



Accepted Manuscript

Article

Perspectives, experiences and choices of parents of children conceived following oocyte donation

Eric Blyth, Wendy Kramer, Jennifer Schneider

PII:DOI: Reference:

To appear in:

Received Date: Revised Date: Accepted Date:

S1472-6483(12)00670-0

<http://dx.doi.org/10.1016/j.rbmo.2012.10.013>

RBMO 805

Reproductive BioMedicine Online

18 June 2012 15 October 2012 16 October 2012

Please cite this article as: Blyth, E., Kramer, W., Schneider, J., Perspectives, experiences and choices of parents of children conceived following oocyte donation, Reproductive BioMedicine Online (2012), doi: <http://dx.doi.org/10.1016/j.rbmo.2012.10.013>

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Title

Perspectives, experiences, and choices of parents of children conceived following oocyte donation

Author names and affiliations

Eric Blyth CQSW BA MA PhD

Professor of Social Work

University of Huddersfield

Queensgate

Huddersfield HD1 3DH

England

Tel: +44 (0) 1484 472457

Fax: +44 (0) 1484 473603

e.d.blyth@hud.ac.uk

<http://www.hud.ac.uk/cacs/staff/professorericblyth.php>

Wendy Kramer

PO Box 1571

Nederland CO 80466

303-258-0902

Director, Donor Sibling Registry

wendy@donorsiblingregistry.com

Jennifer Schneider MD

Arizona Community Physicians,

Tucson, Arizona, USA

jennifer@jenniferschneider.com

<http://www.jenniferschneider.com>

Corresponding author.

Eric Blyth

Present/permanent address.

As above

MANUSCRIPT

ACCEPTED

Perspectives of parents of children conceived following oocyte donation

Perspectives, experiences and choices of parents of children conceived following oocyte donation

Abstract

This paper reports on and discusses the findings of an online survey initiated by the Donor Sibling Registry of 108 parents of children conceived following oocyte donation. Respondents generally supported early disclosure of donor conception to the child, although some bias in favour of disclosure cannot be excluded, given the recruitment source. Even so, extensive uncertainty regarding the optimum time for disclosure was evident. Around half of the parents who had either expressly chosen (50.0%), or had been given no choice of, an anonymous donor (54.1%) subsequently wished they had used an open-identity donor. A total of 87% of respondents showed interest in identifying and making contact with their donor and with other families containing children sharing the same donor, and

19% had already made such contact. The survey revealed considerable variations in respondents' experiences of clinic practices regarding the availability of counselling, information provided about choice of donor type, advice regarding disclosure and the reporting of births, indicating key areas for improved professional practice.

Introduction

The first successful use of donated oocytes was reported in 1984 (Lutjen *et al.*, 1984). Since this time, oocyte donation has become a more common treatment option. In the UK, for example, formal recording of assisted reproduction treatment began in 1991. The number of patients treated with donor oocytes increased from 389 in 1992 to 1380 in 2010; in the same period the number of donor oocyte treatment cycles increased from 460 to 1506, while the number of children born using donor oocytes increased from 122 in 1992 to 593 in 2009 (Human Fertilisation and Embryology Authority, 2012a,b). For treatments involving donor spermatozoa, the number of patients decreased from 1208 in 1992 to 975 in 2010; in the same period the number of donor sperm treatment cycles decreased from 1494 to 1200, while the number of children born using donor spermatozoa decreased from 1781 in 1992 to 1084 in 2009 (Human Fertilisation and Embryology Authority, 2012a,b). In the USA, the number of transfers involving donor oocytes increased from 11,627 in 2003 to 15,504 in 2010 (Society of Assisted Reproductive Technology, 2012); however, available data do not enable accurate calculation of the number of children born using donor oocytes in the USA. Neither are data available for the number of treatment using, nor for children born following, sperm donation. While non-existent or incomplete recording means that it is impossible to generate global data for either the prevalence or outcome of oocyte donation, a survey of 120 countries undertaken by the International Federation of Fertility Societies (Jones *et al.*, 2010), showed general levels of acceptance for oocyte donation. Among 50

MANUSCRIPT

ACCEPTED

countries governed by statutes, oocyte donation was prohibited in 13 only; among 39 countries practising under guidelines, it was prohibited by 10 only; and among 31 countries operating under neither statutes nor guidelines it was not practiced in 12 only. Of the 50 countries operating under statute, sperm donation in conjunction with IVF was prohibited in 10, and prohibited in nine for non-IVF purposes. Eleven of the 39 countries with guidelines prohibited sperm donation, and sperm donation was not practiced among nine of the 31 countries operating

under neither statutes nor guidelines.

Historically, gamete donation (including oocyte donation) has been characterized by donor anonymity and concealment of the nature of the child's conception. A number of studies undertaken in various countries have explored parents' views regarding disclosure to their donor-conceived children of the means of their conception. To date, most of the study populations relating to oocyte donation have been recipients of anonymous donation whose children have been aged up to 8 years (Petree and Weckstein, 1993; Weil *et al.*, 1994; Söderström-Anttila *et al.*, 1998; Baetens *et al.*, 2000; Hahn and Craft-Rosenberg, 2002; Greenfeld and Klock, 2004; Klock and Greenfeld, 2004; Golombok *et al.*, 2004, 2006; Murray *et al.*, 2006; Mac Dougall *et al.*, 2007; van Berkel *et al.*, 2007; Laruelle *et al.*, 2012), although one recent Finnish study has included parents of children aged up to 14 years (Söderström-Anttila *et al.*, 2010). These studies have revealed intended disclosure rates of between 26% and 81%, although not all parents indicating an intention to disclose will necessarily do so (Klock and Greenfeld, 2004; Golombok *et al.*, 2006; Murray *et al.*, 2006; Mac Dougall *et al.*, 2007; van Berkel *et al.*, 2007), and only three studies have included longitudinal data tracking parental disclosure behaviour. One of these was undertaken in Finland (Söderström-Anttila *et al.*, 1998, 2010) and two in the UK (Golombok *et al.*, 1999; Murray *et al.*, 2006; and Golombok *et al.*, 2004; Readings *et al.*, 2011). In the first stage of the Finnish study, children were aged up to 4 years (Söderström-Anttila *et al.*, 1998), at which time 38% of parents intended to disclose the nature of the conception to their child. A later study of families built using oocyte donation when children were aged up to 14 years included parents who had participated in the original study (Söderström-Anttila *et al.*, 2010). Of all parents in the 2010 study population (113 mothers and 100 fathers), 14.6% had decided never to tell their child; 23.5% had already told their child; 37.1% had not told their child but intended to do so; and 24.9% had still to make up their mind. Of parents of children aged 13–14 years, 27.8%, all of whom had participated in the original study, had already disclosed and 16.6% still intended to do so (Söderström-Anttila, personal communication, 18 August 2011). In the later study, while none of the parents of children aged under 3 years had yet told their child, 83.3% indicated that they intended to do so (Söderström-Anttila, personal communication, 18 August 2011). Although this latter group is not directly comparable to the 1998 study participants, the increase between 1998 and 2010 in the proportion of parents intending to disclose is remarkable.

In the first UK study, trends over time are difficult to discern accurately because of differences in the way findings are reported in the first (Golombok *et al.*, 1999) and follow-up (Murray *et al.*, 2006) studies and the conflation of discrete data in

both reports. Twenty- one sets of parents of children conceived following oocyte donation who were aged between 3.5 and 8 years were recruited to the study. Of these, one set of parents had

MANUSCRIPT

ACCEPTED

already told their child about the nature of her or his conception and 38% had decided not to tell their child. The plans of the remaining 53% of parents are not specified. Although, given the possible options, it seems reasonable to assume this group comprises parents who were planning to tell later and those who were

unsure about disclosure, the respective proportions of these groups are not indicated. Seventeen sets of parents participated in a follow-up study when the children were 12 years old (Murray *et al.*, 2006). The only information provided regarding parental disclosure is that 35% of these parents had either told their child about her or his conception already or intended to do so, but the respective numbers in each group are not specified. Furthermore, no distinction is made between parents who remain unsure about disclosure and those who have definitely decided not to tell.

In the second UK study, parents were first interviewed when their child was aged between birth and 12 months (Golombok *et al.*, 2004). Fifty-one families with a child conceived following oocyte donation took part in the study. At that time, none of the parents had told their child, 29 (56%) parents stated their intention to tell their child about the circumstances of her or his conception in the future, 11 (22%) were uncertain and 11 (22%) planned not to tell. Thirty-two of these parents (62.8% of the original group) were interviewed again when their child was aged 7 years. Thirteen (40.6%) had already told their child, 10 (31.3%) were planning to tell, four (12.5%) were unsure whether to tell or not and five (15.6%) had decided not to tell (Readings *et al.*, 2011). Unfortunately, the later disclosure plans are not paired with participants' initial disclosure plans, thus it is not possible to track the parents' specific decision-making trajectories. Nevertheless, these three studies suggest an underlying changed ethos regarding disclosure among parents of children conceived following oocyte donation – at least in Finland and the UK.

MacDougall *et al.* (2007) identified two alternative parental disclosure strategies that impacted the timing of disclosure. The 'seed planting' strategy, adopted by parents to ensure that their child 'always knows', favours early disclosure, while later disclosure tends to be employed by parents who prefer to wait until the 'time is right', when they believe their child would have the maturity to understand biological concepts and have developed a sense of discretion, and who therefore conceive the child's early years as rendering them 'too young' to be told. In the study by MacDougall *et al.* (2007), parents who disclosed early were more at ease with doing so, whereas those who disclosed later were less certain about how and when to disclose and wished they had received more peer and/or professional support and guidance. A Dutch study of 44 families built using oocyte donation, in which the donor was known to the recipient in all cases, indicated considerable variation among parents as to the age at which they intended to disclose (van Berkel *et al.*, 2007). Of the 36 recipient mothers who intended to disclose, only four (9%) – including two who had already disclosed to their child (the only ones to do so) – said they would do so when their child was

younger than 6 years, five (11%) would disclose when the child was between 6 and 12 years of age, seven (16%) would wait until the child was older than 12 years, nine (21%) would disclose when the child was ‘old enough’ – although giving no indication when this might be – and the remaining 11 (25%) had not decided on the age at which they would disclose.

MANUSCRIPT

ACCEPTED

Disclosure is not, in any event, a simple, one-off event, but a longer-term process that involves dealing with a child’s – and often parents’ – potential desires for

information, including, for some, the wish to identify and connect with the child's half-siblings and/or donors (for a recent review of the extant literature on donor-conceived individuals' views, see Blyth *et al.*, 2012). Some jurisdictions facilitate this process through the establishment of confidential registers of gamete and embryo donors, recipients and children born as a result of donation and by instituting open-identity donation, requiring donors to agree to be identifiable to any offspring who have reached either 'maturity' or a specified age (Blyth and Frith, 2009). The number of such jurisdictions is gradually enlarging and currently includes Austria, Finland, Germany, the Netherlands, New South Wales, New Zealand, Norway, South Australia, Sweden, Switzerland, the UK, Victoria and Western Australia. In Canada, the outcome of an appeal against a ruling by the Supreme Court of British Columbia to end gamete donor anonymity is awaited (Hall, 2011).

While services in the USA are characterized by both anonymous and to a lesser extent open- identity donation according to clinic or agency policy (Scheib and Cushing, 2007), in 2011 Washington became the first American state formally to afford donor-conceived people a qualified right to learn the identity of their donor, although the donor may veto disclosure of his or her identity (Washington State Legislature, 2011).

Suggestions from research findings that more parents may be inclined to disclose to their donor-conceived child the nature of her or his conception have paralleled increasing promotion of the desirability of disclosure among professional groups, for example, the American Society for Reproductive Medicine (2004) and the Australian National Health and Medical Research Council (2007). Advocacy of early disclosure has statutory reinforcement in the UK, where clinics providing assisted reproduction treatment are required to inform those contemplating donor conception of: '(a) the importance of informing any resulting child at an early age that the child results from the gametes of a person who is not a parent of the child, and (b) suitable methods of informing such a child of that fact' (Human Fertilisation and Embryology Act 1990, section 13(6C)).

Guidelines for assisted reproduction treatment providers in the USA issued by the American Society for Reproductive Medicine (ASRM, 2004) advocate advance agreement on how and when programs and sperm banks will release donor information to recipients and the storage of medical and genetic information concerning donors. ASRM considers that counselling and informed consent about disclosure are essential for both donor and recipients. It advises assisted reproduction programmes and sperm banks to expect inquiries from donor-conceived people and to consider developing a written policy to respond to

these. It is worth noting as regards the current paper, that the ASRM guidance does not extend to agencies that recruit oocyte donors. However, since the intervention of an assisted reproduction provider is required in order to undertake oocyte donation, both donors and recipients should have access to services as proposed by ASRM.

As part of a drive to improve the availability of information following donor conception, both in the USA and internationally, the second author co-founded the Donor Sibling Registry

MANUSCRIPT

ACCEPTED

(DSR) in 2000. The DSR is open to a global membership and helps parents of donor-conceived children to search for and contact their child's donor and other families with children sharing the same donor, donor-conceived individuals to search for and contact their donor and/or half-siblings, as well as supplying support, news and education for former donors, prospective donors, families that have used gamete donation to build their family and those interested in doing so. Matches between donor siblings and/or donors are facilitated by use of the unique ID number assigned to donors by clinics, sperm banks or agencies where these are provided to recipients at the time of donor selection. The DSR website is used as an information and communication resource for both members and non-members, receiving approximately 10,000 unique visitors and more than 800,000 'hits' each month. As of January 2010, when the survey that forms the basis of this study closed, 26,400 donors, donor-conceived individuals and parents had registered on the site and 7034 individuals had been matched. As an indication of the pace at which both registrations and matches take place, by June 2012, 36,942 donors, donor-conceived individuals and parents had registered on the site and 9310 individuals had been matched.

The current study is derived from an online survey conducted by the DSR in order to enhance the quality of services to its members by extending the current evidence base concerning the perspectives of parents of children conceived following oocyte donation.

Materials and methods

An online survey of donor oocyte recipients was designed by the second author, based on her experience of working with individuals and families through the DSR and previous research conducted with families built using gamete donation (Freeman *et al.*, 2009; Kramer *et al.*, 2009; Beeson *et al.*, 2011; Jadva *et al.*, 2010, 2011). The survey comprised open-ended and multiple-choice questions that were designed to generate both qualitative and quantitative data concerning: information respondents had received about their donor, their views about using an anonymous or an open-identity donor and about disclosure to their children about their genetic origins, their plans for disclosure, whether or not they have identified or hope to find their child's donor or any half siblings and what advice they would give to parents who are unsure whether to tell their child(ren). The survey was available on the DSR's website, blog and Yahoo group and Facebook pages and was open to both DSR members and non-members from November 2009 to January 2010. Consequently, neither the total potential survey

population nor the response rate are known. Since the initial survey was undertaken as an in-house management exercise, no prior ethics review or approval were required or sought. However, approval of the Research Ethics Panel of the School of Human and Health Sciences at the University of Huddersfield was obtained on 10 March 2011 to enable the first author to participate in the secondary analysis of data derived from the survey and on which the current paper is based.

A total of 108 individuals participated in the survey. Of these, 68 (63.0%) were gestational mothers via oocyte donation, 34 (31.5%) were gestational mothers and fathers via oocyte donation responding jointly, three (2.8%) were single non-gestational mothers via oocyte donation, two (1.9%) were pairs of gestational and non-gestational mothers via oocyte

MANUSCRIPT

donation responding jointly; and one (0.9%) was a non-gestational mother and father via oocyte donation responding jointly. In addition to using donor oocytes, 33 respondents (30.6%) also used donor spermatozoa. With the exception of four couples who used a gestational carrier, each of the respondent mothers was the gestational mother of the resultant child. Responses to all questions were optional; thus, not all respondents answered each question.

Of 104 respondents providing information regarding their marital status, two (1.9%) indicated that they were single lesbians, 19 (18.3%) were single heterosexual women, 68 (65.4%) were married heterosexual women, one (1.0%) was a married lesbian; two (1.9%) were in a civil union/domestic partnership, three (2.9%) were same sex cohabiting and nine (8.7%) were heterosexual cohabiting.

Of the 95 respondents who provided information about their geographical location, 58 (61.1%) resided in the USA, 22 in the UK (23.2%), eight in Australia (8.4%) and five in Canada (5.3%). The remaining two respondents were from European countries other than the UK. Declared religious affiliation included 33 Protestants (35.9%), 14 'spiritual but not religious' (15.2%), 13 Catholic (14.2%), 10 agnostic (10.9%), nine Jewish (9.8%), eight atheist (8.7%) and five 'other' (5.4%). Thirty-seven respondents (34.3%) declared their membership of DSR.

At the time of first donor conception, of the 101 respondents providing information, 72 (71.3%) had never had a baby before, four (4.0%) had a child who had died and seven (6.9%) had had a stillbirth or had miscarried. Of the 93

respondents providing information, 66 (71%) became pregnant within 1 year of trying with donor oocytes, most of these within 1 month (i.e. at the first attempt). Participants' age at first conception with donor oocytes ranged from 29 to 49 years (mean \pm SD 41.0 \pm 3.26 years). Respondents had a total of 143 children conceived following oocyte donation aged 1–15 years (5.2 \pm 3.89 years). Respondents' children were clustered towards the younger pole of the age spectrum, with 84 (58.7%) aged under 5 years. Fifty-four respondents reported the birth of a single child, 34 the birth of two children and seven the birth of three children resulting from oocyte donation. Among these children were 32 sets of twins and two sets of triplets.

Results

Choosing an anonymous or open-identity donor

To facilitate donor selection, many potential recipients received a summary profile of their donor (57/85 responses to this question; 67.1%), a three-generation health record (46/85 responses; 54.1%), a personal statement by the donor (43/85 responses; 50.6%), the donor's fertility history (45/85 responses; 52.9%) and child and/or adult photos of the donor (40/85 responses; 47.1%). They were also usually told the donor's year of birth (53/89 responses; 59.6%), country of birth (41/89 responses; 46.1%), educational institution attended (41/89 responses; 46.1%) and the numbers and ages of any siblings the donor may have (53/89 responses; 59.6%).

MANUSCRIPT

ACCEPTED

The clinic or agency is in the position to advise parents regarding the choice of an anonymous versus open-identity donation and what – if anything – to tell their child. **Table 1** provides information from respondents concerning their recollections of clinic/agency discussions and advice.

Ninety-three respondents with at least one child conceived following oocyte donation provided information about the type of donor they had used. Thirty-two (34.4%) chose an open-identity donor, 24 (25.8%) an anonymous donor and

37 (39.8%) used an anonymous donor because their clinic or agency offered no choice. Two recipients who had chosen an open-identity donor subsequently discovered that the donor was in fact anonymous. Two main reasons given for a preference for an anonymous donor were that respondents did not consider the genetic relationship between donor and offspring to be important or feared that the donor might interfere in their family. When asked about their current views about anonymous versus open-identity donation, respondents were evenly divided as regards their current satisfaction: 20 (54.1%) of those who had been given no choice about using an anonymous donor now wished they had utilized an open-identity donor, as did 12 (50.0%) of those who had chosen an anonymous donor. The survey did not ask whether any respondents subsequently regretted using an open-identity donor.

Of the 88 responses to a question enquiring as to whether anonymous donation that enabled respondents to indicate which of three pre-set answers most strongly supported their reasoning should be permitted, 42 (47.7%) supported anonymous donation on the grounds that 'some women that aren't interested in having contact with offspring would otherwise not choose to be donors'; 40 (45.5%) disapproved of anonymous donation because 'it is not fair to the offspring never to have the right to know their genetic origins'; five (5.7%) disapproved of anonymous donation because 'it shields dishonest donors from being found out and inadvertently encourages dishonesty'; and one (1.1%) provided her own rationale for supporting anonymous donation on the grounds that 'I would never want to give my child the opportunity to know his/her maternal genetic origins'. In response to a separate question regarding anonymity and donor probity, to which 89 respondents replied, 41 (46.1%) agreed that 'anonymous egg donors are more likely to lie about their attributes than open-identity donors', while 48 (53.9%) disagreed.

Disclosure to children about their origins

A key issue for families with a donor-conceived child is what to disclose to the child about his or her conception (Human Fertilisation and Embryology Act 1990; ASRM, 2004; National Health and Medical Research Council, 2007). However, respondents reported various experiences in their dealings with clinics.

First, as regards access to counselling, more than 70% of respondents reported that this was offered by the clinic or agency, most of whom made it compulsory. Almost three-quarters of the 105 respondents providing information had received professional counselling in advance of using donor oocytes (**Table 2**).

MANUSCRIPT

ACCEPTED

Sixty-seven of the 78 respondents who had received counselling (85.9%) provided further information regarding what, if anything, had been discussed in counselling regarding disclosure to the child. More than 70% indicated that they had been advised to disclose at some point in their child's life, all except one recalling that they had been advised to do so 'early in [the child's] life (**Table 3**).

Of 94 persons who responded to the question, 48 (51.1%) indicated that they had already told their child about her or his conception by means of oocyte donation.

Of these, 40 (83.3%) made their initial disclosure before their child was 5 years old, four (8.3%) when the child was 5–7 years old and two (4.2%) at age 8–10 years. Two (4.2%) had told their child as a teenager. Thirty-two of 43 respondents (74.4%) providing information indicated that they had imparted this information to children in stages over time, whereas 11 (25.6%) disclosed on a single occasion. In retrospect, 92.9% (39 out of 42) believed the timing of disclosure had been right, one thought it was too early, one too late and one ‘felt the mood was wrong’. None of the parents who had disclosed to their children reported regret or feeling conflicted about doing so.

Thirty-nine respondents believed their children were still too young to be told. Thirty-six (92.3%) of these had children aged under 5 years. The oldest child still considered to be ‘too young’ was aged 11 years, although the mother also stated that lack of information about the donor had also impacted her decision to withhold this information from her child. Four respondents had not yet decided whether to tell or not (children in these families ranged up to 10 years of age) and three had decided not to tell. The data provided an opportunity to undertake an initial investigation of any relationship between parental choice or use of an anonymous or open-identity donor and subsequent disclosure of donor conception to their child. Understanding of this relationship is limited by the high number of parents in the study who had children aged under 5 years and whom they considered to be ‘too young’ to be told. While it is likely that some of these parents may disclose at a later date, it is also possible that some will never disclose. The analysis of the data that was possible, which has been reported separately (Stephenson *et al.*, 2012), indicates that parental use of an anonymous or open-identity donor makes very little difference to the timing of parental disclosure to children.

Seventy respondents provided free text replies to the question: ‘What would you advise to parents who are not sure they want to tell their child(ren)?’ Sixty-four of these (94.4%) unambiguously indicated that the child should be told about her or his conception and none advocated non-disclosure. Of the remaining six responses, one stated ‘I don’t think it’s up to me to advise’. Three others, two of whom had children aged under 4 years, had not yet made up their minds about telling their own child. Another advised ‘Decide early on what you want to do but be aware that secrets always come out in the end’, and the sixth wrote ‘I don’t have any advice other than that we don’t want to tell our children but are planning on telling them because we don’t want trust issues later in life if they found out on their own’.

MANUSCRIPT

ACCEPTED

Twenty-two respondents (31.4%) not only advocated disclosure, but advised that this should be undertaken early, seven following this through by specifically endorsing disclosure as a process over time rather than as a one-off event. Sixteen (22.9%) explicitly emphasized that the 'story' of egg donation was the child's story to which the child had a right. Twenty- three respondents (32.9%) mentioned inter-related themes clustering around the negative impact of secrets in families and parental obligations to be truthful to their children.

Nine respondents (12.9% of those providing free text responses) also used this opportunity to affirm oocyte donation as a positive means of family building rather than seeing disclosure either as an apology to the child for using a less-than-ideal means of bringing them into the world or simply as a strategy in damage limitation, as the following examples illustrate: 'Families come together in many ways – we are proud of all our children, and their origins – they have a right to know their history/identity'; 'I think of it as a positive that all these people collaborated so that this special child could be born'; 'I told her that I had wanted her for a very long time and someone gave me a precious gift which allowed her to be born into my life. I told her I would not want it any other way because she is absolutely perfect and I cannot imagine her being anyone than who she is'; 'Tell your child how thankful you are that someone else helped you become a parent'.

Identifying and making contact with donors and other families with donor siblings

Respondents were asked about their interest in knowing their oocyte donor, making contact with her and finding out about other families with donor siblings who shared the same donor.

Twelve respondents had both identified and contacted their donor (19% of the 63 respondents providing information), eight of whom indicated that they had located her via the clinic or agency and two had undertaken a successful internet search. Another seven respondents had identified their donor but had not contacted her (11.1%). Ten respondents indicated that they were still searching (15.9%), while 26 were potentially interested in identifying their donor, but had not begun to search (41.3%) and eight (12.7%) indicated that they had no interest in identifying her. Respondents who had established contact with their donor reported that the information about her provided by the clinic or agency was mostly accurate, although one said that medical information provided was 'a complete lie'; two reported 'partially correct but misleading' information concerning the cause of death of immediate family members; two reported 'partially correct – a serious omission/fiction' information concerning skills, talents and interests, while one reported this in relation to the donor's occupation and another in relation to the donor's personal medical history.

Fourteen respondents had established contact with other families who included donor siblings to their own children. Of these, five were in email contact, one had phone contact, three had met, one had visited at the home, one family reported that they had stayed in each other's home and three respondents said they

'regard each other as relatives'.

MANUSCRIPT

ACCEPTED

Respondents were asked if they had been requested by their clinic or agency to report any birth resulting from oocyte donation. Ninety-three provided a response, of whom more than half indicated they had been requested to do so either formally (20; 21.5%) or informally (34; 36.6%). Almost a quarter (21; 22.6%) said they had taken the initiative to report their child's birth without being asked to do so. Thirteen (14.0%) said they did not recollect being asked and

five (5.4%) said that this was neither mentioned to them nor did they know about the recording of births.

They were further asked their views about the establishment of a mandatory national gamete donor registry in the USA for the purposes of: (i) maintaining a database of donors and their identities; (ii) keeping track of where donors donate, and the births reported; (iii) recording donors' genetic test results and health information supplied by donors, recipients and offspring; (iv) making available health information to recipients and offspring; (v) permanently maintaining all such records including donor profiles; and (vi) monitoring the sperm banks, egg donor clinics and other agencies compliance with regulations and screening procedures. The question made explicit that the DSR was actively campaigning for the establishment of such a register. Of 73 responses, 54 (nearly three-quarters), explicitly supported the establishment of such a register, while only two (2.7%) did not want such a registry to be set up.

Discussion

Before discussing the findings from this study or drawing conclusions from these, its limitations need to be acknowledged. It was based on a relatively small number of respondents and from a potential study population of unknown size. Data were self-reported by a self-selected group of anonymous respondents. In addition, since some respondents had to rely on their memory of events taking place up to 16 years previously, responses may be subject to recall errors. These factors, and the absence of interaction between the researchers and respondents, emphasized the study's dependence on information whose accuracy could not be independently verified. Since the purpose of the DSR is to facilitate access to information for families built using donor conception and its views regarding access to information are well known, responses may over-represent individuals with similar views. Indeed, the two main reasons given by DSR members for joining are 'to aid my child with his/her curiosity' and 'to find out about half siblings'. Additionally, knowledge of the DSR's 'mission' may encourage respondents to respond in socially desirable ways or to misrepresent their 'real' views in relation to the information they provide. Although only just over one-third of respondents declared their membership of DSR, nevertheless it is possible that non-members accessing the DSR website are sympathetic to the orientation of DSR and that the sample as a whole might be more favourably disposed towards disclosure and contact with the donor and donor sibling families than the wider population of parents of children conceived following oocyte donation. Therefore, this study makes no attempt to extrapolate these findings to the wider population of parents of children conceived following

oocyte donation. Further, it should be noted that the survey was designed as an information tool for DSR rather than as a research instrument.

MANUSCRIPT

ACCEPTED

Anonymous versus open-identity oocyte donation

Attitudes towards the use of anonymous donors among assisted reproduction professionals, policy makers, law makers and people contemplating use of a donor-conception procedure are evolving over time. Current evidence shows

considerable variations across communities and among different jurisdictions. More than 30% of respondents to this survey resided in Australia and the UK, where the use of anonymous donors is no longer permitted, in the case of the UK by statute and in Australia by virtue of legislation in several states and by professional body accreditation applying to all clinics in Australia (Fertility Society of Australia, 2008), and 60% of respondents resided in the USA, where current practice is to use both anonymous and open-identity donors. The majority of respondents, more than 70%, had used an anonymous donor, although 40 of this group (all from the USA) stated that they did so because their clinic or agency had not offered them the choice of an open-identity donor, and nearly half of those who had used an anonymous donor now wished that they had used an open-identity donor instead. (As noted previously, the survey did not ask if those who had chosen an open-identity donor now regretted doing so, although the overall results indicate that very few respondents, if any, were likely to have done so).

Although most respondents indicated their personal preference for using an open-identity donor, they were divided as to whether anonymous donation should be prohibited, with only slightly more than half agreeing that it should be. For the most part, those who opposed prohibition did so because they thought it would deter some potential donors. Similarly, respondents were divided as to whether they thought anonymous donors were more likely than open-identity donors to provide false information about themselves, with a slight majority (53.9% versus 46.1%) discounting such a risk. All respondents who were concerned about the provision of false information were from the USA, where the availability of both anonymous and open-identity donors is compounded by the general practice of paying donors (which is prohibited in the three other countries outside the USA – Australia, Canada and the UK – from which most of the non-US respondents were drawn).

The survey findings suggest that, especially in the USA where the choice of using either an anonymous or open-identity donor exists, clinics and agencies need to do more to widen the options available to their clientele and to facilitate discussion of the implication of those options. Especially since reproductive autonomy is a prized value, those using oocyte donation to build their family should not be faced with unnecessarily restricted choices that they may later regret. This conclusion is supported by the observation that half of all respondents who had utilized an anonymous donor reported that they now wished they had used an open-identity donor. This is perhaps not surprising given the mode of recruitment for the study via the DSR. The findings that nearly one-third of respondents reported that they had not been offered counselling, that more than half said that the use of an anonymous donor had not been discussed

with anyone at the clinic or agency and that more than three-quarters related that the use of an open-identity donor had not been discussed with anyone at the clinic or agency provide further reinforcement of the need for improvements in professional practice.

MANUSCRIPT

ACCEPTED

Related to the historic trend in the USA for use of anonymous donation is the apparent reluctance of some IVF clinics to obtain follow-up information on births. A surprisingly large number of respondents were never requested by their agency

or clinic to report their child(ren's) birth, a practice that contributes to the problem of generating accurate data about the number of children born in the USA following oocyte donation.

Disclosure versus non-disclosure

More than 70% of respondents indicated that they had been advised to tell their child about her or his conception at some point, all except one recalling that they had been advised to do so early in the child's life. This is consistent with formal guidance to clinics (Human Fertilisation and Embryology Act 1990; ASRM, 2004, National Health and Medical Research Council, 2007). However, it is of concern that almost 30% of respondents reported that they had received no such advice. Since these respondents were not confined to those with older children, it is unlikely that lack of professional encouragement or parental disclosure can be accounted simply by changes in professional ethos over time. In keeping with the advice that most respondents recollected having received, nearly all indicated their intention to tell their child, close to half having already done so, and almost all who provided information said that they had done so before their child reached the age of 7 years, thus illustrating the preference of respondents for the 'seed planting' strategy of disclosure over the 'right time' approach (MacDougall *et al.*, 2007). The emphasis on disclosure, and on early disclosure in particular, is reinforced in the respondents' advice to other parents of a donor-conceived child. Despite the possibility that parents favouring disclosure might be over-represented in this survey, these findings are consistent with other studies reporting high levels of both actual and intended disclosure among parents of children conceived following oocyte donation (Söderström-Anttila *et al.*, 2010; Readings *et al.*, 2011). However, although children were aged under 5 years in more than 80% of cases where parents had already told their child, 90% of children who had not been told because they were deemed to be 'too young' were also aged under 5 years. It is plausible that 'too young' may both serve as a rationalization for postponement of disclosure by parents who find it very difficult to tell their child and as a convenient cover for parents who do not intend to tell their child at all, as well as pointing to considerable uncertainty among parents of young children as to the optimum time of disclosure. This is an issue that warrants further research.

Seeking out donors and families with donor siblings

There is an emerging interest in identifying and making contact with gamete donors and donor siblings, both by the parents of donor-conceived children and by donor-conceived persons themselves, although most of this research has

focused on spermatozoa rather than oocyte donation (see, for example, Scheib *et al.*, 2003; Scheib and Cushing, 2007; Scheib and Ruby, 2008; Freeman *et al.*, 2009; Cushing, 2010; Mahlstedt *et al.*, 2010; Beeson *et al.*, 2011; Hertz and Mattes, 2011; Blyth, 2012a, b). This trend is also exemplified by the number of individuals registering with DSR and using its website and, specifically in relation to oocyte donation, by respondents to the present survey. Currently, very little empirical research has been undertaken concerning the experiences and views of oocyte donors, recipients of

MANUSCRIPT

ACCEPTED

donated oocyte and their partners and individuals born as a result of oocyte donation. A retrospective study of 155 US oocyte donors who were surveyed a mean of 9.4 years after their first donation (range 1–22 years) found an overwhelming willingness to have contact with their donor-conceived children (Kramer *et al.*, 2009). Only 36.7% (57 out of 155 respondents) reported having been counselled on the potential interest of the future children in their donor and any donor siblings.

A recent study of sperm and oocyte donors' experiences of anonymous donation and subsequent contact with their donor-conceived offspring included 11 oocyte donors, only one of whom had contacted and met a recipient and her son (Jadva *et al.*, 2011). She reported that she had been in frequent contact with the family and described this as a 'very positive' experience: 'Having met one of the recipient moms and her son conceived from my oocyte, I know how wonderfully healing and affirming such contact can be for all involved' (Jadva *et al.*, 2011: 643).

The present study makes a modest initial contribution as regards recipients of donated oocytes. Obviously, more research is required in order to gain a fuller understanding of the experiences of donor-recipient–offspring-sibling contact in oocyte donation.

In conclusion, this study complements previous surveys undertaken via the DSR website involving gamete donation (Freeman *et al.*, 2009; Kramer *et al.* 2009; Jadva *et al.*, 2010, 2011). It has highlighted what appear to be emerging trends in oocyte donation as regards anonymous and open-identity donation, disclosure to donor-conceived children and contact between donors and recipient families and between families containing donor siblings. It has indicated where current practice in some clinics and agencies needs to be refined as regards the choice of donor type available to recipients, opportunities for discussion regarding the donor type and access to counselling. At the same time, as the majority of respondents to this survey have indicated, it has shown some of the positive experiences enjoyed by parents who have chosen to build their family through oocyte donation.

References

American Society for Reproductive Medicine, Ethics Committee Report. (2004) Informing offspring of their conception by gamete donation. *Fertil Steril*; **81**: 527–531.

Baetens, P., Devroey, P., Camus, M., Van Steirteghem A. C., and Ponjaert-Kristoffersen, I. (2000) Counselling couples and donors for oocyte donation: The decision to use either known or anonymous oocytes. *Hum Reprod*; 15: 476–484. Beeson D, Jennings P, Kramer W. (2011) Offspring searching for their sperm donors: how family type shapes the process *Hum Reprod*; 26: 2415–2424. Blyth E. Genes R Us? (2012a) Making sense of genetic and non-genetic kinship relationships following anonymous sperm donation. *Reprod BioMed Online*; 24: 719– 726.

Blyth E. (2012b) Discovering the ‘facts of life’ following anonymous donor insemination. *I Journal Law Pol Fam*. doi:10.1093/lawfam/ebs006

Blyth E, Crawshaw M, Frith L, Jones C. (2012) Donor-conceived people’s views and experiences of their genetic origins: A critical analysis of the research evidence. *J Law Med*; 19: 769–789.

MANUSCRIPT

ACCEPTED

Blyth E, Frith L. (2009) Donor-conceived people's access to genetic and biographical history: an analysis of provisions in different jurisdictions permitting disclosure of donor identity. *I J Law Pol Fam*; **23**: 174– 191.

Congregation for the Doctrine of the Faith. (1987) *Donum Vitae*: Instruction on respect for human life in its origin and on the dignity of procreation replies to certain questions of the day. http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19870222_respect-for-human-life_en.html [accessed 15 October 2012]

Cushing A. (2010) 'I just want more information about who I am': The search experience of sperm-donor offspring, searching for information about their donors and genetic heritage. *Inform Res*; 15: 428 <http://informationr.net/ir/15-2/paper428.html> [accessed 15 October 2012]

Fertility Society of Australia Reproductive Technology Accreditation Committee. (2008) Code of Practice for Assisted Reproductive Technology Units. <http://www.fertilitysociety.com.au/wp-content/uploads/20080924-rtac-cop-final.pdf> [accessed 15 October 2012]

Freeman T, Jadvá V, Kramer W, Golombok S. (2009) Gamete donation: parents' experiences of searching for their child's donor siblings and donor. *Hum Reprod*; 24: 505–516.

Golombok S, Lycett E, MacCallum F, Jadvá V, Murray C, Rust J. (2004) Parenting infants conceived by gamete donation. *J Fam Psychol*; 18: 443- 452.

Golombok S., Murray C, Brinsden P, Abdalla H. (1999) Social versus biological parenting: family functioning and the socioemotional development of children conceived by egg or sperm donation. *J Child Psychol Psychiat*; 40: 519–527.

Golombok S, Murray C, Jadvá V, Lycett E, MacCallum F, Rust J. (2006) Non-genetic and non-gestational parenthood: consequences for parent-child relationships and the psychological well-being of mothers, fathers and children at age 3. *Hum Reprod*; 21: 1918–1924.

Greenfeld D A, Klock S C. (2004) Disclosure decisions among known and anonymous oocyte donation recipients. *Fertil Steril*; 81: 1565–1571.

Hahn S J, Craft-Rosenberg M. (2002) The disclosure decisions of parents who conceive children using donor egg. *J Obstet Gynecol Neonatal Nurs*; 31: 283–293.

Hall N. (2011) B.C. government appeals landmark sperm donor ruling *The Vancouver Sun*. June 17. http://www.canada.com/story_print.html?id=09a4c413-1f31-4d99-afbe-599679f28e3e and sponsor [accessed 15 October 2012]

Hertz R, Mattes J. (2011) Donor-shared siblings or genetic strangers: new families, clans, and the internet. *J Fam Iss*; 32: 1129–1155.

Human Fertilisation and Embryology Authority. (2012a) Donor conception: births and children 1992–2009. <http://www.hfea.gov.uk/donor-conception-births.html> [accessed 15 October 2012]

Human Fertilisation and Embryology Authority. (2012b) Donor conception: patients and treatment 1992–2010. <http://www.hfea.gov.uk/donor-conception-treatments.html> [accessed 15 October 2012]

Jadva V, Freeman T, Kramer W, Golombok S. (2010) Experiences of donor offspring searching for and contacting their donor siblings and donor. *Reprod BioMed Online*; 20: 523–532.

Jadva V, Freeman T, Kramer W, Golombok S. (2011) Sperm and oocyte donors' experiences of anonymous donation and subsequent contact with their donor offspring. *Hum Reprod*; 26: 638–645.

MANUSCRIPT

ACCEPTED

Jones H W, Cooke I, Kempers R, Brinsden P, Saunders D. (2010) International Federation of Fertility Societies. Surveillance 2010. http://www.iffs-reproduction.org/documents/IFFS_Surveillance_2010.pdf [accessed 15 October 2012]

Klock S C, Greenfeld D A. (2004) Parents' knowledge about the donors and their attitudes toward disclosure in oocyte donation. *Hum Reprod*; 19: 1575–1579.

Kramer W, Schneider J, Schultz N. (2009) US oocyte donors: a retrospective study of medical and psychological issues. *Hum Reprod*; 24: 3144–3149.

Laruelle C, Place I, Demeestere I, Englert Y, Delbaere A. (2012) Anonymity and secrecy options of recipient couples and donors, and ethnic origins influence in three types of oocyte donation. *Hum Reprod*; 26: 382–390.

Lutjen P, Trounson A, Leeton J, Findlay J, Wood C, Renou P. (1984) The establishment and maintenance of pregnancy using in vitro fertilization and embryo donation in a patient with primary ovarian failure. *Nature*; 307: 174–175.

Mac Dougall K, Becker G, Scheib J E, Nachtigall R D. (2007) Strategies for disclosure: how parents approach telling their children that they were conceived with donor gametes. *Fertil Steril*; 87: 524–533.

Mahlstedt P, LaBounty K, Kennedy T. (2011) The views of adult

offspring of sperm donation: essential feedback for the development of ethical guidelines within the practice of assisted reproductive technology in the United States. *Fertil Steril*; 93: 2236–2246.

Murray C, MacCallum F, Golombok S. (2006) Egg donation parents and their children: follow-up at age 12. *Fertil Steril*; 85: 610–618.

National Health and Medical Research Council. (2007) Ethical guidelines on the use of assisted reproductive technology in clinical practice and research. Canberra: Australian Government.
http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e78.pdf [accessed 15 October 2012]

Pettee D, Weckstein L. (1983) A survey of parental attitudes toward oocyte donation. *Hum Reprod*; 8: 1963–1965.

Readings J, Blake L, Casey P, Jadvá V, Golombok S. (2011) Secrecy, disclosure and everything in-between: decisions of parents of children conceived by donor insemination, egg donation and surrogacy. *Reprod Biomed Online*; 22: 485–495.

Scheib J, Cushing R A. (2007) Open-identity donor insemination in the United States: is it on the rise? *Fertil Steril*; 88: 231–232.

MANUSCRIPT

ACCEPTED

Scheib J, Riordan M, Rubin S. (2003) Choosing identity release sperm donors: the parents' perspective 13–18 years later. *Hum Reprod*; 18: 1115–1127.

Scheib J, Ruby A. (2008) Contact among families who share the same sperm donor. *Fertil Steril*; 90: 33–43.

Society for Assisted Reproduction and Technology. (2012) All SART member clinics.

https://www.sartcorsonline.com/rptCSR_PublicMultiYear.aspx?ClinicPKID = 0. [accessed 15 October 2012]

Söderström-Anttila V, Sajaniemi N, Tiitinen A, Hovatta O. (1998) Health and development of children born after oocyte donation compared with that in those born after in vitro fertilization, and the parents' attitudes regarding secrecy. *Hum Reprod*; 13: 2009–2015.

Söderström-Anttila V, Sälevaara M, Suikkari A M. (2010) Increasing openness in oocyte donation families regarding disclosure over 15 years. *Hum Reprod*; 25: 2535–2542.

Stephenson J, Blyth E, Kramer W, Schneider J. (2012) Donor type and parental disclosure following oocyte donation. *A P J Reprod*; 1: 39–45

van Berkel D, Candido A, Pijffers W H. (2007) Becoming a mother by non-anonymous egg donation: secrecy and the relationship between egg recipient, egg donor, and egg donation child. *J Psych Obstet Gynaecol*; 28: 97–104.

Washington State Legislature (2011) HB 1267–2011–12 Clarifying and expanding the rights and obligations of state registered domestic partners and other couples related to parentage. 2011
<http://apps.leg.wa.gov/billinfo/summary.aspx?bill = 1267 and year = 2011> [accessed 15 October 2012]

Weil E, Cornet D, Sibony C, Mandelbaum J, Salat-Baroux J. (1994) Psychological aspects in anonymous and non-anonymous oocyte donation. *Hum Reprod*; 9: 1344–1347.

Declaration: The authors report no financial or commercial conflicts of interest.

MANUSCRIPT

ACCEPTED

Table 1. Discussions and advice given by clinics or agencies regarding choice of anonymous or open-identity donor.

Discussed

Use of anonymous donor 24 (26.7) Use of open-identity donor 12 (14.6)

Values are *n* (%).

Advised not to

1 (1.1) 0

Advised to

14 (15.6) 7 (8.5)

Not discussed Total

51 (56.7) 90 63 (76.8) 82

MANUSCRIPT

ACCEPTED

Table 2. Did you have any professional counselling before you started out along the egg donor route? (*n* = 105)

Response

No, it just never occurred to me/us No, did consider it but decided against it No, the agency/clinic offered it but I/we declined No, for other reasons Yes, I/we discussed it with a counsellor whom I/we sought out alone Yes, the agency/clinic arranged counselling – it was mandatory Yes, the agency/clinic arranged counselling – it was optional

n %

11 10.5 4 3.8 6 5.7 6 5.7 8 7.6 66 62.9 4 3.8

MANUSCRIPT

ACCEPTED

Table 3. If you had professional counselling prior to using donor eggs, did the counsellor advise you (*n* = 67).

n%

47 70.1 1 1.5 0 0 2 3.0 26 38.8 31 46.3 24 35.8 23 34.3 0 0

MANUSCRIPT

To tell the child that s/he was donor conceived early in life To tell the child that s/he was donor conceived at adolescence To tell the child that s/he was donor conceived at adulthood Not to tell the child that s/he was donor conceived Genetics don't make a family A child would likely have curiosity about his/her maternal heritage Knowing one is donor conceived is important for healthcare reasons Your child could have half siblings Telling a child s/he is donor conceived may prevent unwitting incest About the existence of the DSR About other support groups for gamete donor families

Respondents were asked to indicate all responses that applied, so the total number is greater than 67.

ACCEPTED