

Genetic and health issues emerging from sperm donation—The experiences and views of donors*

Ken Daniels¹, Wendy Kramer^{2*}

¹School of Social and Political Sciences, University of Canterbury, Christchurch, New Zealand

²Donor Sibling Registry, Nederland, USA; *Corresponding Author: wendy@donorsiblingregistry.com

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ABSTRACT

164 previous sperm donors completed an on-line survey regarding health and genetic experiences and views. Results highlight that donors desire to act responsibly with recruiting facilities is not always possible. Objective: Obtaining the views and experiences of sperm donors regarding health and genetic matters. Design: On-line survey. Setting: Not applicable. Participants: 164 previous sperm donors. Interventions: Not applicable. Main outcome measures: Views and experiences on health and genetic issues. Results: A variety of approaches are adopted by recruiting facilities in regard to selection and post-donation factors. The vast majority of donors said they had not been contacted by the facility they donated at to update their medical information, while almost one quarter of donors indicated that a health or genetic risk factor had occurred. A great majority of donors felt that they had not received any education or counselling on the potential curiosities of donor conceived people. Donors sought to be honest and open with staff but often found there were difficulties in doing so. Conclusions: Overall, donors indicate that they see donating as involving responsibilities to the offspring and families. The study highlights however that their ability to act responsibly is limited by some of the interactions or lack of them with the facilities where they donated. Implications for recruiting facilities need to be considered.

Keywords: Sperm Donors; Health and Genetic; Recruitment; Policies

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1. INTRODUCTION

The American Medical Association (AMA) says “Gathering a complete and accurate family medical history is extremely important as genetic medicine explains more diseases” [1], while the American Society of Human Genetics (ASHG) says “Your family history holds key information about your past and clues to your future health” [2]. This paper emerges from the medical practice of donor insemination (DI) in which the recipient family is given a limited, one-day snap-shot, of a medical history reported by a young healthy donor when he first enters the donation program. Families rarely receive any further updated medical information on their donor.

Traditionally parents were encouraged to keep their family building history a secret from their offspring and as donors were anonymous, information about or contact with them was not possible. For such families it is not possible to provide a “complete and accurate family medical history” for the offspring.

Over the last 20 years, there has been a marked shift in the views, policies and practices regarding these issues [3,4]. There are, however, many differences between clinics, professionals and countries. In some jurisdictions legislation has been enacted to ban donor anonymity thus making information about and contact with the donor possible. Most consumer/patient groups worldwide now strongly advise parents to be open and honest with their children regarding their use of donated gametes [5]. The American Society for Reproductive Medicine (ASRM) in the 2004 Ethics Committee Report “supported disclosure from parents to offspring about the use of donor gametes in their conception” [6]. There is of course a significant difference between parent decision making on disclosure to offspring and access to information concerning the donor. The debates which have accompanied this shift in the culture of gamete donation have been characterised primarily by a concern for the psychological health and well-being and rights of the offspring and the families of

which they are a part [3,4]. Aside from the debates within the industry, many who have utilised donor conception have come to these conclusions about openness within their families, and taken it upon themselves to make these connections on their own through the Donor Sibling Registry (DSR). The DSR has facilitated mutual consent contact amongst more than 10,000 donors, parents and offspring who are looking for familial connections, many of whom are also seeking medical information and updates. They realize that while donors pass along many traits, it's not just looks that get passed along, susceptibility to disease can also be inherited.

This paper examines another challenge emerging from the cultural changes, namely access by offspring and parents to the genetic and medical information of "their" donor. This in turn raises issues concerning the screening and recruitment of gamete donors and the reporting of any medical issues which arise for the donor or his/her family, post-donation. There have been a growing number of reports which have highlighted medical conditions which have arisen for offspring that have resulted from sperm donation of which the following two are examples.

Callum *et al.* [7] report on a case of gonosomal mosaicism discovered in an anonymous sperm donor after receiving two reports of neurofibromatosis type 1 (NFI) in donor conceived offspring. The authors conclude that "long term communication of medical information among donors, recipients and donor-conceived offspring is beneficial for the health management of all parties". BioNews [8] has subsequently reported that donations from this donor had resulted in 43 children in 10 countries. Of the 43 children, 5 had inherited the disorder.

Sheldon [9] reported on a sperm donor in the Netherlands who developed a serious late-onset hereditary brain disease, autosomal dominant cerebella ataxia. The condition manifested itself several years after the person had stopped donating semen, but by then 18 children had been born using his semen.

In addition, there have been numerous news media reports of offspring who have inherited genetic conditions attributable to the sperm donor. For a summary of these, along with a list of genetic and health issues reported by donors, recipients and offspring see the Donor Sibling Registry Website [10]. More than 160 medical and genetic conditions have been identified by DSR members, with many being shared by groups of half-siblings.

While studies of sperm donors have touched on their views concerning medical and genetic factors, the results reported in this paper seem to be the first to have explored this area in greater depth. In a recent systematic review of 29 studies of sperm donors [11] the topics covered recruitment, motivation, anonymity, attitudes towards offspring, attitudes towards disclosure, attitudes towards

intended parents/recipients, donors' interest in outcomes and attitudes towards counselling. Issues to do with medical and genetic factors were not included, almost certainly because the studies reported did not cover these topics.

A study of previous oocyte donors [12] explored the medical and psychosocial issues which have emerged from having been a donor, while another study [13] reported on the views of oocyte donors (pre-donation, and current) regarding similar issues that were explored with the sperm donors in the current study.

This study reports on the largest number of sperm donors to have taken part in any donor study. An earlier paper reported on the views of these donors regarding their motivation for becoming a donor, the impact of donating on their own family and their views and in some cases, experiences of contact with "their" offspring [14].

This paper reports on the views of the respondents regarding genetic and health issues. Their views and experiences on the associated issues of recruitment and patterns of donating will also be reported. The results will be of particular interest given the recently released Committee Opinion of ASRM and SART on recommendations for gamete and embryo donation [15].

2. MATERIALS AND METHODS

An online questionnaire to collect data from sperm donors was made available by the DSR over a fifteen week period (10/09-1/10). At that time the DSR had a total of more than 26,000 members, with less than 1000 of them identified as sperm donors.

Survey links were posted on the DSR's website and all sperm donors registered on the DSR were invited via email to complete the survey. The invitation to participate was also posted on several other websites, blogs and chat groups which resulted in 26.9% of the participants not being DSR members.

The sample consisted of one hundred and sixty four men who had previously been sperm donors. Almost half (74 - 46%) of donors were aged between 21 and 27 at the time they donated. Fifty two (32%) were aged 28 - 35 and 15 (9%) were over 36. Twenty donors (12%) were under the age of 20 with two of these being under 18.

The majority of donors (75 - 76%) who indicated which country they were domiciled in were from the USA. Most were married or partnered (115 - 71%) and just over half (90 - 58%) had children of their own.

The on-line questionnaire made up of 45 questions and consisting of multiple choice and open-ended questions gathered both quantitative and qualitative data. Responses to questions about health issues, updating of medical information and subsequent contact with clinics, what donors were told on the limits of children, counselling/education received and details on donating to multiple facili-

ties are reported in this paper.

The DSR undertook this survey without any affiliation to a teaching or research institution and, therefore, had no body to apply to for ethical approval. Consent was implied by a willingness to complete the survey which was anonymous.

The DSR was established in 2000 and has a membership of 39,700, with 1050 identifying themselves as sperm donors. Members come from many different countries, the majority being from the USA. This large number of members has provided a unique opportunity for researchers, in collaboration with the DSR, to ascertain the views of offspring [16-18] parents [19-21], sperm donors [14], oocyte donors [12] and sperm and oocyte donors [22]. As a result, information is now available from these stakeholder groups in larger numbers than previously. Gathering information, views and experiences from parents, offspring and donors has been traditionally difficult and most studies have until now covered relatively small numbers. There are clearly limitations to this type of research, however, self selected samples, in the main descriptive statistics, and lack of control groups.

3. RESULTS

Some respondents did not answer all questions.

3.1. Health Issues

In response to the question, “to the best of your recollection, were you 100% accurate with the medical history you provided”, 156 (95.7%) said yes. Seven (4.3%) answered no indicating that they did not disclose family health matters for fear of being disqualified. There were also examples of selective answering such as, “I suppressed mental health problems in a sibling”. Just over half (80 - 54.8%) of respondents said that they had been asked at the time of donation, to enquire from their parents about the family medical history so that medical forms could be properly completed. The remaining donors (66 - 45.2%) had not been asked to make such an enquiry.

The vast majority of donors (131 - 84%) said they had not been contacted by the facility they donated at to update their medical information, while 25 (16%) had had such a follow-up. Fifteen (9.4%) donors said they had been contacted to advise that an offspring had a medical condition with the facility wanting further information from the donor. Some donors reported discovering medical conditions in their DI offspring through the DSR.

Almost 1 in 4 donors (37 - 23.1%) said that a health or genetic risk factor had occurred in them or their close family since donating and they believed the recipient family should know about this. For 12 (32.4%) of these donors the health or genetic factor related to them, for 16

(43.2%) it was in a family member and for 3 (8.1%) it was in one of their children. The remaining 6 (16.2%) did not specify. A number of answers indicated that the respondents had a health issue but they were not sure of the genetic implications for the DI offspring.

Donors who had health or genetic issues were asked if they had been in touch with the facility about this. Eleven (29.7%) donors reported that the clinic/doctor/facility was no longer operating so contact was not possible, and 4 (10.8%) said that the condition was not life threatening and therefore they had not made contact. Three (8.1%) had found it impossible to report the condition because the facility claimed that the records had been “destroyed” or were “sealed” while a further 5 (13.5%) said that they were told the information would be “recorded”. In one instance a donor was not allowed to make any further donations. Four (10.8%) donors reported that the facility staff were not interested in the information they wanted to pass on.

The majority of donors (111 - 70.3%) said that they had not had any genetic analysis undertaken, while 47 (29.7%) had. Asked if the facility had offered the opportunity to have genetic testing, 139 (92.7%) said that they would have accepted testing and 11 (7.3%) said they would not. A number of donors commented that at the time they donated there was a limited range of tests available.

3.2. Patterns of Donating

The vast majority of donors (128 - 79%) had donated at only one facility with 34 (21%) donating at more than one facility. However when asked how many facilities they had donated to 39 replied to the question. Twenty-four (61.5%) had donated at two facilities and 10 (25.7%) had donated at between 3 - 5 facilities. One donor had donated at 10 and another at 15 facilities and 3 (7.7%) had donated at more than 15 facilities. Of those respondents who had donated at more than one facility, 18 (47.4%) said they had declared this, while 20 (52.6%) said they had not told staff. Of those who had said they had not shared the donating to multiple facilities, the most common reason given was that they were “not asked”; however there was limited evidence that for some of these donors, deception was a driver, the motive being to obtain money.

Just over two thirds (112 - 70%) of donors had donated for 1 - 4 years, with 22 (13.7%) donating for less than a year and 19 (22.5%) donating for between 4 - 10 years. Seven (4.4%) reported that they had donated for over 10 years.

3.3. Recruitment Issues

Donors were asked “When you donated, did you receive any education or counselling on the potential curi-

osities of donor conceived people to know their genetic, ancestral and medical backgrounds". The vast majority (121 - 80.1%) said that they had not, with 30 (19.9%) saying they had. Several donors noted that because of the anonymity of their donations it may have been thought that no counselling was needed on this matter. Almost the same proportion (117 - 78.5%) said there wasn't anything they wished they had been informed about to better prepare them for making the decision to donate. Of these those who wished for more information prior to donating (32 - 21.5%), the desired information was centered on the outcomes of their donations (7 - 21.8%) the impact of DI and anonymity on the offspring (10 - 31.2%), the laws and policies regarding anonymity (6 - 18.7%) and issues arising from possible contact with offspring (7 - 21.8%). The following comment from one donor reflected many of the above themes. "I wish I realised that I would feel a connection even although I never knew or met them".

Just over a third of donors (54 - 34.8%) said that the facility had told them there would be a limit to the number of children born to their donations. The most common limit reported was 10 offspring or 10 families, but the range was from 3 to 25. Several donors reported that the facility claimed to set the limits according to geographical considerations. Almost equal numbers of donors had been (79 - 50.6%) or not been (77 - 49.4%) in contact with the facility to seek information on the number of offspring that had resulted from their donations. Thirty contactors (41.7%) were refused any information—"they wouldn't tell me nor would they agree to unseal the record—even at my request", being a typical comment. Twenty eight (35.4%) donors were given information while another 8 (10.1%) were told offspring had resulted, but staff were "vague" about the actual numbers. Five donors (6.3%) were told the numbers were not known, 3 (3.7%) found the clinic had closed and 4 (5%) said the staff never returned calls or replied to emails.

4. DISCUSSION

The Practice Committee of ASRM and the Practice Committee of the SART have recently issued joint recommendations for gamete and embryo donation. In relation to the selection of sperm donors they say "the main qualities to seek in selecting a donor for TDI are an assurance of good health status and the absence of genetic abnormalities" [15]. The focus on the donor and not the donor and his family raises important issues. The AMA and the ASHG—as quoted above—emphasise the importance of the family medical history. This is the position adopted by the Ethics Committee of ASRM in its statement on the Interests, obligations and rights of donors in gamete donation when it says "Before donation, informed consent to recipients requires donors to be honest about the family and personal history..." [23]. Almost all

the respondents (156 - 95.7%) in this study said they had provided accurate information regarding their medical history. In relation to family health issues however, just over half (80 - 54.8%) said they had been asked to enquire from their parents about family medical history, the remaining (66 - 45.2%) had not been asked. This component of the assessment of these donors was therefore missing.

While the majority of respondents (111 - 70.3%) said they had not had any genetic analysis undertaken as part of their selection process, the vast majority (139 - 92.7%) said they would have accepted testing had this been offered. These figures are in sharp contrast to the view expressed by a large international commercial distributor of gametes in Denmark (Cryos) where they state that in their opinion "donors... are usually against genetic disease screening as it would be traumatic for them to receive positive results and consequent rejection" [24]. In that same report they state that their recipients generally want as extensive genetic screening as possible. Genetic screening has a vital contribution to the future health and well being of the resulting offspring in regards to health screenings and preventative medicine. Perhaps part of the preparation for becoming a donor should be full discussion about the implications that may arise from the screening process, including genetic testing (including possible rejection).

While screening for health issues is a critical component of donor selection, health or genetic issues may and do arise post-donation. Almost 1 in 4 respondents (37 - 23.1%) said that either they, or a close family member, had experienced a condition they believed the recipient family should know about. Not all in this group sought to make contact with the recruiting facility but of those who did 14 (53.8%) found that the facility was closed or no longer operating, 3 (11.5%) could not pass on the information because the clinic claimed that records had been destroyed or "sealed", 4 (15.3%) found the facility staff not interested and 5 (19.2%) were told the information would be "recorded". Given that 131 (84%) of respondents in this study said that they had not been contacted by the facility to update their medical information, it might be concluded that this was not seen to be a factor which was important. While 25 (16%) had had a follow up, most of these were due to advising that a child had been born that had a medical condition with the facility seeking further information from the donor. This would seem to suggest that follow-up contact tends to be on the basis of a medical issue which has emerged in the child and with a request for more information. The ASRM Ethics Committee says, "Programmes should strongly encourage donors to provide medical updates if they learn about serious genetic or other conditions that are pertinent to the offspring's health" [23]. In this study some

donors who had information to report were prevented from doing this or in the main found the programmes unresponsive.

The ASRM and SART committees, on the issue of limitations to donor use said, “Institutions, clinics and sperm banks should maintain sufficient records to allow a limit to be set for the number of pregnancies for which a given donor is responsible” [15]. Because no record keeping requirements or systems are in place for tracking donors (or offspring), the results reported here highlight another difficulty in this area, namely donors who donate at more than one facility. One in five respondents had done this. While most had donated at just two facilities 5 (14.7%) had donated at more than 10 facilities and three of these at more than 15. Just less than half (18 - 47.4%) donating to multiple facilities had declared this, the remaining half not making such a declaration. The predominant reason given by this latter group was that they had not been asked. Clearly there is a need for facilities to seek relevant information and keep records concerning the locations and number of donations made, as the recent Committee report recommended [15].

The question of how to develop policies to manage relevant post-donation information is challenging, and could be very time consuming for facilities. The Ethics Committee of ASRM suggests donors have a responsibility to communicate new information, but questions need to be addressed concerning facility responsibility as well. The Combined Committee Report stated “A mechanism must exist to maintain records on the donor as a future medical resource for any offspring produced” and “that there is a need for an ongoing procedure for monitoring their health status” [15]. Presumably for such records to be comprehensive and be maintained pre and post donation information needs to be recorded.

The Ethics Committee of ASRM (2009) says that “the traditional practices of anonymity in gamete donation are slowly changing” [23] and there needs to be a focus on the implications of these changes for the donors. The majority of donors (117 - 78.5%) in the current study did feel that they had been well prepared and there was nothing additional that they wished they had been informed about. Just over 1 in 5 (32 - 21.5%) indicated that they did want more information, with most of these (23 - 71.8%) wanting information concerning the general area of anonymity and contact with offspring. This figure may reflect the fact that the vast majority of respondents were open to contact with “their” offspring, even though some had been recruited as anonymous donors [14]. A third (54 - 34.8%) of donors had been told there would be a limit to the number of offspring that would likely result from their donations. Almost equal numbers had been (79 - 50.6%) or had not been (77 - 9.4%) in contact with the facility to seek information on outcomes. While 36

(46.7%) of these were given information, 8 (10.3%) said that the numbers provided were “vague”. Thirty (38.9%) were refused any information.

The Ethics Committee Report provides a review of the arguments for and against facilities providing information on outcomes. They encourage clinics to provide the option to donors as part of the consent process. They conclude that, “Nevertheless, because there are no data from studies to support either side of the argument regarding disclosure or nondisclosure of the outcome of the cycle, it is ethically acceptable for programmes not to inform donors of the outcome” [23].

The results of this study do suggest that this area needs to be revisited as the Committee did not reference their views to studies of donors and their views.

5. CONCLUSIONS

The result from this largest study of sperm donors provides new information on the views and experiences of the respondents regarding health and genetic factors associated with having been a donor. Overall donors indicate that they see donating as involving responsibilities to the offspring and families. The study highlights, however, that their ability to act responsibly is limited by some of the interactions, or lack of them, with the facilities where they donated.

The way in which a donor is seen by a recruiting facility is clearly important. If the donor is seen as an individual whose only involvement in DI family building is to provide a semen sample and at that point his responsibility ceases (and payment may symbolise that the contract has been completed) then this will be reflected in their policies and practices. If however, as the Ethics Committee [23] indicates, the donor is seen as having an ongoing responsibility to the recipients and offspring, then the findings from this study highlight areas that need further discussion and action. The obligations and responsibilities of donors need to be matched with those of the clinics, with more attention on the health and well being of the families being formed with donor conception.

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