

Chapter 10

ARTICLE 8: RESPECT FOR HUMAN VULNERABILITY AND PERSONAL INTEGRITY

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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.

BACKGROUND

Article 8 is included in the section dealing with the principles that should be observed in all the decisions and practices in the scope of the present Declaration and states the obligation of ‘respect for human vulnerability and personal integrity’. This article was one of the two that were never part of the successive preliminary projects drawn up by the IBC. It was proposed and accepted during the second and final Intergovernmental Meeting of Experts aimed at finalizing a draft Declaration on Universal Norms on Bioethics, in June 2005 (Report expert meeting, 2005).

This principle draws attention to two different realities – human vulnerability and personal integrity – that are inter-related and both fundamental in the field of bioethical reflection and practice. Frequently considered to be ambiguous in meaning and vaguely defined, these expressions need to be explained separately.

The notion of ‘vulnerability’

‘Vulnerability’ is a term of Latin origin, derived from *vulnus* which means ‘wound’. ‘Vulnerability’ is then defined as the susceptibility of being wounded.

This etymological-conceptual meaning is the most common one, used in everyday language, and is also the one that arose within the field of bioethics, in 1978, in the *Belmont Report: ethical principles and guidelines for*

the protection of human subjects of research. Vulnerability is here applied both to individuals, in the section on 'voluntariness', and to populations, in the section on 'the systematic assessment of risks and benefits'. Addressing the topic of 'informed consent', the report specifies some vulnerable populations and underlines the respective need for protection, under the heading of 'Selection of subjects':

One special instance of injustice results from the involvement of vulnerable subjects. Certain groups, such as racial minorities, the economically disadvantaged, the very sick, and the institutionalized may continually be sought as research subjects, owing to their ready availability in settings where research is conducted. Given their dependent status and their frequently compromised capacity for free consent, they should be protected against the danger of being involved in research solely for administrative convenience, or because they are easy to manipulate as a result of their illness or socioeconomic condition (National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, 1979).

Actually, the notion of 'vulnerability' was introduced into the vocabulary of bioethics in the ambit of human experimentation, as a characteristic attributed to particular populations considered, for different reasons, as those most exposed to and poorly defended against the maltreatment and abuse of others. Indeed, historical factors were decisive for the generalization of this characteristic, which is still predominant: human experimentation developed on an ever growing scale throughout the first half of the twentieth century, involving unprotected and/or institutionalized groups of persons like orphans, prisoners, the elderly and, later, Jews and other ethnic groups, considered as inferior and even subhuman by the Nazis, or persons such as the Chinese, who were exploited by the Japanese in order to pursue their scientific and military objectives.

These groups came to be classified as vulnerable. Later, ethnic minorities, socially underprivileged groups and women were added. The description of these groups as vulnerable implies the obligation to defend and protect them, so that they will not be 'wounded' or ill-treated. Bioethics has attempted to justify this, mainly by reinforcing the principle of autonomy and of the consequent demand, increasingly more inclusive and stricter, for informed consent. The principle of autonomy is viewed not merely as the recognition of the capacity common to all persons 'to hold views, to make choices, and to take actions based on personal values and beliefs', but also as the effective

creation of conditions 'enabling a person to act autonomously' (Beauchamp and Childress, 2001: 63). In this sense one can say that vulnerability, held as a provisional and contingent quality of persons and populations to be protected, should be overcome by the reinforcement of their respective autonomy, brought about by the additional demand for informed consent, or rather, to use a more currently acceptable term, by their empowerment.

This has been the predominant meaning of the notion of vulnerability, not only in the distant past referred to above, but also at present, as can be verified in the 1996 revision of the Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects. Article 8 refers to vulnerability attributing it to some 'populations subject to investigation' for whom 'special protection' is required:

Medical research is subject to ethical standards that promote respect for all human beings and protect their health and rights. Some research populations are vulnerable and need special protection. The particular needs of the economically and medically disadvantaged must be recognized. Special attention is also required for those who cannot give or refuse consent for themselves, for those who may be subject to giving consent under duress, for those who will not benefit personally from the research and for those for whom the research is combined with care (World Medical Association, 2004: Article 8).

The first UNESCO declaration on the subject of biomedicine, the Universal Declaration on the Human Genome and Human Rights, of 1997, also refers in Articles 17 and 24 to 'vulnerable groups', individuals and families, as deserving special attention. The International Ethical Guidelines for Biomedical Research Involving Human Subjects, of the Council for International Organizations of Medical Sciences (CIOMS), in its third and most complete version of 2002, makes extensive reference to vulnerability which is always used adjectivally to describe "classes of individuals", subjects, persons, groups, populations, communities, defining 'vulnerability' as 'a substantial incapacity to protect one's own interests'" (CIOMS/WHO, 2002).

More recently, departing from the development of bioethics in continental Europe, which began in the 1980s, the notion of vulnerability, still corroborating its etymological sense, gained a new, broader meaning, arising from the reflection that philosophers like Emmanuel Levinas and Hans Jonas had begun to dedicate to it.

Levinas was the first to treat vulnerability as a philosophical theme, in his work *Humanisme de l'autre homme* (1972), where he defines it as 'subjectivity'.

In accordance with Levinas' view of subjectivity, the self always comes *after* otherness. Thus, when the 'self', the subject, arrives, s/he is already in relation to the other, who waits for her/him, who makes her/him be. Therefore, the self is in dependence to the other and hence vulnerable:

The Self, from head to feet, until the bone marrow, is vulnerability.
 (« Le Moi, de pied en cap, jusqu'à la moelle des os, est vulnérabilité »)
 (Levinas, 1972: 104).

Thus 'vulnerability' enters the vocabulary of philosophy as an intrinsic state of the human, the universal condition of humanity, in so far as the self only exists in relation to the other.

Hans Jonas, in *Das Prinzip Verantwortung* (1979), also draws attention to the relevance of the philosophical meaning of 'vulnerability', first, by specifying its meaning as a perishable characteristic of what exists; later, and in consequence, extending its reality to the whole of nature. Everything that exists, simply because it exists, is perishable and herein resides its vulnerability (Jonas, 1979). The human being is thus naturally and ontologically vulnerable.

Vulnerability is currently regarded as a human condition, inherent to existence in its radical finitude and fragility, so that it cannot be eliminated or surpassed. It requires the care of others, the responsibility and solidarity of others in the recognition and non-exploitation of that condition. It is in this sense that vulnerability comes to constitute a theme for development in bioethics and also a principle to be respected, just as it is presented for the first time, in 1998, in the Barcelona Declaration, in its classification of four fundamental principles for a joint European policy in the field of bioethics and biolaw:

Vulnerability expresses two basic ideas. (a) It expresses the finitude and fragility of life which, in those capable of autonomy, grounds the possibility and necessity for all morality. (b) Vulnerability is the object of a moral principle requiring care for the vulnerable. The vulnerable are those whose autonomy or dignity or integrity is capable of being threatened (*Barcelona Declaration*, 1998).

There are substantial differences between the circumstantial Anglo-American bioethical references to vulnerability and its European treatment as a theme in bioethics, even though they articulate perfectly well: from its adjectival function, qualifying certain groups and persons, vulnerability comes to be used as a noun, describing a reality common to human beings; from a contingent and temporary characteristic, it becomes a universal, indelible condition; from a factor of differentiation (if not one of discrimination – according to some

commentators) between populations and individuals, it becomes an equalizing factor amongst everyone; from privileged consideration in the field of human experimentation, it gains constant attention in the area of clinical assistance and health care policies; from demanding autonomy and the practice of informed consent, it comes to demand responsibility and solidarity.

In fact, in the present world of bioethics, the notion of vulnerability encompasses both meanings: the first, narrower, adjectival sense, commonly and immediately comprehensible; the second, as a noun, broader in meaning and referring to an anthropological perspective, as the foundation of ethics. Both of these meanings are implied in the allusion to vulnerability in Article 8: 'human vulnerability should be taken into account' as an inherent feature of the human condition, seen in its irreducible finitude and fragility as a permanent susceptibility to being 'wounded' that, as such, can never be suppressed; and 'individuals and groups of special vulnerability should be protected' whenever that inherent human vulnerability is aggravated by particular circumstances.

The notion of 'integrity'

The term 'integrity' is also of Latin origin. It is derived from the verb *tangere* which means 'to touch', to 'hit'. This is the root both of the adjective *integer*, which means 'untouched', 'integral', and the noun *integritas* which means 'totality', 'integrity'. The noun 'integrity' evokes both the state in which all the parts are maintained and the quality of that which is unaltered, also functioning then as an adjective.

It was precisely with the latter sense of 'the quality of that which is unaltered' that 'integrity' entered the vocabulary of bioethics and the sense that has been maintained in its most common usage. This was confirmed in 1996, in the Declaration of Helsinki, in which the noun 'integrity' is used in the 'Basic Principles' section as an attribute of the recognized inviolability of the subject of experimentation, which should not be 'touched' physically or psychologically:

The right of the research subject to safeguard his or her integrity must always be respected. Every precaution should be taken to respect the privacy of the subject and to minimize the impact of the study on the subject's physical and mental integrity and on the personality of the subject (World Medical Association, 1996: I.6).

It is with this sense of 'not touching', 'keeping intact', or 'not affecting physically or psychologically' that the Convention of Human Rights and Biomedicine alludes to integrity in its first article:

Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine (Council of Europe, 1997).

At this biomedical level of meaning, 'integrity' is presented as a right to which all persons are entitled, a negative right or a right of non-interference which, as such, demands respect from the others, that is, non-interference of the others in the private sphere of the self.

Similarly, 'integrity' is presented as a virtue, or disposition to act in a certain way, attributed to all those who remain unalterable, incorruptible, particularly by outside influences or pressures. This is the common deontological sense that is found in the two earlier UNESCO declarations: both Article 13 of the Universal Declaration on the Human Genome and Human Rights (1997) and Article 15 of the International Declaration on Human Genetic Data (2003) refer to 'integrity' as a responsibility or virtue that the investigator should develop and society should demand.

Nevertheless, and once again in the wake of the development of bioethics in continental Europe, mainly in its philosophical foundation in a humanist tradition, the meaning of 'integrity' as 'totality' is reiterated.

One could refer to various philosophers, from Maurice Merleau-Ponty, and his conception of a 'lived body', to Paul Ricoeur and his conception of personal identity as 'narrative identity'. Merleau-Ponty, mainly in *Phénoménologie de la perception* (1945), surpasses the traditional, anthropological duality, showing that man is not a sum of the parts, the body and the mind, but rather its inseparable unity, a lived body and an incarnate subjectivity. The multidimensional character of the individual is clearly assumed today in the understanding that his/her physical, psychological, social, intellectual and spiritual dimensions cannot be separated or abstracted without loss of the totality that the individual comprises. Ricoeur (1988) proceeds to a hermeneutics of the subject, and states that the narrative that each individual creates about itself, in a fusion of history and fiction, unifies the events of a life and the transformations of a subjectivity in the course of its historicity, allowing him/her to construct his/her personal identity. Today it is understood that that singular identity is not restricted to a present reality, but is integrated in the history of a life, from past experiences to future fears or expectations, in which the different events are articulated and gain a significance of their own.

'Integrity' is now seen as the totality or oneness that each person comprises, in the plurality of his/her dimensions and throughout his/her existence, as the coherence of a life. Hence a reality which, once again, appeals to the care of others, so that it is never 'touched' or broken up. It is, above all, with this third and final sense that 'integrity' gains prominence in the field of bioethics, although frequently associated with the two former meanings referred to above. The Barcelona Declaration (1998), which includes 'integrity' amongst the four basic principles of bioethics and bio-law, shows the fuller, plural sense that the noun can acquire by defining it as the 'untouchable core' of the person which 'must not be subject to external intervention' as it refers to the 'coherence of life of beings with dignity that should not be touched and destroyed'.

EXPLANATION OF THE ARTICLE

This broader sense of 'integrity', implied in the allusion to the concept in Article 8 of the Universal Declaration on Bioethics and Human Rights through its qualification '*the personal integrity*', is dissipated in so far as the expression refers only to '*such individuals*', those with added vulnerability. The initial proposal that 'human vulnerability and personal integrity should be respected' was not understood in the full sense that 'integrity' expresses, but rather was interpreted in its restricted sense by most of the experts at the meeting in June 2005 and thus applied only to the most vulnerable – an interpretation that remained unaltered until the approval of the final version of the article. So, to sum up, 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 'touched' by the other, subject to diverse and often subtle forms of exploitation or abuse, irrespective of his/her level of autonomy. Secondly, it gives priority to individuals and groups classified as vulnerable, for whom it demands not only protection against being 'wounded' but also respect for their integrity, so that they are not reduced to merely a part of themselves and so considered abstractly.

It is this double meaning that justifies that Article 8 is introduced after the principle of 'Consent' (Article 6) and immediately following 'Persons without the capacity to consent' (Article 7), insomuch as it responds to all the situations that offend the dignity of the person and are not preventable by these two articles, that is, situations in relation to which the principles of autonomy and consent prove insufficient. Indeed, the principle of '*respect for human vulnerability and personal integrity*' should preferably be linked to that

of 'human dignity', which reinforces the statement of the unconditioned value of the human beings by demanding his inviolability.

In this context, and as a result of the initial criticism that 'vulnerability' and 'integrity' are ambiguous concepts (Danis and Patrick, 2002; Morawa, 2003), it follows that they are not clearly of a normative nature; therefore, they fail to be widely recognized of their status as principles, and, consequently, of the expression of any obligation of action. In fact both concepts lie on a descriptive level of human reality – onto-anthropological – but, because they are not axiologically neutral, they simultaneously express a prescriptive meaning, whose norm is contained in the term itself: 'vulnerability' and 'integrity' should be recognized as intrinsically human dimensions, components of personal identity which, as such, deserve to be respected, that is to say, taken into consideration at the various levels of human activity.

APPLICATION OF THE PRINCIPLE

The principle expressed in Article 8 intervenes in a pertinent and indispensable manner at the three levels in which bioethics has developed: human experimentation and biomedical research, clinical practice, and health policies. The principle of vulnerability requires the recognition that the exercising of autonomy and the giving of consent do not eliminate vulnerability which, subtly and surreptitiously, is still susceptible to exploitation, for example through optimistic presentation of clinical trials, for whom volunteers are needed, or the compensation offered to them, such as free medical examinations and clinical assistance, or by the exaggeration of biomedical successes in the media. The latter situation creates unrealistic expectations in patients and in society in general, in which the process of medicalization is being aggravated. Thus people turn to biomedicine as the solution to all human problems, placing unbearable pressure upon it, whilst discouraging alternative means to a solution; an infertile couple may resort to reproductive technology, but may also refuse to be submitted to infertility treatment and accept infertility as a condition of their life. Within the field of clinical assistance, the principle of vulnerability helps to reinforce the rights of patients. At the same time, it appeals to the responsibility of the health professional in establishing symmetrical relationships with the patient and forces institutions to protect citizens even when they make no complaint. The needs and interests of patients or groups of patients with less power to revindicate should not be underestimated, which means that the excesses of patient lobbies can be counteracted. In the field of health policies, the principle of vulnerability demands, both at the social and international level, that the

benefit of some should not be attained by exploiting the weakness of others, as well as the understanding that the greater wellbeing of only some will make the rest, the excluded, even more vulnerable. Hence national policies and also those of bio-industries must not aggravate human vulnerability but rather seek to eliminate it as far as possible and to respect what is beyond their reach.

The principle of respect for human vulnerability and personal integrity demands a new conception of the human body and disease: a body is no longer an object but a subject and hence inseparable from the person it comprises; a disease is not a purely objective phenomenon but only gains reality in a lived body and significance in the history of a life. At the level of experimentation it demands protection which goes beyond that which can be expressed in informed consent and which refers to the prohibition of the objectification of the body or part of the body and demands respect for personal identity in the relationship between the subject of experimentation and the researcher, and also between patient and doctor, at the level of clinical assistance. Here, respect for integrity demands new forms of communication that permit the doctor to focus more on the patient than the illness, which then facilitates the involvement of the patient in his own therapeutic process as a partner in the health team, and, consequently, the development of therapies which are perceived as less invasive and more respectful of the individual, for example, at a cultural or religious level. In the field of health policies, the principle can play an important role in the prohibition of commercializing human body parts, in the regulation of genetic manipulation, particularly in safeguarding the human genome, and in the consideration of patentable human matter.

In short, the principle of respect for human vulnerability and personal integrity inaugurates a new logic in ethical reasoning which no longer implies the claim of persons' rights but the solicitude of obligations that are due to all: the complementarity between a consolidated ethics of rights, based on the freedom of the individual and developed by reinforcing autonomy, and a pressing ethics of duties, based on the responsibility for the other and developed by reinforcing solidarity.

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Background, principles and application

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