Parents' concerns regarding their ART children

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Abstract

A cohort of children conceived by assisted reproductive therapy (ART) – *in vitro* fertilisation (IVF) and intra-cytoplasmic sperm injection (ICSI) has been followed up in a National Child Development Study (Sutcliffe *et al.* 1999, 2001 and Bonduelle *et al.* 2005). Their parents were contacted and asked questions designed to elicit any concerns on their part about their child. 329 replies were received (90% response rate), and 86 of the families posed additional questions. We found that a small number of parents (26% of respondents) raised questions about a variety of issues regarding their ART-conceived child. The most commonly expressed theme (8% of all respondents, or 27/ 86 (31%) of the respondents with questions) pertained to their child's future fertility. This question was asked more frequently by ICSI than IVF parents.

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Introduction

During recent years, studies have looked at parenting and social issues with respect to families who have conceived using assisted reproductive therapy (ART) (Golombok *et al.* 1995, 1996, 2001, 2002, 2004, 2005, McMahon *et al.* 2003, Barnes *et al.* 2004, Peters *et al.* 2005), including the parents' decision to tell their offspring of their conception (Colpin & Soenen 2002, Lycett *et al.* 2004, 2005). Review articles specifically looking at this area have also been published during the past 5 years (Eugster & Vingerhoets 1999, Fasouliotis & Schenker 1999, Colpin 2002).

McMahon *et al.* 1997a describes anxiety during pregnancy in IVF mothers related to their baby's survival, separation from their babies following birth, normality of their unborn babies and possible damage to their babies in childhood.

However at four months and one year post partum the separation anxiety was not significantly different from control mothers (McMahon *et al.* 1997b, Gibson *et al.* 2000b), yet it is interesting to note that this same group of IVF mothers at one year post partum considered their children as 'more vulnerable' and 'special' compared with mothers of naturally conceived children. There are no further details of why and in what way the mothers perceived their children as 'more vulnerable' and 'special'. It is possible that this perception of the parents could be related to anxiety about the health and well being of the child.

Experiences have shown that because of the 'difficult pathway' to conception, parents often have unreasonable

high expectations from their child and parenthood in general. There have been reported difficulties around issues of separation and differentiation, primarily in the form of overprotection and infantilisation of the child.

Parents of ART children sometimes face problematic pregnancies compared with general population. Pullan-Watkins study (1987) show that stressful situation preceding or following the birth of a child, which raises concerns about health and well being of the infant, may predispose to difficult maternal child bonding. Anxious mothers may be overprotective and less able to promote autonomy development and optimal attachment.

There have been additional issues amongst these families in making the decision to tell their offspring of their conception. It has been identified that issues of identity become important in different stages of a child's life, e.g. adolescence and can give rise to parent–child conflict (Coleman & Hendry 1990).

This experience is to a certain extent similar to those experienced by adopted children, who show increased interest in their biological origins (Hoopes 1990) around the age of 11 years. This is also the age around which this group of children demonstrate an increase in emotional and behavioural problems. Recently, several studies have looked into IVF parents' disclosure practices and attitudes (Greenfeld *et al.* 1996, Brewaeys *et al.* 1997, Colpin & Soenen 2002, Peters *et al.* 2005). Most of the studies show that a large majority of parents had not yet informed their child (aged 3–10 years) at the time when the studies were done. Colpin and Soenen (2002) quote that 75% of the parents

have not informed their children. They also comment that IVF parents who have informed their child notice significantly more difficult behaviour in their child when compared with IVF parents who have not yet disclosed mode of conception. The recent report from Peters and others (2005) stress that even though most parents had somebody (close friend, family), only 26% mothers and 17% fathers had discussed mode of conception with child. However they also point out that 58% of mothers 57% of fathers intended to tell their child at some point.

There is, however no report describing parental concern about their ART conceived child's future health and well-being, although several studies on mother-child relationships (Gibson *et al.* 2000, Hahn & DiPietro 2001) describes parental over protectiveness. It could be valuable to practitioners caring for families who have had fertility treatment to have information on what sort of concerns their clients may have. We thought it would be useful to enquire from our National Child Development study families (Sutcliffe *et al.* 1999, 2001, 2005) if they had any concerns about their child's present and future health and development.

Materials and Methods

North Thames MREC has given ethical approval for our ongoing National Child Development Study, comparing

the general health and development of children who have been conceived by IVF and ICSI to that of age-matched naturally conceived controls.

Families were recruited from 22 UK fertility units and these children (now 8–9 years old) were assessed for growth and development at approximately 5 years of age. This study will follow these children up until adulthood with regular contact by post and occasional assessments.

Families were contacted initially by post. Parents who did not respond to the first letter were sent a reminder, and those who still did not respond were contacted by telephone. They were asked if they would be willing to complete the questionnaire by telephone interview.

A letter was sent to update parents on study progress and promised to send them the results of our evaluation at 5 years, once they were ready for publication. Enclosed was a short questionnaire (see Fig. 1) with tick boxes for them to indicate whether they felt monitoring of child growth and development, and/or the investigation of future possible risk of health problems in children conceived by ART was important to them. We asked them to indicate whether they would be interested in participating in further studies in these areas, and then asked them if they had any further questions that could be answered in future studies. A prepaid addressed envelope was enclosed for them to reply, and

Survey questionnaire

Dear Parents
Could you please tick which of the following areas, you think may be important regarding children who have been conceived with extra help. Little is known about these areas. We can only find answers with the cooperation of families, with children such as your own.

	Yes	No
1. Monitoring of general child development (We have done this to age of 5 but feel this need to continue)	☐	☐
2. Monitoring of child physical development	☐	☐
3. Investigating the future possible risk of health problems in children as they grow up	☐	☐

Are there any questions that you would like the answers to that we may be able to investigate in the type of studies we have carried out so far?

- *If parents express interest in particular subjects we will write again, depending on your responses. All correspondence will continue to be strictly confidential.*
- *Please note that we have no evidence that any of these areas may be a problem in the future but having been approached by parents concerned about possibilities, we felt we should ask you your views.*

Figure 1 Sample of questions used in questionnaire sent to parents.

Table 1 Range of questions asked by ART parents.

Question theme	Total no of respondents who asked	ICSI	IVF
Their child's future fertility	27 (8%)	20	7
General health	12 (3.6%)	4	8
How to tell the child	11 (3.3%)	6	5
Anxieties raised by press articles	7 (2%)	1	6
Risks to embryo cryopreservation	6 (1%)	0	6
Education potential/learning difficulty	6 (1%)	3	3
ADHD/hyperactivity	4	3	1
Personality/social skills	4	1	3
Development (non-specific)	3	2	1
Dyslexia	3	3	0
Are ART parents overprotective	2	0	2
Genetic disorders	2	0	2
Leukaemia	2	0	2
Urinary tract infections	2	0	2
Short stature	2	1	1
Weight gain	1	1	0
Visual-perceptual difficulties	1	1	0
Autistic spectrum disorder	1	1	0
Hearing	1	1	0
GORD	1	0	1
Food allergy	1	1	0
Chest problems	1	0	1
Painful genitalia	1	1	0
Asthma	1	1	0
Rheumatic disorders	1	0	1
Loose-jointedness	1	1	0
Encephalitis	1	1	0
Prematurity	1	0	1
Totals	106	53	53

ART, assisted reproductive therapy; ICSI, intracytoplasmic sperm injection; IVF, *in vitro* fertilization; ADHD, attention deficit hyperactivity disorder; GORD, gastroesophageal reflux disease.

they were asked to inform us of any future address changes.

Results

The parents of 362 children were contacted, 186 whom had conceived by ICSI, and 176 who had conceived by IVF. A total of 329 replies were received – 230 via postal contact and 99 by telephone contact. Of the total 329 replies, 169 were from ICSI parents, and 164 from IVF parents.

One family replied by post from New Zealand, and another from Ireland. One family in Ireland were contacted by telephone.

86 (26%) parents who responded appeared to have concerns and 243 responders appeared to have no concerns. From the responses of the 86 responders who had concerns (45 ICSI parents and 41 IVF parents) 28 different question themes (106 questions in total, see Table 1) were identified. The most common question (25%) was concerned with their child's future fertility (Fig. 2). Other common themes were related to telling their child of his/her conception (11/86), and to unspecified general health concerns. The two groups (ICSI vs IVF) asked similar questions, but with different frequencies (Tables 2 and 3).

The majority of parents that replied (295/329) indicated that they would be willing to participate in future studies. Only 9 families definitely preferred to not participate in further studies. Most felt that monitoring growth and development as well as general health problems were important (256/329); but some (10/329) felt that growth

Figure 2 Questions asked by parents whose children were conceived by assisted reproductive therapy.

Table 2 Questions asked by ICSI parents.

Question theme	Number	% Total ICSI parents (169)	% Total ICSI parents with questions (45)
Their child's future fertility	20	12%	44%
General health	4	2%	8%
How to tell the child	6	3.5%	13%
Education potential/learning difficulty	3	2%	6.60%
ADHD/hyperactivity	3	2%	6.60%
Dyslexia	3	2%	6.60%
Development (non-specific)	2	1%	4%
Anxieties raised by press articles	1	0.6%	2%
Personality/social skills	1	0.6%	2%
Short stature	1	0.6%	2%
Weight gain	1	0.6%	2%
Visual-perceptual difficulties	1	0.6%	2%
Autistic spectrum disorder	1	0.6%	2%
Hearing	1	0.6%	2%
Food allergy	1	0.6%	2%
Painful genitalia	1	0.6%	2%
Asthma	1	0.6%	2%
Loose-jointedness	1	0.6%	2%
Encephalitis	1	0.6%	2%

Table 3 Questions asked by IVF parents.

Question theme	Number	% Total IVF parents (164)	% Total IVF parents with questions (41)
Their child's future fertility	7	4%	17%
General health	8	5%	19.50%
How to tell the child	5	3%	12%
Anxieties raised by press articles	6	3.6%	14.60%
Risks of embryo cryopreservation	6	3.6%	14.60%
Education potential/learning difficulty	3	2%	7%
Personality/social skills	3	2%	7%
Are ART parents overprotective	2	1%	5%
Genetic disorders	2	1%	5%
Leukaemia	2	1%	5%
Urinary tract infection	2	1%	5%
Development (non-specific)	1	0.6%	2%
ADHD/hyperactivity	1	0.6%	2%
Short stature	1	0.6%	2%
GORD	1	0.6%	2%
Chest problems	1	0.6%	2%
Rheumatic disorders	1	0.6%	2%
Prematurity	1	0.6%	2%

and development was more important than general health, or (8/329) that monitoring for general health problems was more important than growth and development.

Discussion

The response rate (90%) suggests that parents are interested and motivated to continue participating in the National Child Development Study. 74% of parents that responded appeared to have no concerns, only 26% of parents that responded chose to ask additional questions.

The most frequently asked question was whether or not their child conceived using ICSI or IVF would have fertility problems themselves. This was posed in various different ways by 27 (8% all responders) families (7 IVF and 20 ICSI).

The parents who had undergone the more invasive ICSI treatment were 2.5 times more likely to ask this (20 out of the 45 with questions; 44%) than standard IVF parents (7 out of 41 with questions; 17%).

Both groups had concerns about how, when, or if to tell their child about how they had been conceived. 6/45 ICSI (13%) and 5/41 IVF (12%) asked this. Many asked if a booklet or video was available to help them break the news. Members of the study group have actually produced a booklet which was developed with input from some ART parents. We plan to make this available to our study group on request.

One of the more striking observations was that families have asked about a number of different health conditions, most of which (food allergy, asthma, dyslexia, ADHD, etc.) are unlikely to be due to ART *per se*. Each of those

families received individual responses. These questions must reflect the strong commitment to parenting that these families have, and their understandable anxiety that any disease or condition their child gets could be related to their assisted conception.

Conclusions

Parents have unmet information needs about their child's future fertility and any impact that assisted conception may have on their child's future health. They demonstrate a willingness to continue participating in studies and it would seem that this is partly motivated by their concerns about their child's long-term outcome.

These families feel like 'winners in a lottery' (Barnes *et al.* 2004). They are grateful for any research into the long-term health and wellbeing of their child(ren).

They are keen to find out what has been looked into by other groups and to hear the results of our National Child Development Study. We intend to continue conducting research in this area, to inform these parents and the clinicians looking after them and future generations of assisted conception families.

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