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Parental information sharing with donor insemination conceived offspring: a follow-up study

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BACKGROUND: Studies of parental decision making regarding information sharing with offspring conceived as a result of donor insemination are almost all based on a 'one point in time' design. This study reports on parental decision making at two points in time, Time 1 and Time 2, 14 years apart.

METHODS: Forty-four of 57 families (77%) who had agreed to take part in a follow-up study were interviewed. An in-depth semi-structured interview format was used. In addition, two questionnaires seeking mainly quantitative data were administered.

RESULTS: Fifteen families (35%) had told their offspring of the donor insemination conception at Time 2 (2004). An additional seven families said they had always wanted or intended to tell the children and asked for assistance on how to do this. Where partners were in agreement on information sharing at Time 1 (1990)—either to tell or not to tell—this position was maintained. Where there was disagreement, or uncertainty, two-thirds had not told and one-third had.

CONCLUSIONS: Despite the professional and socio-political culture at the time of treatment, almost half of the families in this study ended up sharing the donor insemination conception with their offspring. The results support the need for appropriate preparation for donor insemination family building.

Key words: donor insemination / disclosure / parent decision making

Introduction

The practice of information sharing in donor insemination, while changing dramatically, remains a contentious issue. Consideration of the issue is likely to focus on whether parent/s tell or intend to tell their offspring and social networks about the way in which they built their family (Blyth and Landau, 2004; Daniels, 2004a; Lalos *et al*., 2007; Greenfeld, 2008; Svanberg *et al*., 2008) and/or offspring having access to information about 'their' donor including the possibility of meeting them (Lorbach, 2005; Morrissette, 2006; van den Akker, 2006; MacDougall *et al*., 2007; Scheib and Ruby 2008). The latter has been the source of considerable debate particularly as a number of jurisdictions have legislated to provide for such information to be exchanged should the offspring want this (Daniels, 2003). In the USA, where there is no such legislation, there does seem to be a trend towards non-anonymous donor conception, with one study showing clinics use of open-identity donors to be on the increase (Scheib and Cushin, 2007). In addition, the American Society of Reproductive Medicine has recently issued guidelines that encourage disclosure (ASRM, 2004).

It needs to be noted that offspring wishing to have access to donor information is a potential consequence of parents sharing with their offspring the nature of the conception.

This paper's focus is on parental decision making regarding information sharing and reports on a study that investigated parents' attitudes and decision making at two points in time—14 years apart.

Only two other follow-up studies of parental thinking and decision making regarding donor insemination children have been located. Lalos *et al* (2007) reported on the follow-up of parents 4 years after the initial data were collected. Sixty-one per cent of respondents had shared information about the donor insemination treatment with their children at follow-up. The authors note 'Because of the anonymous nature of the primary questionnaire study it was not possible to ascertain if these parents intended to tell their children at a later age'. The design of this Swedish study was, therefore, quite different than the present study.

The second follow-up study (Scheib *et al*., 2003) of parents who chose to use identity-release donors found that none of the parents, 13–18 years later, regretted their decision. Their choice of an identity-release donor at the time of treatment indicates their intention to be open with

their offspring. Almost all parents had told their offspring and further they expected the offspring to obtain the donor's identity. Lesbian couples made up 40% of the families. Thirty-eight per cent were headed by a single woman and 22% were heterosexual couples. The authors note that when donor insemination is a preferred method of conception, as it is among many same sex couples and single women, it is also likely to result in higher disclosure rates. They also point out that the absence of a father requires explanation to the child. Respondents in the present study were in heterosexual relationships at the time of treatment and access to open-identity donors was not available.

Almost all of the studies of parental thinking and decision making regarding information sharing with offspring are based on a 'one point in time' design (Brewaeys, 1996; Durna *et al*., 1997; Godman *et al*., 2006; Leeb-Lundberg *et al*., 2006). On the basis of these results some authors have concluded that parental information sharing is very limited (Durna *et al*., 1997; van Berkel *et al*., 1999; Baetens *et al*., 2000). Other authors (Adair and Purdie, 1996; Durna *et al*., 1997; Klock, 1997; Paul and Berger, 2007) have questioned whether parents actually do what they say they intend to do, suggesting that intentions at the time of treatment may differ from what they actually do.

The present follow-up study of a cohort of parents interviewed in 1990 (Time 1) provided the opportunity to explore parental thinking and decision making 14 years later (Time 2). The follow-up interviews were thus conducted when the offspring were young adults, having been aged 1–6 at the Time 1. The results from the Time 1 study are reported in Daniels (1994), Daniels *et al* (1995, 1996) and Gillett *et al*. (1996).

This study took place in New Zealand, a country which for the last 20 years has strongly adopted an openness and information sharing approach to gamete donation (Daniels, 2004b). It was not until 2004, however, the legislation was enacted which provided offspring with the legal right to ascertain—at the age of 18—the identity of the donor, should they wish this. This legislation (HART Act, New Zealand Government, 2004) confirmed the established practice of clinics of encouraging parents to be open with their children and only recruiting gamete donors who were prepared to be identifiable to offspring when they became adults. In addition, the legislation established a Voluntary Register to provide for those offspring and donors who were involved in donor insemination treatment prior to 2004 and who wished to make contact.

Respondents in this study had all received their donor insemination treatments from one clinic (in Dunedin) between 1983 and 1987. During that period, and in line with national changes in professional thinking, this clinic changed its policy regarding what advice it gave to prospective parents regarding information sharing with offspring. It moved from supporting parents' decision not to tell their offspring to encouraging parents to think about the issues with the emphasis being on openness. This change occurred in 1985 (Gillett *et al*., 1996). Again, in line with national practice, the clinic later moved to advising parents to tell the offspring. None of the respondents in the present study were recipients of that latter advice.

The professional and socio-political changes provided the context within which this study took place. Such changes, which are now occurring in a number of jurisdictions, will clearly impact on parental thinking and decision making and subsequently on the offspring and their thinking and decision making concerning contact with donors.

Materials and Methods

Subjects

Follow-up contact was attempted with 57 families who have given birth to a child as a result of donor insemination between 1983 and 1987. All these families had taken part in an initial study and agreed to be contacted with a view to a follow-up study in the future. All children had been conceived as a result of treatment in one clinic in Dunedin, New Zealand. Of the 57 families, 6 could not be located and 7 declined to take part in a second interview. 44 families (77%) were interviewed, but one of the interviews was terminated when one partner became acutely anxious, fearing that others in her small community would become aware of their family origins.

Materials

Qualitative data were generated via in-depth, semi-structured interviews. Each couple was interviewed together; some individuals who had separated or divorced were interviewed alone. The interviews were tape-recorded and transcribed using a thematic analytical approach. In addition, a questionnaire was administered that sought demographic information concerning current family composition. A further questionnaire, which sought individual demographic information and the views of the partners concerning the impact of donor insemination on their relationship, their feelings concerning their donor insemination family and information about others who knew about the donor insemination family building, was completed separately by each partner. The questionnaires were based on those used in the Time 1 study. This paper reports on some of the quantitative data only (for discussion of the qualitative aspects of the research see Grace and Daniels, 2007; Grace *et al*., 2008).

Correlation of these data was made with some of the individual's responses from the Time 1 study. Categorical variables used the chi-square test and comparisons of mean values used analysis of variance. A value of $P < 0.05$ was considered significant.

The study received approval from the National Ethics Committee on Assisted Human Reproduction.

Results

Respondent's marital status at Times 1 and 2

At Time 1, 50 of the 57 couples (88%) were married, 1 was in a de facto relationship and 6 (10%) had separated. At Time 2, of the 43 families that took part, 23 (54%) were in the original marriage. All married couples participated in the interview. A very high 20 (46%) had separated or divorced including all 6 who had separated at Time 1. This included a couple who had separated from their de facto relationship. In this case the female partner was deceased. Of the remaining 19 cases, one divorced couple were interviewed together, another 4 were interviewed separately. In 14 cases, only one partner was interviewed, 11 were women and 3 men. In all, 39 women and 33 men participated in the interview.

Table 1 describes demographic characteristics of the couples who participated at Time 2, in relation to clinical characteristics at Time 1. The original indication for donor insemination was known in 41 of the 43 participants. Vasectomy or failed reversal was the indication in 5 couples, azoopspermia in 15 and for the remaining 21 cases the man was potentially fertile—most of these had low sperm counts. One of these cases was for a genetic indication.

Offspring knowledge of donor insemination conception

At Time 2, offspring in 15 families (35%) had been told of their donor insemination conception. Respondents in a further seven families said at the Time 2 interview that they had always wanted/intended to tell their offspring, but for a variety of reasons had not done so (A separate paper relating to these seven families is in preparation). They asked for assistance from the interviewer as to how to tell their (now) adult offspring. They were told that this matter could be addressed once the research interview was completed thus ensuring that the requested information did not influence their responses to the remaining sections of the research interview. Five of the seven parents subsequently told their offspring, one is intending to tell but because there are some psychological issues for the offspring has not done so yet, and the other parent was persuaded by naturally conceived siblings of the donor insemination offspring not to tell.

Table II describes the influence of a number of social and medical factors on whether the offspring were told of their donor insemination conception. Listed in Table II are the influences of the relationship status, number of donor insemination children, other naturally conceived children, the original indication for donor insemination and whether counselling was offered. None of these factors appeared to influence telling. Couples with naturally conceived children were more likely to tell although the numbers were small.

Donor insemination indication had no bearing on whether the child was told or not. The child conceived from donor insemination for genetic reasons had been told.

When the 43 couples originally sought donor insemination treatment, counselling was provided by the clinic's doctor and he, prior to 1985, supported the veil of secrecy. Table II shows that a higher proportion told after 1985, but this was not statistically significant. Whether secondary counselling (by trained professional counsellor) was given or not was known in 41 couples. There were five couples who received counselling by a professional counsellor—four of them have subsequently separated or divorced. Only one of the five couples subsequently told, this couple also being the one that divorced.

Participants in the Time 2 interview were asked who knew about the donor insemination conception. When others had been told, separate questions sought to ascertain who knew—their parents, siblings, friends or their doctor(s). Because it was not clear which doctor was being referred to, this category was excluded from the analysis. Each partner at the interview was asked if another family member (parent, sibling) or a friend knew of the donor conception. These data were

Table I Relationship status at Time 2 comparing infertility characteristics and outcome for couples undergoing donor insemination 14 years earlier

	Married	Separated/ divorced	All cases
Female age (years) at Time 2, mean	46.8	47.1	47.0
Male age (years) at Time 2, mean	50.2	52.7	51.0
Duration infertility at referral for donor insemination, mean	39 months	37 months	38 months
Indication for donor insemination, *n*			
Vasectomy	2	3	5
Azoopspermia	7	8	15
Male potentially fertile	14	9	21
Number children conceived by donor insemination, mean	1.65	1.40	1.53

Table II Offspring told and not told about donor insemination conception—clinical and social influences

	At interview Time 2, *n* (%)		*P*-value	After interview Time 2, *n* (%)		*P*-value
	Not told	Told		Not told	Told	
Still married	16 (70)	7 (30)	0.5	13 (57)	10 (43)	0.7
Separated/divorced	12 (60)	8 (40)		10 (50)	10 (50)	
One child by donor insemination	13 (57)	10 (43)	0.2	12 (52)	11 (48)	0.9
Two or more donor insemination children	15 (75)	5 (25)		11 (55)	9 (45)	
No naturally conceived children	21 (75)	7 (25)	0.06	17 (61)	11 (39)	0.2
Have naturally conceived children	7 (47)	8 (53)		6 (40)	9 (60)	
Donor insemination indication vasectomy	3 (60)	2 (40)	0.96	3 (60)	2 (40)	0.95
Donor insemination indication azoopspermia	10 (67)	5 (33)		8 (53)	7 (47)	
Donor insemination indication husband has sperm	14 (67)	7 (33)		11 (52)	10 (48)	
Had secondary counselling	4 (80)	1 (20)	0.5	3 (60)	2 (40)	0.8
Did not have secondary counselling	23 (64)	13 (36)		19 (53)	17 (47)	
Assessed for donor insemination prior to 1985	14 (74)	5 (26)	0.3	12 (63)	7 (37)	0.3
Assessed from 1985	14 (58)	10 (42)		11 (46)	13 (54)	

combined from each partner. As Table III shows, in 59% of cases where the child(ren) had not been told, some other person knew of the donor insemination conception. This reduced to 46% when those who told after the Time 2 interview are added. In all cases where the child(ren) had been told someone else also knew.

Intended and actual decision to tell

In the 1990 study (Time 1), a question was asked of each of the participants as to their intention to tell the child of their donor insemination conception. Both partners answered this independently and were classified as yes, no or unsure. These data were combined in a revised combined classification—(1) where both partners agreed to tell, (2) where both agreed not to tell, (3) where both were unsure and (4) where there was some disagreement either one saying no and the other yes, or one was yes or no and the other being unsure. Table IV shows these data when correlated with what had happened at Time 2 and after Time 2.

Where there had been agreement about telling (4) or not telling (7) the parents had maintained their positions. For couples who had disagreed or were unsure the majority had favoured not telling but when after-interview decisions are taken into account the effect was to shift to equal numbers in each group.

The New Zealand legislation

Twenty-three of the 39 women (59%) and 17/33 (52%) men supported the HART Act's provisions for access to identifying information for offspring in the future, while 3 and 7, respectively, did not and 13 (33%) and 9 (27%), respectively, were not sure. These data were combined for each couple to give three groups: where both partners supported the Act or one supported and the other's view was missing or unsure; where both partners did not support or one did not and the other's view was missing or unsure; and where both partners were unsure. Table V summarizes these data. Despite support for the Act, 58% of the couples had not told their child(ren) at Time 2. The five couples who told after interview all supported the HART Act.

Discussion

The policy and practice of the clinic regarding advice on information sharing with offspring changed during the time this cohort received treatment. Prior to 1985, the clinic doctor's position was to support parent's decision not to tell their offspring of the donor insemination conception (counselling by professionally trained counsellors was not then a component of the programme). In 1985, this changed to staff encouraging parents to be open. Given this 'culture' it is of note that at Time 2 (2004), 15 (35%) had disclosed the nature of the conception to the offspring. If the additional 5 who told subsequent to the research interview at Time 2 are added, 20 (47%) have been open with their offspring. It needs to be noted that the seven parents who declined to take part in the follow-up, indicated either explicitly or implicitly when contacted again for the second interview, that the offspring had not been told. A study undertaken in 1994 (Rumball and Adair, 1999) of either one or both partners in 103 couples who had received donor insemination treatment at a different clinic—Fertility Associates in Auckland New Zealand—showed that 30% had told their children and 77% of those who had not told were intending to do so. Counselling services were an integral part of this programme, with sessions being offered to each participant/s. The policy and practice of this clinic during the time these patients received treatment had been to encourage parents to tell their children. By 1994, all clinics in New Zealand were advising parents to tell (Daniels, 2004b).

The cohort that this paper reports on is therefore of particular interest, as the data that was collected at Time 1 when professional views and social attitudes were negative/neutral to information sharing, can be compared with parents actual decision making some 14 years later. The impact of the changed professional and social attitudes and the involvement of counsellors on a regular basis are

Table III Other people's knowledge of donor insemination child

	At interview, *n* (%)		*P*-value	After interview, *n* (%)		*P*-value
	Not told	Told		Not told	Told	
Someone in family knows	22 (59)	15 (41)	0.05	17 (46)	20 (54)	0.01
No one else knows	6 (100)	0 (0)		6 (0)	0	

Table IV Intended and actual decisions re-telling at, or after, Time 2 interview

	At interview, *n* (%)		*P*-value	After interview, *n* (%)		*P*-value
	Not told	Told		Not told	Told	
Agreed no	7 (100)	0	0.01	7 (100)	0	0.01
Agreed yes	0	4		0	4	
Both unsure	10 (59)	7 (41)		8 (47)	9 (53)	
Disagreed	11 (73)	4 (27)		8 (53)	7 (47)	

Table V Telling decision at Time 2 and support for the HART Act

	At interview, *n* (%)		*P*-value	After interview, *n* (%)		*P*-value
	Not told	Told		Not told	Told	
Support for HART Act	15 (58)	11 (42)	0.1	10 (39)	16 (61)	0.01
No support for HART Act	7 (100)	0		7	0	
Unsure	6 (60)	4 (40)		6 (60)	4 (40)	

reflected in the much higher number of parents who had told, or who intend to tell their offspring in the Auckland study. The impact of professionals' views in this area led researchers in Sweden (Svanberg *et al*., 2008) to suggest that negative attitudes towards disclosure among gynaecologists/obstetricians, when expressed to patients, may limit those patients ability to discuss their thoughts and feelings about donation. Shehab *et al*. (2008) found in a study of donor insemination and oocyte donation parents that respondents reported mental health professionals unanimously encouraged disclosure, whereas doctors were more variable in the advice they gave.

Those families who had told their children/offspring by Time 2 were clearly 'swimming against the pervading tide' and those who told after the Time 2 research interview reported that living with the secrecy of the donor insemination family building had been a troublesome burden (Daniels K. R. *et al*., paper in preparation), reinforcing the findings of studies by Hargreaves and Daniels (2007) and Paul and Berger (2007).

The results of this study show that a remarkably high 46% of participants were not in the same relationship that was in existence at the time of receiving donor insemination treatments. At Time 1, 57 women and 53 men took part. Five of the respondent women and three of the men were separated, representing six families. From Time 1 to Time 2, a further 14 couples had therefore left their original relationship. It is our view that the degree to which participants were 'prepared 'for their donor insemination treatment probably contributed to the high divorce and separation rate. Providing the opportunity to explore the issues and implications of infertility and the decision to use donated gametes, requires in our view, discussion of the psychosocial issues and there was little if any provision of this. It was of interest to us to explore if this had been a factor in the decision making about telling children. The results show that relationship status did not seem to influence the parental decision making.

Our study did not identify any factor that increased the likelihood of not telling, although having more than one donor child and having no other naturally conceived children may have contributed. Logistic regression was not used to combine these and other variables since previous studies have shown this model to be unstable with low numbers.

About half of all couples had sought donor insemination in situations where the male partner was still potentially fertile. This might have impacted on openness in that some couples might have believed the offspring to be their own. Nevertheless, when this factor was assessed there was no difference at all in the donor insemination indication and whether the offspring were told.

In the study of parental thinking or decision making at Time 1, the individual parent's views were obtained. As a result it was possible to look at the level of agreement between the partners and to compare this with outcome 14 years later. Just under two-thirds (65%) of couples at Time 1 were in agreement about their position regarding telling. Eleven (26%) had made a definite decision, this being not to tell in seven (16%) couples and to tell in four (9%). All of these couples had carried out their stated intention when interviewed at Time 2, so there was no change. These data, while limited, adds information not previously available on parents carrying though on the stated intentions at the time of treatment (Crawshaw, 2008). In the 15 couples who disagreed at Time 1, the majority (73%) had not told at Time 2, but 3 of these shifted to telling after the interview. The two others who told after the interview were both unsure about telling at Time 1. These figures, which of course, cannot present any insights in to the way the couples arrived at their decision making, suggest that where there is agreement at the time of treatment or soon afterwards, this is likely to be adhered to and that where there is disagreement between partners, or they are unsure about what decision they will make, that some tell and some do not. In this study, almost two-thirds of those who were unsure or in disagreement did not tell and one-third did tell. In a qualitative American study of donor insemination and oocyte donation patients, Shehab *et al*. (2008) found that approximately half of the couples stated that no differences of opinion on disclosure ever existed between them. Of these, one-third was in initial agreement and the remaining two-thirds came to agreement after discussion. The remaining half had views that initially differed but as a result of discussions 95% came to a united disclosure decision. The authors report that parent's discussions reflected a variety of influences and contexts including the local socio-political environment, professional opinion, counselling and support network, their religious and cultural background, and family and personal factors. Given the 'culture' of clinic policy and practice at the time of treatment it would seem that professional advice was only one factor that probably contributed to actual decision making. The changing social culture and the legislation (Daniels, 2004b) regarding access to the identity of the donor when offspring are 18, along with clinics now advising parents to tell children, are all factors that are likely to influence parents/s who now have adult offspring conceived as a result of donor insemination. Daniels and Meadows (2006) have highlighted some of the challenging issues that are likely to be present for those offspring who are told of their donor insemination conception when adults. It needs to be noted that there is a growing literature that is pointing to the advisability of parents sharing donor insemination family building with their offspring at an early stage in the children's lives (Daniels, 2004a; Lorbach, 2005; Lycett *et al*., 2005; Montuschi, 2006).

It is not known, of course, what impact the involvement of a professional counsellor might have had at Time 1. The results of the

study by Rumball and Adair (1999) referred to earlier may well point to the fact that counsellors will seek to explore, with those seeking treatment, the issues associated with information sharing. Where there are two partners involved clearly any disagreement between them along with uncertainty regarding decision making is likely to be explored. This, after all, is one of the reasons that counsellors are now involved in most reproductive medicine clinic teams. A counsellor is the health team member most appropriate to explore with a prospective parent/s the issues concerning family building which utilizes donor insemination. Consideration of information sharing is a central component of that. The parents in the seven families that wanted to discuss with the researchers how to talk with their now adult offspring about their family building, raises questions about what these parents would have done if the researchers had not been undertaking the follow-up study. It would seem that issues regarding information sharing in families are likely to emerge both at the time of treatment as well as after the parents of offspring conceived some time previously have been treated and conceived. An emerging issue, given the move to greater openness, is who do parents seek assistance from and how their needs are responded to. A practical question is who pays for the counselling they seek.

Several studies (Golombok *et al*., 1999; Murray and Golombok, 2003; Greenfeld and Klock, 2004; Brewaeys *et al*., 2005; Lalos *et al*., 2007) have reported that in families that have decided not to inform their children about their donor insemination conception that persons in the wider family network or persons outside the family know of the use of donor insemination. The possibility of an offspring discovering their donor insemination conception from someone other than their parents is therefore a possibility. There have been reports from offspring concerning the negative impact that being told by someone other than the parents has had on them as offspring, or of discovering that others knew before they themselves had been told. Clearly, the more people who know the greater the risk of accidental discovery by the offspring. Such offspring report feeling betrayed by their parents and wondering if they can trust their parents again, or if there is more information that has not been shared with them (Donor Conception Support Group of Australia, 1997; Lorbach, 2005; Morrissette, 2006). The results of this study show that in 59% of cases where the offspring have not been told, some other person/s knew of the donor insemination conception. In one family in this cohort where the parents were divorced, the offspring had been told by a cousin. The father had insisted his son never be told, so the mother was left to manage a very tense situation. The son decided he would not tell his father he knew, and is therefore 'protecting' his father from the truth, while father believes he is 'protecting' the son from the truth.

Time 2 interviews took place soon after the passing of the HART Act (New Zealand Government, 2004) which provides for offspring, when adult, to obtain identifying information about 'their' donor. Respondents were asked about their views concerning this legislation. Fifty-nine per cent of the females and 52% of the males supported the access to information provisions of the legislation. Three women (8%) and seven men (21%) did not support the Act. Thirteen women (33%) and nine men (27%) were unsure. This legislation would not impact on them directly except in so much as a Voluntary Register was established on which their now adult offspring could register.

It is to be noted that 15 (58%) of the families who supported the Act, had not told their offspring, although 5 of these families did tell after the Time 2 interview. This would seem to suggest that while there was support in principle for information sharing, the personal circumstances of these parents meant that they did not feel it was appropriate to disclose information to their offspring at this stage. This might also be suggestive of the change in culture that occurred between Time 1 and Time 2. All seven families where the Act was not supported had not told the offspring. The 10 families who were unsure of their support for the Act would suggest that issues surrounding information sharing and government intervention in this area are not at all clear. This uncertainty was present in six who had not told and four who had. The extent to which legislative intervention giving offspring the right to know the identity of 'their' donor impacts on parent's decision to disclose is unknown. It seems likely, however, that legislative change is only one element in the overall change of 'culture'.

Conclusion

This study is unique in that it looks at parents thinking and decision making at two points in time, 14 years apart. This period of time saw many changes in the socio-political context as well as in professional thinking and attitudes. Change in thinking and decision making among some of the parents did occur and this change was in the direction of parents, being or wanting to be, more open with their offspring. Given that other jurisdictions are experiencing similar changes the results of this study may provide some insights in to the impact of such changes on parental thinking and decision making.

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