The sick fetus: an example of the gradual entry of the principle of vulnerability in bioethics

El feto enfermo: un ejemplo del ingreso gradual del principio de vulnerabilidad en la bioética

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Abstract

The “principle of vulnerability” is among the most important novelties recently introduced in bioethics, strongly stressed in the “Barcelona Declaration”. According to this principle, the condition of vulnerability of a certain entity entails the moral duty of providing him/her with some kind of protection. The aim of this paper is that of showing how this principle has gradually entered bioethics, and of studying a concrete example, which is the care of the sick fetus and of the “terminal” newborn child. On the one hand, the care for the sick fetus can be seen as a protection of a vulnerable being and a particularly fragile one but, on the other hand, this fragility does not seem sufficient for justifying a protection for somebody that “cannot have a benefit from it”. In other words, this is because not everything that is vulnerable or fragile deserves protection. The ethical and legal duty of protection, comes from the fact that the fragile entity has an intrinsic value. In the case of the incurable and hopelessly condemned fetus, who is not going to survive a reasonable time, this intrinsic value consists in its being a human

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person, and also when it is a terminal newborn this condition remains intact, since in all cases this is a human "person" endowed as such with an intrinsic "dignity". The same discourse applies to the care that must be offered to the parents of the baby, during and after pregnancy: they are a different class of vulnerable persons with whom we feel a human solidarity.

Key words: bioethical principles, vulnerability, prenatal diagnosis, terminal newborn, human dignity.

1. Introduction

The concept of vulnerability itself was not born within bioethics, but was developed and used mainly by continental European philosophy and initially applied in discussions of social and political issues. It became an explicit bioethical principle only with the "Barcelona document".[1] This fact is evident if we consider the successive stages of the *Declaration of Helsinki* ("Ethical Principles for Medical Research in Humans") which is the document issued by the World Medical Association that is often mentioned as the first official text in the history of bioethics.

In its first edition (Helsinki, 1964) there is no trace of the concept of vulnerability. The same goes for its seven revisions and two "clarifications" that were made later: (Tokyo, 1975; Venice, 1983; Hong Kong, 1989; Summerset West, 1996; Edinburgh, 2000; Washington, 2002 [clarifications]; Tokyo, 2004 [clarifications]; Seoul, 2008; Fortaleza, 2013). Until the sixth revision in 2008, which includes, among the fundamental principles, respect for the individual and the protection of the person, and it is clearly stated that the welfare and health of the subject have priority. In addition, the growing vulnerability of the individual is recognized and three paragraphs are devoted to the consideration of "vulnerable groups".

Several reasons explain this evolution, and the first one is that the Declaration of Helsinki, as well as its successive revisions, concerns only the problem of clinical research, that is, a much-delimited area of medical ethics itself (we note that the same comment applies to the Belmont Report of 1978).

Secondly, it must be kept in mind that throughout these many years, the development of medical ethics has led to a continuous re-elaboration of the document, in such a way that from the first text consisting of eleven paragraphs, the last one has been reached. Thirty-seven, including certain controversial points (so some countries consider themselves linked only by previous documents issued of the same Declaration).

The Declaration of Helsinki is of particular importance because, without being strictly a legal document a “binding” (being issued and revised by the Assemblies of the World Medical Association), is an almost mandatory reference for doctors of the various countries of this Association.

The Barcelona Principles,[2] on the other hand, do not have intrinsically an international legal value, but, presented in the form of recommendations presented to the European Commission and accepted by it, have become very strong indications that the different states of the European Community have tried in part to translate into legal provisions within it. In any case, they represent fundamental points of reference for the discipline of various bioethical issues within the same Community.

2. The UNESCO Declaration

A much more powerful instrument is the *Universal Declaration on Bioethics and Human Rights* approved by acclamation by the 33rd Session of the General Conference of UNESCO in 2005 (see UNESCO, 2005). This Declaration is the first international ethical instrument that recognizes the link between *bioethics and human rights* and, at the same time, provides *global bioethical principles* to the international community. It is the first document on *world policies* in the field of bioethics, since the principles in the defendant have been adopted by governments; in total more than 192 United Nations Member States have adhered to the Declaration.

The declaration contains 15 articles and it is interesting to note that Article 8 explicitly mentions two of the principles of Barcelona (integrity and vulnerability): "When applying and deepening scientific knowledge, medical practice and associated technologies, human vulnerability should be taken into account. Individuals and especially vulnerable groups must be protected and their integrity respected". Considering this, it is natural that in the sixth revision of the Declaration of Helsinki (of 2008), the vulnerability principle makes its appearance. With respect to the Barcelona Principles, a clear affinity can be noted, with regard to the presentation of different types of vulnerability, and the identification of vulnerable groups. There are significant differences, since the perspective of the UNESCO Declaration is strictly "anthropocentric", that is, limits the application of the notions of integrity, vulnerability and protection to human beings, and does not extend it to other forms of life or to the environment, as the principles of Barcelona do. It deserves to be pointed out that the Declaration does not find a definition of vulnerability, which on the one hand has helped to its wide acceptance, but on the other hand it has lent itself to very different interpretations that have fed a copious academic literature of a critical nature. In *The Barcelona Principles* it is not given an explicit "definition" of vulnerability in a technical sense, but if we can consider it as a "contextual definition" which, as we know, is considered a satisfactory definition form from the epistemological point of view. This type of definition consists of clarifying the reciprocal relationships that connect the concept of vulnerability with the other concepts of the system of principles proposed. This is how the text of Barcelona expresses itself:

"Vulnerability expresses two basic ideas:

a) It expresses the finitude and fragility of life in which, in those persons capable of autonomy, the possibility and necessity of all morality is founded.
b) Vulnerability is the object of a moral principle that requires the care for the vulnerable.

The vulnerable are those whose autonomy, dignity or integrity are susceptible to be threatened. As such, all beings that have dignity are protected by this principle. But the principle specifically demands not only the non-interference with the autonomy, dignity or integrity of the beings but that they receive assistance to be able to develop their full potential".[3]

Looking at things from the outside, one might think that the entry of the principle of vulnerability in the UNESCO Declaration of 2005 was a kind of mature fruit of the reflections on this concept that have been present in literature for some years, in addition to having been chosen as fundamental principle in the Barcelona document. Actually, the thing was not so simple, not only because of the controversies about the very concept of vulnerability that we have spoken about, but because not a few saw with suspicion the acceptance of this principle as a threat to certain "freedoms" in the field bioethics that they considered already conquered. As can be seen in an article by Gonzalo Miranda, who attended the works of the UNESCO Commission that prepared the Declaration, the inclusion of the principle of vulnerability was almost an unexpected event.[4] On the other hand you can find a little more hidden but real reasons for this reluctance to admit the principle of vulnerability. No one can deny that the protection and care of the weak, of the marginalized, of the poor and the sick, are fundamental elements of the ethics of many religions. Thus in a very strong way, Christian ethics, which also recognizes all human beings (and especially the most vulnerable), provides them with a special dignity that overcomes their fragility, in recognizing them as "children of

God".[5] It has to do with an attitude that goes far beyond the feeling of "compassion", which seems the maximum that a secularized ethics can accept as a natural «fact» and that, nevertheless, does not entail a true ethical obligation.[6] Therefore, it does not seem arbitrary to think that, after certain resistance against the inclusion of the principle of vulnerability in bioethics, it operates a distrust towards a supposed interference of "confessional" elements in a bioethics that wants to be "secular".

3. The new attitude towards prenatal diagnosis

Acceptance of the principle of vulnerability has many direct consequences in the bioethical field. These include, in particular, a change in the negative attitude that many "personalistic" and religiously inspired ethics, expressed towards the practice of prenatal diagnoses. Reduced to their essential core, these attitudes saw prenatal diagnosis as a kind of preamble to abortion: the purpose of this diagnosis, that is, if the fetus has or does not have certain diseases or defects, and if it does, it can be decided to abort. Apparently, it is a correct reasoning, because it could even be reinforced, by asking the following question: Why would someone be interested in having a prenatal diagnosis, if he is not willing to accept abortion to be performed anyway? Then whoever asks for it is explicitly or implicitly willing to accept an abortion in the event that the result is unfavourable.

The first weak point of this reasoning consists of a negative preliminary judgment about the *intentions* of a subject who considers as the only plausible one, that of aborting eventually. It may be that this is very frequent, but nobody has the right to judge the undeclared intentions of a moral subject and, in fact, another intention such as "knowing how things are" is very plausible, of informing ourselves about the health status of a human being.

This is what we often do because of loved ones, friends or acquaintances, for a simple human interest and without any immediate perspective of action. In case that it is information, which reveals to us in that person, a state of necessity in which we could help, then we would feel inwardly compelled to offer this help.

This attitude is perfectly logical in the case of the fetus: parents want to receive information about the health status of their child and accept the news, even when they know that he is very sick and disabled, simply because they love him. Such was the situation that occurred a few decades ago, when "there was nothing to do" to improve the health of the fetus and the reason for not aborting it was only of a moral and affective type. Today the situation has changed a lot, and the achievements of prenatal therapies (and in particular of fetal surgery) are amazing. They are performed in such a way, that not only we can confirm that many of the negative predictions of certain prenatal diagnoses (such as amniocentesis) were totally false, but that many fetal pathologies can be treated in the womb, which in the most fortunate cases a true diagnosis is reached achieving a total cure. In other cases, success means significantly reducing the size and impact of the disease, opening the prospect for the future newborn to survive and be able to receive other effective treatments after birth.

The problem is that even now, most couples do not have the necessary information to learn what prenatal diagnosis is, and its benefits.

Since a large number of pregnant patients and their partners, as well as many doctors, including gynaecologists-obstetricians, think that the prenatal diagnosis only serves to detect fetal malformations and chromosome disorders and thus decide the termination of pregnancy. However, the purpose of prenatal diagnosis is not this one. Its purpose is to diagnose various fetal pathologies, and allow the couple to prepare both physically and psychologically for the birth of these foetuses with these pathologies, by providing support during prenatal consultations for the best outcome of pregnancy, and help to obtain the best quality of life through the timely intervention of a multidisciplinary team. In the case of pathologies incompatible with life or with very poor prognosis, help the couple to better understanding, acceptance and resignation.

Although on this subject we do not want to stop here, what matters to us is to emphasize the following: it would not be right to claim that *now* it is possible to consider more favourably the practice of prenatal diagnoses *because* the developments of fetal medicine open clearly *positive* options as far as *favourable* for the fetus. In reality, what has happened is the opposite: the relentless research and activities in this field, have been promoted and carried out *because* people ethically opposed to abortion, have felt morally committed to finding the means to assist and help a small human being who has been determined not to die. Then, as it always happens, one thing stimulates the other, in a circuit of positive feedback, thanks to which it is difficult, in a complex process, to tell cause from effect, since both are cyclically involved.

It is not a simple methodological consideration, but the need of not changing ethical priorities: the moral problem of not killing the fetus persists in cases in which fetal therapies have an extremely low or no chance of success. The problem of the terminal neonate is specifically posted, that is, of a neonate that is born after a path in which prenatal therapies have not been effective and *were even known to be ineffective*. Therefore, it is clear, that in this case the problem ceases to be predominantly medical (since it does not concern the fetus' treatment). It becomes another problem of moral, psychol-ogical, human, social type: in the problem of helping *the parents* (and in *particular the mother*) to accept and give a positive meaning to a possibly heavy pregnancy whose success will be a dying neonate. A problem that concerns the *follow-up* of these people after the death of the newborn, which –within its specificity– could be no less complex than the medical follow-up that a newborn, that could take advantage of the good results from prenatal therapies, but still will need other therapies, surgeries and coverage for several years. Within this framework, the interest for the baby apparently is lost, since the possibilities to treat him medically are reduced to the minimum and almost disappear. In reality, only the type of interest towards the same baby changes, since in his case, the same ethical principles and the same practices that are applied to a terminally patient "are customized": it is not about healing him, but "to accompany him" towards his "dignified" death, with palliative treatments and surrounding him with a "personalized" affection.

The previous considerations, allow us to see at the same time, the usefulness and limits of the principle of vulnerability. Coming back to some considerations already presented at the beginning, we note that, on one hand it is clear that the care of the sick fetus can be considered as protection of a vulnerable and particularly fragile being, but this would not be enough to justify this protection towards a being for whom "it is useless". In other words, not everything that is vulnerable or fragile *deserves protection*. There are many fragile things in the world that we do not consider them protection worthy. We must add a value to the fragile being so that the demand (moral or legal) to protect it arises. Thus, for example, a glass cup is fragile and therefore it is considered reasonable to handle it carefully and "protect" it. But if so happens that it has seriously cracked, we do not continue to care for it and throw it away, unless it is, for example, a dear family memory which gives it a particular value and leads us to save it, but without using it anymore. In the case of an incurably sick fetus and without hope of surviving a reasonable time, its fragility in itself would not imply that we keep it, but it is the intrinsic *value* that we recognize in him as a human being, that makes him morally necessary to keep looking after him. It is the *solidarity among human beings,* what dictates the fundamental word, for the application of the principle of vulnerability. This leads us to respect and "accompany" him, instead of rejecting him, when it is presented as a "newborn" in the last moments of its fragile existence. As Sabrina Paluzzi says: "not being able to give days to his/her life, giving LIFE to his/her days".[7] The same speech, obviously, is valid for the care and protection that we have to provide to the parents of the terminal neonate during and after the pregnancy. They are vulnerable people from a different point of view, with whom we feel solidarity not only as soon as we understand the reasons for their fragility, but also because we feel humanly in solidarity with them.

It is not an argument that we will discuss, but it would be interesting to distinguish the experience of the duty to take care of and protect the terminal fetus on the part of the parents and on the part of the physicians: for both it is a vulnerable subject and worthy of respect as a human being. For the physicians, he is also a patient. For parents he is also a child.

We conclude considering that, the purpose of prenatal diagnosis is to fully study the fetus, as a whole, not only by parts or by organs, and in case of illness, to help him as much as possible. The new attitude towards prenatal diagnosis is to see it not as a tool to perform an abortion, but as a useful tool. To learn about the status of the fetus be it healthy or sick, and to be able to help both the parents and the fetus himself, so that they would have an adequate quality of life both psychologically as well as physically.

Nowadays, several studies both invasive as well as non-invasive help us to learn about the intrauterine status of the fetus. Which is why, people who do not accept abortion, consider the practice of prenatal diagnosis morally correct because, thanks to them, it is possible to discover and try to cure eventual fetal diseases, which in a relatively recent past, was more hypothetical than real, but which is now possible thanks to the advances made in fetal medicine and surgery.

4. Conclusions

As previously mentioned, at this point we can raise some conclusions, which point to the fact that the fetus presents all the characteristics of a *human individual* affected by disease and risk, and which, as such, has to be treated as a *patient* in the proper and complete sense of the concept, as it is understood in medicine. Although this seems obvious, you cannot really say that you have penetrated the mentality of many actors in the health professions and in particular to find the due place in their academic and professional training. The same speech is worth for the care and protection that we have to give to the parents of the terminal neonate during and after pregnancy. They are vulnerable people under a different viewpoint, with which we feel solidarity not only in how we understand the reasons for their fragility, but because we feel humanly in solidarity with them.

Having awareness of it can help us give a sense of care that we have ethically to offer other human beings, who, because of diseases, disabilities, depletion of their forces and vital capacities, they are in a not very different status (an it is not just about the terminally ill). Now one finds in the collective consciousness a willingness to give these people some care, but the present tendency to consider them a social "burden", of which it makes little sense to continue taking care. The reason why we believe that deepening the ethical awareness of the treatment of sick foetuses and of the terminal newborn, could help to develop a correct ethical awareness on the purpose of so many "vulnerable" adults and to develop the therapies and care that is good for them.

Bibliography references

[1] By way of example we mention some works that have tried to specify the specific reference of vulnerability to bioethics: Blacksher & Stone (2002), De Bruin (2001), Flanigan (2000), Hurst (2008), Kottow (2003, 2004), Levine (2004), Macklin

(2003), Morawa (2003), Ruof (2004). Some of these articles criticize the very notion of vulnerability with arguments that are sometimes opposed (some accuse it of being too vague or broad, others of being too narrow). Other works try to develop and enrich the concept of vulnerability, or give it more "flexibility". Finally, when we move from the theoretical discussion to the practical indications, we find a certain need for convergence between the more theoretical, "anthropological" approaches of the European perspective and the more pragmatic, and detailed approaches of the North American approach. It is not the intention of our work to explore this rich variety of studies, for a good synthesis of which we refer back to the work of Solbakk (2011).

[2] With this expression are usually indicated the principles stated in the Barcelona Declaration, which in turn was the result of a long interdisciplinary work to which a group of 22 specialists from different backgrounds were dedicated for 3 years. The project was promoted by the Centre for bioethics and bio law of the University of Copenhagen and the final meeting of this group took place in Barcelona, where the declaration bearing this name was drawn up. It is about the elaboration of bioethical principles inspired by continental European philosophy. The texts produced were published in Rendtorff & Kemp (2000).

[3] Cf. Rendtorff & Kemp, 2000, p. 398.

[4] Cfr. Miranda, 2011.

[5] Cfr. Tham, García, Miranda, 2014

[6] Personal interview with Sabrina Paluzzi, founder of the institution "La Quercia Millenaria".

[7] Cf. Velázquez L, 2017, p. 38

Bibliography

1 Blacksher, E. & Stone, J.R. (2002). Introduction to "Vulnerability". Issues of Theoretical *Medicine and Bioethics*. Theoretical Medicine and Bioethics, 23 (6): 421-424.
2 De Bruin, D. (2001). Reflections on 'Vulnerability'. Bioethics Examiner, 5 (2): 1, 4, 7.
3 Flanigan, R. (2000). Vulnerability and the Bioethics Movement. Bioethics Examiner, 16 (2): 13-18.
4 Hurst, S.A. (2008). Vulnerability in Research and Health Care; Describing the Elephant in the Room? Bioethics Examiner, 22 (4): 191-200.
5 Kottow, M.H. (2004). Vulnerability: What kind of principle is it? Medicine, Health Care and Philosophy. 7: 281-287.
6 (2003). The vulnerable and the susceptible. Bioethics, 7/5/6: 460-471.
7 Levine, C. (2004). The Limitations of "Vulnerability" as a Protection for Human Research Participants. American Journal of Bioethics, 4/3: 44-49.

8 MACKLIN, R. (2003). Bioethics, vulnerability, and protection. Bioethics, 17: 472-486
9 MIRANDA, G. (2011). Come nacque il “principio di vulnerabilità”. Studia Bioetica, 4/2: 5-7.
10 MORAWA, A.H.E. (2003). Vulnerability as a Concept in International Human Rights Law, Journal of International Relations and Development, 6/2: 139-155.
11 RENDTORFF, J.D. & KEMP, P. (eds.) (2000). Basic Ethical Principles in European Bioethics and Bio law. Copenhagen and Barcelona: Centre for Ethics and Law & Borja Institute of Bioethics.
12 RUOF, M.C. (2004). Vulnerability, Vulnerable Populations, and Policy. Kennedy Inst Ethics Journal, 1474: 411-425.
13 SOLBAKK, J.H. (2011). The principle of respect for human vulnerability and global bioethics. In CHADWICK, R., TEN HAVE, H. & MESLIN, E. (eds.). Health Care Ethics in an Era of Globalization, COUNTRY: SAGE Publ.
14 THAM, J., GARCÍA, A., MIRANDA, G. (2014) Religious Perspectives on Human Vulnerability in Bioethics, Springer.
15 UNESCO (2005). Universal Declaration on Bioethics and Human Rights. Retrieved from:http://portal.unesco.org/shs/en/ev.phpURL_ID=1883&URL_DO=DO_TOPIC&URL_SECTION=201.html
16 VELÁZQUEZ, L. (2017). The treatment of the terminal neonate from the bioethical point of view. EUNSA.