Parental attitudes toward disclosure of the mode of conception to their child conceived by in vitro fertilization

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Objective: To survey the level of disclosure of conception method within families of children conceived by conventional in vitro fertilization (IVF) or intracytoplasmic sperm injection (ICSI) and to examine the factors that might influence parental attitudes and plans for disclosure.

Design: In-depth questionnaire.

Setting: Participants recruited through fertility clinics in the United Kingdom.

Patient(s): Parents of children aged 5 to 6 years conceived by IVF/ICSI (n = 181; 51% survey response rate).

Intervention(s): Mothers and fathers of IVF/ICSI-conceived children were sent questionnaires to complete and return in a postage-paid envelope.

Main Outcome Measure(s): Responses to the questionnaire.

Result(s): Most parents had told somebody about their child’s method of conception, mostly close friends and family. Fewer (26% of mothers, 17% of fathers) had already discussed the child’s mode of conception with their child. Fifty-eight percent of mothers and 57% of fathers intended to tell their child at some point. Sixteen percent of mothers and 21% of fathers were undecided. Four percent of fathers never wanted to discuss the subject with their child. Children were more likely to be told if conception was ICSI, rather than conventional IVF, and if an only child. Twenty-nine percent of undecided mothers and 36% of undecided fathers stated that they would tell their child if appropriate, child-friendly explanatory literature were available.

Conclusion(s): The majority of parents wish to tell their child about their conception by IVF/ICSI at some point but are unsure as to the most appropriate timing and method of disclosure. Fertility clinics might have a role to play in providing the necessary support. Child-friendly literature might be helpful. (Fertil Steril 2005;83:914–9. ©2005 by American Society for Reproductive Medicine.)

Key Words: Infertility, IVF, disclosure, parent–child relations

The development of assisted reproductive technologies (ART) over the past 25 years has allowed many otherwise infertile couples to become parents to genetically related children. The level of disclosure within families about the child’s method of conception might vary according to social, cultural, and personal parental beliefs. Only a few studies have attempted to examine the parental attitudes toward disclosing methods of assisted conception and factors that might influence these attitudes. A consistent finding was that the majority of parents with children <10 years of age conceived by in vitro fertilization (IVF) had not revealed the method of conception (1–6); however, two studies found that more than half of the parents did intend to tell their child at some point (1, 2).

The relationship between revelation of mode of conception and child behavior is inconclusive. One study found that parents who had informed their child reported slightly higher, although nonclinical, levels of internalizing child problem behavior (anxiety, worry) compared with parents who had not informed their child (1). Fathers of informed children also reported higher overall problem behavior scores. Another study found no significant relationship (6).

Other studies investigating the issue of disclosure have focused mainly on donor insemination families (7, 8). This work found that donor insemination–conceived children who knew their conception method had less frequent and less severe disputes with their mothers than those who had not been told (7). However, these studies might not be representative of IVF families per se. The use of donor eggs or sperm and the subsequent lack of genetic link to one or other parent might lead to differences in parental expectations of the child’s and the extended family’s reactions.

Studies of adults who were adopted as children have shown that it is important that they are told of their adoption at an early age, and provision of information about their genetic background helped in the development of a stable...
identity (9). Thus, informing children about their mode of conception at an earlier age might result in a more favorable outcome in terms of identity and emotional difficulties.

This study is the largest survey of parental attitudes toward the issue of disclosure of the method of conception of their genetically related IVF-conceived or—more recently—intracytoplasmic sperm injection (ICSI)-conceived child. The aim was to ascertain whether parents had told, or intended to tell, their child how they were conceived and what factors might influence this decision.

MATERIALS AND METHODS

Subjects

As part of a longitudinal study (10), a group of 356 singleton children aged 5 years and conceived after conventional IVF or ICSI were identified through fertility clinics. Children and their families in the IVF and ICSI groups were selected by criteria that matched for social class, ethnicity, parental educational level, and maternal parity. Children were the genetic offspring of both parents. At the time of this survey, the children were aged 5.0–6.5 years. Ethical approval was obtained from a United Kingdom (UK) multicenter research ethics committee.

Procedure

All 356 families were sent an explanatory letter and a questionnaire for each parent, with the request that parents did not confer. Postage-paid return envelopes were provided.

Materials

The survey questionnaire was designed by the authors. A number of points were investigated:

1. Had parents revealed their child’s method of conception to others and if so, to whom?
2. Had parents discussed the method of conception with their child?
3. Had parents decided if they intended to tell their child how they were conceived?
4. If intending to tell, at what age did they wish to inform their child?
5. If undecided whether to tell, what were their concerns?
6. If parents did not want to inform their child, why not?
7. Were parents able to find any literature, short films, or any other material addressing the issue of telling children that they were conceived after assisted conception?
8. Did parents want literature to help them inform their child, and if so, what would be helpful to them?

For each question, a list of potential responses was provided. The parents could check as many answers as were applicable. The survey domains were determined by literature reviews and the authors’ previous research, which has involved many consultations with parents of children conceived by ART. Face and content validity were determined by consultation with other experts in the field and some parents not involved in the study. Although a complete pilot was not possible, a small number of parents gave feedback on the questions, allowing the authors to predict that there would be sufficient variability in responses.

Analysis

The associations between factors and outcomes were tested with the $\chi^2$ test; odds ratios (ORs) were calculated directly from relevant $2 \times 2$ contingency tables. The $t$-tests were used to compare the means of parental age in the responders and nonresponders.

RESULTS

Sample Size

Questionnaires were returned by 51% of families (181 of 356): 80% (145 of 181) with data from both parents, 17% (31 of 181) with data from the mother only, and 3% (5 of 181) with data from the father only.

Nonresponders

The response rate was as expected for this type of postal survey (11, 12) with a single mail-out. No sociodemographic differences between nonresponders and responders could be found, including parental age, social class, and educational level.

We found that few parents who responded said that they never intended to tell their child. It is possible that parents holding this view are less likely to respond.

Revealing the Child’s Conception Method to Family, Friends, and Others

Parental responses to the question of whether parents had already told or intended to tell their child how they were conceived are shown in Table 2. Of the mothers in the study, 26% (46 of 176) had told their child their method of conception, compared with 17% of fathers (25 of 150). Of these
parents, 91% of mothers and 100% of fathers also gave the age of the child when told. The mean (SD, range) age for mothers was 3.7 (1.1, 1–6) years. The mean age for fathers was 3.5 (1.3, 1–5) years. For the 145 children for whom data were available from both parents, 38 had been told about their method of conception. Of these children, 22 had been told by both parents, 3 by the father only, and 13 by the mother only.

Factors Associated with Parental Disclosure to Their Child
Several factors were considered that might be related to a parent’s decision to inform their child of their method of conception.

Sex of Child. Of the 46 mothers (out of 176) and the 25 fathers (out of 150) who had already informed their child, the sex of the child was not associated with the likelihood of parental disclosure. Twenty-four percent of boys (23 of 95) had been told by their mother, compared with 28% of girls (23 of 81) (OR boy:girl 0.81; 95% confidence interval [CI], 0.41–1.58; $P = .53$). There was no effect of the child’s sex on maternal age, OR per year increase was 0.98 (95% CI, 0.90–1.05; $P = .52$).

Method of Conception. More ICSI-conceived children (35%, 33 of 95) were told about their conception by their mother, compared with IVF-conceived children (16%, 13 of 81) (OR ICSI:IVF 2.78; 95% CI, 1.34–5.77; $P = .006$). There was no method of conception effect for paternal disclosures.

Presence of a Sibling. Children were less likely to have been told by their mother if they had one or more siblings: 20% (18 of 91) having one or more siblings, compared with 33% (28 of 85) without a sibling (OR no sibling:at least one sibling 1.99; 95% CI, 1.00–3.96; $P = .05$). Again there was no effect on paternal disclosure (OR no siblings:at least one sibling 1.28; 95% CI, 0.63–2.61; $P = .51$).

Naturally Conceived Siblings vs. IVF Siblings. In cases in which the IVF-conceived study child had one or more siblings, the mode of conception of these siblings (naturally conceived or IVF) was not associated with parental attitudes to disclosure. Of mothers who had at least one naturally conceived child, 78% (35 of 45) said that they had or would tell their child about their method of conception. In contrast, of mothers who had no naturally conceived children, 87% (40 of 46) said that they had or would tell their child about their method of conception. This difference was not significant at the 5% level (OR = 0.53; 95% CI, 0.17–1.59). Of fathers, 72% (31 of 43) who had at least one naturally conceived child said that they had or would tell their child about their method of conception. Of fathers who had no naturally conceived children, 81% (30 of 37) said that they had or would tell their child about their method of conception. This difference was not significant at the 5% level (OR = 0.60; 95% CI, 0.21–1.74).

Age of Parent. Parental age was not associated with whether the child had been told about their method of conception. For maternal age, OR per year increase was 0.94 (95% CI, 0.87–1.02; $P = .13$). For father’s age, OR per year increase was 0.98 (95% CI, 0.90–1.05; $P = .52$).

Relationship Between Informing the Child and Informing Other Adults. Telling others was associated with telling the child in question. Of the mothers who did not mind who knew about their method of conception, 94% (93 of 99) said they had or would tell their own child, compared with 71% of the remaining mothers (55 of 77) (OR = 6.2; 95% CI, 2.4–16.2). Similarly, of the fathers who did not mind who knew, 89% (71 of 80) said they had or would tell their own child, compared with 59% of the remaining fathers (40 of 68) (OR = 5.5; 95% CI, 2.4–12.9). Only 2 mothers and 5 fathers had told no one. It is therefore not possible to assess...

### TABLE 1

**Frequency of responses to question 1, “Who have you told about your child’s methods of conception?”**

<table>
<thead>
<tr>
<th>Who have you told?</th>
<th>Mothers (n = 176)</th>
<th>Fathers (n = 150)</th>
</tr>
</thead>
<tbody>
<tr>
<td>My set of parents</td>
<td>149 (85)</td>
<td>121 (81)</td>
</tr>
<tr>
<td>Partner’s set of parents</td>
<td>135 (77)</td>
<td>127 (85)</td>
</tr>
<tr>
<td>Both sets of parents</td>
<td>133 (76)</td>
<td>117 (78)</td>
</tr>
<tr>
<td>My/our other children$^a$</td>
<td>15 (16)</td>
<td>15 (19)</td>
</tr>
<tr>
<td>Close friends</td>
<td>152 (86)</td>
<td>116 (77)</td>
</tr>
<tr>
<td>Other family members</td>
<td>144 (82)</td>
<td>120 (80)</td>
</tr>
<tr>
<td>Professionals</td>
<td>59 (34)</td>
<td>46 (31)</td>
</tr>
<tr>
<td>We do not mind who knows</td>
<td>99 (56)</td>
<td>80 (53)</td>
</tr>
<tr>
<td>No one</td>
<td>2 (1)</td>
<td>5 (3)</td>
</tr>
</tbody>
</table>

*Note: Data are presented as n (%). $^a$ Answers to this question are restricted to those parents who report having more than one child.*

### TABLE 2

**Intention of parents to inform child of their method of conception.**

<table>
<thead>
<tr>
<th>Intention to inform child</th>
<th>Mothers (n = 176)</th>
<th>Fathers (n = 150)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, already told child</td>
<td>46 (26)</td>
<td>25 (17)</td>
</tr>
<tr>
<td>Yes, at some point</td>
<td>102 (58)</td>
<td>86 (57)</td>
</tr>
<tr>
<td>Undecided</td>
<td>28 (16)</td>
<td>31 (21)</td>
</tr>
<tr>
<td>No, never</td>
<td>0 (0)</td>
<td>6 (4)</td>
</tr>
<tr>
<td>No response</td>
<td>0 (0)</td>
<td>2 (1)</td>
</tr>
</tbody>
</table>

*Note: Data are presented as n (%).*
how likely these parents are to tell their own child relative to other parents.

Disclosure of the method of conception to their child was more likely if mothers had disclosed the mode of conception to their own friends \( \chi^2 (1) = 4.50; P<.03 \), to members of their own extended family (beyond their own parents) \( \chi^2 (1) = 4.96; P<.03 \), and to a lesser extent if their partners had told their extended family \( \chi^2 (1) = 3.38; P<.07 \). Disclosure to children was unrelated to disclosure to the respondents’ own parents.

Disclosure in the Future

Age at Which Parents Intend to Disclose Conception Method to Their Child. Of the mothers who said they intended to tell the child (see Table 2), 41% (42 of 102) specified an age (mean [SD], 8.6 [2.2] years). Of the fathers who said they intended to tell their child (see Table 2), 48% (41 of 86) specified an age (9.9 [2.7] years).

In the 21 families in which both the mother and father said they intended to tell the child and both gave the age at which they intended to tell the child, the correlation between the mother’s and father’s responses was 0.68. The age reported by the father was on average 0.76 years older than that reported by the mother, but this difference was not significant \( (P=.28; 95\% CI, -0.7 \text{ to } 2.2 \text{ years}) \).

Reasons Given by Parents Who Do Not Wish to Disclose Conception Method to Their Child. No mother said that she would never tell her child, but six fathers gave this response (Table 2). Only one of the fathers, however, had told no one at all. The partners of these men intended to tell their child at some point in three cases (age not stated) or were undecided.

Factors that influenced the men’s decisions to never tell were varied and included [1] parental factors, such as parents unable to agree on decision, [2] concern about their child’s reactions/feelings, [3] wider-world concerns, for instance that their child would reveal the method of conception to others or concern about child’s acceptance within the family’s culture (moral, ethical, or religious background), and [4] other reasons, such as there just being no need for their child to be told, unless there were health implications.

Reasons Given by Parents Who Are Undecided About Whether to Inform Their Child. Factors given by the 21% of fathers and 16% of mothers who were undecided included parental factors, child reactions/feelings, and wider-world concerns. Other factors included the wish to wait until sex education as a whole was discussed and concern that the child was too young for the parents to have given serious thought about approaching the topic (Table 3). Seven parents also commented that they felt the subject was not important or relevant to the child.

Parents who intended to tell their child in the future were asked whether it would be helpful to have child-friendly literature to help explain the conception to the child. The majority (92% of mothers, 82% of fathers) reported that they would find literature helpful.

Of undecided fathers and undecided mothers, 29% (9 of 31) and 36% (10 of 28), respectively, stated that they would tell their child if they had access to appropriate, child-friendly literature that explained the topic.

DISCUSSION

This study is the largest survey of parental attitudes toward informing their IVF- or ICSI-conceived child about their mode of conception. The study is strengthened by the inclusion of only families in which children were the genetic offspring of both parents and by the provision of separate responses from both parents.

The majority of parents who responded had already disclosed, or wished in the future to disclose, details about the conception method to their child. The same proportion of mothers and fathers planned to inform their child in the future, but fathers on average would tell their children slightly later, at approximately 10 years compared with 8 to 9 years for mothers. It is of note that, in a much smaller study of 8-year to 9-year-old children, the percentage of parents who were undecided, who intended to tell at some point, and who had already told are very similar to the findings of this study. That study also showed that parents who had informed their child had done so when the children were aged 4–8 years (1).

Children who had already been informed, by the age of 5 years, about their conception status were more likely to have been told by their mothers. However, the questionnaire did not ask how the information was given or in what detail. The very young age cited by some respondents suggests that the question was interpreted as the age at which the subject was first introduced and might not represent an age at which the

| TABLE 3 |
|---|---|---|
| Reasons for indecision | Mothers (n = 28) | Fathers (n = 31) |
| Parental factors | 16 (57) | 13 (42) |
| Child reaction/feelings | 15 (54) | 13 (42) |
| Wider world | 7 (25) | 6 (19) |
| Child too young | 21 (75) | 22 (71) |
| Not discussed sex education | 15 (54) | 10 (32) |
| Not relevant/important | 3 (11) | 4 (14) |

*Note: Data are presented as n (%).* Peters. Parental attitudes: disclosure in IVF families. Fertil Steril 2005.
child fully understood the information. Further research with children could explore this.

Parental decisions about whether or not to inform their child might be influenced by their decision to reveal the method of conception to others. Parents who did not mind who knew the child’s conception status (56% of mothers and 53% of fathers) were more likely to have already informed or to intend to inform their child. The remaining parents might therefore have been more selective in their choice of confidants.

This is illustrated by parental reports that issues outside the family (wider world) contributed to their decision. These parents expressed concern that their child would reveal the method of conception to others or concern about their child’s acceptance within the family’s culture (moral, ethical, or religious background). It has been reported that some cultures outside the UK, for example in Eastern Europe, are more secretive about disclosing conception information and more uncertain about whether to inform their child (13).

Previous studies have suggested that parents might perceive or experience social stigma from questioning by family and friends about their child’s conception: in particular, questioning about whether the child (and by inference the family) was “natural” or “normal,” resulting, in some cases, in moral judgments. Parents might also feel that their masculinity or femininity is brought into question when they conceive with ART. Revealing the mode of conception to others might increase this type of unwanted questioning (14, 15).

However, the majority of parents in this study who were concerned about wider-world factors had told somebody and had not kept the child’s conception method completely secret. Secrecy has been shown to be detrimental to family relationships, creating boundaries between those who do and do not know. Holders of family secrets might experience anxiety about the possibility of disclosure and find discussion of related topics uncomfortable. If the secret is subsequently disclosed, the previously unaware party might feel that their trust has been violated (16).

Almost half the parents (54% of mothers and 42% of fathers) also stated that they were concerned about their child’s response or concerned that child would feel different from siblings or peers. In addition, the presence of siblings was associated with less disclosure. Possibly parents are reluctant to highlight differences between children. However, general parental fear that their child might be singled out if their mode of conception were to be known by others has been reported previously (3), and this concern was also reported by three of the six fathers in this study who did not wish ever to inform their child.

Of this group of fathers, three had children conceived after ICSI, and three had children conceived after conventional IVF. The reason for nondisclosure is therefore unlikely to be related to male factor infertility and paternal concerns that their masculinity would come into question. This has been suggested as a cause for nondisclosure in studies of donor insemination families (15). In contrast, this study found that children were more likely to be informed if conceieved after ICSI rather than IVF. The reasons for this are unclear. Compared with conventional IVF, ICSI is a relatively new technique. Parents might be more anxious about the long-term outcomes of this technique and might wish their child to be fully informed.

Undecided parents were most concerned that their child was too young. All the children of families in this survey were <6.5 years of age. The parents were not asked if the current age of the child was relevant to their future decision about revealing their mode of conception. It might be that parents wish to wait until their child has developed further and asks questions for himself or herself. The majority of parents who stated that their child’s age was a factor also had other reasons for nondisclosure.

Some parents related the decision to tell their child to the timing of sex education. The discussion of sex education between parents and children has been shown to be difficult in cases of natural conception (1, 17), and it might be that these difficulties are compounded by the need to explain assisted conception. The optimal age to discuss sex education is not established, but charities such as the UK Family Planning Association advocate approaching the subject from an early age (18). Many parents might rely on the educational system to teach their child this topic, and in the UK the discussion of assisted reproduction is suggested in the UK national school curriculum for 11-year-olds (19). This might teach children the basic facts, but the child will not discover how they were conceived from this source.

Many parents are unsure of how to approach the subject of assisted reproduction with their child. Parents might not know where to turn for this advice. A previous study found that 24% of parents felt that their fertility clinic could have been more helpful regarding the issue of disclosure (2). This study found that 29% of undecided fathers and 36% of undecided mothers said they would tell their child if they had access to appropriate, child-friendly literature that explained the topic. In addition, almost all those who intended to tell their child (82% of fathers and 92% of mothers) said they would welcome appropriate, child-friendly literature.

The evidence gathered in adoption studies (9) is that informing children early in life of their origins contributes to the formation of successful identity and subsequent well-being. It is likely that informing children of their assisted conception at a young age might also be advantageous. The simple intervention of the provision of child-friendly literature might therefore be helpful to many parents and beneficial in the long-term for their children.

In addition, fertility clinics might have a role in helping parents tackle this issue of disclosure by offering pretreatment counseling that encourages parents to discuss the topic and perhaps by providing practical support. History has a tendency to repeat itself, and it might be that, as with
adoption studies, surveys of the attitudes of IVF-conceived adults in the future might be the most accurate method of establishing how and when the IVF-conceived child should be told, and what they would benefit from knowing.

This study, like most postal studies, is limited by low response rates, which might be a source of bias. It is possible that parents who do not wish to disclose might be less likely to respond. Of those that did respond, parents might further bias the study if they confer or answer questions in a manner that they think the researchers would interpret as “correct” or “good” parenting rather than any strongly held beliefs. We also had a lower response rate from fathers, so conclusions about their behavior need to be more tentative than those regarding their partners.

However, this study emphasizes the need to provide support to families of IVF- and ICSI-conceived children. By examining factors that influence parental decisions about disclosure, the results can be used to give an indication to additional parents about how others in their situation feel and can contribute toward helping fertility clinics to discuss these questions with future couples seeking assisted reproduction treatments.

Acknowledgement: The authors thank the families who participated in their ongoing study. Although this study did not involve UK fertility clinics, the authors are grateful for the previous support of these clinics in helping recruit the original families. The authors have produced a booklet designed to aid parents in explaining ICSI/IVF conception to their children. This can be supplied to clinics on request from the corresponding author (A.G.S.).

REFERENCES