you