The sick fetus: an example of gradual entering of the vulnerability principle, into 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 giving it protection. The aim of this paper is that of showing how this principle has gradually entered bioethics, and also of studying a concrete example, that is, the care of the sick fetus and of the terminal newborn child. On one hand, the care for the sick fetus can be seen as a protection of a vulnerable being but, on the other hand, this fragility does not seem sufficient for justifying a protection for something that cannot have a benefit from it. This because not everything that is vulnerable or fragile deserves protection. The ethical and legal duty of protections comes from the fact that the fragile entity has an intrinsic value. In the case of the incurable fetus this value consists in its being a human 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

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offered to the parents of the baby: 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

Introduction

The concept of vulnerability itself was not born in the inner side of bioethics, but that, was elaborated and used mainly by the continental European philosophy and initially applied in the political and social theme discussions. It was turned in an explicit bioethical principle only with the "Barcelona declaration".[1] This fact becomes evident if we take into consideration the successive stages of the *Helsinki Declaration* ("Ethical principles for medical research in human beings") which is the document issued by the World Medical Association, which is mentioned quite frequently as the first official text in the history of Bioethics.

In its first version (Helsinki, 1964) there is no track of the vulnerability concept, and the same goes for its 7 revisions and 2 "clarifications" that were made afterwards (Tokyo, 1975; Venice, 1983; Hong Kong, 1989; Summerset West, 1996; Edinburg, 2000; Washington, 2002 [clarifications]; Tokyo, 2004 [clarifications]; Seoul, 2008; Fortaleza, 2013), until the sixth revision of 2008, in which it is included, among the fundamental principles, the respect for the individual, the protection of the person and it is clearly stated that the wellbeing and the health of the subject have the priority. Besides it is recognized the increasing vulnerability of the individual, and 3 paragraphs are dedicated to the considering the "vulnerable groups".

Several reasons explain this evolution, and the first one is that the Helsinki Declaration, as well as its successive revisions, are only concerned with the clinical research problem, that is, a much delimited field in the medical ethics itself (we notice that the same comment is applied to the Belmont Report of 1978).

Secondly, we have to consider that along those many years, the developments of the medical ethics have impulsed a continuous re-making of the document, in such a way that the first text constituted by 11 paragraphs, has become in the end of 37, including certain controversial points (in a way that some countries consider themselves linked only by the previous issues of the same Declaration).

The Helsinki Declaration has a special importance because, without being from the strictly judicial point of view, a "binding document" (being issued and revised by the World Medical Association Assemblies), it is an almost mandatory reference for the physicians of the various countries of this Association.

On the other hand, *The Principles of Barcelona,*[2] do not have by themselves an international judicial value, but, presenting them under the form of recommendations presented to the European Commission and accepted by it, they have become very strong indications that the different countries of the European Community have tried in part to translate into legal dispositions in its interior. Anyway, they represent fundamental reference points for the discipline of various bioethical issues within the Community itself.

The UNESCO Declaration

A much more powerful instrument is the *Universal Declaration on Bioethics and Human Rights* approved by unanimous consent by the 33rd Session of UNESCO's General Conference in 2005 (Cfr. UNESCO, 2005). This Declaration is the first international ethical instrument that recognizes the binding between bioethics and human rights and at the same time, provides *world bioethic principles* to the international community. It is the first document about *world policies* in the field of bioethics, because the principles defended in it have been adopted by several governments; in total, more than 192 Member States of the United Nations have joined the Declaration.

The declaration includes 15 articles, and it is interesting to note that article 8 explicitly mentions two of the Barcelona principles (integrity and vulnerability): "*By applying and deepening scientific knowledge, medical practice and the associated technologies, the human vulnerability should be taken into account. People and groups especially vulnerable must be protected and be respected in their integrity*". Taking this into consideration results natural that in the sixth revision of the Helsinki Declaration (of 2008) the vulnerability principle makes its appearance. Regarding the Barcelona Principles, a clear affinity can be noticed with respect to the presentation of different types of vulnerability, and to the identification of vulnerable groups, but there are significant differences, because the UNESCO Declaration's perspective is strictly "anthropocentric", that is, it limits the implementation of the concepts of integrity, vulnerability and protection to human beings, and it does not extend them to other forms of life nor either to the environment, as the Barcelona principles do. It is important to point out that in the Declaration there cannot be found a definition of vulnerability, for what on one hand has enabled its wide acceptance, but on the other hand it has given rise to very different interpretations that have fed an extensive academic literature of the criticizing type. *In the Barcelona Principles* it isn't given an explicit "definition" of vulnerability in a technical sense, but it does, the one we can consider as a "contextual definition" which, as it is known, is considered a satisfactory definition form, from the epistemological point of view. This type of definition consists in making clear the reciprocal relationships that link the concept of vulnerability with the other concepts from the system of principles proposed. This is the way that the Barcelona text is expressed:

> "Vulnerability expresses two basic ideas:
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> a) Expresses the finitude and fragility of life in which, in those persons capable of autonomy, it is based the possibility and necessity of all morale.
> b) Vulnerability is the object of a moral principle which requires the care for the vulnerable.

The vulnerable are those whose autonomy, dignity or integrity are susceptible to be threatened. As such, all existing beings that have dignity, are protected by this principle. But the principle demands specifically not only the no interference with autonomy, dignity or integrity of the individuals, but for them also to get assistance in order to be able to develop all their potential".[3]

Watching things from abroad, it could be thought that the entering of the vulnerability principle to the UNESCO Declaration of 2005 was a kind of conscientious result of the thoughts regarding this concept, present since some years ago in the literature, besides to have been chosen as a fundamental principle in the Barcelona document. In reality the issue was not that simple, not only because of the controversies about the concept itself of the vulnerability of what we have discussed about, but because not few people saw with suspicion the acceptance of this principle as a threat to certain "liberties" in the bioethics field, that they considered already conquered. As it can be seen in a paper of Gonzalo Miranda, who attended the works of the UNESCO Commission which issued the Declaration, the insertion of the principle of vulnerability was almost an unexpected event.[4] On the other hand, there can be found, reasons a little bit more hidden but real of this reluctance in admitting the vulnerability principle. Nobody can deny that the protection and care of the weak, the marginalized, the poor and the sick are fundamental elements of ethics for many religions and, in a very strong manner, of the Christian ethics that, besides, recognizes to all human beings (and especially the most vulnerable): a special dignity that it overcomes its fragility in recognizing them as «sons of God»[5]. It has to do with an attitude that goes far beyond the feeling of "compassion" that seems to be the maximum that a secularized ethics can accept as a natural "fact" and that, nevertheless, does not convey a truly ethical obligation.[6] Therefore, it does not seem arbitrary to think that, after certain resistances against the inclusion of the vulnerability principle in bioethics, a distrust would be operating towards an alleged interference of "confessional" elements in a bioethics that wants to be "secular".

The new attitude towards prenatal diagnosis

The acceptance of the vulnerability principle has many direct consequences in the bioethical field. Among them, it highlights in particular, a change in the negative attitude that many ethics of the "personalist" type and of religious inspiration have shown towards the prenatal diagnosis practice. Reduced to their essential core, these attitudes would show in the prenatal diagnosis a kind of preamble to abortion: the purpose of this diagnosis, that is, if the fetus has or does not have certain illnesses or defects, and if he has them, it can be decided to abort. Apparently it has to do with a correct reasoning, because it could even be reinforced stating the following question: Why would somebody be interested in having a prenatal diagnosis, if anyhow, is not ready for abortion? Then, who asks for it, is explicitly or implicitly ready for abortion in case that the outcome should be unfavourable.

The first weak point of this reasoning, consists in a preliminary negative judgement regarding the *intentions* of a subject that considers as a unique plausible option, to eventually abort. Concretely, it can be that this is very frequent, but nobody has the right to judge the non-declared intentions of a moral subject and, in fact, it is very plausible another intention such as the one "to know how things are", to have us informed about the health status of a human being. We do it many times concerning our loved ones, friends or acquaintances, for a simple human interest, and with no immediate perspective of action. Unless it has to do with information that tells us about that person a state of need in which we could be of help, we would feel internally forced to provide this help.

This attitude is perfectly logical in case of the fetus: parents want to be informed about the state of health of their son and accept the news even though they know he is very sick and handicapped, simply because they want it. Such was the situation that was given some decades ago, when "there wasn't anything to do" to improve the health of the fetus, and the reason for not aborting it was only of the moral and affective type. Today, the situation has changed a lot, and the achievements of the prenatal therapies (specially the fetus surgery) are amazing. Thus, it cannot only be verified that many of the negative previsions of certain prenatal diagnosis (such as the amniocentesis) were totally false, but many fetal pathologies can be treated within the mother's uterus, where in the most favourable cases, a truly total cure can be reached, and in others, reducing considerably the size and impact of the sickness, opening a perspective for the future recently born, to survive and be able to get other efficient treatments after his birth.

The problem is, that even now, the majority of couples do not have readily available, the necessary information to know and understand what prenatal diagnosis is all about, and what its benefits are.

Now that a great number of pregnant patients and their couples, as well as many physicians, including obstetrician-gynaecologists, think that prenatal diagnosis is only used to detect fetal malformations and chromosome disorders, and therefore decide to take pregnancy to an end, yet the purpose of prenatal diagnosis is not this one, the whole purpose of it is to be able to diagnose several fetal pathologies and allow the couple to prepare themselves both physically as well as psychologically for the birth of these foetuses with a pathology, providing them with support during the prenatal consultations, in order to get a better outcome from the pregnancy, and helping to obtain a better quality of life by means of the opportune intervention of a multidisciplinary team. Yet in case of pathologies incompatible with life or of a very poor prognosis, to help the couple to achieve the best understanding, acceptance and resignation.

Although regarding this subject matter we don't want to stop here, what it is important is to highlight the following: it wouldn't be right to declare that *now* it is possible to consider more favourably the practice of the prenatal diagnoses *because* the fetal medicine developments open to us options clearly *positive* as to *favourable for the fetus.* In reality, what has happened is the opposite: the relentless research and activities in this field, have been promoted and performed *because* people ethically opposed to abortion have felt morally committed to find the means to assist and help that little human being who had been decided not to let die. Then, as it always happens, one thing stimulates the other, in a positive *feedback* circuit, thanks to which it becomes difficult in a complex process, to say which one is *the* cause and which one is the effect, since both imply each other cyclically.

It is not a matter of a simple methodological consideration, but of the need of not changing the ethical priorities: the moral problem of not killing the fetus, remains in cases in which fetal therapies have one extremely low or null possibility of success. The problem of the terminal neonate is presented in a specific form, that is to say, of a neonate that is born after a path in which prenatal therapies have not been efficient, and even *it was known that they were not efficient.* Therefore, it seems clear, that in this case the problem stops to be mainly medical (because it is not related to the treatment of the fetus) and becomes another problem of the moral, psychological, human, and of social type: in the problem of helping the *parents* (and in particular to the *mother)* to accept and give a positive meaning to a pregnancy probably difficult whose success will be a dying neonate. A problem that concerns to the *follow up* of these people after the death of a newborn that –within their specific function– can be no less complex, than the medical follow up which would have been receiving a neonate that could have taken advantage of the good results of prenatal therapies, but that will still need other therapies, surgeries and coverages for many years. Within this frame, the baby apparently loses interest, because the possibilities of treating him medically drastically are reduced and almost disappear. In reality, the only thing that changes is the kind of interest towards the baby himself, as it happens in his case, the same ethical principles are "customarily" applied, and the same practices that are applied to a terminal patient: it is not about curing him, but to "accompany him" to his "dignified" death, with palliative treatments and surrounding him with a "specialized" love.

The above thoughts allow us to see at the same time the usefulness and the limits of the vulnerability principle. Retaking some considerations already presented at the beginning, we duly note that, on one hand it is clear that the sick fetus care can be considered as a protection to a vulnerable and particularly fragile being, but all this could not be enough to justify this protection towards an individual to whom "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 worth of protection. We have to add *a value* to the fragile thing, for the emergence of (moral or judicial) demand to protect it. Thus, for example, a crystal glass is fragile and therefore it is considered reasonable to handle it with care and "protect" it, but if it so happens that it has become badly cracked, we stop taking care of it and we discard it. For example, unless we are dealing with a family's loving memory which grants it a particular value, and takes us to save it even though we are not going to use it any more. In the case of the incurable sick fetus and without hope to survive a reasonable time, its fragility by itself would not imply that we saved it, but it is the intrinsic *value* that we recognize it has as a human being, what morally imposes on us to keep saving it. It is the *solidarity among human beings* the one that dictates the fundamental word for the application of the principle of vulnerability, and which takes us to respect it and "accompany it" instead of disposing it, when it is presented as a "newborn" in the last moments of his fragile existence. As Sabrina Paluzzi says: "not being able to give days to his life, giving LIFE to his days".[7] The same speech obviously, is worth for the care and protection we have to provide to the terminal neonate's parents during and after the pregnancy. They are vulnerable people from a different point of view, with whom we feel sympathetic not only because we understand the reasons for their fragility, but because we feel *humanly* supportive with them.

It is not an argument we are going to deal with, but it seems interesting to distinguish the experience of the duty to care and protect the terminal fetus by the parents and by the physicians: for both it is a vulnerable subject worth of respect as a human being. For the physicians it is also a patient. For the parents it is also a son.

We conclude considering that the purpose of the prenatal diagnosis, is to fully study the fetus, as a whole, not only in parts or by organs, and in the case of an illness help him the most. The new attitude towards the prenatal diagnosis, is seeing it not as a tool to perform an abortion, but as a useful tool to learn about the fetus status, either healthy or sick, and being able to help both the parents, as well as the fetus itself, in order to have a proper quality of life both psychologically as well as physically.

Currently there exist several studies both invasive or not, that help us to know the intrauterine status of the fetus, which is the reason why there are people who although do not accept abortion, consider morally right the practice of prenatal diagnosis because, thanks to them, it is possible to discover and try to cure eventual fetal illnesses, that in a very recent past, was more hypothetical than real, but that today it is possible thanks to the advancement achieved in medicine and fetal surgery.[8]

Conclusions

For what is previously mentioned, in reference to this point we can state some conclusions that lead to the fact that the fetus presents all the characteristics of a *human individual*, affected by illnesses and risks, and that, as such, has to be treated as a *patient* in the proper and complete meaning of the concept, just like it is understood in medicine. Even though might seem obvious, in reality it cannot be said that it has penetrated into the minds of many actors of the sanitary professions and, in particular, that finds the proper place in their academic and professional training. The same speech serves for the care and protection that we have to provide to the terminal neonate parents during and after the pregnancy. They are vulnerable people seen from a different point of view, with whom we feel supportive, not only as far as we understand the reasons for their fragility but because we feel humanly supportive with them.

Being aware of that, can help us to provide meaning to the care we ethically have to offer to other human beings, who, due to illnesses, impairments, exhaustion of their strengths and vital capabilities, are in a state which is not very different (and simply does not have to do with terminal patients). For the moment, it is in the collective conscience an availability to provide a certain care to those people, but that the trend of considering them a social "burden", of which it makes little sense to keep taking care of them, is present. Reason for which "we believe that going more in-depth into the ethical conscience about the treatment of sick fetuses and about the terminal neonates, could help us to develop a proper ethical conscience regarding so many "vulnerable" adults, and to develop the therapies and care that are convenient for them",[9]

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[1]As a kind of example we mention some works which have tried to precise 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 notion itself of vulnerability with argument sometimes opposed to each other (some of them accuse of being too vague or wide, and others of being too narrow). There are other works that try to develop and enrich the concept of vulnerability, or to give it greater “flexibility”. Finally, when you go from the theoretical discussion to the practical indications, you confirm of a certain convergence need between the most theoretical and “anthropological” arguments of the European perspective, and the more pragmatic and detailed arguments of the North American approach. It is not the intention of our work to explore this rich variety of studies. For a good synthesis we refer you to the work of Solbakk (2011).

[2] With this expression, usually the principles claimed in the *Declaration of* Barcelona showed that in their turn it was the result of a long interdisciplinary work, to which 3 years were dedicated by a group of 22 specialists of different backgrounds. The project was sponsored by the Center for Bioethics and Biological law of the University of Copenhagen and the final meeting of this group took place in Barcelona, where the declaration that carries this name was issued. It has to do with the issuing of bioethical principles inspired by the Continental European philosophy. The produced texts were published at Rendtorff & Kemp (2000).

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

[4] Cfr. Miranda, 2011.

[5] Cfr. Tham, Garcia, Miranda, 2014

[6] Personal interview with Sabrina Paluzzi, founder of the “La Quesrcia Millenaria” institution.

[7] Cfr. Velázquez L, 2017, p.38

[8] Ibid. p. 179.

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