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A survey of 1700 women who formed their families using donor spermatozoa

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Abstract: This paper reports the results of an online survey of 1700 recipients of donor spermatozoa conducted by the Donor Sibling Registry, aiming to understand the perspectives of respondents who had used donor spermatozoa. The survey examined: choice of sperm bank and donor; reporting of births and genetic disorders; disclosure; contact with donor and half-siblings; regulation of sperm donor activity and genetic testing; and access to medical information. The respondents formed three groups: single women; women in a same-sex relationship; and women in a heterosexual relationship. Some differences between the three cohorts were observed: preinsemination counselling; acceptance of donors without medical records or with chronic or late-onset diseases; awareness of choice of bank and type of donor; and views on the right of offspring to know their genetic origins. However, important areas of common ground were identified: the wish by those who had used an anonymous donor that they had used an open-identity donor; support for, and willingness to pay for, comprehensive genetic testing of donors; and desire for access to their donor's family health information. The implications of these results for policies concerning the use and management of donor spermatozoa will be discussed.

Keywords: anonymity, disclosure, donor limits, genetic and psychological testing, health information, sperm donor conception

Introduction

Previous research into the experiences of parents who have formed a family using donor conception has largely focused on anonymity and disclosure (Almack, 2006; Becker et al., 2005; Bos et al., 2003; Brewaeys et al., 1993; Burr, 2009; Cook et al., 1995; Donovan and Wilson, 2008; Gartrell et al., 2000; Grace et al., 2008; Haimes and Weiner, 2000; Nachtigall et al., 1997; Scheib et al., 2003; Shehab et al., 2008; Suter et al., 2008; Touroni and Coyle, 2002; Werner and Westersthål, 2008) and, more recently, on the experiences of these parents and their offspring with regard to searching for their donor and half-siblings (Blyth, 2012; Freeman et al., 2009; Jadva et al., 2010). Despite this volume of research, the experiences and concerns of the recipients of donor spermatozoa regarding how the sperm banking industry operates has not been thoroughly investigated. This is particularly relevant to the USA, due to the current lack of industry regulation. This study complements an investigation of non-biological parents by Frith et al. (2012) that examined the different experiences and perspectives of the male and female non-biological parent in the donor insemination family partnership and extends the work of Scheib et al. (2003). It is unique in that it compares the

experiences, perspectives and concerns of three cohorts of women who were the genetic mothers of children conceived using donor spermatozoa: single mothers, mothers in a heterosexual relationship and mothers in a lesbian relationship. These mothers used their own eggs with donor spermatozoa and carried their own pregnancies. Additionally, the study investigates whether these mothers' experiences and concerns relate to their relationship status - single or partnered – at the time of first conception using donor spermatozoa. This paper identifies and discusses the similarities and differences between the experiences and perspectives of these groups of mothers.

Materials and methods

Survey method

The Donor Sibling Registry (DSR), founded in 2000, is a global, non-profit organization that facilitates contact between those conceived with donor gametes and their donors and half-siblings and has more than 38,000 members. Between October 2009 and January 2010 the DSR conducted an online survey of recipients of donor spermatozoa, one of seven surveys posted concurrently. All DSR members were invited by email to participate in the study and an invitation was also posted on the DSR's open access sites (blog, Yahoo Group and Facebook page) in order to extend participation to non-DSR members. The survey design and questions were based on the experience of the DSR over the 10 years it had been working with donor families and on previous surveys and research (Freeman et al., 2009). Survey Monkey was used to construct a 147-question survey which covered key areas of interest: choosing a donor; reporting of births and offspring health problems; genetic testing and access to health information; limiting donor use; donor and half-sibling contact; and balance of donor and offspring rights. The questions were answered using tick boxes while some questions provided space for respondents to write comments. The survey results were generated from a convenience sample and was not designed to provide data for use in hypothesis testing, so reliability and validity tests were not conducted (Concato et al., 2000; Smith, 1983). The results are therefore presented as descriptive statistics (in the form of proportions). The overall proportion for any given question is the proportion of respondents who answered in a particular way, out of all the respondents to that question. These are reported as percentages, in-text. Conversely, where differences between cohorts are detected and discussed, proportions (percentages) are presented. As not all respondents answered every question, the response size for individual questions is reported. For some questions, not all the possible response options are reported (due to space) and therefore reported counts will not add up to the total count of those who responded to that question. Thus, the associated proportions (percentages) are related to the total count of all possible responses not just to the sum of counts for the options that have been reported.

The study was a non-intervention study carried out by the DSR, and no formal ethics committee approval was sought prior to data collection. Consent was implied by a willingness to complete the survey, which the respondents voluntarily accessed in their own time. The information given to the respondents at the beginning of the survey was: 'By answering this questionnaire, you will be providing the information the DSR needs to enhance the services it provides, better support its members' needs and also help to better educate the industry and the public.' Ethical oversight of the project was ensured by the collection of data in accordance with the ethical guidelines of the International Sociological Association (2001) and ethics approval for analysis of these data was given by School of Human and Health Science's ethics committee, University of Huddersfield (approved 10

March 2011). Assurances were provided in the ethics application that confidentiality of all participants would be carefully protected, with all original survey data collected anonymously and electronically stored securely by the Survey Monkey system.

Participants

Seventeen hundred women participated in this survey, with 92.8% (1577) clicking through every page – although not answering every question. It was not possible to determine a response rate as the survey was posted online, with open access, and the participant pool was open-ended. A majority of 1587 respondents (61.7%) were DSR members. Of the 1585 respondents who answered the question about their residency, 85.0% (1348) were from the USA, 6.7% (106) from Canada, 4.3% (68) from the UK, 2.2% (35) from Australia and 1.8% (28) from other countries. All respondents were the genetic mothers of children conceived using donor spermatozoa, with over one-third (37.3%) of 1682 respondents reporting that they were single when they first conceived using donor spermatozoa. Approximately one-quarter (24.5%) were co-habiting lesbians, approximately one-fifth (21.3%) were married, and only small fractions described themselves as in a co-habiting heterosexual relationship (1.7%), in a civil/domestic arrangement (8.5%) or divorced (5.9%). These groups have been put into three cohorts: single mothers (5.5% of whom were lesbian), which includes the single, divorced, separated and widowed respondents (n = 740); lesbian couples, comprising co-habiting lesbian mothers and those in a civil/domestic arrangement (n = 555); and heterosexual couples, comprising married mothers and those in a co-habiting heterosexual relationship (n = 387). Cohort allocation was based on respondents’ relationship status at the time of first conception.

These cohorts are used as a basis for comparison. Eighteen respondents skipped the question regarding relationship status, so although their responses are included in overall proportions, they are not included in any cohort comparisons. Thus, in some instances overall counts will be more than the sum of the counts from the individual cohorts: cross tabulations between relationship status at time of first conception and any other question will only include respondents who answer both questions. The tables report the differences between the cohorts.

Results

Participants

Nearly half of 1695 respondents (48.7%) indicated that they were aged 35–40 years when they first conceived using donor spermatozoa. At the time they completed the survey, respondents in a heterosexual relationship were older than single or lesbian-couple respondents (Table 1). At the time of survey completion, the median age of heterosexual couples’ first DI child (10 years) was markedly higher than those of the single (5 years) or lesbian-couple mothers (6 years). More precisely, a lower proportion of heterosexual-couple mothers had children aged between 1 and 5 years (32.8%), compared with 51.5% and 46.2% of single and lesbian-couple mothers, respectively (Table 1). Conversely, a higher proportion of these mothers had children older than 20 years (16.0%), compared with single (3.9%) and lesbian-couple mothers (2.2%).

Table1: Age of respondents and counselling uptake

| Relationship status when 1 st conceived (n = 1,682) | | |
|--|----------------|---------------|
| Single | Lesbian Couple | Hetero Couple |

| | (n=740, 44.0%) | (n=555, 33.0%) | (n=387, 23.0%) |
|---|----------------------|----------------------|----------------------|
| Respondents' age at time of survey (years) | 714 responses | 542 responses | 380 responses |
| Under 30 | 4 (0.6%) | 12 (2.2%) | 10 (2.6%) |
| 30-39 | 159 (22.3%) | 207 (38.2%) | 112 (29.5%) |
| 40-49 | 374 (52.4%) | 260 (48.0%) | 148 (38.9%) |
| 50+ | 177 (24.8%) | 63 (11.6%) | 110 (28.9%) |
| Age of 1st DI child at time of survey (years) | 674 responses | 506 responses | 369 responses |
| 1-5 | 347 (51.5%) | 234 (46.2%) | 121 (32.8%) |
| 6-15 | 255 (37.8%) | 221 (43.7%) | 133 (36.0%) |
| 16-20 | 46 (6.8%) | 40 (7.9%) | 56 (15.2%) |
| 21+ | 26 (3.9%) | 11 (2.2%) | 59 (16.0%) |
| Had pre-insemination counselling: | 736 responses | 549 responses | 380 responses |
| Never occurred to me | 309 (42.0%) | 314 (57.2%) | 186 (48.9%) |
| Sought out personally | 123 (16.7%) | 55 (10.0%) | 42 (11.1%) |
| Arranged by clinic – mandatory | 183 (24.9%) | 104 (18.9%) | 91 (23.9%) |
| Partner did not | N/A | 410 (74.6%) | 243 (63.7%) |
| Counselled to: | 252 responses | 136 responses | 140 responses |
| Tell child 'genetics don't make a family' | 65 (25.8%) | 49 (36.0%) | 55 (39.3%) |

Choosing a bank and donor

Of 1681 respondents, 61.5% did not receive professional counselling before they embarked on conception using donor spermatozoa, neither did 71.6% of partners. A higher proportion of those in a lesbian relationship did not receive counselling and a smaller proportion of single respondents indicated that it never occurred to them to seek professional counselling. Correspondingly, a higher proportion of single respondents personally sought counselling, and of the three cohorts, a lower proportion of lesbian-couple respondents had mandatory counselling arranged by their clinic (Table 1).

Of those who received counselling, nearly two-thirds (61.0%) recalled being advised to tell their child early in life that they were donor conceived and nearly one-third were advised to tell their child that genetics don't make a family (31.7%). A comparatively lower proportion of single respondents were given this advice (Table 1).

Sperm bank selection

When it came to selecting a sperm bank, 777 (47.3%) of 1644 respondents indicated that the level of information about the donor provided by the bank was an important factor, as was the bank's reputation (46.1%). A substantially higher proportion of heterosexual-couple respondents indicated that they did not choose the bank and rated the level of information about the donor provided and the bank's reputation similarly to their single and lesbian-couple counterparts (Table 2).

Table 2: Sperm bank and open identity donor selection

| Question | Relationship status when first conceived (n = 1,682) | | |
|--|--|-------------------------------|------------------------------|
| | Single 740 (44.0%) | Lesbian Couple 555 (33.0%) | Hetero couple 367 (23.0%) |
| Selected sperm bank based on: | 605 responses | 406 responses | 338 responses |
| Geographic proximity | 155 (25.6%) | 97 (23.9%) | 69(20.4%) |
| Reputation | 305 (50.4%) | 194 (47.8%) | 111 (32.8%) |
| Number of available donors | 207 (34.2%) | 128(31.5%) | 89 (26.3%) |
| Level of information about donor | 320(52.9%) | 190 (46.8%) | 110 (32.5%) |
| Availability of identity- release donors | 116 (19.2%) | 71 (17.5%) | 32 (9.5%) |
| Did not choose bank | 102 (16.9%) | 59 (14.5%) | 124 (36.7%) |
| Chose open-identity donor: | 731 responses | 551 responses | 372 responses |
| Yes | 218 (29.8%) | 174 (31.6%) | 55 (14.8%) |
| No | 338 (46.2%) | 255 (46.3%) | 178 (47.8%) |
| No choice | 157 (21.5%) | 107 (19.4%) | 126 (33.9%) |
| Why open-identity donor not used: | 515 responses | 379 responses | 322 responses |
| Bank did not offer open-identity donors | 253 (49.1%) | 172 (45.4%) | 156 (48.4%) |
| Unaware open identity existed | 71 (13.8%) | 34 (9.0%) | 69(21.4%) |

Donor selection

Nearly three-quarters (73%) of 1669 respondents reported that they had used an anonymous donor. When asked why they did not use a donor who had agreed to the release of his identity to offspring who requested this when they turned 18 (an open-identity donor), almost half (47.8%) of 1225 respondents reported that such donors were not offered by their bank. Overall, nearly 15.0% were unaware that open-identity donors existed. Single and lesbian-couple respondents were less likely to be unaware than heterosexual-couple respondents (Table 2). Nearly half of the respondents reported that they had specifically not chosen an open-identity donor (46.7%). Overall, 61.2% of 1191 respondents reported that they wished now that they had used an open-identity donor. However, higher proportions of single and lesbian-couple respondents had deliberately chosen an open-identity donor compared with heterosexual-couple respondents.

Interestingly, a higher proportion of heterosexual-couple respondents indicated that they had not been given a choice compared with single and lesbian-couple respondents (Table 2). Forty-six (2.8%) of 1669 respondents indicated that they thought that they had chosen an open-identity donor, but later discovered that their donor had not agreed to release his identity. Of the 1507 respondents, 54.9% indicated that anonymous donation should be permitted. Specifically, a smaller proportion of heterosexual-couple respondents agreed that anonymous donation should be permitted, compared with single and lesbian-couple respondents, and a correspondingly higher proportion of the parents in a heterosexual relationship believed that anonymous donation was unfair to the offspring (Table 3). In response to a question about linking anonymous donation and ‘dishonesty’, 48.5% of 1531 respondents believed that anonymous donors might be more likely to be dishonest with the information provided to sperm banks. A slightly higher proportion of respondents in a heterosexual relationship adhered to this view (Table 3).

Respondents were invited to identify the five most important attributes when choosing a donor. Of 1597 respondents, almost two-thirds (65.2%) identified donor’s health and one-half

(50.7%) identified donor's family health as one of the five most important attributes. One-half (50.0%) also indicated that the donor's intelligence was one of the top five, with approximately 40% also including donor's height (42.7%) and ethnicity (40.7%). Heterosexual-couple respondents prioritized donor's health, donor's family health and intelligence similarly to the other two cohorts (Table 3). Approximately half (50.8%) of all respondents reported that they had rejected donors who otherwise met their criteria but had health issues in their background. A smaller proportion of heterosexual-couple respondents were of this view, with a slightly higher proportion then likely to reject a donor with certain diseases but prepared to accept chronic or a family history of late-onset disease (Table 3). Over 80.0% of 1678 respondents (82.4%) indicated that they would not have been prepared to buy the spermatozoa of a donor with no medical record provided. Compared with single and lesbian-couple respondents, a smaller proportion of heterosexual-couple respondents held this view, and correspondingly, a considerably higher proportion of these respondents then indicated that they had bought spermatozoa without medical records because they had no choice (Table 3).

Table 3 Views on anonymity and donor selection criteria

| Question | Relationship status when 1 st conceived (n = 1,682) | | |
|--|--|-------------------------------|------------------------------|
| | Single 740 (44.0%) | Lesbian Couple 555 (33.0%) | Hetero couple 387 (23.0%) |
| Anonymous donors be permitted: | 659 responses | 485 responses | 355 responses |
| Yes | 373 (56.4%) | 314 (64.7%) | 162 (45.6%) |
| No, not fair on offspring | 228(34.6%) | 130 (26.8%) | 157 (44.2%) |
| Donor: | 669 responses | 500 responses | 354 responses |
| Anonymous more likely to be 'dishonest' | 310 (46.3%) | 234 (46.8%) | 194 (54.8%) |
| Attributes when choosing a donor: | 714 responses | 544 responses | 323 responses |
| Donor's health | 474 (66.4%) | 368 (67.6%) | 188 (58.2%) |
| Donor's family health | 374 (52.4%) | 303 (55.7%) | 125 (38.7%) |
| Intelligence | 391 (54.8%) | 261 (48.0%) | 137 (42.4%) |
| Height | 310 (43.4%) | 208(38.2%) | 156 (48.3%) |
| Ethnicity | 254 (35.6%) | 245 (45.0%) | 146 (45.2%) |
| Health records : | 709 responses | 543 responses | 331 responses |
| Rejected donor based on health issues | 365 (51.5%) | 297 (54.7%) | 141 (42.6%) |
| Accepted chronic or late onset disease | 258(36.4%) | 179 (33.05) | 127 (38.4%) |
| Medical records: | 732 responses | 552 responses | 378 responses |
| Not bought sperm if no medical records | 624 (85.2%) | 491 (88.9%) | 251 (66.4%) |
| Bought sperm without because 'no choice' | 50 (8.1%) | 37 (9%) | 95 (27.1%) |

Reporting births and genetic disorders

Donor-conceived births

Only about half (55.0%) of 1582 respondents were requested by the sperm bank to report their child's birth. Of all respondents, 18.0% did not recollect being asked and nearly 10.0% didn't even know about recording births. A higher proportion of lesbian-couple respondents were requested by their bank to report the birth of their child, either through a mailed form or informally. However, a higher proportion of single respondents took the initiative to report their child's birth. When asked if their sperm bank was aware of their child's birth, 69.0% of

1560 respondents indicated that they had personally notified their sperm bank about the birth of their donor-conceived child, with just 11.2% indicating that their clinic had reported the birth to the sperm bank. A slightly higher proportion of respondents in a heterosexual relationship indicated that they thought that the sperm bank did not know of the birth of their child and, predictably, a lower proportion of these respondents had personally reported the birth of their child to their sperm bank (Table 4).

Table 4 Reporting of births to sperm banks

| Question | Relationship status when 1 st conceived (n = 1,682) | | |
|---|--|-------------------------------|------------------------------|
| | Single 740 (44.0%) | Lesbian Couple 555 (33.0%) | Hetero couple 387 (23.0%) |
| Reporting births: | 686 responses | 517 responses | 357 responses |
| Personally reported birth to sperm bank | 478 (69.7%) | 382 (73.9%) | 216 (60.5%) |
| Doctor/clinic reported birth | 73 (10.6%) | 58(10.8%) | 46 (12.9%) |
| Think bank doesn't know | 81 (11.8%) | 47 (9.1%) | 69 (19.3%) |
| No, I never let them know | 54 (7.9%) | 32 (6.2%) | 26 (7.3%) |
| Requested by bank to report birth: | 695 responses | 525 responses | 362 responses |
| Reported on own initiative | 137 (19.7%) | 78 (14.9%) | 60 (16.6%) |
| Requested formally by bank | 165 (23.7%) | 150 (26.6%) | 75 (20.7%) |
| Requested informally by bank | 209 (30.1%) | 180 (34.3%) | 90 (24.9%) |
| Was not asked to report birth | 122(17.6%) | 83 (15.8%) | 78 (21.5%) |
| Didn't know about recording births | 62 (8.9%) | 34 (6.5%) | 59 (16.3%) |

Health issues

Four hundred and forty-nine respondents (26.4%) provided information about the health of their child. Of these, 30.3% said their child suffered from allergies; additionally, a range of other conditions were mentioned (Table 5). Of the 352 respondents who suspected that their child had acquired an hereditary disease from their sperm donor, over two-thirds had done nothing yet, with the remainder having reported or tried to report their child's medical problems to the sperm bank personally, through their doctor, or posted it on the DSR listing. A relatively smaller proportion of heterosexual-couple respondents had reported their child's health problems to the sperm bank (Table 5).

Bank response to reports of genetic disorder

Of the 101 respondents who had reported or tried reporting health issues to their sperm bank, one-third (33.3%) indicated the sperm bank's response was to have their geneticist contact them for fuller information. Nearly two-fifths (28.7%) thought the response of their sperm bank showed real concern, but then nearly one-fifth (19.8%) received a denial that the problem could lie with their donor, while exactly the same number encountered disinterest and 14 respondents (13.9%) did not receive any response. Seven (6.9%) respondents reported being passed around and not notified about what the bank was doing (Table 5). Of the 95 respondents who indicated that the bank accepted notification of their child's disorder, over two-thirds (65.3%) reported that they did not know what measures the sperm bank took, 12.6% reported that as far as they were aware they had taken no action, with only eight (8.4%) respondents reporting that the bank withdrew the donor's spermatozoa immediately or restricted the sale to families that had already had children through him (Table 5).

Table 5 Health issues of offspring: incidence and reporting

| Question | Relationship status when 1 st conceived (n = 1,682) | | |
|--|--|-------------------------------|------------------------------|
| | Single 740 (44.0%) | Lesbian Couple 555 (33.0%) | Hetero couple 387 (23.0%) |
| Strongly suspected: | 182 responses | 135 responses | 133 responses |
| ADD or ADHD (n=105) | 34 (18.6%) | 30(21.9%) | 41 (30.8%) |
| Allergies (n=136) | 61 (33.5%) | 37 (27.4%) | 38 (28.6%) |
| Asperger's or Autism (n=46) | 13 (8.2%) | 22 (16.2%) | 9 (6.8%) |
| Asthma (n=105) | 47 (25.8%) | 32 (23.7%) | 26 (19.5%) |
| OCD, anxiety or panic disorder (n=80) | 32 (17.6%) | 16 (9.1%) | 32 (24.1%) |
| Eczema (n=87) | 36 (19.8%) | 23 (17%) | 28 (21.1%) |
| Dyslexia, speech, learning disability (n=71) | 24 (13.1%) | 25 (18.5%) | 22 (16.6%) |
| Bi-polarism or epilepsy (n=22) | 7 (3.8%) | 4 (3%) | 11 (8.3%) |
| Reporting genetic health problems: | 142 responses | 108 responses | 102 responses |
| Reported health problems to bank | 33 (23.2%) | 25.9% (28) | 17.8% (18) |
| Tried to report | 4 (2.8%) | 6.5% (7) | 5.9% (6) |
| Done nothing yet | 100 (70.4%) | 59.3% (64) | 66.7% (68) |
| Bank's response to health problem: | 42 responses | 34 responses | 25 responses |
| Geneticist would contact them | 14 (33.3%) | 14 (41.2%) | 5 (20.0%) |
| Disinterest | 13 (31.0%) | 5 (14.7%) | 2 (8%) |
| Real concern | 11 (26.2%) | 11 (32.4%) | 7 (28%) |
| Denied donor the problem | 9 (21.4%) | 5 (14.7%) | 6 (24%) |
| Did not respond | 6 (14.3%) | 2 (5.9%) | 6 (24%) |
| Measures taken by sperm bank: | 36 responses | 36 responses | 23 responses |
| Don't know what measures | 22 (61.1%) | 22 (61.1%) | 18 (78.3%) |
| No action, kept donor in catalogue | 7 (19.4%) | 4 (11.1%) | 1 (4.3%) |
| Restricted to families with donor's child | 4 (11.1%) | 4 (11.1%) | 0 |
| Withdrew sperm from sale | 2 (5.6%) | 3 (8.3%) | 3 (13%) |

Disclosure and contact

Disclosure of donor origins

Of 1590 respondents, 875 (55.0%) indicated that they had told their child that they were donor conceived. Of the remaining 715 respondents who had not done so, most (608) believed their child was still too young to know, 59 simply reported they had not told their child, 21 were undecided, a further 19 indicated that they had no intention of ever informing their child about their donor origins and eight reported that they will only tell if there is a very good cause (Table 6). A vast majority (87.7%) of those who believed their child was still too young had children younger than six years of age. Since higher proportions of single or lesbian-couple mothers had children of this age, they were more likely to be of the opinion that their child was still too young (Tables 1 and 6).

Respondents were asked to provide the main reason for non-disclosure. Of 83 responses, 68 (81.9%) were from heterosexual-couple respondents. Consequently, of the 13 respondents who reported that the main reason was that there was no reason to tell, 10 (76.9%) were in a heterosexual relationship. Of a further 11 who reasoned that it would hurt their spouse/partner and eight who indicated that it was because they had no information about the donor, all were heterosexual-couple respondents (Table 6).

Thirty-one respondents cited other reasons for not disclosing and these ranged from concerns about child's age, leaving the age of disclosure too late, teenage child's immaturity, partner's anxiety, advice not to disclose and associated indecision and child's medical problems.

Table 6 Telling and contact issues

| Relationship status when 1st conceived (n = 1,682) | | | |
|--|-------------------------------|---------------------------------------|--------------------------------------|
| Question | Single 740 (44.0%) | Lesbian Couple 555 (33.0%) | Hetero couple 387 (23.0%) |
| Told child they are donor conceived: | 693 responses | 524 responses | 373 responses |
| Yes | 397 (57.3%) | 276 (52.7%) | 202 (54.2%) |
| Still too young | 284 (41.0%) | 232(44.3%) | 92 (24.7%) |
| No | 7 (1.0%) | 12 (2.3%) | 40 (10.7%) |
| Undecided | 4 (0.6%) | 4 (0.8%) | 13 (3.5%) |
| Never intend to do so | 1 (0.1%) | - | 18 (4.8%) |
| Will only tell if there is a very good cause | - | - | 8 (2.1%) |
| Main reason for non-disclosure: | 6 responses | 9 responses | 68 responses |
| Other | 3 (50.0%) | 6 (66.7%) | 22 (32.4%) |
| No reason to tell | 1 (16.7%) | 2 (22.2%) | 10 (14.7%) |
| Would hurt spouse/partner | - | - | 11 (16.2%) |
| No information about donor | - | - | 8 (11.8%) |
| Hurt child to know | - | 1 (11.1%) | 6 (8.8%) |
| Partner refuses to allow | - | - | 6 (8.8%) |
| Damage partner's relationship with child | - | - | 5 (6.0%) |
| Too emotionally difficult to discuss | 2 (33.3%) | - | - |
| Half-siblings: | 433 responses | 318 responses | 168 responses |
| Visited in home | 42 (9.7%) | 32 (7.2%) | 4 (2.5%) |
| Met | 56 (12.9%) | 42 (13.2%) | 24 (14.7%) |
| Regard as relative | 46 (10.6%) | 38 (11.9%) | 14 (8.6%) |
| Regulation issues: | | | |
| Donations: | 680 responses | 502 responses | 361 responses |
| Restrictions on donating at multiple banks | 547 (80.4%) | 371 (73.9%) | 284 (78.7%) |
| Selling to other banks/overseas: | 657 responses | 494 responses | 342 responses |
| Concern re access to medical information | 84 (12.8%) | 74 (15.0%) | 70 (20.5%) |

Contact with donor and half-siblings

Only 62 of 1413 respondents (4.4%) had successfully identified and contacted their donor, although 276 (19.5%) were still searching for him and about half (51.7%) indicated potential future interest in discovering their donor's identity. A fifth of respondents reported that they had no interest in learning his identity.

In marked contrast, however, over half (53.0%) of respondents had made contact with their children's genetic half-siblings, with a slightly higher proportion of single and lesbian-couple respondents having visited them in their home. Slightly higher proportions of single and lesbian-couple respondents indicated that, with respect to their children's half-siblings, they regarded each other as relatives and similar proportions indicated that they had met (Table 6). The majority (91.1%) of 1478 respondents expressed the view that offspring had the right to

seek out their donor, regardless of any promises a recipient might have made about not searching out their donor.

Regulation of bank and donor practices

Genetic and psychological testing

Of 1025 respondents, 67.1% agreed that sperm banks should be legally required to perform comprehensive genetic testing on all sperm donors, and of 1552 respondents, 78.2% indicated that psychological testing of donors should be mandatory. Furthermore, the explicit payment of donors was supported by 81.0% of 1528 respondents, and 83.9% indicated that they would be prepared to pay more for spermatozoa to ensure proper testing.

Limiting offspring and donations

When asked their opinion about the maximum number of offspring who may be born from a single donor, 75.0% of 621 respondents specified upper limits between one and 10, with 43.2% indicating exactly 10 offspring per donor. A small proportion (5.0%) of respondents thought that as many as 25 offspring was acceptable. Seventy-eight percent of 1562 respondents indicated that donors should be restricted from donating at more than one bank. Heterosexual-couple and single respondents were slightly more in favour of this restriction than respondents in a lesbian relationship (Table 6). With respect to genetic disorders, 97.5% of 1533 respondents agreed that donation from a man with a serious genetic disorder should be prohibited without disclosure of his family's medical history.

Access to medical information

A vast majority (91.2%) of 1554 respondents were of the opinion that the sperm bank should divulge all reported health issues, and let the recipient parent/s make the decision for themselves as to whether it is a relevant health concern or not, or a risk they want to take, and 84.5% of 1524 respondents believed that women who have offspring with serious genetic disorders who want to obtain more medical information about the donor should be entitled to do so. However, 15.5% (236) of these same 1524 respondents were of the opinion that the donors' responsibilities ended at the point of donation.

Discussion

Limitations

There are some limitations to this study that need to be borne in mind when interpreting the results. First, as with all research based on self-selection, those who were more willing to discuss their experiences of donation were more likely to respond to the survey. Furthermore, the survey was conducted by the DSR and the majority of respondents (61.7%) were DSR members. The DSR was established to assist individuals conceived from donor gametes to make contact with their donor and half-siblings. Therefore, it is possible that this group are more likely to have a greater interest in such contact than non-members and the results should be interpreted in light of this. Further, those who use known donors would not have the same need to join the DSR, although it is evident that some respondents had used an open-identity sperm donor. Nevertheless, it is likely that this survey under-represents the views of those who have used an open-identity donor. In light of these factors, generalizations to the wider population of DI recipients are not possible. A second limitation was the geographic and temporal variation between the respondents and, thus, within the data. Respondents came from varying geographic locations that reflect very different policies and legislative

frameworks and they had used donor spermatozoa to become a parent at different times over many years. This makes it difficult to draw conclusions, especially about trends in attitudes regarding disclosure and anonymity. Furthermore, the survey was conducted online and the respondents did not necessarily answer all the questions, resulting in a low response rate to some questions. Nevertheless, online surveys are a valuable research tool as they provide an opportunity to elicit information expeditiously and economically from a large number of respondents located over a wide geographical area (Wright, 2005). So, despite these limitations, this study can offer some insight into the distinctive concerns of mothers of donor-conceived children and allows comparison between single mothers and mothers in heterosexual or lesbian relationships.

Similarities and differences between the cohorts

There appeared to be little difference between the cohorts regarding their use of an anonymous donor and the subsequent wish of those who had used an anonymous donor that they had used an open-identity donor instead. There was also little difference with regard to the proportion reporting that open-identity donors had not been offered by their bank, and the proportion reporting that they had specifically not chosen an open-identity donor. There was agreement that men with serious genetic disorders should be prohibited from donating unless they divulge their family medical history and that psychological testing should be mandatory. There was consensus among the cohorts that donors should be paid, that they would pay more for more comprehensive genetic testing and that women with children with genetic disorders should have access to more medical information.

There was a marked difference, however, between the cohorts with regard to preinsemination counselling, acceptance of donors with chronic or late-onset diseases and concern about the rights of offspring to know their genetic origins. More specifically, there appeared to be a consistent difference in the experiences, perspectives and opinions of respondents in a heterosexual relationship compared with those who were single or in a lesbian relationship, at the time of conception. Respondents in a heterosexual relationship were generally older than their single or lesbian-couple counterparts and less likely to be aware of, and to use, an open-identity donor. They were then comparatively more likely to accept a donor without medical records, to have bought spermatozoa without medical records and to never disclose donor origins, less likely to know about recording births and therefore less likely to report the birth of their child or to choose their bank. Thus, it would appear that relationship status – single or partnered – does not explain the difference in responses. It could be the socio-political norms surrounding the use of donor conception at the time of first conception that are likely to influence the perspectives and opinions of these mothers (Curie-Cohen et al., 1979; Daniels and Golden, 2004; Shapiro et al., 1990). Since respondents in a heterosexual relationship were generally older at the time they responded to the survey it seems reasonable to suggest that they first used donor spermatozoa at a time when donor conception was mainly available to women in a heterosexual relationship, when the use of anonymous donors was usual practice, when secrecy and non-disclosure was encouraged, when all aspects of the process were controlled by medical practitioners and when there was no option to access donor information and/or to be offered a choice of donor (Cahn, 2008; Sylvester and Burt, 2007).

Choice of donor

Almost three-quarters of respondents used an anonymous donor. There was a marked difference between cohorts in initial preference for using an open-identity donor – a similarly higher proportion of single respondents and those in a lesbian relationship deliberately chose

an open-identity donor than did respondents in a heterosexual relationship. This confirms the findings of Brewaeys et al. (2005) and Scheib et al. (2003). A majority of respondents who had used an anonymous donor indicated that they wished they had used an open-identity donor, and a majority of all respondents endorsed the rights of donor-conceived offspring to discover their donor's identity. These views stand in marked contrast to high levels of support for donor anonymity among all respondents, especially among co-habiting lesbian mothers and single mothers, notwithstanding concerns about the increased risks of donor dishonesty accompanying anonymity. This study did not explore the relationships between these tensions, and they merit further, more detailed research. Nevertheless, it is possible that these contradictions indicate concerns that banning the use of anonymous donors would create a shortage of donors and therefore reduce access to donor services.

About 20.0% of respondents indicated they were not interested in knowing the identity of their donor, and conversely, another 20.0% also indicated they were still searching for their donor. About 50.0% indicated that they were potentially interested in discovering his identity but had not searched him out. Only a few had actually learned the identity of their donor or had contact with him. These proportions indicate that a majority of these respondents considered it was important to have the option of discovering their donor's identity. This is significant because an investigation by Beeson et al. (2011), reported that more than 70.0% of 751 surveyed sperm donor offspring whose parents who had used an anonymous donor wished that they had used an open-identity or willing-to-be-known donor. Mahlstedt et al. (2010) found that a majority of DI offspring supported the provision of extensive non-identifying information or identity release in the practice of sperm donation. While both these studies included populations that might be expected to show a high level of interest in knowing about their genetic origins (due to recruitment sources), these findings are consistent with those identified in a recent review of published research concerning the views of largely sperm donor offspring (Blyth et al., 2012).

Disclosure

The results from this study confirm those of other studies: where lesbian couples appear most inclined to disclose (Baetens and Brewaeys, 2001; Brewaeys et al., 2005; Freeman et al., 2009; Scheib et al., 2003) and that one of the documented reasons for not disclosing donor origins is the lack of information about the donor (Cook et al., 1995). As with the study of non-biological parents (Frith et al., 2012), where only nine non-biological parents expressed having no intention of ever disclosing to their child the nature of their conception, the current study found that only about 5.0% (83) of respondents had no intention of telling. This is a much lower figure than reported by an earlier study of heterosexual couples with a sperm donor-conceived child, where 61.0% had decided against disclosure (Lycett et al., 2005). This lower proportion is likely due to the self-selecting nature of the DSR survey process but could also be indicative of changing views regarding disclosure within the community and encouragement from professional bodies (ASRM Ethics Committee, 2004). Interestingly, of those who received preinsemination counselling, approximately a third of respondents reported being advised to tell their child that genetics don't make a family. Not surprisingly, due to the absence of a father figure, a comparatively lower proportion of single respondents reported being given this advice.

Meeting donors and half-siblings

Very little difference emerged between cohorts in their attitudes towards meeting their child's donor or half-siblings. However, only around 1750 donors, compared with 38,400 parents

and offspring, are registered with the DSR. Thus, the chances of establishing contact with a donor are much less than that of contact with half-siblings. Furthermore, it is the experience of the DSR that, due to concerns about contact with large numbers of offspring, donors are hesitant to connect. This is not an inconsequential problem. Current DSR records indicate that one group of half-siblings known to DSR who share the same donor is approaching 200. There are also: 376 groups comprising 5–9 half-siblings, 82 groups comprising 10–15 half-siblings, 19 groups comprising 16–20 half-siblings, and 18 groups comprising 21 or more half-siblings (DSR Records). In all cases, these numbers are ever-increasing as more matches are established. This picture confirms the concerns that have been raised previously about the psycho-social implications of multiple use of sperm donors (Sawyer, 2010; Scheib and Ruby, 2009)

Policy and practice recommendations

Despite its limitations, important implications for practice and policy arise out of this study concerning donor screening, limiting donations and donor use and the establishment of donor registries.

Donor screening

A vast majority of respondents believed that donors should have psychological as well as medical tests and over two-thirds believed that sperm banks should be legally required to perform comprehensive genetic tests on all sperm donors and they be screened more rigorously than is currently required under US Federal guidelines (F.D.A., 2011). Testing and screening of donors for genetic diseases has been found to vary considerably between banks, both in the number of conditions tested and the rigour with which tests are carried out (Heled, 2010; Sims et al., 2010). As early as 1997, it was suggested that state-by-state guidelines were ineffective and that federal regulation of genetic screening was necessary to ensure that children conceived using DI would not be exposed to inherited genetic diseases (Ginsberg, 1997). Over 80.0% of the current sample indicated that they would not have bought the spermatozoa of a donor without medical records and a similar proportion was prepared to pay more for spermatozoa to ensure proper testing. Furthermore, almost all respondents believed that any donor with a genetic disorder should be prevented from donating without divulging family history and over 90.0% were of the opinion that the sperm bank should divulge all reported health issues and leave it to purchasers to determine the level of risk they were prepared to take. This confirms the findings from previous studies (Frith et al., 2012; Grace et al., 2008) that screening and ensuring the donor's good health is an important consideration among biological mothers of DI children.

Limits on number of offspring and donations

This study demonstrates that an overwhelming majority of respondents were in favour of limiting the number of offspring that any one donor can produce. As has already been indicated, there is evidence that donors are used to produce numerous offspring. This practice was unacceptable to over three-quarters of respondents, who specified that one to 10 offspring would be appropriate: only a very small proportion were in favour of more offspring per donor. Approximately 40.0% of respondents were in favour of exactly 10 offspring per donor, as is currently the norm in some countries (Sawyer and McDonald, 2008). Furthermore, a majority of respondents were in favour of restricting donors from donating at more than one bank and, if their donor's spermatozoa was sold overseas or to another bank, about one-quarter of 1500 respondents expressed concern about increased risk

of consanguinity – one of the primary arguments used when advocating the need for a donor registry (Cahn, 2008, 2009; Elster, 2007; Sylvester and Burt, 2007).

Establishment of donor registries

Only about half of the respondents were requested to report the birth of their child. This is an indication that sperm banks currently have limited interest in monitoring how many offspring are actually born through DI. Furthermore, the vast majority of respondents who reported their child's genetic disorder to the bank did not know what action the bank had taken, and fewer than 10.0% knew that the bank had taken some remedial action regarding future use of spermatozoa from the donor.

As the majority of the respondents (85.0%) were from the USA, the findings have particular implications for US policy in this area. The American Society for Reproductive Medicine (ASRM) and Society for Assisted Reproductive Technologies (SART) have voiced objections to the establishment of donor registries in the USA (ASRM Office of Public Affairs, 2012). The Practice Committee of the ASRM and SART (2013) have recently issued recommendations for clinics and sperm banks to maintain a permanent record of each donor's initial selection process and subsequent follow-up evaluations. This would facilitate health tracking in the event of any reported adverse outcomes for donors or offspring and monitoring the number of births resulting from each donor. However, these are only recommendations. An indication that respondents to this survey would support the establishment of donor registries that maintained up-to-date donor medical records and tracked donor activity, is that nearly 80.0% supported a national gamete registry operated either by ASRM (38.1%) or DSR (39.8%), nearly half selected a sperm bank based on level of information about the donor and a vast majority believed that respondents with children suffering from genetic disorders should have access to more medical information about the donor.

Legislative provisions for the creation of an assisted reproduction registry would ensure that banks would collect and supply accurate up-to-date information about the donor. As advocated by Basu (2004), D'Orazio (2006) and others (Cahn, 2008; Sylvester and Burt, 2007) a nationally mandated donor registry would facilitate the gathering, storage and dispensing of health information, as well as details regarding the donor's identity and his family's medical history and give donor offspring the possibility of having access to this information (if the law so allowed).

An additional argument for the establishment of donor registries is related to an ASRM and SART contention that there is no supporting scientific evidence for placing a cap on the number of offspring that a single donor can produce (ASRM Office of Public Affairs, 2012), although the Practice Committee of the ASRM and SART repeats a previously made 'suggestion' that

'in a population of 800,000, limiting a single donor to no more than 25 births would avoid any significant increased risk of inadvertent consanguineous conception. This . . . may require modification if the population using donor insemination represents an isolated subgroup or if the specimens are distributed over a wide geographic area' (ASRM and SART, 2013).

It needs to be emphasized that without adequate records concerning donor conception, it will be impossible to establish evidence-based donor limits (Sawyer, 2009).

Conclusion

This investigation, which is the first to look at a large group of donor sperm recipients, gives insight into the experiences, perspectives and concerns of 1700 mothers who used donor spermatozoa to form their families. It has generated some interesting results and indications that further research is needed to investigate: trends in the use of preinsemination counselling; whether the differences observed between the cohorts remain if age difference at the time of survey completion are controlled for; the motivating force behind respondents' acceptance of a donor without medical records or with a serious genetic disorder; and similarly, the dynamics of the tensions evident in the simultaneous support both of donor anonymity and of offspring rights to know information about their donor.

The results of this survey have identified some differences between those mothers who were in a heterosexual relationship and those who were single or in a lesbian relationship at the time they first conceived using donor spermatozoa, particularly in respect to issues and concerns surrounding anonymity, choice of sperm bank, and disclosure and donor medical records. There were however, many areas of commonality, primarily with respect of views about the unregulated nature of the current sperm banking industry in the USA: concerns about the recording and availability of medical information, the rigor and consistency of genetic testing and the limiting of donor activity and use.

To address the above issues and concerns it is suggested that the establishment of a comprehensive mandatory national gamete donor registry in the USA would benefit and assist donor-conceived families by permanently maintaining and updating a database of donors and their offspring. This database would assist in: (i) keeping track of donations; (ii) recording donor births; (iii) recording genetic test results and donor health information; (iv) tracking donor-conceived offspring's health information; (v) making available donor health information for recipients and their offspring; and (vi) providing data for evidence-based estimates for donor limits.

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