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UPDATE

Genetic advance and anonymity policies

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Abstract

In recent years, the number of assisted reproduction treatments with the donation of gametes (ovules and/or sperm) has increased in Argentina. The filiation by heterologous assisted reproduction techniques interrogates the traditional "blood inheritance" object of privileged study of the social sciences. In recent decades, the donor anonymity paradigm has changed in many countries. In turn, it has been suggested that rapid and widespread advances in genetic testing could modify anonymity policies. What are the consequences of substantiating the disclosure of genetic/identifying information based on the greater access that genetic tests allow? This reflection is based on two aspects: the public aspect – which analyzes the paradoxes contained in the articles of the new Civil and Commercial Code (2015) – and the intimate one, which locates the coordinates on which the singular transmission of the origins is inscribed.
Keywords: Reproductive techniques, assisted. Bioethics. Direct-to-consumer screening and testing.

Resumen

Avance genético y políticas de anonimato

En los últimos años se ha incrementado en Argentina la cantidad de tratamientos de reproducción asistida con donación de gametos (óvulos y/o espermatozoides). La filiación por técnicas de reproducción asistida heterólogas interroga la tradicional "herencia de sangre" objeto de estudio privilegiado de las ciencias sociales. En las últimas décadas, el paradigma sobre el anonimato de los donantes ha cambiado en muchos países. A su vez, se ha sugerido que los rápidos y generalizados avances en las pruebas genéticas podrían modificar las políticas de anonimato. ¿Cuáles son las consecuencias de fundamentar la revelación de la información genética/identificatoria sobre la base del mayor acceso que posibilitan los test genéticos? La presente reflexión parte de dos vertientes: la pública – que analiza las paradojas que encierra el articulado del nuevo Código Civil y Comercial (2015) – y la íntima, que ubica las coordenadas sobre las que se inscribe la transmisión singular de los orígenes.
Palabras clave: Técnicas reproductivas asistidas. Bioética. Pruebas dirigidas al consumidor.

Resumo

Avanço genético e políticas de anonimato

Nos últimos anos, o número de tratamentos de reprodução assistida com doação de gametas (óvulos e/ou espermatozoides) aumentou na Argentina. A filiação por técnicas de reprodução assistida heteróloga interroga a tradicional "herança sanguínea", objeto de estudo privilegiado das ciências sociais. Nas últimas décadas, o paradigma do anonimato dos doadores mudou em muitos países. Por sua vez, sugeriu-se que avanços rápidos e generalizados em testes genéticos poderiam modificar as políticas de anonimato. Quais são as consequências de fundamentar a revelação das informações genéticas/de identificação com base no maior acesso que o teste genético torna possível? Esta reflexão parte de duas vertentes: a pública, que analisa os paradoxos dos artigos do novo Código Civil e Comercial (2015); e a íntima, que determina as coordenadas sobre as quais se inscrevem a transmissão singular das origens.
Palavras-chave: Técnicas de reprodução assistida. Bioética. Triagem e testes direto ao consumidor.

Declaram não haver conflito de interesse.

The development of genetic testing in general and those offered to consumers specifically, known as "direct to consumer genetic testing", reopened the debate over the end of anonymity. However, criticism of this approach was not long in coming.

The case of the *23andme* Company, which offers online genetic information services, is known, where, without more intermediaries than a saliva sample, different types of information related to ancestry can be accessed. Specifically, this company offers, for a relatively low cost, analysis and decoding services for deoxyribonucleic acid (DNA) in reports on ancestry and family history.

In Argentina, it can be read on the Family Tree website*: Those who falsified data about your birth in order to deliver you to your foster family as if you were their biological child, deleted virtually all administrative data about your true identity. But they couldn't take away an invaluable key piece: your DNA* [1].

Apparently, participating in this experience may be a solution for many of those who were wondering or actively seeking lost relatives. This type of private and "free access" initiative is accompanied by the development of technologies that allow the increasingly accurate "decoding" of genetic information. The prevalence of these technologies, that is, the arrival of genetic tests to an increasingly large number of people and the development of reproductive genetics, pose some challenges to the practice of gamete donation.

Harper, Kennett and Reisel [2], for example, argue that, from the diffusion of genetic tests, anonymity could not be assured. They conclude that in the face of this situation, disclosure should be encouraged for all those people or couples who have resorted to the donation of gametes to have children. What are the consequences of substantiating the decision to reveal based on genetic progress?

There are several important factors when considering the decisions of families formed from the donation of gametes on the disclosure of genetic and/or donor identification information [3-5]. And despite the general recommendations that parents share with their children the fact of donating gametes (as noted in the document prepared by the Nuffield Bioethics Council [6] of 2013) the majority of heterosexual couples who have conceived their children through an anonymous donation decide not to disclose this information or are unsure about doing so [7].

In the following paragraphs, two approaches of analysis will be briefly reviewed to consider the issue of anonymity and non-anonymity of gamete donors. The paradigm shift is mentioned regarding promoting the opening and communication of genetic origin based on the recommendations of the American Society for Reproductive Medicine [8,9], the Nuffield Bioethics Council [6] and in The Human Fertilization and Embryology Authority of the United Kingdom [10]. What connection could be established between the secrecy of the first inseminations with donated semen and the current heterologous filiation? Below are some paradoxes of the Civil and Commercial Code of Argentina [11] in order to problematize the construction of identity in the case of gamete donation.

Access to genetic information and consolidation of a donation culture

Gamete donation has become a common and increasingly frequent practice in users and/or patients of assisted human reproduction techniques (TRHA) who cannot conceive using their genetic material due to some organic or biological impossibility, or because of a structural impossibility such as same-sex couples or women without a partner. *The latest statistics prepared by the Argentine Society of Reproductive Medicine (Samer) reports that in the year 2014, 11,129 procedures were performed, 13,006 in 2015 and 13,823 in 2016, with a trend that continues to increase* [12].

In the beginning, about twenty years ago, professional recommendations suggested concealment. The logic of semen donation was to facilitate an "undetectable substitution" between the donor and recipient phenotype. At the beginning of the 1970s, the implicit model of filiation that served as a reference to reproduction with sperm donation was that of paternity within marriage (heterosexual). In the face of the proven sterility of the husband, married couples resorted to the help of a "lover" to achieve the wife's pregnancy and, under the *pater is est quem nuptiae demonstrant* principle, to convert the husband into the father. The introduction of technical assistance in sperm donation prevents adultery by separating sexuality and procreation. In turn, the anonymity to which the doctor was committed guaranteed that *"nothing has taken place here"* [13].

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There is currently a worldwide trend that encourages openness and encourages the disclosure of the conception mode at an early age of the child as healthy parameters for family building. However, many patients in the consultation with the psychology professional maintain that there is no need to tell the child because beyond having received a donated gamete they are still "a normal family". The norm then resides in the heterosexual (heteronormative) family configuration of a mother and a father, hiding the absence of those who have not contributed their biological material on the premise: *"Why should I tell them? After all I am the mother/father"*.

The place of genetics in biological affiliation, or what might be thought of as "offspring of the same blood" has had a prominent place in cultural, social, anthropological and psychological analyses. The path of adoption, as the legal affiliation of a child to the generational chain, has valuable backgrounds to reflect on the importance of the transmission of origins. In the case of the affiliation by Techniques of Human Reproduction Assisted with Donor (TRHA-D) the blood debt faces many people with the decision on the concealment or the disclosure of the genetic origins to the child:

In other words, in the cases of TRHA, the right to know refers to the genetic origin, to the information that it makes to the genetic identity, to the donor's data as a mere material contributor and to the circumstances of the birth. It is a right to be able to access information that makes their person, which is not a genetic claim, but the possibility of accessing information that is part of one's identity. We do not rule out that in the future, perhaps near, once the importance of genetic contribution has been demystified and really apprehended that in these cases the affiliation is determined on the basis of the procreational will, then the anonymity of the donor can be lifted, as has happened, for example, in the United Kingdom, and in many other countries, this being the global trend as a result of the strengthening of a "culture of donation" [14].

The paradigm on the anonymity of donors has changed in many countries of the world and to make a more precise analysis, the contextual, legal and regulatory particularities of each society must be reviewed. The treatment that each society gives to donor affiliation, whether from an anonymous or non-anonymous system, observing the particularities of the different regulatory systems – for example in the case of semi-anonymous or relative anonymity systems, introduces a slope of analysis that we could call "public".

For example, in Spain, there are currently laws such as 14/2006 [15] that protect the anonymity of donors. A different picture is shown in the United Kingdom where the donation has ceased to be anonymous since 2005. In that country, from a public consultation and reform in 2004 of the Human Fertilization and Embryology Act, those conceived by heterologous techniques (donated semen, ovules or embryos) were allowed, from April 1, 2005, to request identifying information about donors, once they turned 18 years old [10].

The State of Victoria in Australia was one of the first places in the world to introduce legislation regulating the conception by gamete donation. Under the Infertility Act of 1984 (Vic), persons conceived by gamete donation, being 18 years of age or older, parents of children under 18 years of age and donors have the right to request the disclosure of registered identifying information in the Central Registry [16]. In 2011, the Committee on Legal and Constitutional Affairs of the Australian Senate issued a report on donor conception questioning whether donor information should be disclosed to people born before the law mandating the Donor identification, i.e. retrospectively.

That is, it established that anonymity would be respected in those cases in which the donation had occurred until 1988; those who had donated between 1988 and 1997 could decide whether they wanted to reveal their identity or not, while from 1998 onwards the identification data would not be anonymized [17]. Those who donated under a system that ensured anonymity could see their privacy threatened. When these types of measures are implemented with a retrospective scope, people who chose to donate their gametes in a system that guaranteed their privacy and anonymity may feel that their rights have been violated.

In Argentina, gamete donation is considered altruistic. The Código Civil y Comercial – CCyC (Civil and Commercial Code) receives an intermediate system regarding access to information about the donor. This regulation is based on the distinction between non-identifying information, which includes health-related data, and identifying data, providing for a different regime according to the type of information that is intended to be accessed:

Article 563 – Right to information of people born by assisted reproduction techniques. The information regarding the person being born by the use of human reproduction techniques assisted with gametes from a third party must be recorded in the corresponding base file for the registration of birth;

Article 564 – Content of the information. At the request of people born through assisted human reproduction techniques, information on the donor's medical data may: a) be obtained from the intervening health center, when it is relevant to health; b) disclose the identity of the donor, for duly founded reasons, evaluated by the judicial authority by the briefest procedure provided by local law [18].

Articles 563 and 564 show that non-identifying information can be requested by the interested party at any time, and they should only approach the health center that intervened in the medical practice through which they were born. On the other hand, to access identifying information, a judicial process must be initiated, exposing the fundamentals to undermine the anonymity that had been assured to the donor, and by which this person proceeded to donate. We can locate a paradox here. Article 575 establishes the determination of the affiliation in TRHA:

Article 575 – Determination of assisted human reproduction techniques. In the assumptions of assisted human reproduction techniques, the determination of filiation is derived from prior, informed and free consent, given in accordance with the provisions of this Code and in the special law. When third party gametes are used in the reproductive process, no legal link is generated with them, except for the purposes of marriage impediments on the same terms as full adoption [19].

As can be seen, it stipulates that with the donor there is no legal link since the gamete from a third party works as an artifice to achieve the pregnancy of those who will be the parents, filiating that son/daughter as a result of signing of informed consents, which confirms their procreational will as established in article 562:

Article 562 – Procreational will. Those born by assisted human reproduction techniques are children of the one who gave birth and the man or woman who has also given their prior, informed and free consent under the terms of articles 560 and 561, duly registered in the Registry of Marital Status and Capacity of People, regardless of who contributed the gametes [18].

But then, that data that was initially negligible – the data regarding the gamete – becomes a central component on which the identity of the born is based. *The CCyC promotes and protects all information so that the person can know that he has been born from the TRHA with material from a third party, which, unfortunately, is subject to the type of training, intervention, and approach that the health center has had so that people understand that it is a child's right to know how they were gestated* [20].

In this way, the "public" side intersects with a perspective, which we could call "intimate", that introduces the unveiling from a subjective logic crossed by the unique history of the current family, but also by the transgenerational links and stories.

Disclosure cannot be based solely on the advancement of genetics

Zadeh [7] discusses the postulates of Harper, Kennett and Reisel [2] and mentions some problems that arise from substantiating the disclosure of the origins (facilitating access to donor identity) in the fact that in the future and thanks to the development of the genetic tests, children born through the donation of gametes may know their genetic heritage and accidentally discover that they do not share genetic material with any of their parents.

Basing the disclosure on the impossibility of "keeping the secret" can generate, on the one hand, high levels of anxiety in the parents, especially in those who have not disclosed yet. On the other hand, the recommendations for disclosure should be sensitive to the context and situation of the family. Although most of the research carried out with donor-born indicates that curiosity prevails in relation to the donor, there is no need to obtain identifying information, to get to know the donor or to maintain an affective bond, as a general rule [7].

The revelation should therefore not be based on the greater or lesser possibility of accessing genetic information, because it involves a movement of another order, which introduces the processing and subjective assimilation of filiation. Does the decision to tell the child about their origin no longer relate to the framework of that unique and singular story of each family in which that child is housed?

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A rationale for why to disclose genetic origins or not can be based on empirical or conceptual experience. In the latter case, from the consequentialist theory, the possibility of knowing that one was born from a gamete donation is not an action either good or bad, the weighting will depend on the consequences of the action. Thus, more empirical evaluations are required which demonstrate the negative consequences of not revealing genetic information, in order to propose an ethically appropriate course of action.

If we analyze the same situation from the deontological perspective, the act is no longer judged from its consequences, but based on the letter of the regulations in force. If knowing the genetic origins is a fundamental human right, adequate means should be implemented so that this right can be guaranteed, regardless of empirical evidence.

The ethical perspective is based on the autonomy of the people, violating this principle deprives people conceived with gametes donated of the freedom to choose what meaning they want to give to the genetic components of their identity [21].

This way, it is concluded that the responsibility for the transmission starts from a singular logic, which depends on the family framework and linkage, and that, as a phenomenon inserted in the particular context that introduces the current regulatory framework, with its successes and paradoxes, requires a work of elaboration on what the genetic data means, in each case.

Final considerations

At the beginning of this paper, we asked ourselves what were the consequences of disclosing a genetic identity to someone on the basis that in the future it will be almost impossible to hide it. This question led us to analyze the problem from an *intimate* perspective and from the *public* side. The resistance of patients and/or users of TRHA-D to inform children as the law requires says of an impossibility; It is not just ignorance about the procedure, or ignorance of the regulations, it is something else.

For the disclosure to be sustained on an ethical perspective, a *culture of donation* must be consolidated, which in part involves demystifying the place of genetics for heterologous affiliation, but also contributes to the development of public information campaigns and social work in the theme, which remains to be done.

Finally, the processing of this information will depend, to a large extent, on the creation of the Gamete Donor Registry under the orbit of the Medically Assisted Reproduction Program of the Secretariat of Health Assistance of the Ministry of Health and Social Development, but it will also depend on the type of *training*, *intervention* and *approach* that TRHA patients and users have received in the Reproduction Centers so that people understand that it is the children's right to know how they were gestated.

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