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Donor type and parental disclosure following oocyte donation

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ABSTRACT

Objective: To ascertain the perspectives of parents of children conceived via oocyte donation regarding donor anonymity and disclosure of the nature of their conception to their children. **Methods:** Information was gathered by means of an anonymous online survey initiated by the Donor Sibling Registry, in which 108 parents with 143 children conceived following oocyte donation and aged between one year and 15 years participated. **Results:** Parental use of an anonymous or open-identity donor – and regardless of parental choice of donor – makes very little difference to the timing of parental disclosure to their donor-conceived child about their conception. The median age of children at disclosure is about 3½ years; UK/Australian parents seem more ready to tell their children at an early stage (median age around two years) than North American parents (median age around 4½ years), although about three quarters of all children have been told by the age of six years. Considerable ambiguity among parents who intend to disclose to their children as to the optimal age of disclosure is evidenced. **Conclusions:** Parents' experiences of disclosure to children at different ages need to be more thoroughly examined in order to establish a coherent body of knowledge that may facilitate improved evidence-based parental decision making.

1. Introduction

Historically, gamete donation has been characterized by donor anonymity and concealment from the child of the nature of her or his 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 eight years^[1–11], although one recent Finnish study has included parents of children aged up to 14 years^[12]. These studies have revealed intended disclosure

rates of between 26%–81%, although not all parents indicating an intention to disclose will necessarily do so^[6, 8, 9–11] because they may change their mind, may never find “the right time” or may have never intended disclosing in the first place, but wished to avoid giving a response that could be interpreted as a less socially desirable. Three studies have examined disclosure behaviour over the same groups of parents over time, one undertaken in Finland^[3,12] and two in the UK^[7,9,13,14]. Despite some conflation of data and reporting ambiguities in the different phases of these studies, they suggest an underlying ethos towards increasing levels of disclosure among parents of children conceived following oocyte donation – at least in Finland and the UK.

Findings such as these have paralleled the increasing promotion of the desirability of disclosure among professional groups^[15, 16]. Advocacy of early disclosure has statutory reinforcement in the U.K., under Section 13(6C) of the Human Fertilisation and Embryology Act 1990, which requires clinics providing ART services to inform those

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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.

MacDougall and colleagues^[10] identified two alternative strategies that impact the timing of parental disclosure. The “seed planting” strategy, adopted by parents to ensure that their child grows up “always knowing” about the nature of their conception and for them never to experience a time when this information appeared novel or surprising, favors 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 biologic 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. 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^[10]. Other studies of parental disclosure have also noted the operation of these two models, and have generally identified a parental preference for the “seed planting” strategy^[11, 17–24].

In practice, disclosure is not, in any event, reported as a simple, one-off event, but a longer-term process that takes account of the developing child’s increasing understanding of issues relating to conception and also involves dealing with a child’s – and often parents’ – potential desire for information, including – for some – the wish to identify and connect with the child’s donor and/or half-siblings^[24–27].

2. Materials and methods

A questionnaire comprising directed and open-ended questions was constructed to generate both qualitative and quantitative data, based on the first author’s ten years’ experience of working with individuals and families through the Donor Sibling Registry (DSR), and previous research conducted with families built using gamete donation^[24, 27–30]. The DSR website provided a vehicle to undertake the study reported in this paper, and an opportunity to contribute to the current evidence base concerning the perspectives of parents of children conceived following oocyte donation in order to help inform and assist decision-making among potential recipients of donated oocytes and service providers to match services to their clients’ needs. An invitation to complete the survey, which was accessible on the DSR website between November 2009 and January 2010, was posted on the DSR’s Yahoo Group page, the DSR’s

Blog and the DSR’s Facebook page and was open to both members and non-members of DSR. This paper reports on respondents’ views concerning their decisions and actions regarding disclosure to their child of the nature of her or his conception. Findings related to other issues included in the survey (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 donor half-siblings, and what advice they would give to parents who are unsure whether to tell their child(ren) are reported separately (authors – under review).

Data analysis utilized SPSS 18.0 statistical software, using time-to-event (“survival”) methods, in which the time variable was the age of the child at the time of disclosure (the mid-point of the recorded age range of the child). Where parents had not told their child about their conception by means of oocyte donation, the age of the child at completion of the survey was recorded, together with the reason for non-disclosure, where provided. Where parents considered their child to be “too young” to be told, or had not yet decided whether or not to tell their child, the information was right-censored at a time corresponding to the current age of the child. Where parents had decided against disclosure, the information was point-censored at the age of 16 years, since the eldest of the respondents’ children was reported to be 15 years of age. Participants also indicated whether they had chosen to use an open-identity donor, an anonymous donor or whether they had used an anonymous donor because they were offered no other choice and were asked for their current satisfaction with the type of donor they had used. This information facilitated an assessment of the donor type (anonymous or open), based on the complete data set, on the likelihood of conception disclosure at a given age, and an overall comparison over the full age range considered (0–16 years).

From those who had used an anonymous donor (either by choice or otherwise), further information was also elicited relating to whether the parents subsequently remained satisfied with their use of an anonymous donor. This information facilitated an assessment of the effect of satisfaction with donor anonymity, on the likelihood of disclosure about conception at a given age, and an overall comparison over the full age range considered.

The effect of geographical residence was also investigated. However, insufficient numbers of parents from any country except the United States and the United Kingdom were included in the analysis to facilitate an assessment of data from each country represented in the data set individually. Hence parents were classified as originating from either

North America (USA or Canada) or elsewhere (Europe or Australia). Furthermore, following a change in the law in 2005 it has been impossible for parents in the United Kingdom to utilize an anonymous donor (save for transitional arrangements to allow parents who already have a donor-conceived child using an anonymous donor to conceive an additional genetically-matched child or children); hence it was not possible to separate country of residence from donor type in all cases. Thus the effect of geographical residence was assessed in an analysis of those utilizing an anonymous donor only.

For all comparative analyses, time-to-event graphs were derived, and median, upper quartile and lower quartile ages at disclosure identified. The statistical significance of the donor type, donor satisfaction level and geographical location parameters was also assessed.

3. Results

3.1. Respondent profile

The survey drew 108 responses comprising 68 (63.0%) gestational mothers via oocyte donation; 34 (31.5%) gestational mothers and fathers via oocyte donation responding jointly; three (2.8%) single non-gestational mothers via oocyte donation; two (1.9%) gestational and non-gestational mothers via oocyte donation; and one (0.9%) non-gestational mother and a father via oocyte donation. In addition to using donor oocytes, 33 respondents (31.7%) also used donor sperm. 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 survey questions were optional; consequently not all respondents responded to each question.

Of the 95 respondents who provided information about their geographical location, 58 (61.1%) resided in the U.S.; the remainder were from the U.K. (22; 23.2%), Australia (8; 8.4%), and Canada (5; 5.3%) and European countries other than the U.K (2; 2.1%).

At the time they conceived, of 104 respondents providing information about their relationship status, 69 (66.4%) were married (including one same-sex couple), 14 (14.5%) were cohabiting, and 21 (20.2%) were single women. Respondents had a total of 143 children conceived following oocyte donation aged up to 15 years (mean age 5.2 years; SD 3.89). Respondents' children were clustered towards the younger pole of the age spectrum, with 84 (58.7%) aged under five years. Fifty-four respondents reported the birth of a single child, 34 the birth of two children (amongst whom were 32 sets of twins) and seven the birth of three children (including

two sets of triplets) resulting from oocyte donation.

Thirty seven respondents declared their membership of DSR, of whom 13 had already told their child about her or his conception (children aged up to 14 years); nineteen considered their child too young (children aged up to eight years); two had decided not to tell, and three were undecided. There was no strong evidence that DSR members were more inclined than non-members either towards disclosure at all or early disclosure.

Where respondents had already informed their children of the nature of their conception, information was obtained of the age of the child at the time of disclosure, grouped into the following age categories: under five years of age, 5 and under 8 years, 8 and under 11 years, 11 and under 14 years, and over 14 and under 16 years (the eldest child in the study being 15 years of age). Among the 48 respondents who provided information about the age at which they told their children, 40 (83.4%) disclosed initially before the age of five years, four (8.3%) when the child was between 5–7 years old, and two (4.2%) at age 8–10 years. Only two (4.2%) had waited until their child was a teenager before disclosing information about their conception. Thirty-nine respondents believed their children were still too young to be told – these children ranged in age up to eleven years (although the mother of the eleven-year old child elaborated that her decision was compounded by having no information about the donor to impart to her child), and of these 36 (92.3%) were aged under five years. Three respondents had decided not to tell their child about her/his conception, and four remained undecided. It is interesting to note that children aged under five years comprised more than 90% of the cases where parents had not disclosed because they considered their child “too young”, but also more than 80% of cases where parents had disclosed.

Findings reported below are based on 93 valid responses for which full data were provided by respondents. Of the original 108 respondents, thirteen were excluded from analysis because of incomplete information and two were excluded because they were currently pregnant but had no child conceived following oocyte donation.

3.2. Age at disclosure – all families

The median age of disclosure was 3.5 years, with upper and lower quartile ages of 2.5 years and 15.5 years respectively. Figure 1 shows the corresponding time-to-event curves for all families, indicating a rapid decrease in the proportion of children not having been told about their conception at young ages (less than 4.0 years), followed by a slower decrease throughout later childhood. The proportion of children not having been told about their conception reaches

a lower limit of 19.9% by age fifteen.

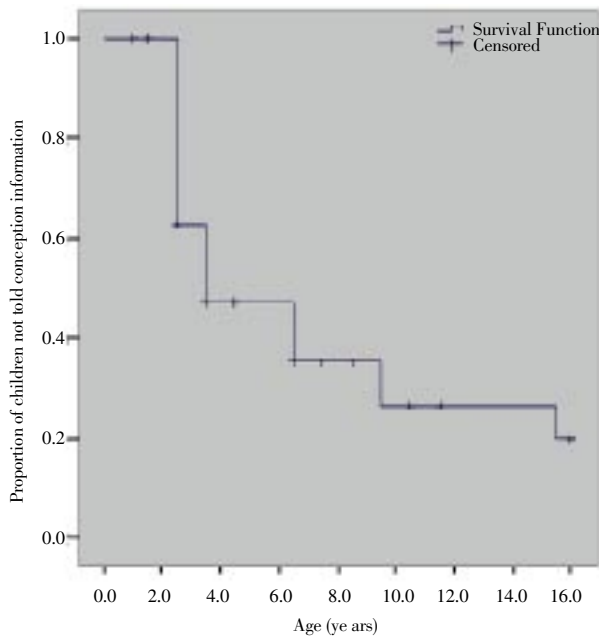


Figure 1. Time-to-event of information about conception.

From this, it is evident that the most common parental approach to disclosure was the “seed planting” strategy to ensure that the child was “always aware” of their origin. This was amplified by 32 of 44 (72.7%) respondents providing information who indicated that they had imparted this information to children in stages over time, whereas only eleven (25.0%) disclosed on a single occasion, and in one case the disclosure was accidental. 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.

3.3. Effect of donor type

The median age of disclosure for all respondents was 3.5 years both for those who utilized an anonymous donor and those who utilized an open-identity donor. The upper quartile age was also not affected by donor type; being 2.5 years for both groups. The lower quartile age was 9.5 years for families who used an anonymous donor, and was not defined for families who utilized an open-identity donor.

Figure 2 shows time-to-event curves for all respondents; differentiated by utilization anonymous donor (coded 1) or an open-identity donor (coded 0). All children whose parents utilized an anonymous donor received information about their conception before the age of 16 years; 36.7% of children whose parents used an open-identity donor were told about their conception by age fifteen. A log-rank statistic of 0.384

was calculated indicating that the donor type was non-significant with respect to time of disclosure ($P=0.535$): non-significance is also suggested by the intertwining of the curves illustrated in Figure 2.

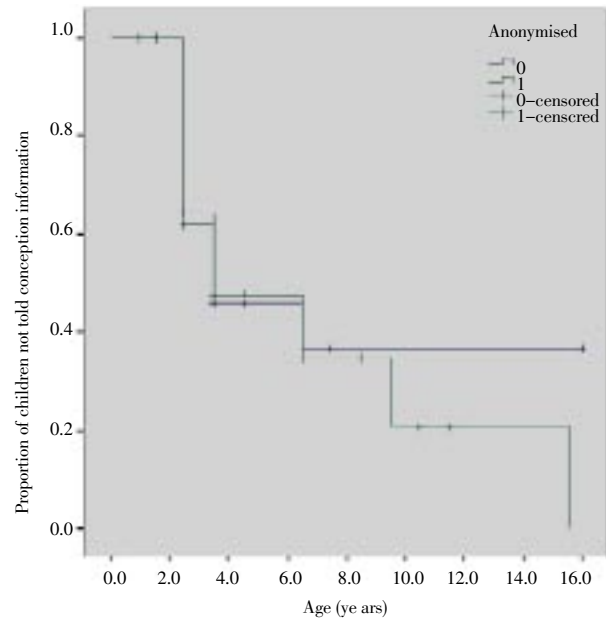


Figure 2. Time-to-event of information about conception: utilization of anonymous and open donors.

3.4. Effect of satisfaction with utilization of an anonymous donor

Twenty four participants (25.8%) utilized an anonymous donor through choice, and 37 (39.8%) did so because they were offered no choice by their clinic or agency. Approximately half of this group (12/24 of those choosing an anonymous donor and 20/37 of those who had no choice but to utilize an anonymous donor) were still content with their choice of donor, while the other half wished they had utilized an open-identity donor. The median age of disclosure by those who were satisfied with donor anonymity was 6.5 years, and 3.5 years for those who were not satisfied with donor anonymity. The lower and upper quartiles were 2.5 years and 9.5 years for both groups. Figure 3 shows time-to-event curves for all parents who utilized an anonymous donor; differentiated by whether satisfaction with donor anonymity (coded 1) or dissatisfaction (coded 0) was reported. By the age of 15, all children whose parents were dissatisfied with their utilization of an anonymous donor and 18.1% of children whose parents were dissatisfied with their utilization of an anonymous donor were told about their conception. A log-rank statistic of 0.340 indicated a non-significant relationship between parental satisfaction with utilization of an anonymous donor and of disclosure ($P=0.560$): non-significance is also suggested by the intertwining of the curves illustrated in Figure 3.

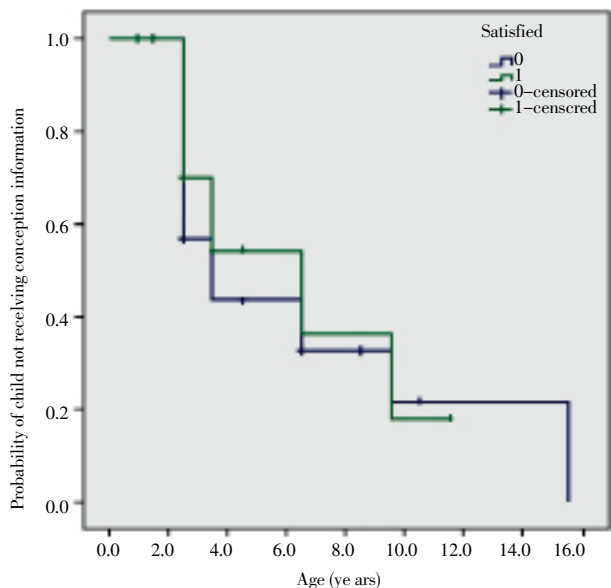


Figure 3. Time-to-event of information about the child’s conception (utilization of anonymous donors only): satisfied and dissatisfaction with donor anonymity.

3.5. Effect of geographical location

Where an anonymous donor had been utilized, the child’s median age of disclosure was 6.5 years for North American (United States or Canada) respondents, and 2.5 years for those originating from Europe (the majority of whom – 22 /24 – were from the United Kingdom) or Australia. The lower and upper quartiles were 3.5 years and 9.5 years for the North American group; and 2.5 and 3.5 years for the Europe/Australia group.

Figure 4 shows time-to-event curves for all parents who utilized an anonymous donor; differentiated by geographical location, with North American parents coded 1 and European/Australian parents coded 0.

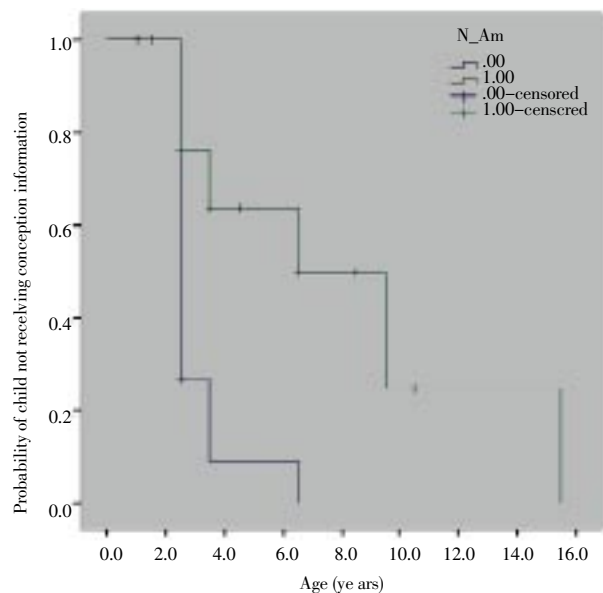


Figure 4. Time-to-event of information about the child’s conception (utilization of anonymous donors only) North American and European/Australian parents.

All children whose parents utilized an anonymous donor

and originated from North America were told about their conception by the age of fifteen years; all children whose parents utilized an anonymous donor and who originated from Europe or Australia received this information by the age of 6.5 years. A log-rank statistic of 15.95 indicates a significant relationship between geographical residence and child’s age at disclosure ($P < 0.001$).

4. Discussion

Respondents to this retrospective online study comprised 108 parents of 135 children aged up to fifteen years conceived following egg donation. The survey sought demographic data about the respondents, the information they received from the clinic or agency about their donor, their views about using open versus anonymous donors and about disclosure to their children about their genetic origins, and their plans for disclosure.

Respondents were recruited via the DSR, a US-based online registry that assists 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 wishing to search for and contact their donor and donor 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.

Before discussing the findings from this study or drawing conclusions from these, we need to acknowledge its limitations. The survey relied on a non-probability sample, since accurate knowledge of the number of parents with children conceived following oocyte donation is unavailable. Participation was accessed via DSR, resulting in a potential bias of respondents subscribing to the DSR’s ethos of disclosure; however this criticism is largely mitigated by the fact that fewer than half of respondents declared themselves to be a DSR member and, among these, there was no greater inclination towards disclosure than among non-members. In addition, the survey was designed by the DSR less for research than for organizational purposes. Data were self-reported by a self-selected group of anonymous respondents. The age of the child at disclosure of information about their conception was recorded as a range (e.g. 4–6 years), rather than as a specific value. In addition, since some respondents had to rely on their memory of past events, 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. Caution should therefore be exercised in extrapolating these findings

to the wider population of parents of children conceived following oocyte donation. Nevertheless, we do believe that the study contributes further knowledge and understanding of the dynamics of parental disclosure in families built using oocyte donation.

Obviously, more research is required in order to gain a fuller understanding of the experiences of donor–recipient–offspring–sibling contact in oocyte donation.

Analysis of the data indicates that the median age of disclosure and the age at which 75% of children have not been informed about their conception are around 3.5 years and 2.5 years respectively, which highlights the impact of responses of “from birth” elicited from a large proportion of parents in the study. Neither of the key factors of donor type or satisfaction with utilization of an anonymous donor significantly affect the age at which disclosure takes place. Analysis of geographic parameters indicates that UK parents were more likely to disclose than their American counterparts. Key characteristics that differentiate donor conception policies in these two countries are first, that in the UK, since 2005, all gamete donors are required to agree to the disclosure of their identity to offspring once the latter reach the age of 18 years; second, since 2005^[31] formal guidance issued to UK fertility clinics has been to ensure that individuals and couples contemplating gamete or embryo donation for family–building are unambiguously advised of the benefits of early disclosure – advice that has been endorsed via legislation since implementation of the Human Fertilisation and Embryology Act 2008 in 2009. In contrast, in the United States, donor anonymity to both recipients and offspring remains the norm and guidance to clinics regarding parental advice on disclosure is more equivocal. While the direct impact of policy and legislation on parental disclosure is difficult to ascertain^[32–34], it is interesting that criticism of the UK government’s decision to prohibit donor anonymity would discourage parental disclosure^[35] is not borne out by the findings of this study.

The non–parametric approach to the analysis of children’s age at disclosure pursued in the current investigation avoids the requirement of a fully parametric approach to specify a particular survival distribution. However, it precludes a rigorous treatment of the issue of interval censored data, which arises in the cases of parents who have reported disclosure of information within a certain time range; in general the exact age of the child at disclosure is not known. This study complements previous surveys undertaken via the DSR website involving oocyte donation^[27–30]. It has highlighted emerging trends in oocyte donation as regards anonymous and open–identity donation, and disclosure to donor–conceived children. It is the first study to our knowledge that has begun to investigate in detail similarities

and differences between parents who have disclosed the nature of their conception to their donor–conceived children and those who state their intention to do so in the future. Hitherto, previous research studies have tended to conflate these quite distinct disclosure options. Neither donor type (anonymous or open) or parental satisfaction with donor type have been found to be significantly related to the age at which information about the child’s conception is disclosed. Geographical area appears to affect the age at which information about the child’s conception is disclosed to the child, with parents originating from Europe or Australia choosing to disclose information significantly earlier than parents originating from North America. Considerable ambiguity among parents who intend to disclose to their children as to the optimal age of disclosure is evidenced. This suggests that parents’ experiences of disclosure to children at different ages need to be more thoroughly examined in order to establish a coherent body of knowledge that may facilitate improved evidence–based parental decision making.

Conflict of interest statement

We declare that we have no conflict of interest.

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