

School-aged children of donor insemination: a study of parents' disclosure patterns

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BACKGROUND: A major concern in relation to donor insemination (DI) is whether children should be told about their genetic origins. This study compared the thoughts, feelings and experiences of DI parents who were inclined towards openness with those who were inclined towards non-disclosure. **METHODS:** Forty-six families with a 4- to 8-year-old DI-conceived child were interviewed about their decision, their reasons and subsequent concerns regarding disclosure. **RESULTS:** Thirty-nine percent of parents were inclined towards disclosure whilst the remaining 61% were not. The two main reasons for favouring disclosure were to avoid accidental discovery and a desire for openness. Non-disclosing parents felt that there was no reason to tell and wished to protect family members. The children who had been told reacted with either curiosity or disinterest. **CONCLUSIONS:** In spite of donor anonymity, parents who were intending to tell their child in the future had optimistic expectations of their child's reaction. Parents who had already told their child generally described the telling experience as a positive one.

Key words: children/disclosure/donor insemination

Introduction

Donor insemination (DI) is a common reproductive technique used by couples facing male infertility. Of concern amongst parents, psychologists and health professionals is whether children conceived through DI should be told about their genetic origins. There are currently few systematic data on the disclosure of donor conception to children, or comparisons between children who have been told and those who have not. This lack of information is, in part, due to the small number of parents disclosing such information to their children.

In the past, the use of DI as a treatment to overcome male infertility was shrouded in secrecy, with legal positions advocating such concealment. In the UK, for example, until 1977, children born through DI were considered illegitimate and parents had to legally adopt the child (Smart, 1987). Parents were recommended to tell the child that he or she had been adopted rather than conceived through DI (Rowland, 1985). Clinicians also endorsed the view that it was not necessary to tell the child (Mahlstedt and Greenfield, 1989). With a policy of secrecy strongly advocated in the past, it is of little surprise that few of those conceived using this technique were aware of their donor origins.

In more recent years, however, many countries have witnessed a change in their legal and policy approach to DI and donor anonymity, in part to encourage disclosure of donor

conception information to children. For example, in Sweden, children can have access to identifying information about their genetic father at an age when they are considered sufficiently mature (Frith, 2001). In New Zealand, parents are strongly encouraged to be open with their child and clinics only recruit donors who are willing to be identified by offspring in the future (Daniels *et al.*, 1995). The state of Victoria in Australia has instituted a recent change in the law whereby children can access identifying information about the donor without his permission (Blood, 1998), thereby putting control in the hands of offspring as opposed to parents, the donor or the clinic. In The Netherlands (Pennings, 1997), and in some clinics in the USA (Scheib *et al.*, 2003), a 'double track' system now operates, giving freedom for parents to choose between donor anonymity or donor identification. In The Netherlands, donor anonymity will soon be removed entirely. In the UK, the practice of DI is regulated by the Human Fertilisation and Embryology Association (HFEA). Although there is currently no mandate obliging parents to tell their child of their donor origins, children born since 1990 can find out whether or not they were conceived through donor gametes at the age of 18 (HFE Act, 1990). Further, the government recently has announced a change in the law whereby children conceived by donor gametes from April 2005 onwards will be entitled to identifying information about their donor on reaching age 18.

With such widespread change in legislation and clinic policies, and in some cases the lifting of donor anonymity, it may be expected that parents would more frequently disclose donor information to their children (Department of Health, 2001). However, in a comparison of the attitudes of DI parents between 1980 and 1996, van Berkel *et al.* (1999) found that parents' level of adherence to non-disclosure of information to the child remained the same over a 16-year period. Moreover, in a study of a representative sample of 111 families with a 4- to 8-year-old child conceived through DI in Spain, Italy, The Netherlands and the UK, not one of the families had told their child of their donor origins, with the majority of parents stating that this information would never be disclosed (Golombok *et al.*, 1996). A follow-up of this sample ~6 years later found that only 8.6% of parents had told their 12-year-old child about their donor conception (Golombok *et al.*, 2002a). Even in Sweden, where parents are expected to disclose donor origins to their children, Gottlieb *et al.* (2000) found that only 11% of parents had told their child although a further 41% intended to tell. Nevertheless, the most recent study of DI parents found a greater reported tendency towards openness, with 46% of DI parents intending to tell their child (Golombok *et al.*, 2004). The children were just 12 months old, however, and too young to have been told at the time of the study. The findings nonetheless suggest that parents' attitudes towards disclosure may be changing.

It has often been claimed that secrecy about DI will have a deleterious effect on family relationships (Rowland, 1985; McWhinnie, 1986). Family therapists have argued that if information about a child's donor origins is kept secret, the relationship of trust and honesty, which is so crucial between parent and child, is entirely undermined, endangering openness and communication (Clamar, 1988). Support for this viewpoint is provided by Turner and Coyle's (2000) study of adults who discovered their donor conception later in life, often under negative circumstances such as parental divorce or death. An examination of these personal experiences pointed towards feelings of mistrust of family members, distinctiveness from the rest of the family, abandonment by the donor and practitioners, and feelings of frustration and loss regarding the unobtainable donor information. Although these findings may be unrepresentative due to the recruitment of participants through DI support networks, the implications for what could occur if the issue is not dealt with sensitively are highlighted by this investigation.

Children whose parents keep their donor conception secret may be able to pick up on hidden clues from them through facial expressions, tone of voice or changing the subject when the topic of whom the child looks like crops up (Golombok, 2000). Moreover, if other members of the family are aware of the child's DI conception, this information could accidentally be revealed, the impact of which is likely to be more detrimental than had they been told during early childhood (McWhinnie, 1995). As ~50% of DI parents tell a friend or family member about the child's donor conception (Golombok *et al.*, 1999; Gottlieb *et al.*, 2000), disclosure by someone other than a parent presents a real possibility. In

addition, improved genetic technology increases the possibility of offspring discovering their genetic origins independently of family members or friends (McGee *et al.*, 2001).

Studies that have examined parental attitudes towards disclosure (e.g. Cook *et al.*, 1995; Nachtigall *et al.*, 1998; Lindblad *et al.*, 2000) suggest that the main reason parents decide against openness is to protect the child from either the distress of discovering their father is not genetically related to them or of not being able to access genetic information about the donor. Secondly, parents wish to protect the father either from the child's potential rejection or from the social stigma associated with male infertility. Lastly, parents often feel unsure of how, when and what to tell their child, and therefore may be inclined to avoid discussion altogether.

Due to the small numbers of parents who have already told their child, little is known about UK parents' reasons for, and experiences of, disclosure of DI conception, and, in turn, about the effect disclosure at a young age has on psychological well-being in the long term. However, there is shorter term evidence of children's reactions to the news of their donor origins. Common reactions include curiosity, interest in the story and a desire to know more about the donor (Snowden, 1990; Rumball and Adair, 1999; Lindblad *et al.*, 2000; Vanfraussen *et al.*, 2001). The children in these studies had generally been told as young children and had neutral or curious reactions, but not negative ones. However, Solomon *et al.* (1996) have argued that young children below the age of 7 do not possess the cognitive sophistication to fully understand the concept of DI, and therefore neutral reactions would be expected. As the children studied so far have mostly been pre-adolescent, any negative response to the information by the child may not surface until adolescence or adulthood. Rumball and Adair (1999) have argued that there are advantages in telling children of their origins at a young age because they process the information in a factual, non-emotional context. If the process of encoding this information does not take place under negative circumstances, the child may be less likely to be distressed.

In light of shifting legal, social and professional standpoints in the debate over disclosure of information to the child, the main aim of the present study was to examine thematically the decision-making and disclosure processes of parents with a young DI child. Specifically, the study ascertained parents' preparation of and reasons for (non-)disclosure. In cases where parents had told their child, the process of the disclosure event and subsequent reactions of the children were explored. Families who endorsed openness are compared with those who do not on quantitative measures of their disclosure experience.

Data were obtained from a clinic that endorsed openness with the aim of maximizing the number of children who had already been told about their donor origins. This allowed a comparison of parental attitudes between those inclined towards disclosure ('disclosers') and those who do not show an inclination towards disclosure ('non-disclosers'). Obtaining data from just one clinic meant that the findings were not necessarily representative of all DI families, or an accurate reflection of current disclosure rates. However, this clinic

was the only known unit actively to endorse and encourage openness of DI and was targeted for that reason.

Subjects and methods

Participants

The families participating in the study were recruited from King's College Hospital Assisted Conception Unit. Eighty-eight families who received successful DI treatment during a 4-year period from 1994 to 1998 were invited to participate in the study through a letter from the clinic. Of the 60 families who had been known to receive the letter, 46 families with a child aged between 4 and 8 years old conceived through DI were recruited to the study, providing a response rate of 77%. Seventy-eight percent ($n = 36$) of interviews were conducted with both the mother and father present, and 22% ($n = 10$) of the interviews were conducted with the mother only. Of these latter interviews, seven couples had separated or divorced, and the remaining three interviews were conducted in the absence of the father due to work commitments. Efforts were made to contact absent fathers through the mothers, but fathers were unable (e.g. time pressures) or unwilling (e.g. strained post-separation relationship, sensitive to topic of DI) to participate. There was no significant group difference in fathers' presence at the interview based on comparisons of parents endorsing openness and those endorsing non-disclosure.

At the initial stage of invitation by the clinic, couples who actively refused to participate were asked to provide reasons for doing so. Reasons specified included illness in parents, wanting to maintain privacy because parents had not told the children and a feeling that they could not contribute anything as their child was happy, healthy and well-adjusted.

There were 22 boys and 24 girls in the sample, and the mean age of the child was 6.6 years. The mothers' mean age was 40 years and their partners' mean age was 45 years. The families' demographic information can be found in Table I. Ethical approval was obtained from the Ethics Committees of City University and King's College Hospital, London. Informed consent was obtained from all the families that took part in the study.

Procedure

A research psychologist (E.L.) trained in the study techniques visited the families at home. Mothers and fathers were interviewed together and the interview was tape-recorded and lasted ~1–1.5 h. Parents first discussed issues relating to the child's psychological well-being and quality of parenting, the findings of which are reported elsewhere (Lycett *et al.*, 2004). Parents were then asked specific questions relating to their experiences of having a child through DI and their views on telling their child about their conception. Both mothers and fathers were invited to the interview because, as previous studies have shown (e.g. Schover *et al.*, 1992; Daniels *et al.*, 1996), the viewpoints of mothers and fathers can differ. Many studies examining the disclosure attitudes of families with a child conceived through DI have relied heavily on mother-only interviews. In the case of DI, it is the father's infertility that is under scrutiny, and therefore differing paternal attitudes towards disclosure are considered important for examination. A joint interview also allowed parents to engage in an in-depth discussion of their attitudes towards disclosure with each other, potentially eliciting more information than an individual interview.

Table I. Socio-demographic information by disclosure status

| | Disclosers ($n = 18$) | | Non-disclosers ($n = 28$) | | <i>F</i> | <i>P</i> |
|--|----------------------------|-------|--------------------------------|-------|----------|----------|
| | Mean | SD | Mean | SD | | |
| Age of child (months) | 80.78 | 15.40 | 78.39 | 14.86 | 0.27 | NS |
| Age of mother (years) | 40.06 | 4.76 | 40.96 | 4.08 | 0.48 | NS |
| Age of father (years) | 44.60 | 4.14 | 47.46 | 7.42 | 1.88 | NS |
| Duration of marriage/cohabitation (months) | 175.76 | 60.55 | 215.26 | 48.47 | 5.71 | <0.05 |
| | <i>n</i> | | <i>n</i> | | χ^2 | <i>P</i> |
| Child's sex | | | | | | |
| Boy | 9 | | 13 | | 0.06 | NS |
| Girl | 9 | | 15 | | | |
| Presence of siblings | | | | | | |
| Yes | 12 | | 11 | | 5.70 | <0.05 |
| No | 6 | | 17 | | | |
| Social class | | | | | | |
| Professional | 8 | | 8 | | 2.12 | NS |
| Managerial | 3 | | 8 | | | |
| Skilled/non-manual | 3 | | 3 | | | |
| Skilled manual | 4 | | 9 | | | |
| Marital status | | | | | | |
| Married/cohabiting | 13 | | 26 | | 3.61 | NS |
| Separated/divorced | 5 | | 2 | | | |
| Mother working | | | | | | |
| No | 7 | | 9 | | 0.22 | NS |
| Yes | 11 | | 19 | | | |
| Father working | | | | | | |
| No | 2 | | 3 | | 1.05 | NS |
| Yes | 13 | | 23 | | | |
| Mother ethnic identity | | | | | | |
| Caucasian | 18 | | 27 | | 0.66 | |
| Middle Eastern | 0 | | 1 | | | NS |
| Father ethnic identity | | | | | | |
| Caucasian | 16 | | 23 | | 1.99 | NS |
| Middle Eastern | 0 | | 3 | | | |

Measures

The interview was standardized in that each of the variables was accompanied by a coding scheme that gave a detailed description of the criteria required for individual rating points on each variable for each parent. The interview was also semi-structured in that it used a flexible approach to questioning that enabled an open-ended but in-depth examination of specific issues surrounding disclosure that had not previously been explored. Data were therefore analysed using quantitative data methods followed by a thematic analysis of parents' attitudes and comments regarding disclosure of DI to the child.

Thematic data

The decision-making process. Specific aspects of the decision-making process were assessed during the interview and the following ratings were made for each family.

(i) *Parents' discussion about disclosure* was rated on a 3-point scale of 0 (no discussions had taken place at all), 1 (some, infrequent and/or superficial discussions) or 2 (much, in-depth and/or frequent discussion had taken place) and based on the extent to which parents had discussed with one another about disclosure of the DI conception to the child.

(ii) *The decision maker* was rated on a 5-point scale from 1 (mother only) to 5 (father only) and assessed which parent was most instrumental in the decision-making process.

(iii) *Difficulty in decision making* was rated on a 4-point scale from 0 (no difficulties) to 3 (major difficulties reported as being impossible to overcome) and measured the kinds of difficulty parents experienced in reaching the disclosure decision, taking into account how easily these kinds of problems were overcome.

(iv) *Discussion with others* was rated on a 3-point scale from 0 (no discussion with others), 1 (some, infrequent and/or superficial discussions) to 2 (much, in-depth and/or frequent discussion with others) and assessed the extent to which parents had discussed the decision to disclose with other family members or friends.

(v) Parents not intending to disclose the DI conception to their child were assessed on the *level of concern* they experienced in the knowledge that the child may accidentally discover their donor origins, rated on a 4-point scale from 0 (no concern) to 3 (extreme concern, constituting continual/overwhelming anxiety or worry about non-disclosure).

Thematic analysis

Parents provided further information from open-ended questioning regarding the following issues.

(i) *Decision-making process regarding disclosure.* Parents were asked about their current decision regarding disclosure, how they had arrived at their decision, the concerns and/or difficulties they had experienced in making a decision, and whether anyone had been influential in helping them make the decision. Parents were invited to give more than one reason for the decision so they were not restrained in giving a single response but had the opportunity to describe all the reasons influencing the decision. It was expected that this would provide a more accurate reflection of parental attitudes. Based on their current situation, the parents were classified according to the four categories of *disclosure, non-disclosure, intending to disclose and uncertain*.

(ii) *Disclosure.* Parents who had already told their child about their donor origins were asked to describe the factors contributing to the decision, to describe the actual telling process, what and how the issue was explained, the age the first process took place and the reactions shown by the child.

(iii) *Non-disclosure.* Parents intending not to disclose the donor conception were asked to describe the factors contributing to their decision, and any concerns and/or difficulties they had experienced from not disclosing the DI conception, e.g. accidental discovery.

(iv) *Intending to disclose.* Parents intending to disclose their child's donor origins in the future were asked to describe the factors influencing the decision and their plans for disclosure such as the child's age and the method they intended to adopt.

(v) *Uncertain.* Parents who were still uncertain about their decision to disclose information to their child were asked to describe the factors contributing to their uncertainty and how they believed their uncertainties might be resolved.

Results

Decision of disclosure

Six of 46 families (13%) had already told their child about their DI conception, 12 families (26%) intended to tell their child in the future, 20 families (43%) had decided not to tell their child, and the remaining eight families (17%) were still uncertain of their intention. The following quantitative analyses were based on the data from all 46 families. For the

qualitative analyses, 85% of interviews were transcribed. Two families declined to be tape-recorded and the remaining five tapes were inaudible. Transcripts were available for 14 families not intending to disclose, eight families who were uncertain, 11 families who were intending to tell and six families who had already told.

The families were divided into two groups depending upon their decision regarding disclosure of information to their child. The first group (non-disclosers, $n = 28$) comprised those who were inclined toward non-disclosure and included parents who had decided against telling their child ($n = 20$) and those who were uncertain about telling ($n = 8$). The second group (disclosers, $n = 18$) comprised those who were inclined toward disclosure and included parents who had already told their child of their donor conception ($n = 6$) and those who intended to tell them in the future ($n = 12$). To compare DI children on measures of emotional/behavioural adjustment, Brewaeys *et al.* (1997) generated a 'preferring disclosure' group by combining the families where parents intended to disclose with those who had already told. Similarly, in the study of Nachtigall *et al.* (1997), parents who were intending to tell their child formed a composite group with those who had already told. In the present study, those who were uncertain about disclosure were combined with those opting for non-disclosure because they did not express strong feelings in favour of openness and disclosure as the former groups had done. There were no significant differences between the 'disclosers' and 'non-disclosers' based on demographic characteristics, with the exception of length of marriage and the presence of siblings (see Table I).

For 82% of families who had reached a decision regarding disclosure ($n = 38$), a joint parental decision had been made as opposed to one parent making a (semi)-autonomous decision. There was no significant difference between the 'disclosers' and the 'non-disclosers', $\chi^2 = 4.00$, NS. Nine percent ($n = 4$) had involved other friends or family members in their decision-making process, $\chi^2 = 0.27$, NS. Of the 38 families who had made a decision regarding disclosure (i.e. with eight 'uncertain' families excluded), 74% ($n = 28$) reported no difficulties in reaching their decision, whilst 26% ($n = 10$) reported minor difficulties. Of the 20 families not intending to tell their child, 70% ($n = 14$) reported having no concerns about their decision whilst 25% ($n = 5$) reported having minor concerns about their decision not to tell. Such concerns included feelings of guilt about not being fully open about the child's genetic origins and of the child accidentally discovering their donor conception, possibly leading to the child's subsequent distrust of their parents. One family had moderate concerns about their decision following suspected inadvertent disclosure of DI information by health professionals, thus leading to the parents' fear of accidental discovery. An analysis of variance (ANOVA) revealed no significant difference between the groups for difficulty in decision making, $F(1,37) = 2.54$, NS, or for parents' discussion about disclosure with each other, $F(1,37) = 0.72$, NS.

Table II. Reasons for inclination towards disclosure

| | |
|--|---|
| (1) To avoid accidental discovery | |
| Disclosure by others (<i>n</i> = 13) | 'Other people know that we've had it [DI], so they could easily drop it out. ... I just think keeping a secret like that is a time bomb waiting to go off.' 'I'm concerned that other people will let them know ...through saying they're like me and not saying they're like [husband].' |
| Technological advances (<i>n</i> = 11) | 'Genetics will play an increasing role in medicine in terms of public knowledge of genetics and, at some point, the genetic mismatch would just be so ... evident.' 'If he's got problems later on...[father] won't be able to help him, and he might ask, 'Well, why can't Daddy help me?'...it's really for that, more than anything ... for the medical side of it.' 'Like simple blood tests they [children] do at school. You know, finding out what blood group you are. It could throw out that she couldn't be [father]'s. in which case [child] starts asking questions.' |
| (2) A desire for openness | |
| Honesty (<i>n</i> = 7) | 'When it was found that... we couldn't get pregnant normally, we decided that it was going to be truth all the way down the line... we'd tell them the truth... of where they came from, how they came there to be with us and all the rest of it.' 'I suppose I really wanted to be open with her [child]' 'In a sense, my preference would always have been to have told her' [child], simply because I like truthfulness and openness' 'I think with the enquiring mind that she [child] has...there has to be an honest answer.' |
| Avoid 'secrets and lies' (<i>n</i> = 2) | 'It's not right to keep a secret' 'I don't think there's any real reason to lie. His relationship with his Dad... is secure enough...and that's what we build on now and make that strong.' |
| Child's right to know (<i>n</i> = 8) | 'We thought she [child] had a right to be the one that knows first [about her conception]... it didn't seem right to tell anyone else, if she didn't have the information' 'I think the big thing for me is that ... if people like my Mum and my Dad know, then it's [child]'s right to know.' '...Before she [child] was born, we were all for not saying anything [about the DI conception]... and as soon as she came out, you realise it's not about you anymore, there's another person involved.' |

Reasons for inclination towards disclosure

With respect to the disclosing group (*n* = 18), the six families who had already disclosed the DI conception and the further 12 who intended to tell their child in the future outlined the reasons for their decision (see Table II). The two main reasons for favouring disclosure were (i) to avoid accidental discovery (88%) and (ii) a desire for openness and honesty (88%). Fifty-five percent of parents (*n* = 11) cited both these reasons for their final decision regarding disclosure.

As 72% of disclosing mothers (*n* = 13) and 40% of fathers (*n* = 7) reported that they had told at least one other person including close family, friends, health professionals, teachers, work managers and childminders about the nature of their child's DI conception, parents feared that the child could find out accidentally through disclosure by others. Accidental discovery was also thought to occur though an increase in routine medical procedures and technological advances.

The second main reason for parents' decision to tell their child about the DI conception was to avoid keeping secrets or lying to the child and a desire to be honest and open with their child. Other parents reported the reason for being open was to avoid being dishonest with their child. Almost half the couples wanted to disclose the DI conception because they believed that the child has an exclusive right to know about the nature of his or her genetic origins.

Reasons for inclination towards non-disclosure

Regarding the non-disclosing group (*n* = 28), the two main reasons for favouring non-disclosure were (i) that there was no reason to tell the child (61%) and (ii) to protect one or

more family member(s) (66%) (see Table III). Parents reported that there was no need for the child to know the details of their conception because such information was not an important issue, was a personal matter between the couple or that the family felt 'normal' and saw no point in disclosure.

The second most common impetus for non-disclosure was to protect family members. Forty-six percent of the non-disclosing parents expressed the desire to protect their child from negative social pressures, which they believed may have a detrimental impact on the child. Others argued against disclosure because of the potential impact on the child of not having access to genetic information, and the potential lack of understanding of DI. Twenty-nine percent of parents expressed fear that the father and the relationship with his child would be severely affected if the child became aware of the donor conception. Some parents expressed fears of rejection from the child. Other fathers were worried that their child would reject them in favour of their 'real' biological father, thus affecting the quality of the father-child relationship.

Parents who intend to disclose

Data were analysed from the 12 sets of parents in the disclosing group who intended to disclose but had not yet done so, about their expectations of their child's reaction, the age at which they planned to disclose the information, and the approach to telling that they planned to endorse.

The expectations that parents have of telling their child in the future are characterized by a diversity of positive feelings, curiosity and indifference. Many parents found it difficult to decide when to tell their child about the DI. Though

Table III. Reasons for inclination towards non-disclosure

| | |
|---|---|
| (1) No need to disclose | |
| Irrelevance (<i>n</i> = 17) | ‘It’s irrelevant...it’s just that he’s [child] my son and that’s it...what has happened to us is very important because [child] is here...it’s in the past and it’s not going to make any difference.’ ‘Their [children’s] names were on the birth certificate...[their] father’s name was on the birth certificate...there’s no reason really to tell them.’ ‘I don’t think it’s that relevant to her [child]...I don’t think there’s any need to say anything.’ |
| Personal matter (<i>n</i> = 10) | ‘...The nature of my sterility is about me and not about her [child].’ ‘You just think, ‘it’s our little secret’...between the two of us...we just thought it was private...it’s nobody else’s business really.’ |
| Desire for normality (<i>n</i> = 4) | ‘We felt that we probably had an obligation to tell them [children], but once they were born...we just felt that everything was normal.’ ‘We felt that it would be easier for them [children] if they grew up thinking that they were just normal, they’d been born in a normal... situation and that there was nothing untoward about them...I don’t see there’s any reason to tell them...we’re a normal family’ |
| (2) Protection of family members | |
| (A) Protection of the child (<i>n</i> = 13) | |
| Negative social pressures (<i>n</i> = 10) | ‘I think it would just cause so much upset, because he’d [child] suddenly feel so many emotions at once in the confusion of it all.’ ‘I think at the moment they [children] are very secure children and I think that [disclosure] would rock their security completely...to suddenly send them to school thinking, ‘we’re different’...it’s not necessary’ ‘...just worries and fear for [child]...[being] alienated from the other kids’ |
| Lack of genetic information (<i>n</i> = 2) | ‘Although she [child] would know that I wasn’t her biological father, she wouldn’t necessarily know who her real father was. She wouldn’t have access to that information. So I guess, in a sense, you could argue what’s the point in telling her, for her not to know who her real biological father is.’ ‘I’m sure he [child] would be very unhappy because he would always want to find out who the real one was.’ |
| Lack of understanding of DI (<i>n</i> = 2) | ‘When they’re young, they can’t understand’ ‘He’s just not old enough yet to take it on board.’ |
| (B) Protection of father (<i>n</i> = 8) | |
| Rejection of father (<i>n</i> = 8) | ‘I think sometimes he [father] worries that... she [child] might reject him if she knew the truth.’ ‘If the day ever came where he [child] turned round and said, ‘You’re not my Dad anyway’, I couldn’t cope with that...No way...I’m not putting him [father] in a position for that, not after all he’s [father] gone through...He’s more than earned his right to be called ‘Dad’.’ |
| Threat to father–child relationship (<i>n</i> = 3) | ‘What I’m afraid [is], he [child] might say, ‘Go away daddy, I don’t want to know you anymore, I want to know my real father. And I want to find out my real father and forget you!’ ‘If they [children] want to look for an alternative father... my relationship with them will never be the same again.’ |

the majority of parents (*n* = 8) had decided to disclose their child’s donor origins between the ages of 7 and 11, and two at age 18, the remainder reported they would tell their child when he or she asks about spontaneous natural conception. Many parents discussed the uncertainty about how they might broach the subject of DI with their child. These thematic data can be found in Table IV.

Parents who have already disclosed

The six parents who had already told their child were questioned about the age at which they had first discussed DI with their child, who had told the child, and how many subsequent discussions had taken place. Parents were also asked to describe the method they used to disclose the information, the reactions of the child and about whether or not the child expressed interest in the donor.

Two children had initially been told at age 3, three children at age 4 and one child at age 5. Thus, all had been told before school age. In three families, it had been the mother who had initiated the process, in two families, it had been the father and in one family, both parents had been involved. Subsequently, between one and four further discussions

about DI with the child had taken place. Each family spoke about how they first told their child. These approaches can be found in Table V.

The six parents who had already told their child about their conception were able to report exactly how their child had reacted to such news. The children generally reacted with either curiosity or disinterest. Parents generally described their child’s reaction to the knowledge that an unknown donor existed as one of interest or indifference. The child’s interest in the donor was met with some caution, particularly by fathers.

Discussion

The present investigation examined the current pattern of disclosure amongst couples who conceived their 4- to 8-year-old child through DI. Those parents who had already disclosed the DI conception to their child provided insights into their decision-making and telling processes. Due to the small numbers of parents who currently disclose, the rationale behind these decisions and approaches given the recent changes in legislation is highly valuable. Although the sample of parents cannot be considered representative of DI

Table IV. Parents who intend to disclose: parents' expectations

| | |
|---|---|
| (1) Parents' expectations of child's reactions | |
| Positive (<i>n</i> = 3) | 'Because she's [child] loyal and... sensitive I think... she'll understand the reasons why...she's very laid back...so I think she can cope with it... I think she'll cope quite well...' 'I don't think they'd [children] ever feel any different about us or hold it against us.' |
| Curious (<i>n</i> = 2) | 'There'll be lots of... wonder ifs and wonder whys... there'll be loads of questions...all the ins and outs.' 'It'll be non-stop questions... 'But why?' and all this...' |
| Indifferent (<i>n</i> = 2) | 'I think she'll be quite matter-of-fact about it' 'She'll [child] go, 'So?'' |
| (2) Age of disclosure | |
| Undecided (<i>n</i> = 9) | 'Part of [the decision is] when is the right time that they would actually understand?' 'My fear is more of making a mistake of doing it at the wrong time.' |
| At a younger age (<i>n</i> = 2) | 'I'd like it to be while she's [child] still at primary school because I think once she gets to secondary school and into teen tantrums, it will be even harder...[child should] find out now and accept it' 'I think it's easier to get into their minds when they're little and they grow up with it. It's a lot less damaging than finding out when they're older.' |
| At an older age (<i>n</i> = 3) | 'I think 18 or something. Get through their teenage years because they're murder.' '[She was] watching a programme funnily enough about the IVF[and] they mixed the sperm and the eggs together and she[child] said, 'Oh yucky, making babies like that', so I know she's not ready yet to be told.' [7-year old child] |
| Fear of leaving it too late to tell (<i>n</i> = 2) | 'You might say, 'Well, is that too late to tell them?' and they [children] might say, 'Well, why didn't I know earlier?' [8- and 5-year old children] 'We should have done it when she [child] was really, really young...because [she'll] always know then.' [6-year old child] |
| (3) Approach to disclosure | |
| Uncertainty (<i>n</i> = 8) | 'I'm not sure how it is going to come out though. I haven't got a clue.' 'It's only fairly recently that we've been saying, well how are we going to tell her? But I'm concerned about telling her in the best way possible.' 'We've started discussions [with child]...but we don't finish them...because I don't know whether I know the answer, basically.' |

Table V. Parents who have already disclosed: experiences of disclosure

| | |
|---|---|
| (1) Disclosure process | |
| Analogy (<i>n</i> = 1) | 'They've [children] seen me giving blood so I said it was like that, like it was giving a blood donation but this was cells for someone else to help make him [child] born and the same was as I didn't know who my blood had gone to, he would never know who had given him cells.' |
| Literary aids (<i>n</i> = 2) | 'We bought a Miriam Stoppard book which she [child] just sort of sat and read through... and [child] was just fascinated by the 'How a Baby's Made' page... a bit later, we said, 'Ah, but for Mummy and Daddy it was a bit different'...we got hold of a book called, 'My Story'... we actually sat with her and used that... we don't want to... hit her with information... we've been very softly-softly' |
| Spontaneous conversation (<i>n</i> = 2) | 'We [father and son] were having a bath together and I was saying to him, 'Your [testicles] will get bigger than mine...because mine don't work very well...' then we told him that we used somebody's seeds.' |
| (2) Reactions of the child | |
| Interested (<i>n</i> = 2) | 'I think he's [child] pleased that somebody special gave him the opportunity to be born and that we wanted him enough to do it... he did really ask me what I had to go through.' '[Child] tells his friends... when he's in class, all his friends ask him questions...so they have a curiosity about it.' |
| Indifferent (<i>n</i> = 3) | 'She [child] just accepted it... she was like, 'Oh right, OK, oh something good's on telly.' And she was quite happy with it, she didn't want any more information...' 'We don't...go over and over it again, because he just sighs [and says], 'Yes, I know, you told me that' and that's it...I don't think he's particularly bothered at the moment.' |
| Indifferent-avoidant (<i>n</i> = 1) | 'He's [child] usually switched off long before we've finished saying what we're saying [about DI conception] anyway... (laughs)... and has moved on to something far more interesting.' 'He [child] says, 'So what?' He doesn't seem to ask very many questions about it...I do actually feel that he...almost doesn't want to know...there's a component of him which is refusing to go into this.' |
| (3) Child's interest in donor | |
| Interest (<i>n</i> = 4) | 'She [child] understands...that it's a donor and she said, 'Oh I'd like to meet him some day.' 'I don't think she [child] would be normal if she wasn't curious... it's just human nature... she's going to be curious.' |
| (4) Parental reaction to child's interest in donor | |
| Fear of rejection (<i>n</i> = 2) | 'I would be possibly upset if I found that she [child] was anxious to learn as much about the donor as possible. That would come across to me as certain rejection.' 'I think it would... depend on how far she [child] wanted to take it as to how disturbing I might find it.' |
| Concern about lack of identifying information (<i>n</i> = 2) | '[My] only concern is that I wouldn't want him [child] to have illusions about [the donor]... thinking that would be...a Holy Grail that he must find or something.' 'I'm just hoping that they [children] won't have that huge curiosity to go out and try and find something they can't get hold of.' |

parents as a whole, the findings do suggest that a marked proportion of parents recognize the importance of sharing DI information with their child. The findings also provide further insight into why parents continue to be opposed to disclosure despite changing legislation and having received treatment from a clinic that encourages openness.

Those parents who were inclined towards disclosure attributed their reasons to two main areas: the avoidance of accidental discovery and a desire for openness and honesty. The largest proportion of parents in favour of disclosure were fearful of accidental discovery by the child through medical and technological advances that have occurred in recent years such as genetic testing and matching which is becoming more commonplace and widely understood (McGee *et al.*, 2001). Compared with parents from earlier studies, these couples may be more aware of scientific advances and realize that in future years, the child's donor conception may be disclosed by routine medical procedures rather than the parents themselves. Accidental discovery in this way is believed to pose more of a threat to the parent-child relationship than the child's negative reaction to the concept of DI conception. In fact, most of the disclosing parents believed their child would not react negatively to such knowledge and were confident that the issues would be dealt with in a positive way, particularly if discussions began at an early age. Parents also feared that their child would discover their donor origins through disclosure by friends and family who were aware of their conception and preferred to tackle the issue of disclosure themselves to lessen the psychological distress that accidental discovery could have on the child.

The second reason for disclosing the donor conception to the child was a desire to be open and honest with their child. These parents fully appreciated the damage that secrets and lies could impose on the child, should they ever discover their donor conception in the future. Other parents wished to disclose for the fundamental reason that the child had every right to the knowledge of their donor origins, particularly if other family members and friends had been told. Parents believed that the 'ownership' of the conception is wholly the child's, and they have no right to withhold that information.

Of interest, however, was the wariness of parents, particularly of fathers, of their child's potential interest in the donor. It seems that the donor posed a threat to some fathers in terms of how the child may react to the knowledge that a third party was involved. Some fathers had strong concerns that the relationship with their child may be compromised by the knowledge about a different 'biological' father. Other fathers were worried about the effect on the child's identity development of not having access to identifying information about the donor.

The couples who had already disclosed the donor conception to the child had generally found the experience to be a positive one. Some parents drew on the help and resources available to them, whilst others approached the process in a less structured, ad lib manner. Whichever way the child had been told of their donor origins, the information was met with either curiosity or disinterest. The finding that some children are curious about the donor and their relationship to

him is in line with those findings of Vanfraussen *et al.* (2001), and may be a reflection of the parents' openness about a 'real person' that was involved in the child's conception. For those exhibiting disinterest, it may be the case, as Solomon *et al.* (1996) argued, that the children simply did not understand what was being explained to them. Conversely, other parents did describe their child's curiosity and coherent questions about the donor, demonstrating some understanding of the concept even at a young age. This may be a function of how frequently the parents and child had discussed the issue subsequent to the initial discussion.

The reasons cited by parents who were not inclined towards disclosure of the donor conception were categorized into two main areas. The most common was that parents did not feel the donor conception had any bearing on the parents' or child's life and therefore there was no need to tell the child. Many of these non-disclosing parents reported that they never thought about the donor, or the fact that their child was conceived using donor sperm. Moreover, some parents had convinced themselves that the child may have been the result of a natural, spontaneous conception. Indeed, the fact that the mother carried the child through pregnancy and the father was named on the birth certificate further enabled parents to keep their DI treatment private. Parents did not place a great deal of importance on the reality that conception occurred using donated sperm, and this appeared to have an impact on the importance they attached to making the child aware of their donor origins.

The second most common reason for non-disclosure lay in the fear that telling a child about his/her donor origins may have a negative impact on the child's well-being. Many parents were concerned that their child would be upset and shocked by the knowledge that their father was not genetically related to them. This finding reflects those of earlier studies (e.g. Cook *et al.*, 1995) that the worry of their child's negative response was a main reason for deciding against disclosure. Parents feared that disclosure may lead to the child being ostracized by other adults and children or, at such a young age, may confuse the child in some way. Many parents highlighted the lack of information available about how disclosure to children may be beneficial. Instead, they referred to anecdotes about adoption from friends and family, which suggested that disclosure may be upsetting for children. Not surprisingly, these parents do not want to risk any kind of potential upset within their family. This lends support to the findings of earlier studies (Cook *et al.*, 1995; Lindblad *et al.*, 2000) that parents do not disclose donor origins to the child due to a fear of a detrimental effect on the child.

Many parents also feared the negative impact that disclosure may have on the father-child relationship, a finding which mirrored that of earlier studies (Nachtigall *et al.*, 1997). Both mothers and fathers strongly believed that the father's status as a parent could be undermined if the child reacted negatively to the knowledge of their donor origins. Further, parents felt that such damage to the relationship would lead to an increasing interest in the donor and the unobtainable search for the 'real' father. This fear was also reflected in parents' attitudes towards the current legal

position allowing adults access to donor conception information at the age of 18, with non-disclosing mothers and fathers significantly more opposed to the legislation.

Interestingly, the finding documented by Nachtigall *et al.* (1997) and Lindblad *et al.* (2000), amongst others, that parents are opposed to disclosure because they feared other people discovering the father's infertility, was not a reason explicitly given by the current set of parents. Although the nature of the fathers' infertility was, at times, discussed in the context of DI as a whole, neither mothers nor fathers specifically referred to the fear of social stigma surrounding DI as a motivating factor in deciding not to disclose. The reasons given by parents in the current investigation focused much more upon the child's well-being or the father-child relationship rather than on how the father would be perceived by other people in terms of his virility or masculinity.

In terms of the significant demographic differences between disclosers and non-disclosers, the study revealed that in families where there were two or more siblings, parents were less inclined to disclose the DI conception to their child. It could be the case that couples who had an older child already had made a decision not to disclose information to that child in a climate where disclosure was not necessarily encouraged. Following the birth of a second child, despite a change in disclosure climate, parents may have altered their viewpoint, but, to maintain consistency, chose not to disclose information to either child. Likewise, couples who had been cohabiting or married for a longer period may have made a decision in a non-disclosing climate long before the birth of their child not to disclose.

A limitation of this study is the difficulty in making generalizations from the small sample about the approaches to disclosure of parents who have already told their child about their conception. This is unavoidable given the low rates of disclosure by parents in the UK. It may have been possible to recruit parents from DI consumer support groups who were more likely to have told, enabling an examination of a wider range of experiences of telling, particularly in older age groups. However, this sample would not have been representative of the DI population as a whole. In addition, having made composite groups of those intending to disclose and those who have already disclosed, caution must be exercised in interpreting the quantitative data, particularly with small sample sizes. However, by complementary thematic analysis of the data, it is possible to examine specific decision and disclosure processes of the families independently.

It will be of particular interest to know what proportion of these parents who intend to tell their child of their donor origins actually follow through with their intentions at the age they plan to disclose. Golombok *et al.* (2002b) found that in a European follow-up of DI children first studied at age 4–8 years whose parents had definitely intended to disclose, nearly one-third of the parents had still to do so by the time the child had reached early adolescence. These findings demonstrate that intention is not necessarily followed by practice. In addition, the fact that the couples in this study received treatment from a clinic endorsing and encouraging openness seems to have had

very little impact on the majority of parents when considering the issue of disclosure to the child. The data obtained will certainly have practical implications for clinics, for example, in the provision of counselling both pre-treatment and longer term post-treatment. This may be particularly valuable for parents who are unsure about how and when to inform their children and about the possible outcomes and reactions they may face.

The present study was conducted with parents who had made a decision about whether or not to disclose their child's genetic origins, under the legislation currently in place, i.e. children conceived through donor gametes cannot access identifying information about their donor. New legislation, which will be in force from April 2005, will allow children born after this date to access the donor's identity on reaching adulthood. The implications of this legislation could mean that a greater proportion of parents will be encouraged to disclose the donor conception to their child, as has been the case in Sweden (Milson and Bergman, 1981; Gottlieb *et al.*, 2000). However, it remains to be seen how the new legislation will affect parental attitudes towards disclosure in the years to come.

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