

Autonomous Choice and the Right to Know One's Genetic Origins

BY VARDIT RAVITSKY

In “The Ethics of Anonymous Gamete Donation: Is There a Right to Know One’s Genetic Origins?” Inmaculada de Melo-Martín deconstructs the interests the right is supposed to protect. She argues that these interests are not set back or thwarted when one has no access to one’s genetic origins. The basis of her argument is that we lack robust empirical evidence that donor-conceived individuals suffer certain alleged harms, and that even when such harms are present, they do not provide strong enough justification to ground the right.

Indeed, the research on the needs, preferences, and well-being of donor-conceived individuals is scant. In fact, we lack robust empirical evidence regarding all aspects of donor conception. I argue, however, that the right to know one’s genetic origins (which I shall refer to simply as the “right to know”) does not rest on empirical evidence. Some donor-conceived individuals who are unable to know their genetic origins may suffer great harms. Others may suffer no harm at all. For some, being donor-conceived may be an important element in the formation of their identities, narratives, and relationships. Others

may find it irrelevant or insignificant. But *all* are treated wrongly when they are deprived of the ability to access information about their genetic origins.

People can be wronged without being harmed. This can occur when they are put at risk unjustifiably or when social arrangements fail to accord them liberties to which they are entitled. For example, the right to privacy is not grounded in the notion that violations of privacy are necessarily harmful. My personal financial information may be exposed without causing me any harm. However, that exposure puts me at risk and deprives me of certain freedoms. Similarly, not all donor-conceived individuals are harmed when their right to know is violated, but they are put at risk of such harm. More importantly, they are deprived of an important aspect of their autonomy: the liberty to choose what meaning they assign to the genetic components of their identity.

For some donor-conceived individuals who argue for a right to know, not having access to their genetic origins constitutes a life-long struggle that has caused much psychological harm. Others have never experienced their circumstances as harmful and rather perceive the search for their donors and donor-siblings as a fulfilling journey that is emotionally adventurous and intellectually stimulating and full of potential for new relationships. But for all of them, the right is grounded, not necessarily in a need for protection from harm, but rather in their autonomy to make choices about what their genetic origins mean to them, at different points in their lives. This choice is linked to fundamental aspects of human existence: our understanding of who we are and how we are connected to others.

This point is too often missed in the debate surrounding the right to know. Ignoring it leaves a straw man, as it is easy to demonstrate that not all donor-conceived individuals are harmed and that not all are even interested in knowing their genetic origins.

Pathologizing Individuals and Families?

The distinction between harming and wronging donor-conceived individuals is also crucial when addressing de Melo-Martín’s counterargument to the right

Vardit Ravitsky, “Autonomous Choice and the Right to Know One’s Genetic Origins,” *Hastings Center Report* 44, no. 2 (2012): 36-37. DOI: 10.1002/hast.286

to know, namely that “claiming the existence of such a right can actually contribute to the harms it is intended to prevent.” By “stressing the importance of genetic information,” argues de Melo-Martín, proponents of the right to know promote genetic essentialism. She describes three outcomes of claiming a right to know: it pathologizes individuals who lack access to information about their genetic origins; it treats individuals who have no interest in finding this information as suffering from some pathological deviation; and it supports a normative ideological framework that idealizes biological families, treats them as superior, and sees all other family structures as “pathological deviations that require adjustment.”

These are serious allegations, but distinguishing harm from wrong makes them easy to dismiss. The right to know does not imply that all donor-conceived individuals are harmed by not knowing, nor that they are “deviant” if they choose not to know. Knowing one’s genetic origins may or may not be an element in the “forging of a healthy identity,” but it is surely not a *necessary*—or even a central—element in identity formation for all people.¹ Acknowledging a right to choose what meaning one assigns to genetic information cannot qualify as “pathologizing” those who choose to know or not know. It is compatible with a broad range of healthy choices, preferences, and identity formation processes.

Similarly, acknowledging this right to choose does not pathologize families whose members are not genetically related. It is compatible with acknowledging numerous forms of family structures as equally healthy environments for children’s development. All it claims is that donor-conceived individuals should be able to choose autonomously what meaning they assign to the component of genetic relatedness in the construction of some of the most fundamental relationships in their lives and in their understanding of kinship. The right to know ensures the possibility of accessing information that may or may not become crucial to the well-being of individuals at some point in their lives.

The Meaning of the Right to Know

The right to know is a right to access information that may be crucial to one’s well-being without being hin-

dered by unfair social arrangements. But de Melo-Martín dismisses this view, arguing that “there are all kinds of information that people might benefit from being able to assess” but that “no one argues has to be given to them.” This argument is flawed on two counts. First, it treats genetic information as something that society “gives” to individuals, as if it were some special resource to which donor-conceived individuals feel entitled and that we, as a society, need not provide them. But this is a distorted description. It is society that enabled the mechanisms that led to their conception with the involvement of a third-party, and it is society that adopted policies that protect the anonymity of their donors rather than their autonomy

to access information that the rest of us are free to access. The right to know is not about giving them information; it is about removing barriers to access, barriers that we created around a process we enabled.

Second, genetic information is hardly comparable to “all kinds of information.” It is profoundly linked to physical well-being, and for many it is also linked to personal identity and family relationships. It is hard to imagine what other kinds of information de Melo-Martín has in mind that would be analogous to

genetic information in this sense. Under this reasoning, why not turn back the clock and allow a veil of secrecy around adoption as well? Why have we come to the conclusion, as a society, that adoptees are entitled to precisely this kind of information?

What makes us who we are and what connects us to our families is complex, culturally dependent, highly subjective, and dependent on a variety of particular circumstances that are unique to each case. Not all of us require knowledge of our genetic origins to thrive, but some of us do. Acknowledging a right to this knowledge is to acknowledge the diversity and the richness of the human experience.

1. De Melo-Martín cites an article of mine (V. Ravitsky, “Conceived and Deceived: The Medical Interests of Donor-Conceived Individuals.” *Hastings Center Report* 42, no. 1 (2012): 17-22, at 19) as an example of this position. My position is more complex, however, as this commentary tries to make clear.

When the right to know is violated, donor-conceived individuals are deprived of the liberty to choose what meaning they assign to the genetic components of their identity.
