

Medical and legal authorization for therapeutically induced childbirth in anencephaly cases: ethical implications

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Abstract

Anencephaly is a congenital anomaly in which the neural tube closes improperly, affecting the formation of the cranial vault and much of the brain. Therefore, in anencephaly, the hypothesis of fetal unfeasibility is considered. In cases of unfeasible extra-uterine fetal life or maternal health risk, it is possible to resort to the therapeutic induction of childbirth. This article discusses the ethical implications concerning the authorization of therapeutic induction of childbirth in case of anencephaly, such as: the physician's influence on the patient's decision making; failure to implement the methods of preventing this anomaly; legal differences between abortion and therapeutic induction of childbirth. The latter is a novelty within the legal field in Brazil, since the Penal Code criminalizes abortion, except in cases of life-threatening pregnancy or pregnancy resulting from rape.

Keywords: Abortion. Anencephaly. Folic acid. Bioethics. Legislation.

Resumo

Liberação médico-jurídica da antecipação terapêutica do parto em anencefalia: implicações éticas

Anencefalia é anomalia congênita na qual o tubo neural fecha-se incorretamente, comprometendo a formação da abóbada craniana e de grande parte do encéfalo. Por isso considera-se, em anencefalia, a hipótese de inviabilidade fetal. Em casos de vida fetal extrauterina inviável ou saúde materna em risco, há possibilidade de recorrer-se à antecipação terapêutica do parto. Este artigo aborda as implicações éticas acerca da liberação desse procedimento diante do quadro clínico ora debatido. Entre essas implicações estão: influência do médico na tomada de decisão da paciente; falhas na implementação dos métodos de prevenção dessa anomalia; diferenças legais entre abortamento e antecipação terapêutica do parto em anencefalia.

Palavras-chave: Aborto. Anencefalia. Ácido fólico. Bioética. Legislação.

Resumen

Enfoque médico y legal a la liberación de la anticipación terapéutica del parto en la anencefalia: implicaciones éticas

La anencefalia es una anomalía congénita en la que el tubo neural se cierra incorrectamente, poniendo en peligro la formación de la bóveda craneal y de gran parte del cerebro. Por lo tanto, en la anencefalia se considera la posibilidad de inviabilidad fetal. Se sabe que en los casos de inviabilidad de la vida fetal extrauterina o riesgo a la salud materna, es legítimamente posible interrumpir el embarazo. Este artículo discute las implicaciones éticas relativas a la liberación de la anticipación terapéutica del parto en casos de anencefalia, tales como la influencia médica sobre la toma de decisiones del paciente; la falta de aplicación de los métodos de prevención de esta anomalía; las diferencias legales entre aborto y anticipación terapéutica del parto en anencefalia, esto como una novedad en el sistema jurídico brasileño, ya que el Código Penal penaliza el aborto salvo en caso de amenaza de la vida de la embarazada o gestación resultante de estupro.

Palabras clave: Aborto. Anencefalia. Ácido fólico. Bioética. Legislación.

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There is a natural connection between medicine and law, since both areas of knowledge share the function of caring for the lives of human beings: the former in the psychic and physiologic dimensions, and the latter in the social and humanistic dimensions. To talk about controversial themes such as abortion, therapeutically induced childbirth and anencephaly, it is necessary to intertwine specific and generic knowledge in the medical and legal fields in the attempt to reach the most consistent and beneficial position¹.

It is necessary to delineate the differences between abortion and therapeutically induced childbirth. Abortion is a word that derives from Latin – *ab* means deprivation and *ortus*, birth² –, and is characterized by the interruption of pregnancy until the 20th week, with or without the ejection of the fetus with potential life and, therefore, a physiological product, and as a result the fetus is dead. Therapeutically induced childbirth, however, a term proposed by anthropologist Débora Diniz³, is the interruption of pregnancy when there is a pathological development of the fetus, which results in an unsustainable life outside of the womb.

Anencephaly is the hypothesis of an unsustainable pathologic development which has become more and more prominent in the current medical-legal realm – the word comes from the Greek *an* (without), *en* (inside), and *kefalé* (head)⁴. This pathology is a lethal congenital anomaly which results from the absence of fusion of the posterior neural tube during the fourth week of pregnancy. As a consequence the formation of the cranial vault, cerebral and cerebellar hemispheres are compromised, although a rudimentary brainstem and cerebral islands are present in living children^{5,6}.

Abortion practices date back to the early days of human history. There are reports of abortions in eastern societies from about 2,500 years BC. With the advent of the Christian doctrine, ethical and moral questions about this theme came up. The Catholic Church only took an official position against abortion in 1869, when Pope Pius IX declared all kinds of abortion as murder⁷. Currently, the legislation is in conformity with this line of thought and criminalizes abortion practices. In the Código Penal Brasileiro (Brazilian Criminal Code), put into effect in 1940, an abortion is a crime except if it is necessary to save the life of the mother or when the pregnancy is the result of rape⁸.

There has been jurisprudence since 2012 ratified by the Supremo Tribunal Federal (Brazilian Federal Supreme Court) (STF), the highest court in the Brazilian legal system, which authorizes the

interruption of pregnancy in cases of unmistakable proof of anencephaly in the fetus⁹. The Conselho Federal de Medicina (Federal Council of Medicine) (CFM) defends the autonomy of the mother in the decision making process regarding the maintenance or interruption of pregnancy in cases of anencephaly, and demands impartiality of the doctor to not influence the mother in either direction¹⁰. However, medical studies reveal that doctors face difficulties in keeping neutral upon advising pregnant women¹¹.

In an attempt to identify how other governments legislate on the therapeutically induced childbirth and abortion, it can be observed that in European countries these practices are dealt with in a very liberal way, and abortion is authorized in many situations - in cases of rape; fetal malformation; upon the mother's request; when there is risk of life or physical or mental health for the mother; or by social and economic reasons. In this respect the Netherlands, Belgium, Germany, Sweden, United Kingdom and Denmark are noteworthy¹².

Up until December 2013 Spain also allowed unrestricted abortion until the 14th week of pregnancy, but has since radically changed its position by criminalizing abortion except in exceptional cases similar to the Brazilian legislation. In South America, Chile criminalizes abortion practices with no legal exceptions; Paraguay and Peru allow it only to save the life of the mother; in Argentina, in addition to that, abortion is also allowed when the mother is "idiotic or demented"; in Venezuela, to protect the honor of the woman or man¹³.

Anencephaly has great importance nowadays, given its considerable national prevalence. In Brazil there are approximately 18 cases out of every 10,000 children born alive, which represents a rate up to 50 times higher than that observed in countries such as France, Belgium, Austria and the United States¹⁴. The occurrence of anencephaly is higher in female fetuses⁶ and in those generated by women above the age of 35, although studies show no relationship between the age of the mother and the occurrence of anencephaly¹⁵. In addition, the risk of incidence increases in 5% for each subsequent pregnancy¹⁶. Several genetic, nutritional and environmental factors are involved in the establishment of this pathological condition, such as low intake of folic acid, use of teratogens and lawful drugs, and exposure to radiation and viruses during the first months of pregnancy¹⁴.

Given that anencephaly is a fetal malformation with high prevalence; that countries differ in the application of legislation, either to allow or criminalize; that there are resources for considerable prevention

of this anomaly; that Brazilian medical agencies face therapeutically induced childbirth as one of the possible decisions that the mother has; one can see an early precedent for the interruption of a life, considering that the tutelage and valuing of life are parts of State priorities and, therefore, these are all factors which lead to a deeper study about this theme. This paper aims at approaching the possibility of therapeutically induced childbirth in anencephaly cases and its ethical implications from the medical and legal standpoints.

Materials and Method

The following keywords were selected for the literature survey: “therapeutically induced childbirth”, “abortion”, “anencephaly”, “folic acid”, “bioethics”, “fundamental rights” and “legislation & jurisprudence”, surveyed on the SciELO, PubMed, Google Academics and Lilacs websites. Medical and legal dictionaries, books and journals, the Constituição (Brazilian Constitution), the Código Penal (Criminal Code) and extravagant legislation have also been used. There was a 90% return with the selected keywords, followed by the use of 76% of the obtained references. The research had a bibliographic aspect for qualitative discussion.

Medical approach

Possibilities of prevention of anencephaly

The etiology of neural tube defects (NTDs) is not totally clear due to the limitations presented by studies with fetuses. However, it is known that there is a relationship between these anomalies, especially anencephaly, and the exposure to teratogens, pre-pregnancy diabetes, obesity of the mother and hyperthermia in the mother. In a smaller proportion, food poisoning with fumonisin, magnetic fields and pesticides are worthy of note¹⁷. Genetic defects are also associated with anencephaly, mainly those related to the metabolism of folic acid, such as the gene of the 5,10 Methylene tetrahydrofolate Reductase enzyme¹⁸.

However, the main factor indicated by several studies as the cause of anencephaly is low ingestion of folic acid, a fundamental compound in the biosynthesis of DNA and RNA both before and during pregnancy¹⁹. In the United States, after the implementation of government measures to supplement foodstuffs with folic acid, a 19% reduction in the occurrence of neural tube defects has been observed. In Newfoundland Island, Canada, a 78% reduction in the NTD prevalence was observed²⁰.

In Brazil, government actions have been established to reduce folic acid deficiency in women and for other morbidities such as anemia. In 2002 the Diretoria Colegiada da Anvisa (Anvisa Collegiate Directorship) installed Resolution RDC 344 and, in 2009, Ordinance 1793 from the Ministério da Saúde (Ministry of health)^{21,22}. The former determines the mandatory addition of 4,2 mg iron and 150 µg of folic acid in wheat and corn flours²¹. The latter established the Comissão Interinstitucional para Implementação, Acompanhamento e Monitoramento das Ações de Fortificação de Farinhas de Trigo, de Milho e de seus Subprodutos²² (Inter-institutional Commission for the Implementation, Follow-up and Monitoring of Fortification Actions for Corn and Wheat Flours and their Byproducts).

Although studies demonstrate a considerable increase in the serum levels of folic acid in the population, other surveys reveal failures in the execution of these government measures and even an absence of significant reduction in anencephaly cases. A research carried out in Campinas, SP²³ evaluated five lots of three flour brands and determined that the concentration of folic acid was unstable in the samples, most of which had a lower concentration than that determined by the resolution. Another study²⁴ carried out between 2000 and 2006, therefore before and after iron and folic acid fortification, did not show a significant difference in the prevalence of anencephaly.

The poor performance of the food fortification policies in Brazil and Latin America, according to the Pan American Health Organization, is due to the lack of coherent interaction of several necessary factors: clear and specific norms for fortification; an adequate official methodology for the dosage of micronutrients; current scientific evidence on the prevalence of nutritional deficiencies and anomalies; regular inspection and monitoring at the public sector and degree of impact of the adopted policies; and mainly social marketing²⁵. In addition to the planning and execution flaws, the fortification of wheat and corn flours alone is not enough to increase the intake of folic acid, since the daily home medical availability is 106,1 g²⁶. This amount allows for a folic acid offer of only 0,16 mg/day. In addition, the average variation of home access to flour products in different regions in Brazil must be considered. In the North and Central-West regions, for example, consumption is 70 g/day and the folic acid offer is lower than 0,1 mg; in the South, flour acquisition is 144 g/day, which contributes with about 0,217 mg of folic acid²⁷.

Evidence in the literature shows a larger reduction of the incidence of neural tube defects with periconceptional folic acid supplement, between one and three months of conception up to the end of pregnancy, than with food fortification¹⁸. Studies show that daily supplement doses above 5 mg of folic acid reduce between 75% and 91% the occurrence of such anomalies, depending on the basal serum concentration of folic acid and on the age of women.

However, in spite of the known importance of folic acid supplementation, it has not been effective in the Brazilian population. A study done in Pelotas, RS, showed that 31.8% of the women interviewed used this vitamin at some point of their pregnancy and only 4.3% used it in a periconceptual way. In addition, of the women who consciously used folic acid during pregnancy, 57.5% did it due to medical prescription and 42.5% after suggestions from friends, relatives, other health professionals and the media¹⁹.

The influence of the doctor in the therapeutically induced childbirth in anencephaly cases

In 2004 the Federação Brasileira das Associações de Ginecologia e Obstetrícia (Brazilian Federation of the Gynecology and Obstetrics Associations) (Febrasgo) voted in favor of the *free decision by doctors and patients for therapeutically induced childbirth in cases of anencephaly*¹⁶, which shows support towards the exclusion of the need of a court authorization for this procedure. Court authorization was, however, mandatory until April 12, 2012, the date of conclusion of the judgment of Arguição de Descumprimento de Preceito Fundamental 54 (Claim of Non-Compliance with Fundamental Precept 54) by the STF, and thereafter abortion was no longer considered a crime, in terms of the código penal brasileiro (Brazilian Criminal Code), in the cases of anencephaly¹⁰. The Febrasgo guidelines suggest that obstetricians introduce the possibility of therapeutically induced childbirth to the mothers as a way to ensure the woman's reproductive rights founded on the autonomy and freedom of choice and the right to health and human dignity, by means of access to adequate medical treatment for induced birth¹⁶.

Another study¹¹ evaluated the medical approach in face of serious fetal anomalies in the United States. It concluded that an objective evaluation of the strategies used by obstetricians is necessary for the management of pregnancy in cases of lethal anomalies such as anencephaly, considering the lack of existence of well-defined care standards for this condition. Although there are studies based on the

opinion of specialists on what obstetricians should do, there is little information on what is actually done.

The US study revealed that, regarding the interruption of pregnancy in the cases of lethal anomalies, 99% of the obstetricians would discuss this approach with their patients. Moreover, if the mother decides to go on with the pregnancy, the practice of "non-intervention" in favor of the fetus as per the mother's request was a consensus among obstetricians. On the other hand, the practice of "complete intervention" in favor of the fetus - which includes Cesarean section, fetal monitoring, neonatal resuscitation -, as per the mother's request, was discouraged by most obstetricians and, therefore, remains controversial. For the case of uniformly lethal anomalies, such as anencephaly, 29% did not fulfill the mother's request for complete obstetric intervention in favor of the fetus¹¹.

In the Brazilian panorama, after the decision of not considering therapeutically induced childbirth in anencephaly cases as a crime of abortion as defined in the Código Penal (Brazilian Criminal Code), the STF demanded that the CFM define medical criteria for the diagnosis of fetal malformation. It also stipulated that the CFM create specific guidelines for medical assistance to the expecting mother, since therapeutically induced childbirth in anencephaly cases would not remain a the legal competence but would become a procedure of women's health programs¹⁰.

CFM resolution 1989/2012¹⁰ states that the council has limited itself to dealing with the criteria for anencephaly diagnosis, since it believes in the sufficiency of the Código de Ética Médica (Medical Ethics Code) (CEM) to deal with the specific guidelines for medical assistance to the expecting mother. According to the CFM, the CEM deals with issues on the objection of conscience of the professionals, which exempts them from the obligation of acting in the therapeutically induced childbirth; autonomy of the expecting mother, respecting the patient's decision; obtaining informed consent, which requires that the doctor obtains the consent of the patient after clarifying her on the procedure to be carried out; and secrecy, since therapeutically induced childbirth in anencephaly cases has become a matter that is restricted to the doctor-patient relationship.

The CFM resolution defends the autonomy of the expecting mother in the decision of maintaining or interrupting her pregnancy anencephaly cases. It determines that, in regard to the management of the pregnancy, the doctor must offer the expecting mother all the necessary clarification without imposing authority to induce her to make any decision, and that it is

the right of the mother to ask for a medical committee or seek another opinion on the diagnosis. Furthermore, according to the CFM, it is the doctor's duty to inform the mother of the consequences, including the risks from both decisions¹⁰. The CFM has not, however, created specific guidelines for medical assistance in approaching pregnancy in case of a lethal anomaly, such as anencephaly, nor does the CFM indicate them.

This way, as the US study reveals, obstetricians have demonstrated difficulty in maintaining, in practice, non-directive counseling to expecting mothers, and were rather led by their personal opinions to either encourage or discourage the patient to decide on "non intervention" or "complete intervention" in favor of the fetus¹¹.

Another study²⁸ corroborates the idea that if the parents are influenced by health professionals, the decisions regarding the maintenance of pregnancy are based on the very individual preferences of the neonatal doctors and nurses, from whom the parents seek guidance and information. It also revealed that health professionals tend to classify quality of life in terms of health more negatively than the very patients or their relatives. According to this research, health professionals who deal with newborns with extreme low weight classify possible health conditions, particularly those that show a serious disability, with lower levels of use than those that classified teenagers who were newborns with extreme low weight and their parents.

Legal approach

In the legal world there is always strong disagreement when discussing clashes between fundamental rights. Abortion, or therapeutically induced childbirth, seems to be the practical case of this confrontation. For this reason it is necessary to make some brief remarks on these current, but equally controversial, themes. Abortion is a criminal conduct defined in the Código Penal (Brazilian Criminal Code)²⁹ in articles 124 to 127:

Art. 124 - To provoke an abortion on oneself or to allow that someone provokes it:

Penalty - detention, one to three years.

Art. 125 - To provoke an abortion without the consent of the mother:

Penalty - detention, three to ten years.

Art. 126 - To provoke an abortion with the consent of the mother:

Penalty - detention, one to four years.

Sole Paragraph. The penalty in the previous article is applied if the mother is not above the age of 14, or is alienated or mentally retarded, or if the consent is obtained by fraud, serious threat or violence.

Art. 127 - The penalties imposed in the two previous articles are increased in one third if, as a consequence of the abortion or of the means employed to provoke it, the mother sustains serious bodily injury; and are doubled if, from any of these causes, the mother dies.

It also lists the excluding cases of unlawfulness, that is, the possibility of abortion without the characterization of a defined and punishable conduct. Other than these exceptions, an abortion is considered a crime.

Art. 128 - An abortion practiced by a doctor is not punishable:

I - if there is no other way to save the life of the mother;

II - if the pregnancy is the result of rape and the abortion is preceded by consent from the mother or, when incapacitated, her legal representative.

Article 128, I, classifies a necessary abortion as one which is the only way to save the mother's life. It is accepted to safeguard a life, in this case the mother's, which means giving up one life in the defense of another. Item II mentions humanitarian abortion, a non-punishable abortion practice since it is the result of another crime, rape, a clear violence towards a woman's right to sexual and bodily freedom; therefore, one gives up a life to defend the sexual and psychological freedom of another person³⁰. These exceptions to punishability in the doctrine and in the opinion of most of the legal community are correct and in compliance with the fundamental principles.

After 2012, as a result of the judgment of ADPF 54 (Claim of Non-Compliance with Fundamental Precept 54) by the STF, another abortion practice, therapeutically induced childbirth, was judged as non-punishable in the cases of anencephaly diagnosis: *uphold the action to declare the unconstitutionality of the interpretation according to which the interruption of a pregnancy of an anencephalic fetus is a conduct defined in articles 124, 126 and 128, items I and II, of the Código Penal (Criminal Code)*⁹. The main argument used to justify this new authorization is that there is no abortion, since in

cases of anencephaly there is no potential for life. Therefore, one cannot talk about a crime as defined in the abovementioned articles, but only about therapeutically induced childbirth³¹. This authorization is seen as a progress from the point of view of several operators in legal sciences, but is seen by many others as a setback³². In this case, the setback would be opening a precedent for a future and faraway, but real, decriminalization of abortion, made positive by the women's right to sexual freedom.

For the authors, the argument raised by the life potential of the anencephalic fetus must be considered as relative. We consider that the law is equal to all, regardless of the fact that some individuals have the potential for life or are fully capable of performing civic life actions. Therefore, it is our understanding that a sort of pre-selection would be going on, because if there is no life potential for a fetus, who is technically alive because it is in development, its life may be limited and dispensed with by a mere matter of quantification. In other words, we believe that due to the fact that the length of the fetus' life or survival is considered short, that fetus would not deserve to have its gestation completed.

Its interruption is authorized by the justification that there is the possibility of damage to the mental and psychological health of the mother upon completing a pregnancy whose fruit will live only for brief moments³¹. For the authors, the quantification of the life of a fetus is contrary to fundamental rights such as the right to life and human dignity. However, it is worth mentioning that this proviso has never been written in a legal text³³.

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Final considerations

With the effectiveness of this new jurisprudence, which has broadened the interpretation of the theme under the Criminal Code, the government plans regarding food fortification and supplementation with folic acid as a preventive method for anencephaly and other congenital anomalies must be made more effective. In Brazil, as has occurred in many Latin American countries, a thorough analysis is needed on the use of folic acid by pregnant women for possible remediation of these errors and reduction of the prevalence of this anomaly - and as a consequence the reduction of therapeutic induced childbirth.

Given the clearance for therapeutically induced childbirth in anencephaly cases without the need for legal authorization⁹, further studies are necessary to evaluate how the management of pregnancies with lethal anomalies is accomplished in practice¹⁰, since obstetricians have difficulties in giving non-directive counseling to the mothers¹¹.

Even if stated by the Suprema Corte do Brasil (Brazilian Supreme Court), this new jurisprudence seems to us to be in evident non-conformity with the principles of Brazilian Law, since it opens new legal precedents for abortion practices from the severe evaluation of the life potential of each human being in gestation. According to the understanding of the authors, this fact characterizes a violence towards the right to life and human dignity, that is, towards fundamental rights and guarantees listed in the 1988 Constituição Federal (Federal Constitution), for the aforementioned reasons.³⁴

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