

Children born of a gift: Will the widespread availability of genetic testing end anonymity?

*Susanna Marinelli¹, Stamatios Petousis², Chrysoula Margioulas-Siarkou²,
Alessandra Lopez³, Valentina Billone³, Gianluca Montanari Vergallo⁴*

¹School of Law, Polytechnic University of Marche, 60121 Ancona, Italy; ²Second Department of Obstetrics and Gynecology, Aristotle University of Thessaloniki, Greece; ³Department of Obstetrics and Gynecology, Villa Sofia Cervello Hospital, University of Palermo, Italy; ⁴Department of Anatomical, Histological, Forensic and Orthopedic Sciences, "Sapienza" University of Rome, Rome, Italy

Abstract. In the field of genetics, the proliferation of direct-to-consumer genetic testing tools is calling into question the principle of gamete donor anonymity, still codified in many legislative frameworks. While ethicists debate whose rights should be prioritized, many donor-conceived people and intended parents are currently sharing their genetic information. Those who attempt to conceive with donor sperm or eggs face many obstacles: they often experience the social stigma associated with infertility, and therefore choose not to reveal the existence of a donor to their children. Sometimes it is the children, when they are informed that they were conceived through gamete donation, who claim the right to know their genetic origins. Many states still do not allow this possibility because the principle of anonymity is in force. In this scenario, it is necessary to discuss the right to know one's genetic origins and the need for legislation on heterologous fertilization, since the lack of specific legislation makes discrimination and inequality more likely, for homosexual as well as heterosexual intended parents. This article focuses on the importance of accessing information in relation to identity formation, laying out the complexities and distinctive features that such dynamics entail (www.actabiomedica.it).

Key words: medically-assisted procreation (MAP), legislation, anonymity, direct-to-consumer genetic testing, right to know one's genetic origins

Introduction

Over the last 40 years, scientific and technological advances in medically-assisted procreation (MAP) have made giant strides. In Italy, for instance, according to the Report of the Minister of Health to Parliament on law 19 February 2004 n. 40 (law 40), 14,162 children were born through MAP techniques as of 2021. Among these, 2289 were conceived through gamete donation (1,2). Gamete donation, however, has raised the issue of whether anonymity should be granted to male and female donors.

Methods

The issue of donor anonymity in MAP procedures has absolute relevance, in that it can affect the rights, prospects and lives of gamete donors as well as children, whose right to know about their genetic origins has been reaffirmed by various rulings. Still, it is of utmost importance to strike a balance between such apparently conflicting rights, however difficult and delicate that may be from a legal and ethics standpoint. The current availability of novel tools that may disclose such information makes it even more

essential to identify new legal and regulatory means to reconcile the rights of all those involved. The authors have drawn upon available research findings as well as legal, judicial and regulatory sources in order to identify the complexities and distinctive traits arising from such issues, which pose major ethics quandaries as well. Ultimately, excluding sources centered on essentially clinical aspects, 34 sources were selected for the purpose of this succinct analysis, through a search in PubMed/Medline, Scopus, Embase, Web of Science. Search strings included the keywords “medically-assisted procreation (MAP)”, “legislation”, “anonymity”, “direct-to-consumer genetic testing”, “right to know one’s genetic origins”.

Overriding the principle of anonymity

In the 1980s and 90s, the principle of anonymity was substantially established in the field of gamete donation in MAP techniques. The fundamental goal was to protect the private sphere of both donors, recipients and donor-conceived children. However, anonymity in MAP can extend to a wider and more diverse set of elements: in fact, non-identifying elements may also not be disclosed, i.e. somatic features (gender, height, eye colour, hair colour) and skin), social ones (country of birth, religious faith, employment and interests) and relational ones (existence of spouse and children).

Some systems instead allow access to both non-identifying traits and the complete identity of donors. Directive 2004/23/EC of the European Parliament established that the principle of anonymity can be overridden only if it is necessary to protect the health of the “donor conceived child” (3-6). It also established that mutual traceability between donor and recipient must be guaranteed, for a minimum period of 30 years, through a system based on unique codes (art. 8). Over the years, a growing number of jurisdictions around the world, including Australia, Austria, Croatia, the Netherlands, Norway, Finland, New Zealand, Sweden, Switzerland, the United Kingdom, Uruguay, Argentina and Ireland are facilitating access to identifying donor information, and prohibiting donor anonymity (5). In these jurisdictions, donor-conceived

children can have access to a register of gamete donors, or those kept at the fertility clinic, or in addition file a lawsuit to gain information on the donors involved in the procedures (7-9). In Germany, the Supreme Court has recognized the right of donor-conceived individuals to access donor identifying information at any age (10). On the one hand, Jones et al (11) and Ravitsky (12) believe it useful to add a provision to the birth certificate, or even provide a specific “donor conception certificate”. The authors of the present writing do not agree because they believe that the indication of birth through the gift of gametes would constitute an invasion of privacy and family life. A more effective and respectful alternative to the interests at stake could be to encourage parents to be honest by disclosing such information to their children (13-15). In fact, the issue of gamete donor anonymity is connected to the right of donor-conceived children to know their origins.

Commercial genetic testing

The use of commercial genetic tests (Direct-to-consumer-genetic-testing, DTCGT), which can be used at home to trace genetically connected people to reconstruct one’s genealogy, is a rapidly-growing phenomenon (16,17).

The United States is a leader in this sector, though the DTCGT market is also growing rapidly in European and East Asian countries, particularly China and Japan (18).

Such tests work in a rather simple way: the customer only needs to provide a saliva sample and deliver it to companies specialized in scanning thousands of points of their genome to obtain information on the origin of their ancestors, or to identify matches with genetic relatives.

After getting the results, customers can upload a DNA file obtained from one company to other DNA databases, usually for free or for a small fee. This increases the chances of finding genetic matches (19,20). Thanks to these services, it is no longer necessary for donor-conceived individuals to undergo a test to find out if they are genetically related to some donor, if other people (donor relatives) in their family circle register

on these sites their DNA test results (21,22). Donor-conceived individuals are not always able to trace the gamete donors, because the donors may have asked not to be identified, even if their genetic sequences are present in the database used. They ignore, in fact, that in numerous cases both those born from the gift and their parents do not look for the gamete donor as a person, but rather for information on their origins in a broad sense, for example they want to know the genealogy, ethnicity, health-related features, medical records.

In other cases they rely on DTCGT to increase the chances of being identified, even if their identification conflicts with the norms guaranteeing donor anonymity (23). With the spread of DTCGT, despite some countries having adopted strict regulations to guarantee anonymity, it is easier to access the data stored in the DNA analysis database, and therefore to get around the restrictions imposed by the regulations in force in some countries. In France, for example, in order to avoid such regulatory circumvention, the use of DTCGT was not only prohibited, but also punishable with a fine of €3,750 (art.226-28-1 Code Pénal). Nonetheless, taking advantage of foreign DNA analysis services, following the autonomous domestic collection of samples by the interested parties, every year between 100 and 200 thousand people apparently resort to such tests (24).

Information to children about their genetic origins: Whether and when to provide it

No legislative framework has yet established the obligation either for parents or for the state to inform donor-conceived children that they were born through such means. However, medical-anthropological research views such information as a moral duty. Until a few decades ago, parents who used donated gametes or embryos were advised not to tell their children how they were conceived (25).

However, many heterosexual couples who use donated gametes or embryos choose not to disclose this information to their children and family members, or are uncertain whether or not to do so (26). According to Crawshaw (17) there are essentially four reasons

why DTCGTs are performed. First of all, since the Western world places great importance on genetics, parents may decide not to tell the truth about their birth to their child, because they fear that the revelation could negatively affect them psychologically. Secondly, parents, by concealing the truth, usually want to protect their child and themselves from negative reactions of society in general (27). Furthermore, by not revealing the truth, parents want to protect the relationship between the donor-conceived children and the parent who is genetically unrelated to them, considering the fact that Western societies ascribe great importance to genetic data. Finally, the aim is often to hide infertility from society and not just from the family.

At the same time, social stigmatization of infertility should be avoided because reproduction and sexuality are two distinct concepts. Instead, precisely because of the confusion between these two situations, the infertile man may come to consider infertility as a slur to his manhood. The same happens infertile women, who often perceive such a condition as a major life failure.

From a psychological perspective, it is preferable to explain to children born from the gift the methods of their conception from childhood, using a narrative approach suitable to their age (28). Rosanna Hertz has shown that if parents and families in general keep secret the fact that the child was born from a gamete donor, this can adversely impact their psychological and emotional well-being, because it can cause feelings of anxiety and anguish (29). Amanda Baden in her studies on adoption has highlighted that late discovery of adoption (i.e. beyond 3 years of age) is linked to psychological distress and feelings of anger, betrayal, depression and anxiety (30). Therefore, it would be preferable for a family member to inform the child as soon as possible about their conception, because such information will help them build their personal identity and elicit reasonably neutral, if not positive, reactions (31). Many donor-conceived adults and young people believe they should know their genetic and biographical history (32-34). A 2011 study has shown that due to anonymity, they cannot have information about their origins and may perceive this situation as a "loss of identity" (35,36), feeling deceived and aggrieved in their very status as human beings.

Conclusions

Through a partial and summarized assessment of research findings, it appears quite clear that there is a need for a comprehensive debate is more needed than ever. Such a broad-ranging discussion should be not only legal, but above all ethical-philosophical, and centered around the meaning that is intended to be attributed to genetic links, in particular in the case of gamete donation. In this context, a dialogue that involves not only scholars, but those directly involved in a MAP process and prospective gamete donors as well, is essential. The institutions must take action because *in vitro* fertilization has been a reality for forty years now, but many people have to go abroad to fulfill their parenthood dream, since Italian law does not allow it, given the social taboo features of infertility, also with regards to gamete donation. No targeted legislation currently governs assisted fertilization with gamete donation, and this further hinders the development of an open debate on the topic. Instead, the authors believe it is important to eradicate the continuous stigmatization not only of same-sex relationships, but also of infertile heterosexual couples who have undertaken a family project thanks to gamete donation. A discussion on the topic of heterologous fertilization via gamete donation is therefore of utmost importance to build a more inclusive social environment, in which DNA is not the only founding element of parenthood.

Acknowledgements: None

Funding: None

Ethic Committee: Not applicable

Conflict of Interest: Each author declares that he or she has no commercial associations (e.g. consultancies, stock ownership, equity interest, patent/licensing arrangement etc.) that might pose a conflict of interest in connection with the submitted article.

Authors Contribution: GN, LDP and GMV designed the study and outlined the article's structure; GMV analyzed the data, all three authors equally contributed to writing the manuscript.

References

1. Report to the Italian Ministry of Health as to the implementation of Law 40/2004. Issued to the Italian Parliament on 11th November 2021. Available online: https://www.salute.gov.it/portale/documentazione/p6_2_2_1.jsp?lingua=italiano&id=3162 (Accessed on 15th April 2024).
2. Montanari Vergallo G, Zaami S, Bruti V, Signore F, Marinelli E. How the legislation on medically assisted procreation has evolved in Italy. *Med Law* 2017;36:5-28.
3. Directive 2004/23/EC of the European Parliament and of the Council of 31 March 2004 on setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells. Available online: <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32004L0023> (Accessed on 15th April 2024).
4. Zaami S. Assisted heterologous fertilization and the right of donorconceived children to know their biological origins. *Clin Ter.* 2018 Jan-Feb;169(1):e39-e43. doi: 10.7417/T.2018.2052.
5. Allan S. Donor Identification: Victorian Legislation Give Rights to all Donor-conceived People. *Fam Matters* 2016;98:43-55. Available online: https://www.ohchr.org/sites/default/files/Documents/Issues/Children/SR/Surrogacy/AcademicInstitutions/SoniaAllanOAM_CF_DeakinUniversity_Annex3.pdf (Accessed on 15th April 2024).
6. Zaami S, Busardò FP. Elective egg freezing: can you really turn back the clock? *Eur Rev Med Pharmacol Sci.* 2015 Oct;19(19):3537-8.
7. Gullo G, Perino A, Cucinella G. Open vs. closed vitrification system: which one is safer? *Eur Rev Med Pharmacol Sci.* 2022 Feb;26(4):1065-1067. doi: 10.26355/eurrev_202202_28092.
8. Darroch F, Smith I. Establishing Identity: How Direct-to-Consumer Genetic Testing Challenges the Assumption of Donor Anonymity. *Family Court Review* 2021;59:103-20. doi.org/10.1111/fcre.12553
9. Gullo G, Basile G, Cucinella G, et al. Fresh vs. frozen embryo transfer in assisted reproductive techniques: a single center retrospective cohort study and ethical-legal implications. *Eur Rev Med Pharmacol Sci.* 2023 Jul;27(14):6809-6823. doi: 10.26355/eurrev_202307_33152.
10. van den Akker OB, Crawshaw MA, Blyth ED, Frith LJ. Expectations and experiences of gamete donors and donor-conceived adults searching for genetic relatives using DNA linking through a voluntary register. *Hum Reprod.* 2015 Jan;30(1):111-21. doi: 10.1093/humrep/deu289.
11. Jones C, Frith L, Blyth E, Speirs J. The role of Birth Certificates in Relation to access to Biographical and Genetic History in Donor Conception. *International Journal of Children Rights* 2009;17:207-219. doi: 10.1163/157181808X389254
12. Ravitsky V. Knowing Where You Come From": The Rights of Donor-Conceived Individuals and the Meaning of Genetic Relatedness. *Minn JL Sci & Tech.* 2010;11:665-684.

13. Frati P, La Russa R, Santurro A, et al. Bioethical issues and legal frameworks of surrogacy: A global perspective about the right to health and dignity. *Eur J Obstet Gynecol Reprod Biol.* 2021 Mar;258:1-8. doi: 10.1016/j.ejogrb.2020.12.020.
14. Ethics Committee of the American Society for Reproductive Medicine. Informing offspring of their conception by gamete or embryo donation: an Ethics Committee opinion. *Fertil Steril.* 2018 Apr;109(4):601-605. doi: 10.1016/j.fertnstert.2018.01.001.
15. Montanari Vergallo G, Marinelli E, di Luca NM, Zaami S. Gamete Donation: Are Children Entitled to Know Their Genetic Origins? A Comparison of Opposing Views. *The Italian State of Affairs. Eur J Health Law* 2018;25:322-37. doi: 10.1163/15718093-12530378.
16. Gilman L, Redhead C, Hudson N, et al. Direct-to-consumer genetic testing and the changing landscape of gamete donor conception: key issues for practitioners and stakeholders. *Reprod Biomed Online.* 2024 Jan;48(1):103421. doi: 10.1016/j.rbmo.2023.103421.
17. Crawshaw M. Direct-to-consumer DNA testing: the fallout for individuals and their families unexpectedly learning of their donor conception origins. *Hum Fertil (Camb).* 2018 Dec;21(4):225-228. doi: 10.1080/14647273.2017.1339127.
18. Nagai K, Tanaka M, Marcon AR, et al. Comparing direct-to-consumer genetic testing services in English, Japanese, and Chinese websites. *AS* 2023;131:3-13. doi: 10.1537/ase.220905.
19. Horton R, Crawford G, Freeman L, Fenwick A, Wright CF, Lucassen A. Direct-to-consumer genetic testing. *BMJ.* 2019 Oct 16;367:l5688. doi: 10.1136/bmj.l5688.
20. Solomon BD. The future of commercial genetic testing. *Curr Opin Pediatr.* 2023 Dec 1;35(6):615-619. doi: 10.1097/MOP.0000000000001260.
21. Harper J, Jackson E, Spoelstra-Witjens L, Reisel D. Using an introduction website to start a family: implications for users and health practitioners. *Reprod Biomed Soc Online.* 2017 Apr 7;4:13-17. doi: 10.1016/j.rbms.2017.02.001.
22. Hazel JW, Hammack-Aviran C, Brelsford KM, Malin BA, Beskow LM, Clayton EW. Direct-to-consumer genetic testing: Prospective users' attitudes toward information about ancestry and biological relationships. *PLoS One.* 2021 Nov 29;16(11):e0260340. doi: 10.1371/journal.pone.0260340.
23. Frith L, Gilman L, Redhead C, Hudson N, MacCallum F. Donor conception and Commercial Genomics: how are donor conceived people, their parents and donors using direct-to-consumer genetic testing? *Human Reproduction* 2022;37:1129-1130.
24. Rigaud N. Tests génétiques « récréatifs » : Juste un jeu ?. *Inserm le magazine (Paris),* 2019, N° 42, p. 42-43.
25. Chisholm R. Information rights and donor conception: lessons from adoption? *J Law Med.* 2012 Jun;19(4):722-41.
26. Greenfeld DA, Klock SC. Disclosure decisions among known and anonymous oocyte donation recipients. *Fertil Steril.* 2004 Jun;81(6):1565-71. doi: 10.1016/j.fertnstert.2003.10.041.
27. Harper JC, Kennett D, Reisel D. The end of donor anonymity: how genetic testing is likely to drive anonymous gamete donation out of business. *Hum Reprod.* 2016 Jun;31(6):1135-40. doi: 10.1093/humrep/dew065.
28. Cheshire S. DNA tests are the Christmas gift that keeps on giving, but unexpected results can bring you more than you bargained for. *Human Fertilization & Embryology Authority.* Issued on 30th September 2020. Available online: <https://www.hfea.gov.uk/about-us/news-and-press-releases/2020/dna-tests-are-the-christmas-gift-that-keeps-on-giving-but-unexpected-results-can-bring-you-more-than-you-bargained-for/> (accessed on 15th April 2024).
29. Hertz R, Nelson MK, Kramer W. Donor conceived offspring conceive of the donor: the relevance of age, awareness, and family form. *Soc Sci Med* 2013;86:52-65. doi: 10.1016/j.socscimed.2013.03.001.
30. Baden AL, Shadel D, Morgan R, et al. Delaying Adoption Disclosure: A Survey of Late Discovery Adoptees. *Journal of Family Issues* 2019;40:1154-80. doi: 10.1177/0192513X19829503.
31. Paulin J, Sorjonen K, Sydsjö G, Lampic C. Using the theory of planned behavior to predict parents' disclosure of donor conception to their children: a longitudinal study. *Hum Reprod.* 2024 Apr 9;dea070. doi: 10.1093/humrep/deae070.
32. Marinelli S, Del Rio A, Gullo G. The best interest of children born through medically assisted procreation procedures as construed in 2021 Italian Constitutional Court rulings 32 and 33. *Clin Ter.* 2022 Feb 7;173(1):46-49. doi: 10.7417/CT.2022.2390.
33. Marinelli S, Del Rio A. Beginning of life ethics at the dawn of a new era of genome editing: are bioethical precepts and fast-evolving biotechnologies irreconcilable? *Clin Ter.* 2020 Sep-Oct;171(5):e407-e411.
34. Rodino IS, Burton PJ, Sanders KA. Donor information considered important to donors, recipients and offspring: an Australian perspective. *Reprod Biomed Online.* 2011 Mar;22(3):303-11. doi: 10.1016/j.rbmo.2010.11.007.
35. Turner AJ, Coyle A. What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy. *Hum Reprod.* 2000 Sep;15(9):2041-51. doi: 10.1093/humrep/15.9.2041.
36. Frati P, Zaami S, La Russa R, Pinchi E, Busardò FP. A Mix-up During Assisted Reproductive Technique: What is in the Best Interest of the New-Born? *Curr Pharm Biotechnol.* 2016;17(4):326-9. doi: 10.2174/1389201017666160118103910.

Correspondence:

Received: 7 April 2024

Accepted: 7 May 2024

Alessandra Lopez, MD

Department of Obstetrics and Gynecology,

Villa Sofia Cervello Hospital, University of Palermo, Italy

E-mail: alessandra.lopez91@gmail.com