

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 fathers and 36% of undecided mothers 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).

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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 χ^2 test; odds ratios (ORs) were calculated directly from relevant 2×2 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

Most parents had told somebody about their child's method of conception, and they were most likely to have confided in close friends and family (Table 1). More than half (56% of mothers; 53% of fathers) did not mind who knew, whereas only 1% of mothers and 3% of fathers had told no one.

Parental couples did not always agree in their response. For the families with data from both parents, in 10% (15 of 145) the father did not mind who knew but the mother did, whereas in another 10% (15 of 145) the mother did not mind who knew but the father did. In 3 families, the father had told no one but the mother had told close friends. There were no cases in which the mother had told no one but the father had told someone.

Informing the Child of Their Method of Conception

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

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