

Responsibility towards the unborn. Teratogenesis and bad life. Comments to the book by Dr. Alberto Campos

Responsabilidad hacia el nonato. La teratogenia y la mala vida. Comentarios al libro del Dr. Alberto Campos

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ABSTRACT

The Zika virus (ZIKV) epidemic in Brazil in 2015 revived the abortion controversy because of the association between intrauterine infection and a combination of very severe and disabling malformations during the lifetime of live births. The book under review here questions whether it is enough to be born to disregard profound disabilities throughout a lifetime. It asks whose responsibility it is to carry out an abortion or whose responsibility it is for the lifelong suffering of a baby born with malformations and profound disabilities if such an abortion is not carried out. The fundamental premise of the book is that to understand the controversy and moral dilemma it is necessary to go to the epistemology of the medical problem. Then, instead of answering questions with statistics, valid recommendations can be made about possible consequences and moral implications of a dilemmatic choice. The book analyzes moral, ethical, legal, and social issues of decision making. It also encourages reflection on a current ethical problem and on other bioethical dilemmas in the practice of medicine.

RESUMEN

La epidemia del virus Zika (ZIKV) en Brasil en 2015 reactivó la controversia sobre el aborto por la asociación entre la infección intrauterina y una combinación de malformaciones muy graves y discapacitantes durante la vida de los nacidos vivos. El libro que aquí se revisa cuestiona si es suficiente nacer para que no se tomen en cuenta discapacidades profundas a lo largo de toda una vida. Pregunta de quién es la responsabilidad de llevar a cabo un aborto o la del sufrimiento vitalicio de un nacido con malformaciones y discapacidades profundas si tal aborto no se lleva a cabo. La premisa fundamental del libro es que para entender la controversia y el dilema moral es necesario ir a la epistemología del problema médico. Entonces, en vez de responder preguntas con estadísticas podrán hacerse recomendaciones válidas sobre consecuencias posibles e implicaciones morales de una elección dilemática. El libro analiza aspectos morales, éticos, legales y sociales de la toma de decisiones. Mueve también a la reflexión sobre un problema ético vigente y sobre otros dilemas bioéticos en la práctica de la medicina.

I thank our Mexican Association of General Surgery, and in particular Dr. José Alberto Campos Campos, for the invitation to present his book *Responsibility towards the unborn. Teratogeny and bad life (Responsabilidad hacia el nonato. Teratogenia y la mala vida)*. I would like to begin by mentioning two antecedents that seem very important to me.

1. Dr. Campos' thesis for the degree of Doctor of Science entitled *Genesis and*

consequences of bioethical dilemmas from scientific controversies received the "Aurora Arnaiz Amigo 2019 Award for the Best PhD Thesis in the Field of Bioethics".

2. Shortly thereafter, the book I am now commenting on, and which I presented at the XLIII International Congress of General Surgery, was the winner of the "Writing for Bioethics Contest", organized by the University Bioethics Program (PUB) of the National Autonomous University of Mexico, UNAM.

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Having said the above, it is convenient to indicate that some of the concepts analyzed in the 360 pages of his doctoral thesis are applied in this book presented today, which fortunately is brief and concrete, consisting of only 50 pages, with very demonstrative illustrations and an ample bibliography, updated and limited in the text.

The first part talks about the recent Zika epidemics, its epidemiology, pathogenesis and anatomopathological alterations. It focuses on the one that occurred in Brazil in 2015. It clearly describes the congenital Zika syndrome (CZS), the way in which the Zika virus (ZIKV) is transmitted by *Aedes africanus*, *Aedes aegypti* and *Aedes albopictus* mosquitoes, and which produces alterations in the central nervous system and the peripheral motor system, resulting in two joint syndromes:

1. Disruption of the fetal brain sequence (DSCF). The neurotropic Zika virus attacks the progenitor cells of the brain and produces necrotizing viral encephalitis with destruction of brain tissue, which in turn results in decreased intracranial pressure, causing the vault to collapse toward the base of the skull, with bone nodding and microcephaly.
2. Fetal akinesia deformation sequence (FADS). ZIKV also produces alterations in electrical signaling in the neuromuscular plate, which prevent nerve conduction, followed by a characteristic sequence of events that result in muscle atrophy. The most plausible mechanism is the tropism of ZIKV for motor neurons, central or peripheral.

It is worth mentioning that most SZC survivors do not develop beyond the age of a two-month-old child. They suffer seizures and painful contractures and dysphagia and die at an early age.

Although the brain structures are complete at 12 weeks, the total number of neurons is not complete until week 18. Therefore, it is probable, and even more frequent, that in the first 12 weeks the alterations of the central nervous system are not detected.

Dr. Campos says in this book that to understand the moral issue it is necessary to go

to the epistemology of the medical problem, so as to be able to make valid recommendations on the consequences of the alterations, and not only answer the questions of pregnant women with figures, since the frequency of malformations of a disease and the probability of its occurrence in a given patient are not the same thing. Frequency figures and data alone do not say much. The moral dilemma does not lie simply in the disease or its pathogenesis, but in the management of the patient in the face of severe congenital alterations for which there are no treatments, the option of which is late termination of pregnancy, a palliative intervention that produces relief (for the mother) but does not cure either her or the fetus.

To give some order to my presentation, I will divide it into 1. moral issues, 2. ethical issues, 3. legal issues, 4. social issues and 5. a final reflection and possible conclusions.

1. Moral issues. Decision-making by health personnel and parents is influenced by the norms and moral values derived from their religion, conditioning their personal beliefs and ideology. This is where they find psychological balance and moral self-sufficiency, and where they feel existentially secure. But, in general, the influence of health personnel, whose opinion has an impact on the parents' decision, is strong.

Alberto says: there is a panoply (complete armor with all its pieces) of arguments, ill-formed and without logical consistency, arguments such as "life is sacred", the fetus is "in potential" a human being, "it must be born, live and die as God wills", and other similar ones. If such reasoning were accepted, medicine would have to be discarded and everything would have to be left to natural evolution. Pregnancy at term of fetuses with anencephaly, incompatible with life, would be allowed, and many of us would have died, "as God wills", from diseases such as appendicitis or pneumonia, which can be cured.

In the case of SZC, arguments can be discussed as to which alterations compromise life and which give rise to anatomical or functional changes that make it intolerable, such as seizures and painful muscular contractures, of such magnitude that they can cause dislocation of the elbows or knees.

When the diagnosis of SZC is made, the fetus may already be viable, but if the pregnancy continues and culminates in birth, what alterations will the newborn have and suffer? And the few survivors, and for a very short time, what quality of life will they have?

The fetus and the newborn are an essential part of the dilemma, but they are not autonomous, they cannot decide, so the decision corresponds to the parents or the legally responsible person.

There is no doubt that killing an innocent person is immoral, ethically, and legally unacceptable and punishable. But in the case of SZC, the fetus is a victim, whose suffering, in the short or medium term, will have repercussions on the mother and the family, who will be affected physically, psychologically, morally, and socially. That is why it is convenient to change the idea of “killing an innocent person”, since it is evident that a fetus is not an aggressor. The dilemma is to interrupt the development of a fetus with very severe abnormalities, with little chance of survival and no chance of having a normal life.

Dr. Campos cites in his book the comments of Jorge Mario Bergoglio, Pope Francis I, in February 2016, who with a negative critique disqualified doctors who terminate pregnancy, comparing them to the mafia, and saying that abortion is “an absolute evil” and that “one person is murdered to save another [...] to live comfortably”. Francis I compared abortion to eugenics, equating the doctors’ actions to “a version of the Nazis’ attempts to create a pure race by eliminating the weakest”. Pope Francis’ statements influenced many women infected with ZIKV not to terminate the pregnancy and were then, in effect, condemned to suffer the care of those born alive with severe disabilities, some of whom died shortly thereafter.

The author discusses the moral dilemma very extensively, so it is advisable to read the book carefully, if necessary two or more times, to understand its essence. There he discusses the following dilemma: a) to terminate the pregnancy upon diagnosis of brain damage by ZIKV to avoid the suffering of a child who would be born with severe disabilities, which would leave the mother with a very severe moral residue in the form of remorse or guilt, or b) to allow the

birth of a child with irreversible organic and functional brain damage, which together with the alterations of the peripheral nervous system will lead to severe disabilities and suffering, with the consequence that the few survivors would not live a normal life.

The decision is up to the mother, in accordance with her beliefs and values, but influenced by the information that appears in the mass media (press, Internet, social networks) and the opinions of personalities such as Pope Francis I.

Doctors devote little time to each case to provide, in the face of uncertainty, understandable information that helps the mother and family to decide and to give or not to give truly informed consent. But that does not solve the dilemma.

2. Ethical issues. A profound reflection on moral precepts, values, the relationship of ethics with the law and with other disciplines of the humanities is required. An ethical controversy that is secular and open is necessary. An analysis of each case, after evaluating the social, economic, and psychological conditions of the parents and the family, their ideology, their religion, and beliefs should be done, which in any case must be respected.

To have a pertinent question and an adequate answer, it is necessary to convert ideological problems into factual problems and to consider them from the point of view of the sufferer, and not to rely on the beliefs of other moral actors, who do not suffer the problem, and do not understand it in first person. From this ethical reflection may arise, for example, the following questions: what is better for a severely malformed fetus: a good death or a bad life? Is allowing the birth of these children worse than not having been born at all? Is fetal euthanasia morally different or equal to adult euthanasia?

3. Legal issues. When Dr. Campos addresses the conflict between ethics and law, he refers to the Universal Declaration of Human Rights, which in its 3rd article states, “Everyone has the right to life, liberty and security of person.” In this case, the question arises: what is being preserved, life or security? The preservation of that right would become the obligation to live with profound, severe disability, with endless

pain and suffering. Article 5° stipulates that “no one shall be subjected to cruel, inhuman or degrading treatment or punishment”, as in fact happens to those born with SZC, who are subjected to torture and the penalties of their disease. Forcing them to live in this way is cruel, inhuman, and degrading. Thus, the spirit of Article 5 contradicts the spirit of Article 3.

In the Political Constitution of the Mexican United States, Article 1 states that “every person shall enjoy the human rights recognized in this constitution and in the international treaties to which the Mexican State is a party”, while Article 4 mentions that “every person has the right to the protection of health, to a healthy environment for their development and well-being”, which for these fetuses does not exist, neither in the intrauterine environment nor after birth. On the other hand, Article 188 of the Regulations of the General Health Law of the Federal District speaks about the obligatory nature of gestational age and genetic or congenital anomalies, based on specific studies. The legal framework exists, but it is not commented on, much less used.

We can see that there are legal loopholes that leave aside serious moral problems. The right or obligation to be born, generates a conflict between ethics and law, between the hypothetical and the real. The preservation of the right to life becomes an obligation to live with profound disability, which implies the violation of other rights.

Duties, responsibilities, and justice towards the unborn are established from the moment of the diagnosis of SZC; so, there is a moral relationship. The parents, the physician and even the State can prevent severe disabilities by allowing the termination of the pregnancy and thus act, strange as it may seem, for the benefit of the unborn child. The mother’s inaction due to negligence or fear leads to advanced stages in which it is no longer possible to act, or acting is already illegal, where late-term abortion is confused with neonaticide.

4. Social issues. The interruption of a pregnancy or the birth of a child with severe disabilities and condemned to a premature death has a great impact on the parents, the family, and its entire social context. Their system of life, their activities, and the relationship of all

the components of this system will be altered, which in some cases can destroy the family.

There is much and often enough talk about the unfair discrimination against the disabled. On the contrary, terminating a pregnancy is an attempt to prevent them and their families from being discriminated against after birth, since they receive no support, neither public nor private. The State does not allocate sufficient public resources to address this serious problem.

5. A final thought. The only way to put an end to teratogenesis is to stop the process by interrupting the pregnancy. In this dilemma, both action and omission generate moral responsibility, sometimes difficult to establish, because neither the consequences nor their magnitude can always be predicted.

For example, does the mother deserve punishment when she acted under moral pressures and social criticism? In deciding her culpability there is always a conflict of interest between the family, health personnel and religious ministers. The mother is not responsible for the disability of the newborn, but she is responsible for continuing or not the pregnancy and even more so for a clandestine abortion, such as the many that were carried out in Brazil.

In “avoiding maleficence” by allowing the birth of these babies, are they really being spared an evil and doing them a good? By allowing these births, we unjustly allow the suffering and bad life of this human being. We must also reflect on what is good and what is right, but sometimes, as in these cases, that is very difficult to determine.

Some possible conclusions are

1. SZC produces morphological and functional alterations and severe disabilities for which there is no treatment. At the moment of diagnosis, responsibility is acquired for the unborn child, the mother and the family. But deciding who acquires this responsibility is a difficult problem to solve.
2. Without responsibility, justifications and excuses arise, which are often confused. Justification implies accepting responsibility, but denying the harm done. Excusing is accepting maleficence, but not the intention

to cause it; the intention of not wanting to do harm is insufficiently invoked in the face of the harm itself. Both are ways of evading responsibility.

3. The moral dilemma is not the ZIKV infection, nor the malformations of the nervous system per se, but to terminate the pregnancy to avoid teratogenesis and severe disability, or to let the child be born and suffer from them, with the consequent suffering of the child and all those around him/her.
4. The mother's decision by commission (termination of pregnancy) or omission (letting the child be born) is influenced by her ideology and religious beliefs. Her understanding of her problem, as well as her decision, is often more emotional than rational.
5. The intention here is not to kill, but to prevent suffering through fetal euthanasia, a dignified humanitarian solution for the mother, fetus, and family. Avoiding maleficence by terminating the pregnancy or accepting the injustice of a future life full

of disabilities and suffering. I repeat, isn't a good death better than a bad life? Abortion relieves the mother, but does not cure her, and does not cure the fetus either. For these malformations there is no cure.

6. As Dr. Campos rightly says, it is important to understand epistemology to assess moral dilemmas and then to be able to offer some kind of alternative that suits those directly involved, so that they can make an already difficult decision. There is a need for secular proposals with scientific evidence and support in moral, ethical, social, and legal issues.

I congratulate Dr. Campos once again. His book encourages reflection on a current ethical problem. Its reading will help in making difficult decisions in this serious problem, but also in the solution of other moral and bioethical dilemmas that often arise in the practice of medicine and surgery.

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