

Chapter 2

Vulnerability: How did the principle Come About?

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2.1 Introduction

In June 2005, delegates of the Member States of UNESCO gathered in Paris to review the draft of the *Universal Declaration on Bioethics and Human Rights*¹. I was present as a delegate of the Holy See. Immediately after the approval of the “Principle of Vulnerability,”² one of the delegates, a friend, came to me and said: “It’s a miracle! Do you realize the implications? Who is the most vulnerable among the vulnerable?” “Yes, I know, I know,” I replied. The implicit reference was to unborn human beings: embryos and fetuses.

This little anecdote helps us see why it may be interesting to examine the genesis of the Principle of Vulnerability during the drafting of the Declaration.

2.2 A New Principle

The text of the Principle, in article 8, states: “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.”

It is true that—as stated at the beginning of the Report on the principle recently published by of the International Bioethics Committee of the UNESCO (IBC)—“This notion is not new. The concept of vulnerability appears in important national documents, starting with the US Belmont Report of 1978, and in international docu-

¹ From now on “the Declaration.”

² From now on “the Principle.”

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ments, such as the third and most complete version of the International Ethical Guidelines for Biomedical Research Involving Human Subjects of the Council for the International Organizations of Medical Sciences (CIOMS) (2002) and in the latest (2008) version of the Declaration of Helsinki, which makes specific reference to vulnerability in articles 9 and 17” (IBC 2011).

Nevertheless, the concept of vulnerability was not really present in the texts of Bioethics or in the official documents related to medical ethics. Indeed, in the original draft of Declaration prepared by the IBC, there was no article stating the Principle of Vulnerability.

Let us see, therefore, how and under what circumstances, the Principle arose.

2.3 The Difficult Process of Revision of the Declaration

This Principle, as I said, did not exist in the text prepared by the ICB and proposed to the delegations of the Member States of UNESCO for revision. It was during this review process, and specifically in the meeting of June 2005, that the principle was introduced in the Declaration. That in itself is interesting, since the fundamental task of the delegates was not to create new principles of bioethics, but more simply to review the proposals made by the IBC.

It should be noted that the deliberations of the delegates, and the revision of the text by all of us, was not an easy or a simple task at all. Let me give an example.

In the previous session to that of June, the review process had reached a stalemate, because of the frontal opposition among the delegates who demanded the introduction of an expression for the respect for human life and those who absolutely refused it. One of the delegates opposed to it told me very clearly that his government could not accept that statement, because in his country “therapeutic cloning” is allowed. It took three days, during the meeting in June, to arrive at a consensus on this point (while advancing in parallel on several articles of the Declaration). Some delegates had to ask for permission from their governments before they finally agreed to accept the wording: it would not be a principle, but only be mentioned in article 2, which sets out the aims of the Declaration. It was decided to add the expression “by ensuring respect for the life of human beings” (IBC 2013).

2.4 Immediate Approval of the Principle

Knowing the complexity of the deliberations in the revision of the Declaration, one can understand our surprise when the proposal of the new Principle of Vulnerability was approved in few minutes.

There had been much work before this on the principle of “Informed Consent.” In addition to the complexity and difficulty of the application of this principle, it was evident that most of the delegates were concerned about protecting people who

are not able to give true consent in the practice of medicine and in medical research. There was already, in article 5 on autonomy and individual responsibility, an indication of the duty to take special measures to protect the rights and interests of people who are not able to exercise their autonomy. In addition, article 6 had several phrases aimed at protecting individuals and groups most vulnerable to abuse. So many clauses and specifications were added to this section that it was finally decided to split the article into two different items (the current articles 6 and 7).

After finishing this review, one of the representatives asked the floor to propose the introduction of a new article. She was asked to dictate the text, and no one opposed her. The chairman proposed to analyze the new article after the mid-morning break, inviting anyone who wished to do so to work with the delegate who had just made the proposal on improving the draft text. After the break, and after just a few brief touches, the text was approved with unusual speed.

I believe that this phenomenon was due, in part, to the “ethical concerns” which had already been expressed in the review of previous articles. There was a general agreement on the need to protect and respect the weakest, the most vulnerable. Perhaps the rapid approval was also due to a certain weariness among the delegates. It is also likely that some delegates were not really aware of the important implications of those few lines just added to the Declaration.

2.5 Towards a Report on the Principle

As you know, the IBC has been given the task, once the declaration was formally approved in October 2005, to develop and deepen some of the principles shaped in it. The Committee immediately began working on the elaboration of a report on the Principle of Informed Consent and on the one called the Principle of Social Responsibility. During the 14th session of IBC, held in Nairobi in May 2007, a report on the Principle of Vulnerability was also proposed. The proposal was justified based on the novelty of the principle, and because of its priority over other principles of the Declaration, since it describes a general human condition. Some of the problems arising from developing the Principle were also highlighted.

The discussion that followed, by members of the committee and some observers, seem to me very significant. Some stressed the importance and expediency of the Principle. Others, by contrast, showed a certain “uneasiness” before the Principle and of some of its possible implications.

One member of the committee had suggested earlier—when analyzing the draft of the Report on informed consent—that the protection of those who cannot give consent should not begin from the moment of birth, but should also include the prenatal period, as during gestation harmful actions can be performed against a human being who cannot give consent. This same delegate, commenting on the proposal to study the Principle of Vulnerability, pointed out that it should also be applied to embryos and human fetuses who are also vulnerable. In opposition to this, one observer opined that the concept of vulnerability can only be applied to humans

who are conscious, arguing that being vulnerable means to be aware of the possibility of being damaged.

At this point I ventured to ask to speak, in order to remind everyone that according to the Oxford English Dictionary, “vulnerable” simply means: “exposed to the possibility of being attacked or harmed, either physically or emotionally.” Therefore, the condition of vulnerability has nothing to do with the eventual consciousness of the individual who can suffer an attack; indeed, individuals who are not aware of the danger are probably more vulnerable, because they cannot defend themselves from it.

Several speakers in public, and some in private in the corridors, proposed that any further study of the Principle of Vulnerability be done not in an *ad-hoc* document but simply as part of the Report on the Principle of Social Responsibility. Some wanted to include it in the Principle of the Protection of Plants and Animals, an enlargement that seemed inadequate to me. It is true that the concept of vulnerability applies perfectly to any reality that can suffer damage: a person, an animal, a plant, and also a statue... But article 8 of the Declaration establishing the Principle speaks of “*human* vulnerability”; and thus the expression: “especially vulnerable individuals and groups” refers only to human beings.

All these seemed to me strategies in order to “water down” the Principle.

Eventually, the idea was approved to develop a report on the Principle of Vulnerability. The Report was published in June 2011.

And today we are here thinking about this Principle, which I consider an important part of the Declaration and of Bioethics and Human Rights in general. Our religious traditions can and should explore the concept—considering its important implications in the medical health sciences—with the sincere desire to promote respect for all, especially the most vulnerable individuals and groups.

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