

# Anencephalic newborns as organ donors

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## Abstract

### Anencephalic newborn as organ donors

This article is based on discussions about the use of anencephalic newborns' organs in transplantation therapies. Anticipation of the anencephalic fetuses birth is widely discussed in relation to its ethics. Some argue that the anencephalic fetus has a brain malformation and preservation of life during pregnancy is only possible by accessing the umbilical cord. Others argue that, as long as there is a functioning brain stem, the diagnosis of fetal death is not permitted. The question is that the removal of organs, only after brain death confirmation, may cause damage to the organs to be used. Cardiovascular and respiratory functions deteriorate gradually and cause ischemic injury to the organs to be transplanted, making them unusable. We conclude that these issues need a wide debate and that there is a necessity to create new legislation that will help to solve ethical dilemmas.

**Key words:** Congenital abnormalities. Organ transplantation. Bioethics. Anencephaly.

## Resumo

Este artigo baseia-se na discussão do uso de órgãos de recém-nascidos anencéfalos para transplantes terapêuticos. A antecipação do nascimento de um feto anencefálico é debatido amplamente em relação a sua ética. Alguns defendem que o anencéfalo possui malformação cerebral cuja manutenção da vida é possível apenas pelo acesso ao cordão umbilical. Outros alegam que enquanto houver tronco cerebral funcionante não permitem o diagnóstico de morte fetal. A questão é que a remoção de órgãos após o diagnóstico de morte encefálica pode causar danos aos órgãos que serão utilizados. As funções cardiovasculares e respiratórias se deterioram gradualmente, causando lesão isquêmica nos órgãos a serem transplantados, inviabilizando-os. Concluímos que esse tema deve ser debatido extensamente e que faz-se necessário criar novas leis que possam ajudar a resolver este dilema ético.

**Palavras-chave:** Anormalidades congênitas. Transplante de órgãos. Bioética. Anencefalia.

## Resumen

### Los recién nacidos anencefálicos como donantes de órganos

Este artículo está basado en la discusión sobre el uso de órganos de recién nacidos anencefálicos para trasplantes terapéuticos. La anticipación del nacimiento de un feto anencefálico es debatido ampliamente en cuanto a su ética. Algunos argumentan que el niño anencefálico posee una malformación cerebral y que la preservación de la vida es posible solamente mediante el acceso al cordón umbilical. Otros aducen que mientras el tronco cerebral esté operante no se permite el diagnóstico de muerte fetal. La cuestión es que la remoción de órganos luego del diagnóstico de muerte encefálica puede causar daños a los órganos que se utilizaron. Las funciones cardiovascular y respiratoria se deterioran poco a poco, lo cual provoca una lesión isquémica a los órganos a trasplantarse, tornándolos inutilizables. Concluimos que este tema debe ser debatido extensamente y que es necesario crear nuevas leyes que puedan ayudar a resolver este dilema ético.

**Palabras-clave:** Anomalías congénitas. Trasplante de órganos. Bioética. Anencefalia.

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### What is anencephaly?

Anencephaly is a congenital defect that is incompatible with life, which occurs in roughly 1:1,000 pregnancies<sup>1</sup>. According to the World Health Organization (WHO), Brazil is the country that holds the fourth highest incidence of anencephaly in the world, after Chile, Mexico and Paraguay<sup>2</sup>.

The majority of cases result due to the failure of the neural tube to close (NTD), but there are other etiologies, like embryopathy by diabetes, chromosomopathies, genetic diseases and amniotic adhesions. The fetus presents exposed cerebral tissue, with or without malformation, lacks cranial bone lining and a scalp. Due to the etiological differences that interfere with the natural history of the illness, researchers tend to classify anencephaly only in cases resulting from NTD where there is a malformation of the cerebral tissue, cranial bone and the scalp, without malformations in other organs. There is, however, a confirmed clinical heterogeneity<sup>1,3,4</sup>.

In Ireland, where one cannot legally interrupt a pregnancy because of anencephaly, a study was conducted on the natural history of this disease with 26 cases between the period of 2003-2009 and the average life expectancy reported was 55 minutes, varying between 10 minutes and eight days<sup>5</sup>. However, there are reports of cases where survival lasted months to years, but the empirical observation demonstrates that a large part of children in this condition suffer a prenatal death and that those who survive childbirth, in general, do not live for more than 48 hours<sup>4</sup>.

The etiology of anencephaly is implicated by a genetic predisposition, mainly associated with folic acid deficiency. The interruption of the pregnancy for these fetuses is common in developed countries. This diagnosis is simple, capable of being performed after a 12 week gestation. The ultrasound gives a sure diagnostic in about 100% of cases. The pregnancy and birth may be complicated by problems such as polyhydramnios, dystocia of labor and post-partum hemorrhaging<sup>1,5-7</sup>. A reduction in the cases of anencephaly was obtained in many countries through the fortification through fortification of source of food for the population with folic acid<sup>4</sup>. Nevertheless, despite medicine's

entire arsenal, today the anencephalic is born to die.

### The situation in Brazil

In Brazil, there is ample debate on the anticipation of the birth of an anencephalic fetus. Some argue that an anencephalic is a dead fetus due to cerebral malformation and, for this reason, there is not any motive for defending its life, which will be extinguished naturally after labor, as it is only guaranteed by the transference of nutrients from the mother through the umbilical cord. Others argue that while there is a brainstem there can be no talk of a dead fetus. The cerebral death of the anencephalic is debated within the scientific and professional community<sup>8-10</sup>, leaving doubts as to whether it is related to mankind's conscience or to the maintenance of vital functions.

Since the 1990s, obstetricians from Ceara and their team, comprising social worker, psychologist, clinical geneticist and ultrasonography experts, already dealt with the topic of expecting birth in cases of anencephaly, respecting the will of the family. It was even proposed that there be a term for court requests in these cases. Only in 2004 did the states of the South and Southeast regions began a discussion of this issue, which is now a national debate<sup>1,8</sup>.

The Federal Council of Medicine states in Decree 1.752/04 that the anencephalic are cerebral stillborns<sup>11</sup>. By basing itself on Law, there is no way of punishing abortion for anencephaly if a material object is missing; if there is not any materially active life since conception, then one cannot speak of life from the legal perspective<sup>6,12</sup>. Care should be taken, therefore, not to confuse the physical criteria of cerebral death and the concept, comparing the condition of the anencephalic and that of people who do not have a brain deformity and may be in a brain dead diagnostic condition for organ transplant.

### Medical Aspects

May individuals in a vegetative state be considered as brain dead and candidates to be the donors for transplant organs? Fetuses that do not have a cerebral cortex may also be in a vegetative, state and, therefore, could they not also be considered for organ donation? To Cefalo and

Engelhardt Jr., it is noteworthy that the donation of an anencephalic organ would not injure the person's dignity.

However, the issue seems to have various ripples that spread beyond the utilitarian objective of increasing the supply of organs. In donating the organs of an anencephalic, one should also consider that there is an ontological issue with the respect for human beings as well. Philosophy recognizes the idea that the ends do not justify the means and, therefore, one may not treat potential donors as mere resources for obtaining organs<sup>13</sup>.

It becomes necessary to ponder if the principle of beneficence, imperative to do good, may be applied to a person in need of an organ transplant, the principle of protection of the more vulnerable may be applied to an anencephalic child, which should not be treated as means for benefiting someone else.

Through the evolution of technology, it is possible to sustain the organs of an anencephalic child using machines that support the maintenance of vital functions like circulation and the exchange of gases. However, in its technical aspect, doubt is centered on when we may remove these organs based on the diagnostic of brain death without the anticipation of this moment causing injury to the organs targeted to use. If injury occurs, two lives will be lost: the donor and the organ recipient. But the technical issue merges inextricably with the moral question, which continues to be the great dilemma in debating the topic, whose practice posed an ethical problem to the medical community, which cannot be solved by the attending physician<sup>14,15</sup>: would it be lawful to await the birth of an anencephalic for the sake of maintaining these organs for another individual?<sup>10,16,17</sup>

The use of transplant organs from anencephalic children received ample publicity at the end of 1980, after the Loma Linda's case, Baby Gabriel, when a heart transplant was performed with the organ of an anencephalic fetus. In 1989, twelve children received intensive care to facilitate the declaration of cerebral death. Nevertheless, the anencephalic do not satisfy the criteria of brain death for individuals in a vegetative state due to their respiratory and heart rate after birth and to the functioning of the brain stem.

In 1999, Parisi *et al* related a case of heart transplant whose organ was taken from an anencephalic child who was diagnosed with anencephalic death during its first day of life. The authors consider the result of the transplant as a success, despite the child having died prematurely due to necrotizing enterocolitis<sup>18</sup>.

In the face of this uncertainty, the Canadian Pediatric Society and the American Academy of Pediatrics concluded, yet in 1992, that the anencephalic are not appropriate organ donors and rejected the arguments that defend the criteria of encephalic death in these cases for organ transplants<sup>16,17</sup>. Furthermore, both entities advised against organ transplants donated by the anencephalic due to the risk of losing society's confidence in transplant programs, the public's respect for the intrinsic value of life and generalization of arguments in favor of the brain dead diagnosis in children with severe brain injuries<sup>16</sup>. These societies' recommendations are:

*Organ donation from anencephalic infants should not be undertaken due to the serious difficulties surrounding the establishment of brain death in these infants and the lack of evidence to date supporting successful organ transplantation;*

*There should not be any change or modification in infantile standard of brain death criteria to include infants with anencephaly;*

*Families requesting the opportunity to donate their anencephalic child's organs should have information and educational material explaining why this practice is not supported<sup>17</sup>.*

The Standing Committee for the Study of Ethical Aspects of Human Reproduction, of the International Federation of Gynecology and Obstetrics (FIGO), also made a pronouncement related to the ethical dilemma in using anencephalic infants' organs transplants. FIGO does not advise against the transplanting of organs from anencephalic children when it stipulates that, with permission from parents, the child may be put on an artificial ventilation machine for the purpose of organ donation. The definition of death, which is mandatory,

may be revised in light of the scientific development of criteria related to encephalic death in new-borns<sup>19</sup>.

The wait for an ethical and judicial regulation enabled the surfacing of specific problems related to donation and to the death process of the anencephalic. Some studies have shed doubt on the value of hearts from anencephalic infants as donation material. The query arose from the alterations in the measurements of the left ventricle wall of the anencephalic infants' hearts relative to that of normal children<sup>20</sup>. The prerequisites on the death process of anencephalic infants also demands accurate consideration, as the cardiovascular and respiratory functions deteriorate gradually, causing ischemic lesions on the organs to be transplanted before the terminal event, making them unviable, and life support has not altered this condition. It was confirmed that the failure of multiple organs occurs despite advanced life support<sup>6,14,16,21</sup>.

The definition of biological death with irreversible cardio and respiratory arrest, and the definition of cerebral death are not clear in cases of anencephaly<sup>10,15,22</sup>. Some consider that the anencephalic fetus is dead because it is unfeasible<sup>23</sup>. In this case, abortion would not be an illegal action because the fetus is already dead. But what is the definition of cerebral death for the malformed brain of an unviable child? It is essential to remember that the definition of the death criteria is important to protect society from medical interventions by unscrupulous individuals. However, a consensus as to the definition of death has not been achieved in society yet<sup>13</sup>.

Despite the existence of these moral dilemmas, it is undeniable that organ transplant has saved many lives. The possibility of recovering children born with heart problems, like a single left ventricle, nephropathy and other diseases for which there are no treatment, based on the donation of organs from unviable anencephalic fetuses, has been unveiled as a reality. This situation demands changes in legislation<sup>14,24</sup>. In order for a transplant of an anencephalic organ to occur, it is essential to create rules that may settle doubts and overcome the dilemmas imposed by current legal and ethical concepts.

## Legal Aspects

Brazil prohibits abortion on penalty of law, except in cases of rape and risk of death for the mother. However, it is known that more than 3,000 injunctions for the abortion of anencephalic fetuses were carried out. One of the justifications given was that when a fetus is incompatible with life then there is no affront to the values of said life to be protected by the Penal Code<sup>25,26</sup>. This justification is very clear when it stands upon the unfeasibility of the concept. Based on this, the freeing of organs from a child with anencephaly to contribute to the life of another who would die without a transplant could occur. Even knowing the risks of transplant, in some cases it is the only hope for survival and, therefore, is still a procedure practiced in medicine.

Currently, however, the exceptions for the legal authorization of abortion, like in cases of anencephaly, were revoked. Judges rulings are mixed due to lack of understanding on the subject and personal and religious convictions, thus, there is not a consensus on anencephaly and a new debate will begin in the country's highest court<sup>27</sup>.

The Medical Code of Ethics in force since April 13 of 2010, in article 41 of its Chapter V, states that *"the doctor is forbidden to shorten the patient's life, even at his request or his legal representative. In cases of an incurable or terminal disease, the physician should offer all palliative care available without applying useless or obstinate diagnostic or therapeutic actions, always considering the express desire of the patient or, if that is not possible, that of his or her legal representative."* For its part, article 45 of the Chapter VI prohibits the physician from *"removing an organ from a live donor when said donor is legally incompetent, even if authorization of his or her legal representative exists, except in cases permitted and regulated by law"*<sup>28</sup>.

The donation of organs from the anencephalic is not regulated by law; therefore, the anencephalic fetus ends up being considered as an individual with severe cerebral malformations.

## Ethical Aspects

Death has moral, religious and political connotations.

It is not something that is purely empirical, but laden with sentiments, values and beliefs. The definition of death is of extreme importance for legal values. It is necessary to establish the moment of death in order to respect social and psychological values, but this moment varies both temporally, due to technique, as well as for individuals and cultures<sup>13</sup>.

There are still in many countries debates on legal authorization for abortion of anencephalic fetuses<sup>29</sup>. In these debates, between philosophers, religious people, and civil society, the rhetoric is centered on arguments regarding the difference between a human being and a human subject<sup>4,26</sup>, according to philosophical, ontological and biological differences. Should a human being without cognitive functions be recognized as a person with legal rights or simply a human form that breathes?<sup>30</sup>

Some criteria may be used to define humanity, such as physical (genotype, physical form and appearance) and cognitive, which include intelligence, perception and autonomous functions - sucking, grabbing and breathing reflex -, social and interpersonal abilities, individual signature due to creativity, self-consciousness, self-control and personality. Of these, to be considered a human, the criteria of greatest influence includes the capacity for reasoning and a consciousness<sup>23,31</sup>. Thus, in western societies technological and moral development stage, the question that asserts itself when reflecting on this issue is: is the definition of cerebral death related to consciousness?

And what changes with the presence of consciousness? Most argue that what defines human being' *ethos* and ontological *status* in western culture is the understanding that the individual who does not have a consciousness is not a person and, therefore, does not have legal rights. From this perspective could one perform organ transplants to save other lives with these individuals' organs? Does the same apply to the severely mentally retarded? The difference is that this vulnerable group of the population may not have a consciousness, but they have conditions to survive, which is not the case with the anencephalic.

There are those who are adepts of the concept that the irreversible loss or absence of cerebral

functioning be used as the definition for encephalic death. In these cases, would the anencephalic fetuses be declared dead as soon as they were diagnosed? Would the law permit the transplant and tissue from anencephalic infants while they were still alive? From this point of view, consciousness defines the difference between the human's biological life and the life of a person considered human. The problem is that defining this aspect for the anencephalic raises concern as to the generalization for individuals in a vegetative state<sup>24</sup>.

All these discussions rekindle the fear of eugenic practices. Could they constitute an opening for proposals of ethnic cleansing? Could not some extremist groups, like the neo-Nazi, for example, attempt to extend the rules in regards to anencephaly to other individuals that, according to their interpretation, also lacked cognitive function or social value?<sup>11,24</sup> The discussions in the U.S. attempted to settle the dispute with the conclusion that the child with anencephaly is not dead and should be protected. It is not a monster because of its physical appearance. Although severely deformed, it is a human being and, therefore, should be treated in the same fashion as any other human being, with respect and dignity, and may die in peace, from natural causes<sup>24</sup>.

Nevertheless, if this conclusion seems to partially settle the controversy, the issue persists relative to the abortion or not of anencephalic fetuses. It is not ethical to pressure mothers into sustaining a pregnancy of a child with anencephaly simply to contribute with the donation of organs<sup>4,16</sup>. According to Horowitz, geneticist from the Oswaldo Cruz Institute (Fiocruz), the couple's autonomy should be respected, whose suffering should be spared, discounting the application of the status of person on the anencephalic due to their infeasibility<sup>12</sup>. On the other hand, when a pregnant woman chooses to take the pregnancy to term, is it ethical to let die children who need a transplant because philosophically we do not know when to declare the cerebral death of someone born with a malformed brain? If it is possible to interrupt the intrauterine life of the anencephalic, diminishing the psychological and obstetric risks to the mother, why may one not interrupt it after birth to provide for the survival of another child, benefiting the receptor and their family without causing injury to the donor's family?<sup>6</sup>

## Final considerations

Families who desire the transplant of organs donated by children with anencephaly should be guided in respects to all the legal, ethical and medical dilemmas involved in this issue. Each case should be analyzed according to each family's story, respecting the principles of bioethics and the laws in force in each country. The debates over the transplant of organs from anencephalic donors should continue with the participation of society, so that new laws may be created specifically for this issue.

Anencephalic children may not have legal rights and not be considered people, but we should have the same respect for them as we do for other human beings. Furthermore, we should also respect the sentiments of the mothers, who have the right of burying their anencephalic children with all the cultural rituals of their country and religion. The issue, therefore, is not the debate over who is a person or not, but to standardize an instrument that determines the period when one may establish an anencephalic as an organ donor, just as it was done with candidates for organ transplants, accepted throughout the country.

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