The right to know the biological origins of the child conceived by AHRT: reflections from the situation of donor anonymity

El derecho a conocer los orígenes biológicos del niño(a) concebido por TRHA: reflexiones desde la situación del anonimato del donante

Niza Valdivia Gómez*
University of Antofagasta, Valparaíso, Chile

https://doi.org/10.36105/mye.2024v35n4.01

Abstract

This paper intends to lead to a bioethical reflection on the right of the child to know his/her genetic origins and the complications based on the anonymity of the donor in certain legislations. By virtue of this, it will be imperative to reflect on how anonymity intervenes in this right, does it imply protection? limitation? concealment? and how several controversies can originate nowadays as biotechnology advances. Will it be

---

* Lawyer, licentiate in legal sciences, Universidad de Antofagasta, Valparaíso, Chile. Magister in Artium in Philosophy, Universidad Francisco Marroquín, Guatemala. E-mail: valdivianiza@gmail.com https://orcid.org/0009-0005-7478-7437
Reception: 26/10/2023 Acceptance: 13/04/2024

appropriate to propose a different nomenclature to the gamete donor? because of the social taboos that originate around the issue, several appreciations can be had. Beyond the medical issue itself. This essay is not focused on medical analysis, statistical expositions or psychological studies of donors or technical appraisals of HAART, but rather on exposing reflections on the subject that make a and profound study of it imperative, considering the issues involved and their repercussions.

Keywords: filiation, donor, HAART, infertility, law, genetics.

1. Introduction

Talking about assisted human reproduction techniques (AHRT) is a complex subject, which has several edges that we intertwine and form the complex figure of a little researched reality, but apart from everything that can be written about assisted human reproduction techniques themselves and how they should be regulated in each State, it is questionable what happens to the child who is conceived through assisted reproduction when talking about his or her identity and origin.

How did it come about and why is it of such vital importance today? This is what we ask ourselves, by way of introduction, Professors Turner-Molina and Momberg pointed out that:

> The origin of the right to know one's biological identity is related to the development of the legal treatment of filiation that occurred in Germany due to the influence of the National Socialist ideology, which felt it necessary to be able to distinguish subjects of Aryan race from those who were not.
>
> For these purposes, the jurisprudence began to recognize the right of the non-marital child to the declaration of biological filiation (...) with the end of the National Socialist regime, the German doctrine based the origin of this action on the fact that the right to know one's own identity is a personality right (13, p. 16).

In the words of De Lorenzi "the identity of the person is the X-ray of his being and his feelings, which allows us to identify him as such and to distinguish him from any other human being, for being unique, unrepeatable and identical in himself" (5, p. 123), this concept is vital when it comes to knowing the hereditary characteristics of people, because they not only define the person itself, but the family as a whole, and the way biotechnology and genomic medicine are advancing, it is becoming increasingly important to know the genetic origin of the child born by HAART.

Professors Alkorta and Farnós state the following:

> Knowledge of the genome of the parent is an increasingly important component in guaranteeing people's right to health. Preimplantation genetic diagnoses are becoming increasingly numerous, and, in many cases, they can determine the treatment of the disease or prevent it decisively (...). It is also very relevant when the person born from gamete donation decides to have children. The progressive generalization of genome analysis leads one to think that in the future it will be inevitable that the newborn will know, sooner or later, that he or she has no genetic link with his or her legal parents (1, p. 165).

This has a different nuance because in the case of HAART, for Famá "the procreational will departs from the idea of identity as a synonym of biological or genetic link, and instead, inspires the content of the right to identity in a broad sense" (6, p. 175).

But what is the real scope of this right today and what did the Convention on the Rights of the Child mean when in its art. 7.1 it states: "The child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by his or her parents". Well, there he uses the expression "as far as possible", two things are different when speaking of rights inherent in the person; One refers to its content and scope and the other refers to its protection as such, because when there is no real protection of a right, that right does not exist socially if it cannot be exercised as such, because it is subject to the existence of informative data, as is the case with the right to know one's biological origins, and this data does not "exist" for the child or adolescent, it makes no sense to speak of the cosmic existence of this right, and even more so when the idea of "as far as possible" is left to the will of each State (reversing the burden of proof) where not even all the aspects arising from HAART are regulated, such as mitochondrial replacement and gene editing, topics which, due to the extent of their content, are not within the scope of this work.

2. The debate on the ethical-legal implications of donor anonymity

It must be made clear that one thing is filiation itself and another is the action that the child would exercise to make effective the right to know his or her biological origin, whose filiation is already determined. In this regard, Drs. Barcia and Riveros point out that:

> Certain guidelines can be established for the exercise of the civil action of knowledge of biological origin. This action with respect to children and adolescents can be exercised, with the prior authorization of the judge, through petitions from adolescents, who are those over fourteen years of age, and girls or girls who have the necessary maturity to file the action, without the need for parental representation, or in exceptional cases through legal representation (3, p. 220).

However, questions arise as to how it is possible to create guidelines for the exercise of an action of knowledge when there is no discussion about who provides the genetic material (donor) or about its anonymization, since the approaches should be directed to pay attention to situations that are linked to something as important as how to truly know ourselves.

https://doi.org/10.36105/mye.2024v35n4.01

And this is not a completely settled issue in Comparative Law, since in Spain today there is still discussion on the prohibition of donor anonymity, and even the Spanish Bioethics Committee is calling for an end to confidentiality, in this sense:

> We consider that, from an ethical-legal perspective, it seems appropriate, in the terms promoted by the draft Recommendation of the Parliamentary Assembly of the Council of Europe, a legal reform of Article 5.5 of the Law on Assisted Human Reproduction that eliminates the current legal regime of anonymity in the donation of gametes for assisted human reproduction.

The issue of anonymity has not been easy to regulate, much less unanimous among the different countries, thus we have those that establish an anonymous or identifiable mode of donation, at the choice of the donor himself (model known as *double track*) such as: EU, Canada, Belgium, Germany, Iceland and Holland before 2002, then there are countries that have opted for the possibility of knowing the donor (prohibition of anonymity), such as: Sweden, Austria, Switzerland, Holland after 2002: Sweden, Austria, Switzerland, Holland after 2002, United Kingdom (with new fertility law 2023 anonymity was lost from the moment the child is born), Australia, New Zealand, and Portugal since 2018. Regarding Uruguay and Argentina, as the only countries in Latin America, which despite the anonymity of the donor being the general rule, have taken the first steps in the opposite direction, but neither recognizes the right to know the biological origins, but only the possibility of requesting the identity of the donor in court.

Thus, Professors Alkorta and Farnós indicate, in this sense, that:

> When the State prevents access to identifying or non-identifying information about the donor, it is depriving the person conceived with his gametes of an important aspect of his individual autonomy: the freedom to choose what meaning he gives to the components of his identity (1, p. 171).

https://doi.org/10.36105/mye.2024v35n4.01

The right to know one's biological origins is very different from speaking of a legal status as a son or daughter, and for this reason it is necessary to be clear that the recognition of the existence of parents, donors or gestational parents in the begetting of a person only reinforces the two roles in their proper dimension, and on this point it is very interesting what the French anthropologist Irene Théry says, who points out:

> Instead of implicitly considering them as two rivals for a single position, donors and parents are assumed as individuals who play different roles and occupy complementary places that are mutually reinforcing.
>
> The whole of this approach only makes sense if the begetting donor, no longer in the shadows, no longer nullified and reified by anonymity, is instead recognized as a person, a being capable of acting and feeling in a human way and, consequently, capable of having, as is generally the case with people, a face, a name, an identity and, as a legal person author of an act considered socially very honorable, and in this sense, holder of rights, avoiding being reduced by the recipients or intermediaries to the status of instrument and responsibilities of not retracting from the commitment acquired at the beginning of the process (12, p. 28).

It is beyond discussion that gamete donation does not imply any right or duty in relation to the child to be born, here what is being defended is that the lifting of anonymity is related to the open possibility of the child to know its identity, to whom it is up to use it or not without limitations and to justify this "measure of what is possible".

3. For or against donor anonymity versus the right to know genetic origins

There are many tendencies to be in favor or against anonymity, even though we all recognize that there is a right to know the biological

https://doi.org/10.36105/mye.2024v35n4.01

origins, but under certain characteristics, and we know that, as the act of engendering has become an eminently social act invested with great value, it can be affirmed that in matters of procreation, evoking a purely physical substance and calling it “the biological” is unfounded in this context.

Dr. Eleonora Lamm points out that:

> While in filiation by nature the conflict is between the biological and the volitional, in filiation derived from HAART the conflict is between the genetic and volitional. Now, the biological is a plus with respect to the genetic; and since the genetic lacks this plus, the volitional acquires more importance and relevance. In short, the volitional element acquires superlative importance in the filiation derived from the HAART, so that when in the same person the genetic, the biological and the volitional elements do not coincide, the latter must be given preponderance. Consensual and desired paternity prevails over genetic paternity. We are faced with new realities that imply a “debiologization and/or de-genetization of filiation”, and by virtue of which the concept of filiation has gained new contours, beginning to speak of “voluntary parenthood” or “procreational will” (...) the HAART have provoked a new return to the voluntary truth in which filiation is no longer determined by the genetic or biological element, but by the volitional element (7, p. 81).

This requires a deep perspective, because when we refer to HAART we are not in front of a natural way of conceiving as it is through coitus, therefore we well know that it is possible to speak of “reproduction without sex”, we can well leave out the concept of procreation since there is no derivation to it, and if so, we are left to discuss the genetic and/or the volitional, where there is no problem when those same people who undergo HAART both contribute their genetic material to be parents, the issue becomes complicated when, as already mentioned in this work, there is a third party who contributes that genetic material, in which we deny its total identification in the future for that child because it is considered that the mere fact of wanting to be a parent predominates over the one who made it possible. There is a very interesting aspect, related to the subject, raised by the professor of bioethics Vardit Ravitsky, in response to an approach given by Professor Inmaculada Melo, indicating that:

> She argues that these interests are not delayed or frustrated when one does not have access to one's genetic origins. The basis of her argument is that we lack solid empirical evidence that donor-conceived persons suffer alleged harms, and that even when such harms are present, they do not provide a strong enough justification to argue the right (...) I argue, however, that "the right to know one's genetic origins does not rest on empirical evidence. Some donor-conceived persons may suffer great harm. Others may suffer no harm at all (10, pp. 36-37).

There is a confusion in the understanding of this right, since enjoying a right does not have to do with the empirical evidence that "we are suffering" by not enjoying that right and therefore enjoying it, it has to do with the risk of not recognizing that right in the whole community and not referring to persons. Thus, when we talk about "recognizing" it does not mean only to increase the list of rights that a person enjoys by the mere human existence, but to protect its free exercise, that is, to watch over the effectiveness of that right because it belongs to him/her and not because it could present or not damages or harm in the future if he/she does not have it, because otherwise, what would be the sense of prohibiting the anonymity of the donor if the exercise of that right is subject to the will of the parents to deliver or not the information to the child about his/her origins? Or as is currently the case in Spain, where there is a right to general donor information that does not include the donor's identity, which right has a broad exercise only when there is a certain danger to the life or health of the child. This perfectly leads us to conclude that the right to know their origins can be exercised in its fullness only when there is a danger to the life or health of that child, and not because that child is worthy of knowing where it comes from and who contributed to its begetting.

4. Is a child connected to parents also important for children?

Miller already indicated that "donor-conceived offspring have formed a subculture for "asymmetrical" or "half-adopted" children, establishing support groups (...) and talking about the "genetic bewilderment" that many feel when they do not know where they come from" (8, p. 27).

Referring to Marquardt, the author points out that:

> Donor conception is inherently problematic, no matter how openly or lovingly it is done, because it intentionally separates children from at least one of their biological parents (...) In donor conception, the people who raise them are also the ones who decided before they were conceived that relationships should not matter to them (8).

Here Marquardt sees a curious contradiction at the heart of donor conception:

> We are told that love forms a family, but parents choose donor conception because they want a child biologically connected to them. If biology is important to parents, Marquardt asks, why wouldn't it be important to children as well (8, p. 36).

I think it is necessary to stop at this point, since when we talk about the importance of genetic truth in a person, the moral aspect inserted in the social environment where that child has been raised, based on almost manipulated questioning where they argue phrases like "why make your parents feel bad, they are your real parents, and that is what matters", does not have to take precedence over the definition of their own identity, of their reason for existence.

In fact, it seems questionable the argument that Professor Penning outlines when he says, in relation to the right to know one's biological origins, that:

> It is emphasized that the interests and rights of child donors are paramount and must override the interests and rights of all persons involved (...). The "interests of the child are paramount" is moral demagoguery that appeals to people's general intuitive weakness for children. The rights and interests of vulnerable groups must be protected, but that does not mean that their rights have automatic priority (9, p. 2883).

It is necessary, on the basis of this argument, what is its real meaning, because when one speaks and structures an argument on the basis of discriminating the importance of one thing over another, one person over another, we reach the odious apology of nonsense, because contrary to what Penning states, why would the persons involved have full rights over the real identity of the child that is the product of a conscious decision? And if so, where is its theoretical basis, besides, when he states that it would be a "violation of the ethical rules of equality and impartiality", it is not clear with respect to what equality he is referring to, is he talking on the one hand, about the secrecy of the parents; and on the other hand, about the anonymity of the donor?

And what is even more questionable, it speaks of violation of such rules only under the idea that it is about adults who make a contract in relation to a being who had no power of decision, a being who is associated to the group of "vulnerable", as if alluding that the defense in knowing the biological origins was based on a populist rhetorical discourse in defense and proclamation of the rights of the child and adolescent, It also refers to an "automatic priority" which is confusing and contradictory, because we ask ourselves, is it a priority or not, or is it a partial priority as long as it is convenient for those interested parties who, being adults, have the power of decision?

https://doi.org/10.36105/mye.2024v35n4.01

There is a disturbing aspect mentioned by the same author in relation to the strong feminist struggles against oocyte donation that led to the blocking of embryo research, and who argue today that the right to know the biological origins would serve to discredit gamete donation, and that the way to achieve this will be when the child is raised by his or her genetic parents and the social parents become adoptive parents.

Now, in the face of what feminism may argue in this regard, it should matter little when analyzing an issue as complex as HAART, whose edges have involved a deep debate in the scientific, ethical, legal and even philosophical area and not a mere hormonal revolt of passionate outbursts as has been seen in other issues that concern society, Therefore, these are aspects that should not be mixed, which does not mean that they do not influence many people, and that is why we are cautious about who we involve in the various debates, as they could lead to unimaginable consequences in our society.

5. Conclusions

Without prejudice to the above, there are certain arguments based on the fact that if the clinics where the donations are made carry out all the necessary medical controls, ranging from basic blood typing to the detection of genetic disorders such as cystic fibrosis, why would it be necessary to make the biological origin known to the child? and they propose that it would be enough to devise useful information to satisfy the child's "curiosity" and trust the parents to tell their children that they were conceived by a donor, which leads one to reflect that there are vested interests in not wanting to reveal an identity and that it may even be thought that this would be to cover up negligence on the part of the clinics themselves, And this idea has its historical foundation and goes back to the first world case of artificial insemination, where it was the first sign of secrecy and silence in 1884 at Jefferson Medical College where the situation of a couple was discussed where the man was azoospermic, then the solution was found to inseminate the woman by a "hired man", without her consent and while she was anesthetized. Later the doctor confessed to the husband what had been done, who showed his approval of the action, and suggested that he never tell his wife, thus generating legal uncertainties and important implications for the offspring, for which some States have decided to maintain secrecy or anonymity, which does not mean that the issue is resolved.

This culture of secrecy in gamete donation has been imposed for decades as something "natural", due to the stigma of infertility, a sense of shame that has led many parents to hide mainly to "others" (their social environment where they live) and then to their child a stigmatized reality that they do not face as part of human nature, This stigma has not only been created at the social level, but also at the medical level when, by virtue of a supposed ethical professionalism, it is recommended to the couple not to talk to their children in the future about the use of gamete donation or to reduce the subject to a lucrative market that encourages donation as science advances.

How, then, is this stigmatized reality to be tackled when the foundations on which it is built are denaturalized? Perhaps first, certain concepts need to be modified, as is the case with the concept of "donor", which in 1981 had already been criticized by Professor George Annas, who pointed out that it should be referred to as "sperm seller" (2). Then in 2007 in the words of Ken Daniels, he pointed out that:

> A donor donates; therefore, if payment is made, this word is not appropriate. Furthermore, the word "donor" has a social value, which is not insignificant. Someone who donates, whatever the donation, is generally seen in positive terms because they are acting altruistically (...) The word donor is inappropriate when payment is made (...) the present author (referring to himself) has suggested the word "provider" (4, p. 119).

Théry proposed to designate the new status with the expression "begetting donor" (12, p. 27). In my opinion, this concept of "provider/

seller" does not seem to me to be the most appropriate if we are talking about a social labor in allowing the begetting of a child, also because it is difficult to make a pecuniary valuation for donated sperm or egg, although payment today is made by ejaculation and/or ovodonation, but not on the basis of the product itself that is finally delivered but for the action of the person who performs it. I believe that we could use words such as "sire" "genetic provider" or "genetic facilitator", although it will clearly lead to discussion of such precepts, it could lead us to an appreciation more in harmony with multiculturalism and, with it, to a change of perspective from and towards the parents who decide to resort to HAART, where transparency should be not only in the information that we decide to provide about that person and how we recognize their importance as a human being, but also in the tools of support-restoration of trust that are given to those who resort to HAART.

In view of the major problems we are facing, it will be necessary to reflect on this issue from the perspective of the donor, the parents and the child, or on any of them, are they reconcilable, it will be necessary to open the debate to focus on these problems. *Donor Conception Network*, for example, is a UK-wide support network that provides educational materials, books for parents to read with their children that explain how a child is conceived. Also, in Ravitsky's words:

> Donor counseling would be required to make donors aware that their commitment extends into future years and to educate them to see donation not as a one-time act but rather as an ongoing responsibility for the welfare of potential offspring and recipient families. As these tools become more widespread, the way in which offspring, parents and donors perceive their own and each other's essence will change (11, p. 20).

Having said the above, it could lead to that overprotective concern in relation to the fear of legal responsibilities that it is believed there would be, which should not be clearly discussed, as the right of parents to decide, may lead to concern for the child in knowing their genetic origins, possessing the seal of their identity history, according to various situations where the parties are involved in a process other than the sexual act as a way of conceiving, as in the case of HAART, and its new forms: mitochondrial replacement, postmortem reproduction and other realities that exist and also require imminent regulation. This topic needs a deep and updated analysis not only for the reasons already expressed in this work, but also because it involves "models" of human embryos created from stem cells, which could be edited for the possible prevention of hereditary diseases.

Referencias

1. Alkorta I, Farnós E. Anonimato del donante y derecho a conocer: un difícil equilibrio (Donor Anonimity and Right to Know: a Challenging Balancing), Oñati Socio-Legal Series, Derechos reproductivos y reproducción asistida. Género, diversidad sexual y familias en plural. 2017; 1(1):148-178. Available at: https://ssrn.com/abstract=2782321
2. Annas G. Fathers Anonymous: Beyond the Best Interest of the Sperm Donor,Child Welfare, 1981; 60(3):161-174. https://www.jstor.org/stable/45393772
3. Barcia R, Riveros C. El Derecho al conocimiento del origen biológico como un derecho fundamental de naturaleza civil-constitucional derivado del derecho a la identidad y de la dignidad humana. Ensayo contenido en libro: Gómez de la Torre, Maricruz y Lepin Molina, Cristian (2013), Técnicas de Reproducción Humana Asistida. Desafíos del siglo xxi: Una mirada transdisciplinaria. Legal Publishing Chile, Thompson Reuters. 2013:189-221.
4. Beetar B, De León GI, Suárez WY. El derecho a conocer el origen genético vs el derecho a la intimidad del donante, planteamiento del debate y soluciones para Colombia. Saber Cienc Lib [Internet]. 2022 [cited 2024 Apr 13]; 17(1):78-109. Available at: https://revistas.unilibre.edu.co/index.php/saber/article/view/8468
5. Daniels K. Donor gametes: anonymous or identified? Best Practice & Research Clinical Obstetrics and Gynaecology. 2007; 21(1):113-128. https://doi.org/10.1016/j.bpobgyn.2006.09.010
6. Comité de Bioética de Catalunya. El derecho a conocer los orígenes biológicos y genéticos de la persona. Aprobado en la 97ª reunión plenaria del Comité de Bioética de Cataluña del día 24 de febrero de 2016:1-31. https://canalsalut.gencat.cat/web/.content/_Sistema_de_salut/CBC/recursos/documents_tematica/derecho_origenes_biologicos.pdf

https://doi.org/10.36105/mye.2024v35n4.01

7. De Lorenzi M. El derecho a conocer los orígenes biológicos. La necesidad de su reconocimiento para garantizar el derecho a la identidad personal de los adoptados y nacidos por reproducción asistida. [PhD Thesis, Universitat de Barcelona]. 2015. Available at: DE LORENZI_TESIS.pdf (ub.edu)
8. Famá M. El derecho a la identidad del hijo concebido mediante técnicas de reproducción humana asistida en el proyecto de código civil y comercial de la Nación. Lecciones y Ensayos. 2012; (90):171-195. http://www.derecho.uba.ar/publicaciones/lye/revistas/90/fama.pdf
9. Lamm E. La importancia de la voluntad procreacional en la nueva categoría de filiación derivada de las técnicas de reproducción asistida. Revista de Bioética, Observatori de Bioética i Dret, Barcelona. 2012; (24):76-91. http://www.ub.edu/fildt/revista/RByD24_master.htm
10. Miller C. Donated Generation. The New Atlantis. 2008; (21):27-44. https://doi.org/10.1186/s13584-016-0125-0
11. Penning G. How to kill gamete donation: retrospective legislation and donor anonymity. Human Reproduction, 2012; 27(10):2881-2885. https://doi.org/10.1093/humrep/des218
12. Ravitsky V. Autonomous choice and the right to know one´s genetic origins. Revista The Hastings Center Report. 2014; 44(2):36-37. https://doi.org/10.1002/hast.286
13. Ravitsky V. Conceived and Deceived: The medical interest of donor-conceived individuals. Hastings Center Report. 2012; 42(1):17-22. https://doi.org/10.1002/hast.9
14. Théry I. El anonimato en las donaciones de engendramiento: filiación e identidad narrativa infantil en tiempos de descasamiento. Revista de Antropología Social. 2009; 18:21-42. https://www.redalyc.org/articulo.oa?id=83817222002
15. Turner S, Molina M, Momberg R. Técnicas de reproducción humana asistida. Una perspectiva d.esde los intereses del hijo. Revista de Derecho (Valdivia). 2000; 11(1):13-26. http://revistas.uach.cl/pdf/revider/v11/art02.pdf

https://doi.org/10.36105/mye.2024v35n4.01