

THE ETHICS OF ANONYMOUS GAMETE DONATION:

Is There a Right to Know One's Genetic Origins?

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A growing number of jurisdictions hold that gamete donors must be identifiable to the children born with their eggs or sperm, on grounds that being able to know about one's genetic origins is a fundamental moral right. But the argument for that belief has not yet been adequately made.

The demand for gametes, and especially for eggs, has been increasing worldwide, in part because of delayed childbearing in the developed world. In 2009, donor eggs or embryos were used in approximately 12 percent of all assisted reproductive technology cycles performed.¹ Gamete donation can be useful for men and women with a variety of fertility problems, such as low sperm count, premature ovarian failure, or ovarian failure due to cancer treatment. It is also helpful for couples who are at risk of passing on a serious genetic disorder if they conceive using their own gametes.

Currently, the vast majority of gamete donations worldwide are made anonymously, and in some countries, including Spain, France, and Denmark, the anonymity of donors is explicitly protected by

law. Nonetheless, a growing number of countries have called into question the morality of such practices and are enacting laws allowing children access to identifying information about their gamete donor.² Sweden, Austria, the Australian State of Victoria, Switzerland, The Netherlands, Norway, The United Kingdom, New Zealand, and Finland now mandate that donors be identifiable to their genetic offspring. Nonanonymous gamete donation is also taking hold in some jurisdictions in North America. In 2011, the Supreme Court of British Columbia banned anonymous gamete donation,³ and Washington State recently passed legislation allowing donor-conceived children to have access to a donor's identifying information unless the donor explicitly elects not to disclose the information.⁴

A significant reason for the growing legislative support for nonanonymous gamete donations is the belief that donor-conceived children have a fundamental moral right to know their genetic origins

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and that the right should be legally protected by policies that prohibit anonymous donations.⁵ Often, however, this right is assumed rather than explicitly justified. Of course, the presumed right to know one's genetic origin is not new. It has been used as grounds to promote openness in adoption records. Nonetheless, a variety of factors, such as the increasing number of children born by means of gamete donation, advances in genetic science and technology that make it easy to discover the identity of a person's genetic parents, and the widespread belief that genetic information is important for protecting people's health, have made this alleged right quite salient, even leading some to challenge the ethical appropriateness of gamete donation practices altogether.⁶

The purpose of this paper is to call into question the ethical justifications that are often thought to ground a right to know one's genetic origins. Different ethical theories lead to different justifications for rights, but many would agree that at least one important function of rights is to protect some weighty human interest—an interest that makes an important contribution to well-being or flourishing.⁷ Proponents of a right to know one's genetic origins—whom I shall call, for the sake of brevity, rights proponents—usually argue that such a right protects at least three vital interests: the interest of donor-conceived people in having strong family relationships, their health interests, and their interest in forming a healthy identity. These different interests might be protected by different aspects of the right to know one's genetic origins: knowing one's mode of conception, accessing medically relevant information, and accessing identifying information about one's genetic parents. I will discuss each of these interests and explore whether and how these interests might be set back by an individual's lack of access to information about his or her genetic parentage. I will also evaluate whether donor anonymity policies

are, as many of their opponents argue, morally impermissible because they fail to protect these important interests.

If the argument goes through, I shall at least show that the case for a right to know one's genetic origins requires more defense than has so far been provided. I shall then go on not just to question the argument for this alleged right, but to provide a counterargument: I shall argue that claiming the existence of such a right can actually contribute to the harms that the right is intended to prevent.

An Interest in Strong Family Relationships

Proponents of a right to know one's genetic origins argue that donor-conceived individuals have a vital interest in strong family relationships and that this interest is set back by the secrecy that often accompanies donor conception. Indeed, in one

become independent adults. Rights proponents contend that withholding the truth about donor-conceived children's mode of conception is likely to have negative consequences on family relationships.¹⁰ They argue that this nondisclosure and related secrecy can produce family tensions, anxiety, loneliness, stress-related symptoms, and self-doubt. Secrecy about a child's origin, rights proponents insist, hinders active parent-child communication, undermines trust, creates unnecessary estrangements, and promotes distance and suspicion.¹¹ Evidence suggests that those who use gamete donation usually tell a family member or friend,¹² and rights proponents claim that it could be traumatic for a child to learn about the gamete donation from someone other than his or her parent. They argue that accidentally finding out about the gamete donation can cause irreparable damage to trust within the family.

Some studies have shown that not telling children they were conceived with the help of a donor seems to have no negative effects on their psychological well-being or family relationships in general.

study, evidence about rates of disclosure in families that conceived a child with a gamete donation show that despite a shift in professional attitudes toward openness, at age seven, about half of the children conceived by egg donation and nearly three-quarters of those conceived by donor insemination had not been told about their mode of conception.⁸ Because of the need to explain the absence of a father in the home, single and lesbian mothers have been found to have higher rates of disclosure than heterosexual couples.⁹

Strong family relationships are necessary for the psychological and social development that allows children to

Few would deny that people have a vital interest in strong family relationships. It is not clear, however, that disclosing an individual's mode of conception is necessary to protect this interest. The evidence is ambiguous. Some studies have found that families that had disclosed showed lower levels of parent-child conflict than families that had not.¹³ Others have found that secrecy can affect family relationships in various ways, for example, conflict, cohesion, or emotional expressiveness.¹⁴ Other studies have suggested a correlation between accidental disclosures and strained relationships or mistrust within rearing families.¹⁵ Nonetheless, other studies

have shown that lack of disclosure seems to have no negative effects on children's psychological well-being or on family relationships in general.¹⁶ Of those studies that have found some differences in the level of conflict between disclosing and nondisclosing families, for instance, the evidence showed that such differences represented especially positive ratings in the disclosing group rather than dysfunctional relationships in the nondisclosing families.¹⁷ Even in those studies in which secrecy negatively affected family relationships, donor-conceived children rated family functioning as moderately high.¹⁸ And some studies found, contrary to expectations, that children who knew the circumstances of their birth showed greater adjustment difficulties.¹⁹

Moreover, some studies indicate that the conceptualization of family secrets that is typical of literature on donor conception may offer an impoverished image of the complexity of what happens in families that fail to tell their children that they are donor conceived.²⁰ Literature by rights proponents often depicts the keeping of family secrets as a categorically problematic activity that has negative effects on family relationships. However, some autoethnographical studies present a more empathic and compassionate view of secret holders, one that is more attuned to people's vulnerability and that reveals understanding and acceptance of those who have kept secrets.²¹ Indeed, some evidence suggests that the categories of "secrecy" and "openness" might be inadequate when considering families with gamete-conceived children, as many parents engage in different levels of openness about their child's conception, both with their child and with family and friends.²²

In this more complex picture of how secrecy functions in the context of donor conception, disclosure is not obviously necessary to protect donor-conceived individuals' interest in strong family relationships. Rights proponents might still argue

that secrecy is impermissible on deontological grounds, but this claim, too, needs defense. It is not clear that secrets are *prima facie* wrong or even that all secrets are in need of justification.²³ Secrets can protect important aspects of human life, even when they can also invite abuse. Indeed, rights proponents are not proposing an end to all family secrets, or even to all secrets that relate to mode of conception. For instance, there has been little effort to argue that people born through in vitro fertilization or other reproductive technologies have a right to know how they were conceived. And this is the case in spite of the fact that parents who use IVF often do not disclose the mode of conception to their children and have concerns about disclosure,²⁴ which suggests that they would have some anxiety and other stress-related symptoms that could negatively affect family relationships. Similarly, it would be implausible to suggest that parents have a duty to reveal all personal information about their relationships that might have affected their children's coming into being.

If secrecy about gamete donation is wrong, then, it has to be wrong because of something particular to this context. But that argument is hard to make, especially when one considers the importance normally given to parental autonomy in making decisions that affect children's welfare. If it is not clear that nondisclosure harms children's interests in strong family relationships and if secret-keeping in general has not been shown to be *prima facie* wrong, then giving parents the power to decide whether and when to disclose the use of a donor seems consistent with the value that we assign to parental autonomy.²⁵

Anonymity policies do not mandate nondisclosure, and many parents who have used anonymous gamete donations do disclose this fact to their children. Thus, even if donor-conceived children have a right to know this information, anonymous gamete donations are not inconsistent with disclosure. Furthermore,

some evidence suggests that there are no differences in plans to inform a child based on the use of a known or an anonymous donor,²⁶ and the rates of disclosure do not seem to be different in countries with and without anonymity.²⁷

Anonymity policies might still pose a threat to donor-conceived individuals' interest in strong family relationships. If and when they learn of the donation, they might want to know the donor's identity, and anonymity policies create barriers to access such information.²⁸ But there are problems with this objection. First, it seems that if disclosing the mode of conception in the context of anonymity seriously disrupts family relationships, then that fact might be an argument against disclosure rather than against anonymity policies.²⁹ Second, there is no evidence that family functioning has been damaged when disclosure has occurred but anonymity remains.³⁰

Health Interests

Rights proponents have also argued that the access of donor-conceived individuals to health information about their donors is necessary to protect their vital interests. Genetic, environmental, and lifestyle factors influence the development of most common diseases affecting human beings. Since these factors are often shared by family members, a family medical history has the potential to provide information that illuminates a person's risk of getting common diseases such as diabetes, stroke, cancer, and heart disease. Arguably, therefore, having knowledge of one's family medical history is important for making informed decisions about one's health. Similarly, appropriate information about family medical history can lead to the use of adequate screening measures and to early treatment.³¹ Evidence also suggests that health advice tailored to an individual's familial risk can motivate healthy behaviors.³²

Rights proponents contend that donor-conceived individuals who do not have access to genetic information about their donors are denied the benefits of a more complete family medical history and, thus, of information necessary to make informed decisions about their health. But even though donor-conceived people do not share their genetic make-up with both of the rearing parents, they certainly can share cultural and behavioral factors, such as lifestyle and nutritional habits. Thus, even when donor-conceived individuals might lack access to the donor's genetic information, to the extent that the clinical utility of family medical history is grounded on environmental factors, their health interests are in no way set back, as they can obviously access information about their family's culture and behavior.

Notwithstanding the relevance of cultural and behavioral factors in health, family medical history can offer crucial information related to genetic factors. For instance, it can play an important role in identifying patients who may benefit from predictive genetic testing.³³ And information about highly penetrant genetic mutations, such as those responsible for Huntington's disease and some forms of breast cancer, can be crucial to a person's health interests. Knowledge of family medical history can also be central to determining who might benefit from genetic testing or how to properly interpret genetic test results. Studies have shown the clinical utility of family history for identifying persons with particular genetic syndromes or illnesses, such as hereditary breast and ovarian cancers.³⁴ Some evidence suggests that information about family medical history also seems useful for the assessment of risk for some common diseases in which genetic factors play a less clear role, such as most cases of diabetes, cardiovascular disease, and mental health disorders.³⁵

Nonetheless, there are several problems with the claim that access to a donor's medical history is

necessary to safeguard the person's interest in health. First, the role that knowledge about heritable factors plays in promoting health might be overstated. Even if people had accurate information about their genetic relatives, there is not sufficient evidence to conclude that access to family history improves risk prediction, changes people's risk perceptions, and leads to better health outcomes.³⁶

Risk perceptions appear to be relatively resistant to change even when individuals have detailed information about elevated disease risk based on family history.³⁷ Indeed, knowledge of genetic risk, even if the knowledge is the result of genetic testing and not just of hearing a family history, seems to have little effect on people's health-related behaviors.³⁸ Moreover, if knowledge of genetic risks is

to disclose information about them to their genetic children. Furthermore, although primary care providers often report high rates of collecting family medical histories, evidence from practice suggests that a thorough exploration of a family history may be more the exception than the rule in adult primary care.⁴¹ When that history is collected, studies show that it is not collected appropriately.⁴²

This is not to argue that because people often are misinformed or lack sufficient information about their family history, failing to disclose relevant health information to donor-conceived individuals would be acceptable. Rather, it is to point out the apparent dearth of strong evidence indicating that people who are uninformed or even misinformed about their family medical history

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important for health outcomes, the so-called revolution in personalized or precision medicine aims to give individuals the ability to have their own genome sequenced and analyzed, thus providing them information about relevant genetic risks without the need for access to genetic information about their progenitors.³⁹

Second, clearly many parents either lack or fail to disclose relevant health information to their genetically related children. People generally believe that their family history is important, but few collect health information from their relatives to learn this history.⁴⁰ People often lack relevant details about their relatives' health history or fail to recall pertinent information. Moreover, because some diseases have stigmatizing consequences, parents might choose not

are adversely affected by their lack of knowledge. Of course, that dearth might be the result of inadequate collection practices or insufficient scientific knowledge. If at some point the evidence indicates that having accurate information about a family medical history is necessary to protect one's health interests, then this would count as an important reason to ensure that donor-conceived individuals have access to it.

However, donor-conceived individuals might be negatively affected not simply because they lack access to genetic information from a progenitor but because they mistakenly believe that their rearing parents are also their biological parents and so are mistaken about their own medical history.⁴³ This mistake can lead to misdiagnoses and can cause

donor-conceived people to fail to take steps that might promote their health or to fail to seek medical help when they should. Nevertheless, as mentioned earlier, anonymity policies do not mandate nondisclosure and seem to have no effect on whether parents disclose. Additionally, although current practices are variable, gamete donors usually undergo genetic screening for a significant number of heritable diseases and are also routinely asked to provide extensive information about their family medical history. Even when anonymity is enforced, parents of donor-conceived children are given access to this information when selecting a donor, and they are free to give that information to their children. It might be that better methods need to be implemented to ensure updated donor medical information that might be relevant to donor-conceived individuals. But such strategies can be implemented in ways that maintain anonymity without necessarily hindering donor-conceived children's health interests. Thus, anonymity policies do not seem to thwart the health interests of donor-conceived persons.

An Interest in Forging an Identity

Those who defend a right to know one's genetic origins have also argued that donor-conceived people have a vital interest in forging healthy identities and that access to the identity of the donor is necessary to protect their interest.⁴⁴ In this view, knowing one's genetic origins is necessary to appropriately understand oneself. Access to the identity of the genetic progenitors is also thought to be necessary to help make sense of one's talents, interests, or physical characteristics. It gives context to questions about family resemblance. It also can help foster a sense of belonging and a connection with the past, a sense of continuity. Thus, lacking information about where certain traits come from, and access to a context that provides evidence of or helps clarify

family resemblance, is said to hinder donor-conceived children's project of self-understanding.⁴⁵ According to these rights proponents, to the extent that personal identity requires at least some degree of self-understanding, a lack of access to genetic relatedness information will contribute to donor-conceived individuals' having a defective sense of identity.

Rights proponents often use reports by donor-conceived or adopted persons who do not have identifying information about their genetic parents to support claims about the difficulties donor-conceived people face in their project of self-understanding and identity formation.⁴⁶ These reports indicate that at least some donor-conceived individuals have feelings of a loss of identity, a sense that they lack understanding of who they really are and how they fit in the world. Indeed, some commentators have argued that donor-conceived people who do not know their genetic parents suffer from "genealogical bewilderment."⁴⁷

Having access to the elements necessary for forging a healthy identity is quite clearly a vital human interest. If access to identifying information about one's genetic parents is indeed necessary for healthy identity formation, then this would constitute a strong reason against both nondisclosure and anonymous donations and in favor of giving donor-conceived individuals access to information about their genetic origins.

There are, however, several problems with these claims. First, the role of genetics in constituting personal identity is highly contested.⁴⁸ I think we can acknowledge that genetic relatedness, in one way or another, informs most people's self-understanding and sense of identity. It is also true that the emphasis culture places on family resemblances—normally understood as holding among genetically related family members—can make the process of self-understanding more challenging for individuals who lack information about their genetic progenitors. But many people who lack

access to this information still have perfectly healthy identities. Indeed, as work on relational theories of the self illustrates, personal identity cannot be disentangled from contingent facts about the social, historical, and physical circumstances of the self and from the interrelatedness between the self and various others.⁴⁹ In this theoretical approach, many kinds of relational properties will be important aspects of self-understanding and identity formation. Self-knowledge and the development of personal identity are dependent on interpersonal relations with others. Genetic relatedness can play a role in the construction of the self, but the role that it plays can be different for different people and at different times.

Second, although some anecdotal evidence indicates that at least some donor-conceived individuals are distressed by the lack of identifying information about their genetic parents, there is no robust empirical evidence showing that donor-conceived children on the whole suffer "genealogical bewilderment." On the contrary, several studies investigating donor-conceived children's social and emotional development have shown no significant differences in socioemotional adjustment between donor-conceived children and those naturally conceived.⁵⁰ This is not to say that no donor-conceived child suffers from a lack of access to identifying information about the donors. It is simply to point out that the evidence does not support the claim that such information is necessary for forging healthy identities.

Third, even if many donor-conceived people had a very strong interest in knowing their genetic origins and suffered when they lacked that knowledge, depriving children of such information would still not be shown wrong. People have all kinds of interests that we would be reluctant to say *must* be satisfied. Unless one presupposes—problematically—that knowledge about genetic parentage is necessary to develop healthy identities, then it does not seem that

the legitimate interest of donor-conceived people in identity formation is *thwarted* by lacking such knowledge. Arguably, that interest depends chiefly on social conditions—such as education and opportunities for meaningful work, love, and civic participation—and there are no reasons to believe that donor-conceived individuals who lack information about their genetic parents are deprived of these conditions.⁵¹ The interest that rights proponents want to protect is not an interest in developing a healthy identity but an interest in developing a particular *kind* of identity, one that conforms to culturally dominant narratives. But, of course, it is not at all obvious that we ought to satisfy one's interest in a particular identity.⁵²

One must presuppose the importance of genetics in order to argue that any identity-related distress suffered by donor-conceived people is caused by a lack of information about their genetic origins. If this presupposition is called into question, the cause might be, not the lack of information, but the fact that lacking such information is thought to be a problem in the first place.⁵³ In a social context where information about genetic parentage is presumed necessary for identity formation, those who lack such knowledge might indeed have serious difficulties forging a healthy sense of self. It might then certainly be true that access to information could relieve the suffering of donor-conceived individuals. But deemphasizing the value of genetic information could also accomplish this.

The Special Significance of Genetic Information?

If the arguments here are correct, knowledge about one's genetic origins has not been shown necessary for protecting donor-conceived people's interests in thriving family relationships, health, and the forging of an appropriate sense of self. Thus, insofar as a right to know one's genetic parentage is grounded on the need to

safeguard such interests, the extant defenses of this right are problematic. A further challenge for rights proponents, however, is that the arguments offered on behalf of the right might actually contribute to some of the harms that the right is intended to prevent.

Whether or not those who defend this right presuppose the validity of genetic essentialism (that is, the tendency to reduce the self in all of its complexity to genes), the defense of a right to know one's genetic origins imbues genetic information with a very special significance. To argue that this right is simply a way to ensure that donor-conceived individuals have a chance to assess the importance of this information for themselves does not counter this.⁵⁴ There are all kinds of information that peo-

The arguments offered on behalf of the right to know one's genetic origins might actually contribute to some of the harms that the right is intended to prevent.

ple might benefit from being able to assess but that no one argues has to be given to them, as a matter of moral or legal right. It is precisely because genetic information is thought to be of particular relevance that one might believe that access to this information is of fundamental value. A defense of a right to know one's genetic parentage thus presupposes the particular significance of genetic information for people's lives. Given the increasing emphasis on the idea that genetics can explain all kinds of things about human beings,⁵⁵ stressing the importance of genetic information might well promote problematic beliefs about genetic essentialism.

Emphasizing the importance of genetic information might also have the effect of pathologizing individuals who lack access to information about their genetic parentage. Because they seem to lack something presumed

essential to advance weighty benefits, they could be stigmatized and considered in need of some psychological attention. And if they have no interest in finding this information, they might be thought of as suffering from some pathological deviation, insofar as they fail to conform to the going views about what is important for their well-being. Indeed, the question that is often presented as evidence for the importance of access to information about the donors—"who would not want to know their biological origins?"—betrays this pathologizing effect.

Emphasizing the importance of genetic relationships might also encourage problematic beliefs about the superiority of biological families. Presumably, these are the families where children's interests in nurtur-

ing relationships, health, and identity formation are best protected. After all, children in these families know who their genetic parents are, have access to more information that allows them to acquire self-understanding, and can easily gain at least some knowledge about their risks for diseases with genetic bases. If emphasizing the importance of genetic information has the effect of idealizing the biological family, then it may actually undermine the interests of donor-conceived individuals. Even when information about the donors is available, families that depend on gamete donation are unlikely ever to measure up to the biological family. An uncritical, even if implicit, support of the biological family as the ideal makes any family that does not conform to this ideal into a pathological deviation that requires adjustment.⁵⁶ Insofar as proponents of this

right fail to question the moral value of heredity, they are at least complicit in supporting a normative ideological framework that calls for critical evaluation.

Of course, donor anonymity and secrecy might be morally problematic for reasons other than those discussed here, which are the usual grounds for defending a right to know one's genetic origins.⁵⁷ The arguments presented here have attempted to problematize that presumed right. Some of the interests that this right is intended to protect—strong family relationships and health—can be recognized as weighty ones, but there is no evidence that they are set back by anonymous gamete donations. Anonymous donations do not prevent parents from disclosing the mode of conception to donor-conceived offspring. Similarly, allowing for anonymous donation is not inconsistent with giving those individuals access to relevant health information. Furthermore, the evidence that failing to disclose one's mode of conception adversely affects these interests is at best ambiguous and at worse nonexistent.

Anonymous donations prevent donor-conceived individuals from gaining access to identifying information about their donors. This constraint does not thwart a vital interest in forming a healthy identity; it might threaten an interest in developing a *particular* identity, but the moral weightiness of an interest in forging a particular identity is questionable.

Because of the privileging of genetic relationships presupposed by a defense of a right to know one's genetic origins, the defense could have negative effects on the well-being of donor-conceived people and their families. Overemphasizing genetic connections might not be the best way to ensure the well-being of non-biological families. Indeed, if genetic connections were not imbued with such significance, then perhaps parents would be less reluctant to disclose that gametes were donated and to reveal whatever information was available about the donor.

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25. The arguments presented here should in no way be taken to endorse nondisclosure or secrecy. These arguments simply show that failing to disclose does not seem to affect people's interests in strong family relationships and thus that promoting such interests does not necessitate disclosure. Obviously, there might be many other reasons that parents should be encouraged to disclose. It is not the purpose of this paper to address such reasons.

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