Gamete donors’ and recipients’ evaluation of donor counselling: A prospective longitudinal cohort study

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Background: Those considering donating or receiving gametes are required to undergo counselling to ensure that they are aware of and consider the psychosocial, emotional and ethical complexities of donor conception before proceeding.

Aims: The aim of this study was to evaluate gamete donors’ and recipients’ views about donor counselling and beliefs about disclosure of the use of donor gametes to conceive, before and after attending counselling.

Method: All donors and recipients and their partners who attended donor counselling at Monash IVF, Melbourne, Australia, for the first time between February 2003 and March 2004 were asked to complete self-report questionnaires. Using seven-point Likert scales where higher scores indicated more positive views, participants rated the importance of discussing a range of topics before, and the usefulness of discussing these after attending counselling.

Results: Pre-counselling questionnaires were completed by 152 of 184 (83%) individuals and 72 (47%) of those also completed the post-counselling questionnaire. Donors’ post-counselling ratings were significantly higher than their pre-counselling ratings. For recipients the pre- to post-counselling changes were less pronounced. Both donors and recipients rated matters relating to disclosure and the possible future interaction between donor and child the most useful to discuss. More participants favoured disclosure after than before counselling (84% vs 66%, \(P = 0.01\)).

Conclusions: This study suggests that counselling is beneficial for those contemplating donor procedures, particularly donors, and that most have a positive attitude towards disclosure after counselling.

Key words: assisted, counselling, evaluation, infertility, psychology, reproductive techniques.

Background

For some infertile couples the only way to have a child is through the use of donor sperm, oocytes or embryos in an assisted reproductive technology (ART) procedure. Donor insemination (DI) to overcome male infertility has been used for many decades, and over the last 20 years the number of couples using donor oocytes or embryos to conceive has increased. In Australia and New Zealand, over 51,000 ART treatment cycles were performed in 2005 and of these 6.6% were DI cycles and 5.7% involved the use of donor oocytes or embryos.1 Donors may be recruited by the clinic and remain anonymous to the recipient. Alternatively, couples who need donor gametes may recruit them, in which case they are known and sometimes related to the recipient.

There is universal agreement that the psychosocial, emotional and ethical complexities of donor conception require thorough exploration both for those donating and those receiving gametes.2–6 In most clinics, a mental health professional such as a counsellor, a psychologist or a social worker meets with prospective donors and recipients to explain the known psychological, social and legal implications of third-party reproduction and ensure that these are considered before proceeding. It is argued that the assistance of a mental health professional is essential to promote complete examination of the many dilemmas faced by those who donate or receive gametes.7–10

One of the roles of counselling is to assess prospective donors for their suitability to undergo these procedures in terms of psychiatric and genetic history, personality characteristics and motivations for donating gametes.11–13 The other important purpose of counselling is to ensure that those considering donor procedures are fully informed about technical procedures and have considered the unique aspects of third-party reproduction such as secrecy versus openness towards a future child and members of the social network.
the role of a known donor in the recipient’s family, the effect of the donation on the donor’s own family and the risk that the donation does not result in the birth of a child. Parents considering donating embryos also need to contemplate their feelings about donating a potential genetic sibling to their own child or children.14

The Reproductive Technology Accreditation Committee (RTAC) oversees ART practices in Australia and New Zealand and it is a requirement for RTAC accreditation that donors and recipients receive counselling before proceeding with donor procedures. Similarly, the Human Fertilisation and Embryology Authority in the UK stipulates in their Code of Practice that counselling needs to be provided to those considering donor procedures.15 There is also agreement between the major professional ART bodies, the European Society of Human Reproduction and Embryology (ESHRE) and the American Society for Reproductive Medicine (ASRM) that counselling should be an integral part of donor procedures, due to their potential psychosocial consequences.16,17

The most debated issue in relation to donor conception is whether a child born as a result of a donor procedure should be informed that conception was by donor, be able to access identifying information about the donor and/or allowed to contact the donor. Some believe that donor-conceived children have an absolute human right to information about their biological origins and that withholding this information is a transgression of this right.18-21 Others have argued that due to the limited available evidence about the risks and benefits of disclosure versus openness, neither view should be imposed on couples using donor gametes.22-24 Over the last ten years there has been a decline in the number of writers supporting this view, and openness is increasingly being favoured.

Legislators’ responses to this debate vary. In some countries, such as France, Denmark and Spain, gamete donation only occurs with reciprocal anonymity between donors and recipients. In others, such as the UK, Austria, New Zealand, Sweden and some states in Australia, irrespective of whether the donor is anonymous or known, it is a legal requirement that identifying information about the donor is recorded to enable a child born as a result of a donor procedure to access it in the future. However, in order to access information about a donor, a child needs to be informed a donor was used to conceive him or her. In most existing studies about patterns of disclosure, it is clear that the majority of parents of donor-conceived children have not told and do not intend to tell their children about the way they were conceived.25-29 Reasons for non-disclosure include the desire to protect the child, the belief that disclosure is unnecessary, and concerns that family relationships may be damaged as a result of disclosure.27

Despite the universal view that counselling before proceeding with a donor procedure is essential, to our knowledge no studies have investigated donors’ and recipients’ views on the value of counselling systematically.

To ascertain whether donor counselling is useful to those considering donor procedures, the aim of this study was to evaluate donors’ and recipients’ views about donor counselling and beliefs about disclosure of the use of donor gametes to conceive.

The study was conducted in Victoria, one Australian state where it is a legal requirement for donors, recipients and their partners to attend at least a single session of counselling with a specialised infertility counsellor before undergoing a donor procedure.30 It is also mandatory for clinics to report identifying information about donors and recipients to a central register, managed by the Infertility Treatment Authority, if a child is born as a result of a donor procedure and this information is available to donor conceived children from the age of 18. Furthermore, the Infertility Treatment Act30 stipulates that counsellors should advocate that parents who use donor gametes disclose the donor origins to any children born.

Methods

Study sample

This was a prospective, longitudinal cohort study. All donors and their partners and recipients who attended donor counselling at Monash IVF, Melbourne, Australia, for the first time between February 2003 and March 2004 constituted the study sample. Donors were those who donated genetic material (women donating oocytes, men donating sperm and couples donating embryos) and those who were required by law to attend donor counselling because they were a partner of a donor. Recipients were female and male partners of couples who were considering using donor oocytes, sperm or embryos.

Materials

Self-report questionnaires, where the subject matters routinely covered in counselling were listed, were administered before the first counselling appointment, time 1 (T1), and after the last appointment, time 2 (T2). Before counselling respondents were asked to rate on a seven-point numerical Likert scale the importance of each of the subject matters that are routinely discussed in counselling (1 = ‘Does not need discussing’ to 7 = ‘Needs to be discussed in depth’). After completion of counselling, they were asked to rate their perception of how useful it had been to explore the same topics (1 = ‘Unnecessary to discuss’ to 7 = ‘Extremely useful to discuss’). Before and after counselling respondents were also asked to state whether, in their opinion, a child and others in the social network should be informed about the use of donor gametes to conceive. At T2 they were asked whether they were proceeding with treatment and to indicate on a seven-point numerical Likert scale whether counselling had influenced their views about disclosure.

Procedure

Written information about the purpose of the study, a consent form and the T1 questionnaire were given to all potential study participants when they arrived at the clinic.
for their first counselling appointment. They were asked to read the information and, if they agreed to participate, to leave the signed consent form and the completed questionnaire in a designated box. The written information included a statement that responses would be compiled by a research coordinator and not be available to individual counsellors. The T2 questionnaire was mailed after the last counselling appointment to those who had completed the first questionnaire. Participants who after one month had not returned it were followed up with one phone call.

The study was approved by the Epworth Hospital Research and Ethics Committee and the Monash Surgical Private Hospital Human Research Ethics Committee.

Statistical analyses

Data were entered into SPSS version 11.5 (SPSS Inc., Chicago, IL, USA) and analysed using descriptive statistics and univariate measures of association. Student’s t-test was used to test differences between two group means and the chi-square to test for frequency differences. Paired t-test was used to test for changes in ratings between the first and the second questionnaire among those who responded to both. A P-value of < 0.05 was considered statistically significant. In the analyses, donors refer to those considering donating gametes and their partners and recipients to male and female members of couples considering using donor gametes.

Results

A total of 184 individuals attended donor counselling between February 2003 and March 2004 and were invited to participate in the study. The T1 questionnaire was returned by 152 (83%) individuals, of whom 72 also completed the T2 questionnaire (47% of those who completed the T1 questionnaire). The distribution of respondents at T1 and T2 is shown in Table 1.

Most (107 of 152, 71%) were contemplating donating to or receiving gametes from someone they knew, 43 of 152 (28%) were donating or receiving gametes anonymously and two (1%) did not respond to the question.

Table 2 shows donors’ and recipients’ pre-counselling ratings of the importance of discussing specific subject matters. Where comparison was possible, there were no differences between donors’ and recipients’ ratings.

Among donors, 31% attended one counselling session, 63% two and 6% attended three or more times. For recipients, the corresponding proportions were 25%, 63% and 12%. There were no differences in T1 ratings between donors who returned the T2 questionnaire and those who did not except on the question about the importance of exploring personal history. Those who returned the T2 questionnaire rated the importance of discussing personal history as significantly...
higher than those who did not return it (3.3 vs 2.5, 95% confidence interval (CI) for the difference 0.07 to 1.56, \( P = 0.03 \)). Among recipients there were no differences in T1 ratings between those who did and did not return the T2 questionnaire.

Among donors who completed both questionnaires (\( n = 37 \)), T2 ratings were significantly higher than T1 ratings for 12 of 15 (80%) of the subject matters (Table 3). For recipients, however, (\( n = 35 \)), T2 ratings were higher than T1 ratings only for three of 14 (21%) of the listed topics (Table 4).

There were no differences between donors and recipients in mean T2 ratings except for the item ‘personal history’ which recipients rated lower than donors (3.3 vs 4.6, respectively, 95% CI for the difference −2.12 to −0.45, \( P = 0.003 \)). For both donors and recipients, T2 ratings of the usefulness of discussing matters relating to disclosure of the use of donor gametes and possible future interaction between the donor and a child born as a result of the donation were significantly higher than the T1 ratings of beliefs about the need to discuss these issues.

At T1 and T2, respondents were asked about their views regarding who should be informed about the use of donor gametes. T1 views were similar for donors and recipients who only completed the T1 questionnaire and those who completed both questionnaires. The proportions with positive views about disclosure among those who returned both questionnaires are shown in Table 5.

The only significant change between T1 and T2 views about disclosure was recorded among donors who were more likely after counselling than before to believe that a child should be informed about its donor origin (91% vs 64%, \( P = 0.007 \)).
The influence of counselling on views about disclosure was rated on a seven-point numerical Likert scale (1 = ‘Not at all’ to 7 = ‘A great deal’). The mean score for donors and recipients was almost identical (3.8 and 3.7, respectively). Approximately one quarter of participants (26%) reported no impact at all, but 28 of 69 (41%) rated the influence of counselling as five or more, suggesting that counselling had some effect on their attitudes towards disclosure.

Among donors four of 37 (11%) decided not to proceed with gamete donation after they had had counselling. Of the 35 recipients, 34 decided to proceed with treatment while one was undecided at the time of completing the questionnaire.

**Conclusion**

To our knowledge, this is the first study that has explored gamete donors’ and recipients’ views about the usefulness of donor counselling, and the impact of counselling on attitudes towards disclosure.

A limitation of the study is the relatively low return rate of the T2 questionnaire. The different ways of administering the two questionnaires may in part explain this. The response rate to the T1 questionnaire was very high (83%). As reception staff gave this to potential study participants while they were waiting to see the counsellor they may have felt an obligation to complete it or that it was a way of making use of the waiting time. The return rate of the T2 questionnaire was lower than anticipated (47%), perhaps because they were mailed rather than given out personally. Therefore, although T1 ratings were similar for participants who returned one or both questionnaires, the results need to be interpreted with some caution.

Donors and recipients appear to enter counselling with similar perceptions about the importance of covering the range of topics described. The majority of topics were rated on average above the neutral score of 4, which suggests that most participants believed that they were relevant and worthy of discussion in counselling.

The most striking finding was that donors’ T2 ratings of the usefulness of discussing most topics were significantly higher than their T1 ratings. This suggests that donors may not have been aware of or considered in depth the broader implications of being a donor and that counselling increased their insight and allowed them to reflect on the potential impact of gamete donation on themselves and others. The T1 to T2 changes among recipients were less pronounced and may indicate that recipients gather information and contemplate the implications of using donor gametes in greater detail before attending counselling than donors. It is, however, noteworthy that all changes for both donors and recipients were in the positive direction with T2 scores on average higher than T1 scores.

The T2 ratings suggest that for both donors and recipients, the most important matters to discuss in counselling relate to disclosure and the possible future interaction between the donor and a child. When the donor and recipient are known to each other, the potential impact of the donation on their future relationship also appears to be a salient matter to explore in counselling. Furthermore, for recipients, it is evident that the lack of genetic tie between the child and one or both parents is essential to discuss. Also, legal matters and those relating to the impact of the registered information are of significant interest to those donating and using donor gametes.

Compared with other studies, a higher proportion of participants had a positive attitude towards disclosure of donor origins to the child and close relatives. This may indicate a shift away from secrecy towards increased willingness to reveal mode of conception among donors and recipients in Australia which may be a result of a very active public debate in recent years, about children’s right to know their genetic origins.

In conclusion, this study suggests that counselling helps those contemplating donor procedures become better informed by exploring the many and complex personal, social and legal consequences of donating and using donor gametes. In addition to providing empirical evidence that those attending donor counselling benefit from this, the findings of this study also contribute to better understanding of what gamete donors and recipients perceive as the most important matters to discuss in counselling. Finally, for some participants counselling leads to a more positive attitude towards disclosure of the mode of conception. This may allow more donor-conceived children the opportunity to find out about their genetic origins in the future.

### Table 5 Proportions of donors and recipients expressing positive views about disclosure of the use of donor gametes at time 1 (T1) and time 2 (T2)

<table>
<thead>
<tr>
<th>Who should be informed?</th>
<th>Donors T1 n = 36 (%)</th>
<th>Donors T2 n = 34* (%)</th>
<th>Recipients T1 n = 34 (%)</th>
<th>Recipients T2 n = 34 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The child</td>
<td>23 (64)</td>
<td>31 (91)</td>
<td>23 (68)</td>
<td>26 (77)</td>
</tr>
<tr>
<td>Close family</td>
<td>21 (58)</td>
<td>24 (71)</td>
<td>22 (65)</td>
<td>22 (65)</td>
</tr>
<tr>
<td>Extended family</td>
<td>8 (22)</td>
<td>9 (27)</td>
<td>4 (12)</td>
<td>9 (27)</td>
</tr>
<tr>
<td>Close friends</td>
<td>6 (17)</td>
<td>11 (32)</td>
<td>8 (23)</td>
<td>8 (23)</td>
</tr>
<tr>
<td>Anyone</td>
<td>2 (6)</td>
<td>2 (6)</td>
<td>2 (6)</td>
<td>3 (9)</td>
</tr>
</tbody>
</table>

*Two donors who were not proceeding did not respond.
References

20. McWhinnie A. Gamete donation and anonymity: Should offspring from donated gametes continue to be denied knowledge of their origins and antecedents? Hum Reprod 2001; 16: 807–817.