



As anonymity disappears the focus becomes limits on donor offspring

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The five commentators who responded to our article, 'Gamete donor anonymity and limits on numbers of offspring: the views of three stakeholders',¹ raised several of the same issues; they also expressed some quite different concerns. We thank the readers for these varied and thoughtful readings. In our brief response, we outline our major findings. We then respond first to the shared points and then to two that we view as being unique. In our last section, we introduce some new data that might help elucidate the debates at stake here.

BRIEF REVIEW OF FINDINGS

Drawing on data from separate online surveys of gamete donors, donor-conceived offspring, and parents who used donated gametes to conceive, we reviewed stakeholder attitudes toward the issues of anonymity and limits on the number of offspring produced by a single sperm donor.

We found that among all three stakeholders, attitudes toward anonymity tended toward neutrality with large numbers of each group neither agreeing nor disagreeing with the statement that donors should *not* be anonymous. Offspring were the group most likely to 'strongly agree' with this issue and we return to this point below. We also found that parents and offspring tended toward agreement with the statement that donors should be limited in the number of children they can produce; donors were less likely to agree but expressed a stronger tendency toward neutrality. In our discussion below, we provide additional nuance to our finding about limits which was of least concern to our commentators.

¹ Margaret K. Nelson, Rosanna Hertz & Wendy Kramer, *Gamete Donor Anonymity and Limits on Numbers of Offspring: The Views of Three Stakeholders*, 3 J. & L. BIOSCI. 39–67 (2016).

SHARED CONCERNS OF COMMENTATORS

Two of the commentators focused exclusively on the issue of anonymity, arguing that concerns about anonymity—or origins—are not unique to individuals involved in assisted reproductive technologies. Needless to say, we agree entirely. As Cahill² suggests, lots of people ‘*whether traditionally or alternatively conceived*, [have] at one time or another fantasized about [their] familial origins and even experienced the feelings of rootlessness, alienation, and disorientation that have come to be identified over the past few years with a particular minority: the donor conceived’ [emphasis in original]. But this is hardly *our* point. The donor conceived exist in a separate category of individuals who might not know as children—and might never know even as adults—half or even all of their *genetic* ‘familial origins’. For donor-conceived individuals, this uncertainty is neither about fantasy nor feeling; it reflects reality. We suggest as well that the analogy to adoption made by Jacobson³ fails to take into account the sharp differences between that set of social arrangements and donor conception. Among these differences we highlight three. First is the simple fact that the adopted are born into a different family from the one in which they are subsequently raised, whereas for the donor conceived the two families are one and the same. Second is the equally simple fact that eggs and sperm are sold on an open market and the market decides a price for those products. The same is not the case for babies in the USA today. Third, children placed for adoption are not body parts but fully human individuals.

The second point, shared by Markens,⁴ Suter,⁵ and Ertman,⁶ has to do with the importance of obtaining good, representative data in order to create policy. Once again, we agree entirely, while raising our own distinctive concerns. In order to accurately take into account the voices of all three stakeholders, there must be some way to obtain a fully representative sample of each group. We note, however, that under current conditions this is impossible: no single organization oversees donor conception or maintains lists from which these samples could be drawn. Even individual banks would not be able to send out surveys to all stakeholders. They do maintain lists of active and former donors and adults who purchased gametes, but the follow-up on live births is not required. Banks do not have lists of donor-conceived offspring.

UNIQUE ISSUES

Suter⁷ raises the question of ‘should’ which we carefully avoid answering in our article. For two reasons, she reads our data to suggest that offspring should be the ones whose voices are most taken into account in deciding the issue of anonymity: first, because they are the group of individuals with the strongest opposition to anonymity, and second, because of ‘the importance of relational autonomy and the ways in which donor

² Courtney M. Cahill, *Universalizing Anonymity Anxiety*, J. L. & BIOSCI.

³ Heather Jacobson, *Anonymity in Third Party Reproduction: An Old Dilemma in New Packaging?*, 1–6 J. L. & BIOSCI. 2 (2016).

⁴ Susan Markens, *Third-Party Reproductive Practices: Legislative Inertia and the Need for Nuanced Empirical Data*, 1–7 J. L. & BIOSCI. 4–6 (2016).

⁵ Sonia M. Suter, *The Limits of Empirical Data: How to Understand Survey Results With Respect to Gamete Donor Anonymity*, 3 J. L. & BIOSCI. 377–82 (2016).

⁶ Martha M. Ertman, *Drinking from the Data Well*, J. L. & BIOSCI.

⁷ Suter, *supra* note 5, at 381.

anonymity can threaten relational autonomy'.⁸ We entirely agree that the voices of offspring should be reflected in whatever regulations are developed and we discuss below, more fully, what those voices now say. We have openly acknowledged the limits of *our* published data. We would hope that before the opinions of offspring views become a relevant basis for policy development, less limited data would be collected.

Ertman⁹ is the only one of the five commentators who addressed the question of limits on the number of offspring a single donor can produce, one of the two major issues discussed in our article. We had predicted that 'future proposals for reform will focus on limiting the number of children conceived by any particular donor'.¹⁰ She writes that she is 'less confident of this prediction than others [we] put forward'.¹¹ In our discussion below, after addressing the issue of anonymity, we turn to our new understanding of the issue of limits, and why we believe that it is likely to remain an important one for all three stakeholders.

NEW POINTS

Much of the focus of the commentary on our article concerns the issue of anonymity. We introduce findings from new research and then turn to the general question of whether anonymity is moot; we then explore more fully the issue of limits.

Today's donor-conceived offspring add their voices

Since our article was published, we have conducted face-to-face interviews with what we acknowledge to be a non-random sample of over 150 donor-conceived offspring along with over 250 parents who conceived using donor gametes. The offspring we interviewed in depth have mixed reactions to contacting their donors. Among those who are 18 or older, the majority would not want to advocate for revoking the anonymity that the banks guaranteed donors; this is the case even among those who believe in the future all donors should be open. However, this does not mean they are not curious. They would like to know more about their own donor regardless of whether that person is an identity-release¹² or anonymous donor. *Offspring often conflate the issues of anonymity and their interest in meeting their own donor. That is, in general they believe anonymity should be a choice for donors, but they still want their individual donor to have contact with them.* As much as one of our respondents, James, an 18-year-old college freshman, believes that donors should be allowed to be anonymous, he adds a caveat: 'If he doesn't want to have a connection with us [his donor siblings] he has that right I feel which is disappointing to me, but just from his rights standpoint I think he should be able to remain anonymous if he feels this is best for him.'

⁸ *Id.* at 381.

⁹ Ertman, *supra* note 6.

¹⁰ *Id.* at 6.

¹¹ *Id.* at 6.

¹² The Sperm Bank of California (TSBC) was the first bank that offered this option. It explains that 'Donors who choose this option sign a contract that authorizes TSBC to reveal their identity only under the following circumstances: A donor's identity can be released only to the donor-conceived individual; The donor-conceived individual must be at least eighteen years old; The donor-conceived individual must request the donor's identifying information in writing and go through a release process before the identity is released. The information is not automatically released'. In practice identity release allows an offspring to write a one-time letter that is passed through the bank; there is no assurance that the donor will respond. The Sperm Bank of California. <https://www.thespermbankofca.org/content/identity-release-program> (accessed Sept. 7, 2016).

Further, in the course of interviewing families, we found that several anonymous donors did agree to answer a one-time letter. Offspring pin their hopes on the possibility that their donor might be among the anonymous who agrees to this minimal contact. Offspring who have identity-release donors are not really clear that having an identity-release donor is not a *guarantee* of meeting the donor or even simply receiving a picture, which is one thing most offspring would like.

Interestingly, at age 18 when these offspring have the legal right to contact the donor through their bank, they do not always do so. Since we interviewed within networks of offspring who share the same donor, we are able to compare responses within a single network as to whether offspring already had contacted the donor and, among those who had not, whether they planned to do so or even would want to do so some time in the future. No matter what kind of donor they have, donor siblings in the same network are often split and they may even have talked about their different opinions. Those who do not plan to contact a donor are respectful of those with other interests, supporting *their* right to contact the donor.

In effect, we have found that offspring support the general principle of anonymity as the donor's 'right' and as part of the deal their parents made. However, many of them want some information and they would support their donor siblings who want contact with the donor even if it means an attempt to violate a donor's anonymity. Presently, donors have no knowledge of whether their donations resulted in children. Banks could let donors know their best estimate of the number of children their sperm has produced. This information might spur donors to consider having some minimal contact with their offspring an ethical responsibility. That contact would not necessarily undermine their anonymity and it would mean a lot to some of these offspring.

Anonymity is becoming moot

In any case, that anonymity might be under siege for other reasons. Since our article was published, Harper et al.¹³ have argued compellingly that genetic testing is likely to make this issue moot in the future because donors may be 'traced if their DNA, or that of a relative, is added to a database'. In fact, they conclude that 'donors should be informed that their anonymity is not guaranteed'.¹⁴ On the basis of our interviews with parents, we would add that the kind of information donors are asked to provide by the facilities that gather sperm and eggs quite often makes it easy to identify donors on the Internet, even without genetic testing. As one mother said, she simply relied on obvious search terms based on what she had read on the donor's long-form questionnaire:

I found him years ago, before Facebook. I found him on MySpace, because I put in random facts from his profile, and the first hit was him, and I was like, 'that has to be him.' It just had to be him because everything matched from where he went to school to where he was born. ... The icing on the cake was [he listed] his favorite movie [which he had stated on his donor profile].

¹³ Joyce C. Harper, Debbie Kennett & Dan Reisel, *The End of Donor Anonymity: How Genetic Testing is Likely to Drive Anonymous Gamete Donation out of Business*, 31 HUM. REPROD. 1135–40, 1 (2016).

¹⁴ *Id.* at 4.

Further, a lesbian couple who inseminated at home discovered that the bank they used did not remove the donor's birthdate on the vial; combined with the information he had provided about schools he had attended, they knew they could identify him—if they chose to do so—as one of their college classmates. The Internet has made possible unforeseen possibilities to locate donors, raising new ethical concerns about contacting these donors themselves and new questions about how meaningful anonymity really is. More parents are now disclosing donor conception to their children; once they have grown older, those offspring are also likely to be able to locate their donor through quick Internet searches. On the basis of our interviews, we not only agree with the conclusion put forth by Harper et al., but we would continue to argue, as we wrote before, that the time for 'vigorous debate' on this issue might well have passed.¹⁵

Limits are likely to grow in importance

Drawing on data collected by Hertz and Mattes in 2009¹⁶ in comparison with similar data (collected five years later), we wrote an article in 'The Journal of Family Issues' about patterns of contact within groups of parents who had used the same donor.¹⁷ We found that both the rate and the form of communication with shared-donor families have changed over time. First, 'the rate of communication has escalated enormously', and second, 'while much communication remains group oriented (eg group e-mails) there is also more talking on the phone with another individual'. We also found that the 'frequency with which parents meet face-to-face following identification of donor-conceived relatives has also risen enormously: like communication, meeting appears now to be part of the package of searching for donor siblings with half of all families meeting'.¹⁸ Finally, we found that offspring 'communicate at the same rate as do parents' and that they are even more likely than parents to have met in person a donor sibling (50 per cent of parents had met a child's donor sibling in comparison with 64 per cent of the offspring themselves).¹⁹ In short, these networks are becoming more frequent and the members are more likely to spend some time together. A new generation of parents who have had children since 2010, after the first decade of the Internet explosion, knew when they purchased sperm that the possibility to make contact with others who shared the same donor existed through online registries. The members of this new generation of parents are likely to make contact with their child's donor siblings at earlier ages than was the case in the past. In short, connections to other offspring who share the same donor are likely to continue to increase as more parents sign on to these networks as a routine addition to donor conception.

In conjunction with these data, the interviews we have conducted recently help us understand the concerns of both parents and offspring about limits on the total number of offspring one donor might produce. In addition to what we noted already, that parents believe that they have been lied to by the banks and that they are concerned

¹⁵ Nelson et al., *supra* note 1, at 28.

¹⁶ Rosanna Hertz & Jane Mattes, *Donor-Shared Siblings or Genetic Strangers: New Families, Clans, and the Internet*, 32 J. FAM. ISSUES 1129 (2011).

¹⁷ Rosanna Hertz, Margaret K. Nelson & Wendy Kramer, *Donor Sibling Networks as a Vehicle for Expanding Kinship A Replication and Extension*, 1–37 J. FAM. ISSUES 29–30 (2016).

¹⁸ *Id.*

¹⁹ *Id.*

about the health consequences of large numbers of siblings,²⁰ we can add that parents do continue to worry especially about the possibilities of inadvertent incest.²¹ Offspring and parents both worry about two additional issues. First, they worry that large numbers of offspring might well overwhelm an identity-release donor and that therefore the quality (or even likelihood) of contact with any given individual would be undermined. The offspring and parents, in their commentary about numbers, thus link the issues of anonymity and limits: they fear that without limits fewer donors will be willing to be identity-release donors because the donors themselves will be concerned about the possibility of vast numbers of offspring making claims on their time and attention.

Offspring also worry about the dynamics within their own groups of donor siblings. They note that a large group can be unwieldy and can fragment more easily, an argument made by theorist Georg Simmel who developed a geometry of social life.²² Offspring also explain that ‘newcomers’ (people who are identified to others later in time) do not share the group memories and will find it more difficult to be included than do those who form the group first. Twin newcomers, aged 18, who had just discovered their donor siblings, commented that as excited as they were to have found them, it was not easy becoming members of an established and well-articulated group: ‘I feel like kind of there’s a sense of urgency with meeting them. I want to talk to them as soon as possible.... We’re only 2 people and we have to meet 15 people and try to learn about these 15 people and they only have to learn about 2 more.... They played together when they were younger.... It is hard to get to know them now as adults’.

Taken together, these findings about limits lead us to a slight modification of our earlier conclusion. We now *see even more* reason for all parties to become involved in debates about the issue of limits. As more offspring identify donors, their experiences of contact are likely to be reported in the literature;²³ potential donors are thus also likely to become concerned and they might well refuse to donate unless they can be assured that they will be protected either by anonymity or by limited numbers of offspring. We have already heard from parents that we interviewed that in deciding which bank to use they take into account the limits on numbers of offspring set by their potential choices. The fertility industry does not have to ‘cede’ its place to respond to the market as it makes its wishes known. Finally, as offspring have contact with donor siblings, they can more easily than in the past become a collective voice in debates about these issues. And, we can be pretty confident that that voice will favor the adoption of limits.

²⁰ Nelson et al., *supra* note 1.

²¹ Interestingly, we find this common heteronormative narrative among both lesbian and heterosexual parents.

²² Georg Simmel, *On the Significance of Numbers for Social Life*, in *THE SOCIOLOGY OF GEORG SIMMEL* 87–104 (KURT H. WOLFF trans and ed., 1950).

²³ Several articles have already been published that describe this contact. See, for example, Rosanna Hertz, Margaret K. Nelson & Wendy Kramer, *Sperm Donors Describe the Experience of Contact With Their Donor-Conceived Offspring*, 7 *FACTS VIEW VIS. GYNECOL. OBSTET.* 91–100 (2015); V. Jadva et al., *Sperm and Oocyte Donors’ Experiences of Anonymous Donation and Subsequent Contact With Their Donor Offspring*, 26 *HUM. REPROD.* 638–45 (2011).