Right to knowledge of biological origin in Human Assisted Reproduction: bioethical and legal reflections
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Abstract
This article discusses the right to know the biological origins of a person generated by the Heterologous Human Reproduction technique, presenting arguments and issues related to this complex process, which involves different interests. In this sense, a hypothetical-deductive study is developed based on intersections of nature and content between Bioethics and Law. The study progresses by approaching the risks brought by technological advances and the expectations of all subjects involved, as well as vulnerabilities, the need for consent for gamete donation and donor anonymity. It further debares the concepts of “genetic identity” and the right to know one’s “biological origins”, drawing an analogy with Brazilian adoption law. Finally, the study addresses the so-called “secrecy right”, considering arguments found in legal literature, including the idea of “de-biologization” currently defended by the Brazilian higher courts.

Keywords: Bioethics. Right to health. Reproductive techniques. Privacy.

Resumo
Direito ao conhecimento da origem biológica na reprodução humana assistida: reflexões bioéticas e jurídicas
Este artigo discute o direito ao conhecimento da origem biológica da pessoa gerada por técnica de reprodução humana assistida, apresentando argumentos e problemas envolvidos nesse complexo processo que inclui diferentes interesses. Nesse sentido, foi desenvolvido um estudo hipotético-dedutivo, com base referencial teórica sustentada na bioética e no direito, na medida em que esses dois campos se interseccionavam quanto à natureza da matéria. O estudo avança, ainda, abordando os riscos decorrentes dos avanços tecnológicos e das expectativas dos sujeitos envolvidos, inclusive a vulnerabilidade, o consentimento para doação de gametas e o anonimato dos doadores. Discute, também, os conceitos de “identidade genética” e direito ao conhecimento da “origem biológica”, traçando analogia com a legislação brasileira relativa à adoção. Por fim, trata do chamado “pertencimento do segredo”, refletindo sobre os argumentos encontrados na literatura afim, inclusive o contexto de “desbiologização” atualmente defendido pelos tribunais superiores.


Resumen
Derecho al conocimiento del origen biológico en reproducción humana asistida: reflexiones bioéticas y legales
Este artículo aborda el derecho al conocimiento del origen biológico de la persona generada por técnica de reproducción humana asistida, presentando los argumentos y problemas implicados en este complejo proceso que involucra diferentes intereses. En este sentido, se ha desarrollado un estudio hipotético-dedutivo, con sustento teórico en bioética y derecho, y la intersección de estos dos campos respecto a la naturaleza del tema. El estudio avanza, haciendo relación a los riesgos de los avances tecnológicos y las expectativas de los participantes, la vulnerabilidad, el consentimiento para la donación de gametos y el anonimato de los donantes. Son analizados también los conceptos de “identidad genética” y el derecho a conocer el “origen biológico”, haciendo una analogía con la legislación brasileña relativa a la adopción. Por último, se aborda la llamada “pertenencia del secreto”, al reflexionar sobre los argumentos de la literatura al respecto, incluyendo el contexto de “desbiologización” actualmente defendida por los tribunais superiores.


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Declaram não haver conflito de interesse.
Although the assisted human reproduction techniques (RHA, acronym in Portuguese) have been introduced in Brazil in the early 1980s\(^1\), the country today has no specific legislation on the subject. In these almost 30 years of use, the practices related to the new reproductive technologies developed in the country have been guided primarily by normative resolutions produced by the Federal Council of Medicine (FCM) and directed primarily to physicians. More recently, the Council applied the FCM Resolution 2.013/13\(^2\), nationally regulating RHA regarding the performance of psy - professionals responsible for technical assistance and ethics for artificialized reproduction - actually ended indirectly by regulating the practice, considering the legal vacuum on the subject.

In the Civil Code of 2002\(^3\) contains only isolated approaches to RHA. Thus, the debate is open, creating difficulties for the resolution of social, ethical and legal conflicts in several instances and situations. This fact justifies and encourages ethical reflection on the subject, along with other similar reflections that have come out in the literature.

Current legislation does not undermine the achievement of such techniques\(^4\). This does not mean, however, that we are away from the many ethical dilemmas that may result from such procedures, both in an environment of emerging situations that, according to Garrafa, are provided by advances such as those achieved in the field of genetic engineering and its consequences\(^5\), as persistent situations, which according to the author are mainly related to the lack of universal access of people to health goods consumption and equitable use of these benefits for all citizens without distinction\(^6\). Given the characteristics of RHA and its consequences in the social dimension, one can characterize the practice in both situations.

The issue here exposed, therefore, consists of a concrete problem to be faced in the bioethical debate not only about the ethical decisions on the establishment of rules of the progress made in society with regard to the use of assisted reproduction techniques, but also in the sense of difficulty the public access to these advances.

**Method**

This study is context the discussion about the possibility of understanding the knowledge of biological origin as a right of the person generated by RHA heterologous technique, aiming at presenting bioethical and legal arguments related to the subject as well as their possible interpretations and risks.

Therefore, the construction of the research came from hypothetical-deductive study, with review and theoretical framework of analysis of bioethics and law, as these two areas of knowledge intersect the nature of matter. The problem analysis incorporated also international bioethical and legal instruments for the observance of ethical determinations consensus built the scientific and academic communities and world politics.

**Assisted human reproduction in Brazil**

The concern in the Brazilian context, about the possible dilemmas about the genetic origin of the individuals was first raised in 1978, the Brazilian Congress of Legal Medicine, and called at that time of “ancestry” of births, given the first international results at the time on cardiopulmonary human Fertilisation\(^6\). At that time, the international press turned his attention especially for Louise Brown case in England. And, in 1984, discussions on the RHA also began in Brazil, after the birth of Anna Paula Caldeira. In both cases we used in vitro fertilization (IVF) as innovative technique.

Among the different techniques of assisted human reproduction used today are the following, for purposes of this analysis, artificial insemination and in vitro fertilization, in which you use germinal material donors.

FCM, through FCM Resolution 2013 / 13\(^2\), considers that the advance of scientific knowledge allowed finding solutions to problems relating to human reproduction. This progress, which today reaches the everyday, according to the Council itself, lacks adequate standards for their use, which in a way the FCM Resolution 2.013 / 13 attempts to resolve through its General Principles. Also, the document says the auxiliary role of facilitator and RHA techniques, the use of which is considered legitimate, in that it is presented as having effective probability of success tool. The rules also allows for the use of the techniques under a previous judgment of weighing benefits and serious risks to both the health of the patient enjoys the advances, the health of that which is suggested as a possible downward.
Technological advances, risks and expectations of those involved

Initially, fit two brief reflections to the central analysis of the subject. The first concerns the health risks arising from technological advances that require the evaluation of the possible damage, a situation which refers to the principle of non-maleficence, which suggests the obligation not to cause intentional harm to anyone, and not harm, refraining -if impede the achievement of third party interests. In the same context, we must consider also the principle of beneficence, which proposes to promote the act for the good in a broad sense, encompassing actions intended to benefit in general and evaluating the disadvantages that may arise. Both principles were thus formulated by Beauchamp and Childress in the early days of bioethics 7.

Guarding similar theoretical sense, but entering into broader dimension, is Article 4 of the Universal Declaration on Bioethics and Human Rights, formulated by Unesco in 2005, which deals specifically with the benefit and harm principle: The direct and indirect benefits to patients, research subjects and other affected individuals should be maximized and any possible harm to such individuals should be minimized in the case of the implementation and advancement of scientific knowledge, medical practice and associated technologies 8.

To these reflections can add the principle of responsibility, proposed by Hans Jonas 7, suggesting the responsibility of humans for their actions in the use of new technologies. In its proposal to build a new ethics for the technological civilization, the author draws attention to the fact that the consequences of decisions and actions taken today will fall on future generations, which will fit the burden of facing them and pay for its price.

The second reflection is related to the probability of success on the possible expectation of the subjects involved. In this sense, was taken as reference the study by Samsla and collaborators 9, which investigated the expectations of women awaiting treatment through RHA techniques at a public hospital. Interviewing 51 women, among them newly referred patients and patients already diagnosed with infertility waiting in the queue for care, the authors identified their expectation of motherhood, and the question about the real possibility of being benefited by the treatment. According to the study, this possibility decreased dramatically due to insufficient number of vacancies in the care system and the lack of material and medicines available to treatments. As a result, the waiting time in the public institutions increased enormously, causing significant advance in the age of the women who initially young, gradually passed to an unwanted pregnancy risk situation.

In these terms, it is corroborated the idea that freedom to procreate, understood as demand affirmation of patients by health care, part of the issues regarding the allocation of public resources, according adds Correa 11. Thus, both the prior finding of effective probability technique of success in patients, as the previous scan of resources available for such purpose, are presented as instruments for protecting individuals who intend to benefit from the RHA.

Who can use the RHA techniques in Brazil?

Addressing the freedom of individuals to procreate or not, Mori 12 calls these two situations of positive freedom and negative freedom, respectively. For the author, the profile of freedom within the breeding involves autonomous and voluntary choice, which separates the concepts of sexuality and procreation, appearing in both cases, as a person’s self-realization idea. This line of thought, however, conflicts with the traditional view of marriage, understood by the author as a social institution to oversee the transmission of life from one generation to another. In these terms, there is the change of the current Brazilian perspective on marriage and stable relationships, to the extent that the family institution receives new clothes able to protect the right to freedom and equality and the fundamental principle of human dignity. Exemplifies this the fact that they are recognized in the country both homosexual unions, as stated homaafetivas families, as single parents, social or biological nature, formed by either parent and their descendants 13.

Unlike the previous text of FCM Resolution 1358/92 14, which dealt with the matter, the FCM Resolution 1.957/10 already admitted as patients of RHA techniques everyone who can, and not just the woman, which involved also the approval of the spouse or partner 15 in the case of this woman meet the criteria to exercise the right to conscientious objection.
Anyway, in his few approaches to the RHA techniques, the Civil Code also includes this approach when, in Article 1.597, heading and section V, presumably considers designed during marriage the *children born by heterologous artificial insemination, provided you have prior authorization of the husband*. In the same article are presumed to be children also those accruing by homologous artificial insemination, *even if the deceased husband and accruing at any time, in the case of surplus embryos resulting from artificial homologous design*. 3.

Although this discussion on the need for consent when the child generation with genetic material from different partner, the focus in this study did not permeates the consideration of gender in stable unions and marriages - important debate, but that does not follow the objectives of this research. However, it was considered essential to emphasize the relevance of this discussion in the literature, which deals with enhancing the social constitution of affective ties that support the relational perspective of the links biologically or socially formed between heteroafetivos or homosexual couples, especially in circumstances where social vulnerabilities are gifts.

**Social vulnerability, consent for gamete donation and anonymity**

A relevant data, collected by the aforementioned study Samrsla at al. 10, was the finding that most of the women interviewed who were waiting for treatment over time expressed a willingness to donate eggs in exchange for free care for their own treatments. This finding makes us reflect about the vulnerability of people who undergo the techniques, especially when put into the context of obvious social and economic weakness.

Corrêa and Diniz reported that, by the year 2000, the development of AHR techniques in Brazil gave in 99% of cases in the private sector, in a context where private clinics promoted courses and relied on *volunteer women* 16. The same authors still claim the paradoxical fact that significant visibility and dissemination of RHA techniques, to the detriment of the social context in which the difficulties of access to health services remained evident.

Given these facts, fit two questions: There vulnerability among individuals who donate or these grants consist solely of demonstrations will deliberate with altruistic purpose, without coercion arising fragility of circumstances? You can locate the possible vulnerability as addition to the arguments against the disclosure of information to knowledge of the biological origin of people born?

Shall we consider that donor people of certain material were being subjected to RHA techniques and have failed, despite the expectation. Cogitemos also that these same people to find donors, below, people searching for their biological origins, with which will have no social bond of kinship established, although biological connection. In this situation it would face a possible problem of moral and social order to be discussed by bioethics, in which individuals are involved weakened by not reach your expectations and restricted as the right to family participation, with another individual who is the son of condition along the lines of biological parentage.

There is, then, the discussion about the act of giving in this practice, their agreement and preliminary points. The FCM Resolution 2013/13 requires doctors to obtain informed consent from all *patients undergoing assisted reproduction techniques*. Moreover, the *same standard prescribes that the medical aspects totality of the circumstances surrounding the application of a technique RA are extensively discussed, as well as the results that treatment plant using this technique. It must also achieve biological character data, legal, ethical and economic*. 2 Similarly, the *Universal Declaration on Bioethics and Human Rights addresses in Article 6, the principle of consent, which states that: Any preventive medical intervention, diagnosis and treatment should only be undertaken with the prior, free and informed consent of the individual involved, based on adequate information*. 8

In attention too the reflection to the donor or donor figure in advance can observe the three key features of consent and their specificities for this condition: 1) be prior, which leads to the person donating the requirement of prior consent to the use of the donated material RHA; 2) be free, which makes us reflect on the risk of limiting the freedom of the donor in person socioeconomic vulnerability, as reported in Samrsla study and 10 employees, in which women expressed their willingness to donate eggs in exchange for funding for their treatments; 3) be clarified, that is, directed to the person in donor understandable vocabulary, based on adequate information, which includes the Communication on secrecy about its social and biological data, this secret that might be broken according to the debates in favor any subsequent breaking of confidentiality.

The FCM Resolution 2.013/13 supports the idea that the identity of the donor and the receiver can not be known by them each other, forcing doc-
tors to maintain the confidentiality of both identities. It is provided solely in relative secrecy break, which is not absolute, since it requires the health motivation and the guard of civil identity. To this end, the Resolution provides that the clinics, centers or services that employ the donation shall, at all times, a record of clinical data of a general nature, phenotypic characteristics and a sample of cellular material from donors.

Note, therefore, that the donor or the donor’s anonymity, appearing on contract to reduce the term of the agreements and standards agreed between the parties, it is now essential condition for the realization of the donation. According to Zanatta and Enricone, the objective of establishing such standards among the subjects participating in the RNA techniques, including donors, is providing security and stability. For the authors, such security exists in the sense that it is carried out contract where the donor agrees to have his identity preserved and expressed its unwillingness to know the identity of the beneficiaries. Similarly, the recipient agrees not know the identity of anonymous donor.

This weighting also involves necessary for establishment of the relationship between doctors and patients, the commitment to medical confidentiality. In these terms, add the right to anonymity and confidentiality, contractual and ethical and regulatory requirements.

Likewise, the Code of Medical Ethics is in Chapter IX of questions about professional secrecy: sealing the doctor in Article 73, to reveal the fact that you have knowledge in the exercise of his profession, except for cause, legal duty or consent in writing of the patient. Therefore, a) just cause, in which case it is understood to be just cause for the breach of confidentiality; b) legal duty, where notifiable diseases must be reported to government agencies and; c) written consent of the patient, where there is an express declaration of consent for the disclosure of confidential information, are the situations allowed by the medical ethical regulations for disclosure of data acquired professionally.

In this direction, there is no consent, as donors relied on anonymous and only with the break condition on the genetic information confidential, for health reasons, only to the medical staff, the question now is needed is: knowledge about the biological origin such as right of an individual seeking the doctor responsible for RHA technique that generated is a just cause? To reflect on this question, it is essential to consider, above, about the possible existence of that right.

Genetic identity and right to knowledge of “biological”

Teixeira and Moreira, to discuss the genetic identity in Brazil, said there is no need to talk about a single form of identity, but a plurality of identities that constitute and reconstitute in a network of dialogues and interdependence. They have it, then as a reflection of the exercise of autonomy, leaving the individual to make choices and set its contents to achieve recognition of its context and understanding of themselves to the world.

At the same time, the right to genetic identity is built on the right to privacy and the privacy and the fundamental principle of human dignity, all present in the text of the Constitution of 1988 and components of the right to personal identity, in compliance with the individual dimensions and relational of a single individual. This analysis is embodied above all in the possible identification of the biological matrix of the subject, which gives it the prerogative of the biological assets that identify, among them the knowledge of their origin.

That is why Article 3 of the International Declaration on Human Genetic Data, UNESCO, refers to the identity of the person, adding that each individual has a characteristic genetic make. However, it can not reduce the identity of a person to genetic characteristics, since it consists of the intervention of complex educational, environmental and personal factors as well as affective, social, spiritual and cultural relations with other individuals, and implies an element of freedom.

Added to that provision under Article 7 of the Universal Declaration on the Human Genome and Human Rights, also of UNESCO, that genetic data associated with individual identifiable, stored or processed for use in research or for any other purpose must be held confidential, as provided in the legislation. It happens that the subjects are agreeing donors and those who want to have children, but not the children themselves, arising from these techniques heterologous.

Analogy with the legislation on adoption in Brazil

For Pedrosa Neto and Franco Junior, after the imposition of new technologies RHA, both maternity and paternity or the extended family per-
spective can be made - legally and ethically - without the genetic link, a situation which already had as an example and affirmation the institution of adoption. Although in the Reñaica’s agreement concluded in 1995 between the countries of Latin America, the heterologous reproduction was seen as acceptable practice, in analogy with the bond created between social parents and children in cases of adoption.

Fidelity to the relational dimension, Salles 25 talks about the close connection between identity and the right to personal historicity. According to the author, this concept is embodied by Otero in his “personality and personal identity and genetics of the human being”, 1999, in pointing as a right of every human being to know its origin, and the genetic heritage, relevant element for prevention of certain diseases and the development of personality. It means that every human being has the right to know the identity of their parents, that is, who their biological parents 26.

Law 12.010/09 27, which provides for adoption, brings in its Article 48 the discussion about the right to knowledge of biological origin, then changing the Statute of Children and Adolescents (ECA) 28. The adopted has right to know their origin biological, and to obtain unrestricted access to the process in which the measure was applied and its possible incidents after completing 18 (eighteen) 27. Ensures even the practice of law by less adopted, ensuring you the guidance and assistance legal and psychological. In granting permission the individual adopted knowledge about their biological origin, the Adoption Law is considering their right to personal historicity 26.

It is important to note the similarity of circumstances between the two scenarios: the adoption and the RHA. In the first situation are present: a) the biological parents who or naturally conceived the individual; b) those who have adopted the social-affective parents; c) people adopted, which now seek the right to know their biological origins. In the case of RHA, there are also: a) the biological parents, who are donors of germ materials; b) the social-affective parents, who are those who used the RHA techniques and ported the order effective to have children; c) the person born, which now calls for knowledge of its historicity.

Anyway, to pursue the possibility of this analogy, it is essential the perception that, as in the adoption of the institute, the formation of socio-emotional family bond must be irrevocable and is not re-established legal family ties with the germinal material donors even with the death of parents considered socially.

The secrecy right

For the continuity of ethical reflection, the question that is needed relates to who owns the secret (the belonging of secret) on the genetic information of the donor. Belonging to the donor secret about your data, since it is genetic and social information of the scope of their intimacy and defended the Constitution, it does not seem there are doubts. However, in relation to a person born, the reflection that this study proposes is on its concomitant belonging, which would cover part of the membership of the donor person in that ordinance the right to know the biological origin in an effort to form of its social, subjective and genetic identity.

Thus, the framework studied shows the contradiction between the right to privacy of the donor and the right of the generated person to know their biological origin, to the extent that there is disagreement about the revelation of the secret. On the one hand, there are those who think that anonymity is important, given the need to prevent future emotional and legal anomalous situations between donors, recipients and people born on the other, there are those who defend the right to personal identity and knowledge about the genetic ancestry of these people, which are in line with their personal rights, arising from the dignity of the human person.

Also, it is considered important to know, by the person born, the identity of their biological parents, however no related legal consequences, such as inheritance and right to a name, due to the nature of the procedure, which gives the absence of breeding attempt and as only mere donation of germinal matter by donors. As Costa reflects the allocation of maternity and paternity in the use of reproductive technologies allows for the separation of reproduction idea of women and men participated in this process. Therefore, the author argues that such questions refer to the judgment of which of these elements (relation between the couple, gametes or pregnancy) will be considered as the most important in the allocation of motherhood and fatherhood 29.

In this context, some argue the constitution of membership and establishment of maternity and paternity as effectively relational concepts, and this is a family relationship established between two people, one of which is considered the daughter of the other 30. According to this reasoning, membership would be a result of establishing emotional ties built daily, who value the social bond beyond the biological.
Social-affective parents and the “de-biologization”

Having links formed with the social-affective parents, knowledge of biological origin by the person generated may ultimately not involve the construction of kinship or generation of moral or legal obligations to donors, still affecting the essence of the agreement that there was a donation and the use of germinal material. However, the social risks related to the technical implementation, viewed more broadly, also require a reflection on gender and vulnerability of the subjects receptors, considered social-affective parents.

In a study aimed at identifying the intention of revealing the ovodoação the children, family and friends, Montagnini, Malerbi and Cedenho affirm the complexity of the confidentiality issue of gamete donation, which can not be ignored or answered with simple and general rules and should -if take into account the specificities of each family and its context. Further argue that the decision to reveal or not to the child its origin is one of the inevitable consequences with which couples participating in assisted reproduction programs will face in the future, and is far from simple 31.

Recalling the positive aspects of passing information to the children, these authors suggest that, as in the adoption of the institute, it may be supposed that the lack of knowledge or information about the origin can be harmful to the child and consequently the family relationship 31. They show data of interviews with receivers couples, asked about the reasons leading them to reveal to the child the technique with which it was generated and the use of donor genetic material. Many couples interviewed expressed fear at the revelation, showing the intention to prove the completeness of the facts only if it was really noticeable were not the biological parents, as in many adoption of situations in which there was the period of pregnancy and social view of motherhood and considered paternity. Among these concerns, there is a strong presence of fear of the emotional impact on the child, and he finds out by other means than dialogue with parents. It was also observed in the initial research that, when they were reduced the chances that others reveal the child or that he discovered by some means, was very low the intention of the parents to disclose.

Regarding the donor breach of confidentiality in RHA techniques, Diniz points out that arguments such as the right to recognition of the right to biological origins or identity contain moral grounds, pointing out that despite this, are not necessarily defensible under current Brazilian constitutional perspective. The author also discusses the issue, adding that the secrecy of the disruption appears as a strategy to curb the possibility that other marital arrangements than heterosexual family have access to technical, since few people would donate sperm or egg before the risk of future identification and legal consequences of the act. Also said to be present in this context the styling of subterfuge argumentative 32, since this would be an appeal to the autonomy of the future child with the aim, in fact, to limit access of women without spouses and homosexual couples to new reproductive techniques.

Criticism therefore turns to the possibility of using only biological criteria in the arguments that contradict the family perspective as relational beings in their social roles. Consistent with this reflection is proposed de-biologization the concepts of motherhood and fatherhood, which is also present from an analogy and critical reading of the Adoption Act, as it gives children the irrevocable constitution of families without necessary biological link, valuing especially the rights of children and adolescents to family 27.

In this sense also has positioned the jurisprudence of the Supreme Court, in 2011, in Declaratory Action of socio-affective paternity, arguing the desbiologização of paternity: The thesis of the son of state ownership as generating legal effects which may define membership in leads to question whether the true paternity is explained only by genetics. We know not. Both the legislation broadens the legal institution of adoption, enshrined in the Federal Constitution, art. 226, § 6 gives children, accruing or not the marriage relationship or adopted the same rights and qualifications, prohibited any discriminatory designation of their filiation 31.

Final considerations

From the foregoing, it is observed that the absence of legislation on RHA has occasioned important bioethical and legal debates, demanding reflection leading up to the laws. From the application of RHA techniques in Brazil, there have been situations and emerging and persistent conflicts so that ethical confrontation involves both the environment linked to the use of new technologies, as the socio-economic issues related to access to health and issues gender.

The discussion about the possibility of understanding the knowledge of biological origin as a right of the person generated by RHA heterologous
technology brings arguments that are still controversial. Issues such as sexuality and procreation end up composing the reflection, especially in the Brazilian moral context in which the various family constitutions still remain the target of debate, despite constitutional norms in favor of equality.

Standardizing the practice of RHA in Brazil, FCM has shown, through its resolutions, appropriate elements for organization of professional medical practice, providing the ethical use of these new technologies and bioethics that come of them. After admitting patients as everyone who can, FCM Resolution 2.013/13 provided a breakthrough with regard to individuals. However, the question that arises is the possible legitimacy of the protection of the interests of the data generated to meet their biological origin, which breaks with the other regulations concerning the confidentiality and involving reflections on medical confidentiality and personal autonomy.

Before vulnerable conditions in which they live actors involved in the circumstances, the highlights are the donors, recipients or social-affective parents and children generated. Remain, then three fields of analysis: the supposed right to knowledge of biological origin, the reflection on the membership of the secret and the desbiologização of maternity conditions and social parenthood. In these terms, it is observed that even making analogy with the principles of adoption in Brazil, as it does not give the family ties of establishment or legal obligations, the issue is not easily resolved, keeping in mind the complexity of the condition and its related ethical consequences, which can not be ignored.

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Referências


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