

Legislated right for donor-insemination children to know their genetic origin: a study of parental thinking

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BACKGROUND: In Sweden, a child born as a result of donor insemination (DI) has the right to receive information both about the DI and the identity of the donor. The present study aimed to elucidate parents' thoughts regarding these possibilities, and whether, how and when they had told their offspring about the DI. An additional aim was to examine the parents' experiences of the attitudes of healthcare providers. **METHODS:** A follow-up study using semi-structured telephone interviews with 19 couples, including 19 women and 17 men. **RESULTS:** More than half of the parents (61%) had told all their child/ren about the DI, but almost everyone had told another person. Mean age for disclosure was 5 years for the first child. Reasons given for disclosure were to avoid accidental discovery, a desire for openness and a persons' fundamental right to know his/her genetic origin. Parents who did not intend to tell their child/ren considered DI a private matter and were afraid of other people's attitudes. Sixty-one percent of the parents had not yet told their children about the possibility of identifying the donor. Healthcare staff had impacted on the parents' thinking, and a majority of those who had been encouraged to tell their child/ren about the DI had done so. **CONCLUSIONS:** There was a discrepancy between the intentions of the legislation and how parents act in relation to them. To improve compliance, it is crucial to organize education, support and ethical discussion among professionals, and to offer parents, and parents-to-be, counselling, support and group sessions with other DI families.

Keywords: disclosure; donor identity; donor insemination; legislation; parents

Introduction

Donor insemination (DI) of a woman with spermatozoa from a man other than her husband has been performed for more than a century and is one of the oldest techniques in reproductive medicine. Until 1985, DI was performed worldwide without any legal restrictions. The semen providers were anonymous both to the recipient couple and to the DI offspring. On 18 March 1985, the Swedish Parliament enacted a law (SFS, 1984) that gives the child born as a result of DI the right 'when sufficiently mature' to receive identifying information about the semen provider. 'Sufficiently mature' is not defined in the text of the Act. However, in the formal instructions from the National Board of Health and Welfare from 1987, where the application of the law was clarified, the age is specified as 'the upper teens' with reference to the government bill (SOSFS, 1987).

The law does not indicate who is to inform the child. In the preparatory work for the drafting of the law, the importance of parental openness was emphasized, and it was taken for granted that parents would tell their children about their genetic origin. According to the same legislation, the donor is to remain

anonymous to the recipient couple and vice versa, and records of the DI are separated from official medical records. Thus, the child's only possibility of finding out that he/she was conceived as a result of DI is if the parents reveal it — or if someone else inadvertently tells them or it becomes obvious after genetic testing or when learning about biology at school.

There is currently a lack of systematic data regarding whether or not parents who have undergone DI have, subsequent to the passing of the new law in 1985, informed their children about their genetic background. Information is not only lacking about whether children have been informed but also about when and if parents are satisfied with their decisions. A Swedish study of DI parents in 1998 found that a small majority (52%) stated that they had either told (11%) or intended to tell (41%) their children (Gottlieb *et al.*, 2000; Lindblad *et al.*, 2000). Among the rest, 19% were not intending to tell their children, 18% were uncertain and 11% did not answer the question. However, half of those who had not told their child had told someone else, in most cases a close

family member. The mean age of the children who had been told by their parents was 5.5 years and for those whose parents intended to tell them, the mean age was 3.5 years. The researchers concluded that compliance with the Swedish legislation must still be regarded as low, since most of the children had not been informed about the DI conception, even though the number of parents willing to inform their child was high from an international perspective (Gottlieb *et al.*, 2000; Lindblad *et al.*, 2000).

European studies as well as reports from the USA indicate that most DI parents have not told and do not intend to tell their children about the DI (Golombok *et al.*, 1996; Nachtigall *et al.*, 1997a,b; Blyth, 1999; van Berkel *et al.*, 1999; Brewaeyns, 2001). However, in most of these families the identity of the donor proved impossible to establish, and it was argued that disclosure of the DI conception without the identity of the donor could be harmful to the child. One exception is in the case of lesbian parents, where a semen donor was obviously involved. However, in recent years, there seems to have been a trend towards more openness and an increased tendency, whenever possible, to choose a non-anonymous donor (Rumball and Adair, 1999; Gottlieb *et al.*, 2000; Brewaeyns *et al.*, 2003; Scheib *et al.*, 2003; Scheib *et al.*, 2004; Lycett *et al.*, 2005; Leeb-Lundberg *et al.*, 2006). Not only in Sweden but also in several other countries, there have been major changes in policies and practice, and some have instituted new laws abolishing donor anonymity. Austria, Switzerland, the UK, Norway, the Netherlands, New Zealand and just recently Finland are among these countries as well as the states of Western Australia and Victoria in Australia. In addition, an increasing number of donors, recruited under the anonymous system, are now coming forward to register their names on the voluntary registers that have been established in Western Australia and Victoria in Australia, in the United Kingdom, New Zealand and in the USA (Daniel, 2007).

At this time the first children born after the groundbreaking Swedish legislation was passed have reached an age when they can ask for identification of the semen provider. In addition, similar legislation relating to oocyte donation was approved in Sweden in 2003, which gives offspring the possibility of obtaining identifying information about the oocyte provider. Recently, all the regulations regarding assisted reproduction and genetic integrity have been collected in one law (SFS, 2006). All in all, the demand for further knowledge has increased considerably both from parents and parents-to-be as well as from staff working with assisted reproduction.

The present study aimed to discover how mothers and fathers are thinking regards their children's right to obtain information about their genetic background and whether they intend to tell, or actually have already told, their child/ren. Among the latter, a further aim was to investigate how and when they had shared this information with their children and what the reactions were. An additional aim was to examine the parents' experiences of the attitudes of healthcare providers regarding disclosure of DI to the offspring.

Materials and Methods

The present study is a follow-up of the Swedish study (Gottlieb *et al.*, 2000), in which a semi-structured questionnaire consisting of 17 questions was sent to the couples that conceived a DI child after being treated at the two largest DI centres (Karolinska University Hospital, Stockholm and University Hospital, Umeå) after the Swedish law was introduced in 1985 up until 1997 (Gottlieb *et al.*, 2000; Lindblad *et al.*, 2000). In the Gottlieb *et al.*, (2000) study, a separate letter was included with the questionnaire asking whether the couples were willing to participate in a follow-up interview study. Twenty-seven of the 148 couples (18%) in the study agreed to do so. For 26 families, it was possible to obtain official information about their postal address and telephone number (one woman had a secret address and telephone number after the couple's divorce). To meet ethical requirements, all 26 women and 26 men received a registered letter during the year 2003 containing information about the study and its voluntary approach and guarantee of anonymity. Each couple were asked to answer separately in writing stating whether they were still willing to participate in an interview and, if so, to sign the enclosed informed consent form and, in a letter of reply, set a suitable date and time for the first telephone contact. Those who confirmed their interest in participating (36 individuals in 19 families, i.e. a response rate of 73%) were interviewed by telephone over a period of almost a year, ending in 2004. The interviews were semi-structured, lasted between 45 min and 1, 5 h and covered topics such as psychosocial background, current living conditions, partner relationship, family life and experiences and thoughts regarding sharing information with the child/ren about how they were conceived and the possibility of them getting to know the identity of the donor.

The dialogue focused mainly on the following questions: What factors had influenced the parents most in their decision to tell or not to tell? What happened when the partners did not agree? Did children who were not told suspect anything or ask about their origin? In what way had the parents disclosed the DI to the child/ren and how had they reacted? What impact, if any, had disclosure had on the partner relationship? Had the parents informed relatives, friends or others about the DI? Did the parents request guidance and support before telling the child/ren about DI, and if so, were they offered any? What were the parents' experiences of the attitudes of the health providers regarding sharing information with the child/ren?

Interview design

The methodological approach was primarily qualitative, meaning that focus was on describing and understanding the process and meanings associated with telling and sharing information. In investigating complex phenomena such as emotional experiences and the thoughts of individuals, a questionnaire study is not sufficient. Therefore, semi-structured in depth interviews were considered to be the most adequate method. A semi-structured form with specific, carefully prepared questions was designed, which was identical for both women and men. It was divided into three sections, one for those who had told their child/ren, one for those who intended to tell them and the third for those who not were going to tell their offspring. It was not possible to pilot this semi-structured form due to the non-available parents, however, it was developed in consultation with a senior multidisciplinary research group.

In order to avoid dropout of participants, the interviews were conducted over the phone as the couples were spread all over the country and even lived abroad. Furthermore, we thought it was important to have the same interview design for both women and men. Since the aim was to elucidate the individual's specific thoughts and feelings, and not the interaction between the parents or their joint

views, it was essential to talk to mothers and fathers separately. In addition, the research team had very positive experiences of previous interview studies conducted over the telephone, using the same tested model with women and men separately, concerning such delicate issues as the impact of gynaecological cancer and induced abortion (Lalos, 1997; Kero and Lalos, 2005).

The interview situation was organized so that the informants would have the best possible opportunity to tell their story. Therefore, after having returned the written replies, the responders were contacted in order to set up a suitable, undisturbed time for a telephone interview. They were free to choose where and when, but no more than a maximum of a couple of days was to elapse between the two interviews for each couple. It has to be acknowledged that given the time laps between the interviews of the partners, there was the potential for them to discuss each other's views.

The same person (the first author A.L.), who is a senior researcher and medical social worker trained in the study techniques, conducted all the interviews. The reflective open-ended questions gave the respondents the chance to express themselves freely and gave the interviewer the possibility to probe more deeply into the questions. The interviews were not tape recorded, however, in order to ensure an adequate understanding of what the parents wanted to answer, the interviewer wrote down their responses and then repeated them back. Thus, individual questions could be dropped and new ones introduced as and when indicated by the dialogue. The participants' answers to the open-ended questions were transcribed by the interviewer both during and immediately after the interview. Thereafter, the text was analysed by content and classified into categories and themes, and these were finalized by the entire research group. The Ethics Committee of the Medical Faculty of Umeå University and that of Karolinska University approved the study.

Results

The families

Of the 26 couples who had completed the questionnaire study performed about 4 years previously, and then confirmed their interest in participating in a follow-up study, 19 were still willing to participate in the interview study (73%). However, in two cases the husband thought it was sufficient that only the woman participated. Thus, a total of 36 out of 52 possible respondents participated; 19 women and 17 men. The participation rate among those treated in Umeå and those in Stockholm was almost identical (75% and 71%, respectively).

Table 1 shows that in the 19 families a total of 29 children were conceived after DI. In 11 families, there was only one child born after DI (Table 1). However, in five of these further children were born but of a different genetic origin; three were adopted and two were conceived in the mother's previous relationship. All but one family still lived in Sweden, and most couples had been living together for a long period of time (Table 1).

The majority considered their marital relationship satisfactory and that it functioned well; 42% ($n = 8$) of the women and 53% ($n = 9$) of the men described it as very good and harmonious, 42% ($n = 8$) of the women and 41% ($n = 7$) of the men said it was acceptable or rather good and two women thought the relationship was quite bad. In addition, one couple was in conflict and had just separated, since the

Table 1: Some characteristics of the women ($n = 19$), the men ($n = 17$) and the children conceived by donor insemination (DI) ($n = 29$)

	Years (mean)	Years (range)
Age of women	42	(32–54)
Age of Men	44	(35–52)
Length of couple relationship	18	(12–29)
Length of couple relationship when the (first) child was born	9	(4–16)
Age		
Children (16 girls and 13 boys)	7	(1–15)
First child (1 child in 11 families)	9	(5–15)
Second child (two children in six families)	6	(4–8)
Third child (three children in two families)	3	(1–5)

woman had started a new relationship with another man. They intended to share custody of their two children in the future. There was one further divorce in the sample. In this case, the mother had lost custody due to domestic violence towards the child born after DI treatment. The father, who was granted full custody, had remarried and had two more children after DI. Both he and his present wife participated in the study. The previous partner could not be included as she had a secret address and phone number. The participants had a range of occupations, and as regards educational background approximately half had graduated from university, but this number included four times as many females as males.

Relatives and friends

For almost every woman and man in the study (89%, $n = 32$), there was one or more persons outside the family who knew about the DI treatment. Only one woman and three men declared that they were absolutely convinced that no one but their partner knew about it. However, two of the men had wives who had told a close friend without their husband's knowledge. The most common situation was that both relatives and close friends knew about it but quite often also some neighbours and staff at the day care centre and school. Thus, in all but one family there was at least one adult outside the nuclear family that knew about the DI treatment. In eight of these 18 families, the child/ren had not (yet) been told about their conception.

The following discussion is divided into three main sections: parents who had told their children about the DI treatment, parents intending to tell them and parents with no intention of telling their children. In addition, there is a section at the end that deals with the experiences of the whole group of parents regarding the attitudes of the healthcare providers and the parents' needs for guidance and support. A selection of quotations will be given in *Italics*.

Parents who had told the child

The child's awareness of the DI treatment

More than half the parents participating in the study (61%) had, at the time of the interview, shared information about the DI treatment with all their child/ren (Table 2). These 11 women and 11 men, however, did not constitute 11 couples but represented 13 families. In one couple, the man did not know

Table 2: Number of women ($n = 19$) and men ($n = 17$) who have told, intend to tell and do not intend to tell their offspring about being conceived by DI and about their right (when sufficiently mature) to obtain information about the identity of the semen provider

	Women	Men
Openness about being conceived by DI		
Have told all the children	11	11
Have not told (all ^a) the children but intend to tell	5	3
Have not told any child and do not intend to tell	3	3
Openness about the right to obtain information about the identity of the semen provider		
Have told all the child/ren	6	8
Have not told (all ^a) the child/ren but intend to tell	9	6
Have not told any child and do not intend to tell	4	3

^aOne mother had told two out of three children.

that his wife had told their son, in another the man had told all the three children, whereas the woman had not told the youngest one, and in the third case the interview with the woman took place the day before the couple told their child and the husband was interviewed the day after.

All in all, six of the women and seven of the men said that at the time of the previous questionnaire study, they had not shared information about the DI treatment with their child/ren. Most had considered the child to be too young at that time. 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 age of the child when it was told

The very first time the parents had told their child/ren about the DI treatment, almost all had done it with their partner. Eight women and six men had also talked about it with the child/ren more than once, alone or together with their partner. The time span that had passed since they had first told their offspring ranged from 1 day to 10 years. In four families, the occasion of sharing information came very close to the time of the interview, 1 day, 3 weeks, 4 and 6 months before.

The most common age for the first or single child to be told for the first time was about 5 years (median 5 years, range 1 month–10 years). If there were siblings, the younger one had usually been told at a younger age (median 3.5 years, range 1 month–5 years). In all the couples but one, both the parents had agreed to tell their child/ren about the DI. It had not usually been difficult to reach a joint decision. Several described how they had ‘always’ been in agreement about informing the child and had regarded it as a matter of course. Either the occasion for telling the child had been prepared and planned in detail or it was precipitated by a mere coincidence, for example, when the child asked specific questions about where babies come from. A couple of parents also said that they have ‘always’ talked about it with the child, ever since it was on the changing pad.

Motives for telling the child

Regarding the question of what influenced the parents, the most in their choice to be open towards the child about the DI treatment, a majority of them (64%, $n = 14$) spontaneously

responded that it would be impossible not to tell because of their strong conviction that a child has a fundamental right to be told. Other comments dealt with anxiety about the risk of someone else revealing it to the child, nervousness that the child itself would figure it out as well as an overwhelming feeling that it would be a disaster for the family to live with such a secret and the lies entailed in keeping it.

- (i) *It's impossible not to tell them! Because we told other adults the children have to know.*
- (ii) *... if you haven't told the children you also have to lie to your close friends.*
- (iii) *Everyone has a right to know about their origin... I don't understand what you are afraid of if you haven't told them! It's not shameful or strange.*
- (iv) *As a parent I couldn't live with a lie.*
- (v) *It can be dangerous for the child not to know; I think children can intuitively sense a family secret.*
- (vi) *It's about fundamental trust and security... you send a signal that it is dangerous to know – what's the danger, really?*

Different ways of telling the child/ren and their reactions

The way in which the parents had told the children about the DI treatment varied a lot, partly due to the different ages of the children. About a third of both women and men (36%, $n = 8$) wanted their child first to be told how children are normally conceived whereas others began with a more fairy-tale approach. When explaining to the child, one of the most frequently used words was ‘seed’, and several talked about ‘the doctor’, ‘the hospital’ and ‘a kind man’.

- (i) *I simply answered his question about where babies come from... the mummy has an egg and the daddy has thousands of seeds, but your daddy didn't have any seeds so he borrowed some from another nice man... .*
- (ii) *Not everyone can have a baby the normal way. Some people adopt and your mum and I... a kind man gave his seed to the doctor and the doctor put it in your mummy's tummy... .*
- (iii) *During the day we had decided that we couldn't postpone it any longer. It was evening, we sat and chatted about how much she knew about where babies come from, and she had heard stories about it. Then we simply told her that you can borrow sperm from another man and that's what we did and that's how she was conceived. We didn't go into details and we didn't say anything about hospitals.*
- (iv) *... sometimes sperm have no backpacks, they are sick and then you can't make babies... that's why daddy had to borrow sperm from the hospital... .*
- (v) *...we started by explaining generally where babies come from, not in detail, nothing about willies... and X (the father) explained that he had been born with a condition which meant that he didn't have any sperm and because of this he had had to borrow sperm from another man at the hospital... and that the sperm are in a kind of drinking straw and are kept in the freeze... .*

In general, the parents said that the children's spontaneous reaction when told about the DI was straightforward. For example, in the last family quoted above, the boy had responded 'but that's where ice-cream is supposed to be!' and then claimed 'If I am going to have a sibling I want to join you and see how it's done'. However, the vast majority of both women and men (91%, $n = 22$) told that the children had not asked any specific follow-up questions, but had instead reacted more or less with short comments like 'aha?!' and 'so what?!'. The youngest ones particularly had paid it little attention, which left several parents feeling both blank and relieved. All the parents thought it was good that the child was now aware of how it was conceived.

The impact of telling the child/ren on the partner relationship

Apart from the couple where the man did not know that his wife had already told their son, sharing information about the DI with their offspring had had a positive impact on the couple's relationship. Most women and men (91%, $n = 22$) described experiencing feelings of relief and pride, for example, over having been honest with the child.

- (i) *We can be proud that we have told our child ... and that we're not ashamed of anything.*
- (ii) *We feel really good that we dared to take this step together. We feel a lot better now it's done, we'll have to see what the future brings ...*
- (iii) *... relief, we did the right thing and now no one else can reveal the secret...*
- (iv) *Now we don't have to guard our secret... the issue has become simple.*
- (v) *Relief... this has been hanging over us, we tried earlier... wasn't the right time...*

Awareness about the semen provider

When talking with the parents about whether they had also told their child about its right (when sufficiently mature) to obtain information about the identity of the semen provider, it became obvious that this issue was not as self-evident as telling the child about the DI treatment. Less than a third of the women and half the men had informed all of their children of this possibility (Table 2). However, among the rest, all but one woman intended to inform the child/ren in the future.

Parents intending to tell the child

The appropriate age at which to be told

A typical dilemma described by the five women and three men who intended to tell their child/ren was that they had postponed telling them because it was difficult to find an appropriate time for both the oldest and the youngest child, or a period of time when the oldest one could keep quiet about what he/she had been told.

The offspring in these six families ($n = 10$) were aged between 5 and 15 years (median 8 years, mean 10 years), and their parents believed that the most suitable time for all their children to share information about DI was when the oldest child had reached the age of 12, which in turn meant that the youngest would be about 8 years. Thus, this was

more than twice the age compared with the previous group of children who had already been told.

Motives for telling in the future

The factors influencing this group of parents who intended to tell their children correspond closely with those expressed by those parents who had already told their children. They highlighted, for example, the impossibility of living with such a big secret, their fear of someone else revealing it and their conviction that children have the right to be told. When the children got older, the parents became increasingly nervous that they would figure it out for themselves. They also said that they wanted to find a suitable occasion to tell the child/ren together. They all expressed their intention to tell their offspring, when mature enough, about their right to information about the identity of the semen provider (Table 2).

The sex of the child was found to have had a specific influence on openness in one case only. This was a woman who believed that if they had a girl instead of a boy they would probably already have told their child "... because a girl would have asked more ... girls are more interested, they play at being pregnant ...".

Impact of not yet having told the child/ren on the partner relationship

Half of the informants said that their failure to tell the child/ren had a certain negative impact on their partner relationship, and several had severe difficulties in communicating with each other about the topic.

- (i) *Don't know... I don't know what she thinks about it now...*
- (ii) *It's hard, we can't talk about it... it feels as if we've failed, we had decided that xxx would be told by now, at the latest...*
- (iii) *I'm concerned, I have questions... others know, what if someone else says something... time is just going by...*
- (iv) *It is a burden for us that we cannot deal with right now during the divorce. It had become a new/another dilemma...*
- (v) *I don't know how we are going to solve this problem later on... I'm afraid of losing my children, I'm not their father. I'm not the real one... x and y (the children) might see their mother's new man as a father...*

The last comment was made by an anxious father of two children, filled with fear of being replaced by his previous wife's new (fertile) partner.

When asked about possible advantages of not yet having shared information about the DI with the child/ren, the women and men mentioned that neither the child nor the home situation had, so far, been stable enough. However, several stated that the longer they delayed and hesitated the harder it became. The disadvantages of not yet having disclosed the DI they mentioned were the risk of someone else giving it away or that the child already had started to suspect. One woman and two men gave illustrative examples of how their children had started to ask delicate questions about how they were conceived or their appearance, and how

difficult it was for the parents to avoid answering. For example, one boy had repeatedly insisted on knowing why he was the only one in the family to have a jaw, which required dental surgery (the dentist also tried to figure it out).

Parents not intending to tell the child

Factors influencing the decision not to tell

The three women and three men who did not intend to share information about the DI treatment with their children also constituted three couples. The average age of the children ($n = 5$) was 7 years (range 1–15 years, median 6 years). For two couples, it was a mutual decision not to tell the child/ren, and ever since the infertility investigation started they had considered it as self-evident that they would not tell. In the third couple, however, the woman really wanted to tell the children but her husband refused, and she was not able to go against his will. This put a severe strain on her and, therefore, she has had frequent discussions about it for years with her closest female friend. Her husband, however, was unaware of this; on the contrary, he was convinced that no one knew about the DI.

When asked what had influenced them most in their decision to never to reveal the DI treatment to their children, a couple of main areas was found. One common reason was that parents did not feel that the donor conception had any bearing on the parent's or the child's life, and they did not place a great deal of importance on the reality that conception had occurred using a donor's sperm, thus, there was no need to tell the child. One couple had even convinced themselves that their child was the result of natural, spontaneous conception. Another common reason for non-disclosure was the fear that telling the child about his/her biological origin may have a negative impact on the child's wellbeing.

They were uncertain regarding the child's ability to manage the knowledge of conception by DI and assumed he/she would be upset when they became aware that their father was not genetically related to them. Furthermore, the parents feared that disclosure might lead to the child being ostracized by other adults and children and even subject to disapproval from relatives. In addition, some of the males' comments revealed a fear of no longer being seen as the real father.

- (i) *X (the husband) doesn't want to... he's afraid the children will shun him, that something will be ruined as they have always believed something else...*
- (ii) *I'm old fashioned. We see it like this – what difference does it make? I can't see that it would make anything better... it could have the opposite effect... and I wouldn't be a dad anymore...*
- (iii) *It's private... it is our decision to make. It's our responsibility... no one else can or should get involved. It something between us two adults.*
- (iv) *My husband's side of the family thinks it is very important to be "biological" ... there are adopted children and foster children ... who have done badly ... and they blame it on their not being their biological children. We don't want x (the child) to feel inferior...*
- (v) *... there are bad people... there is fighting and hate... this kind of thing is worse in the country, if this was brought into the open it would harm x (the child).*

- (vi) *He's just like me... I really think he is mine. I will never test myself. I have never questioned it, it is exactly...*

Behind the last comment is a father who believed that he was his son's biological father since they were so similar in appearance and character. However, none of the parents answered in the affirmative to the direct question of whether the child's sex or looks had influenced the decision not to tell the child about the DI treatment. Nevertheless, the last quotation seems to indicate that appearance can play a certain role. Since this group of parents had not told their children about the DI, obviously neither had they told them about the possibility of getting information about the identity of the semen provider (Table 2).

Attitudes within healthcare

Experiences linked to the DI treatment and the staff

All the women and men in the study said that both partners within each couple had initially considered DI to be the most suitable option, and the majority (63%, $n = 12$) thought that they had been equally in favour of it. In six of the seven couples, it was the women who had been slightly more positive towards DI.

Concerning the parents' experiences of staff' attitudes towards openness, and whether the couples had been encouraged or not to talk with their children about the DI treatment, about half of the women (53%, $n = 10$) and three quarters of the men (77%, $n = 13$) said they had received indistinct signals and sometimes contradictory messages from the personnel. In 12 couples, both partners mentioned that staff had used the expression '*do what you want*'. In five couples, one partner had experienced one attitude and the other the opposite approach from the health care staff, and in only two couples had both the woman and the man been clearly and directly encouraged to tell the child-to-be. In total, the overall impression among 20 parents (nine women and 11 men) was that they had not been encouraged by staff to be honest and open with their child, whereas 16 (10 women and six men) thought that they had been partly or directly recommended and encouraged to do so.

Comparing those who had been encouraged by healthcare staff with those who, de facto, had informed their child/ren, it was found that 13 out of the 16 people who had been encouraged to tell their offspring had in fact told them. Furthermore, it was found that 10 parents out of the 22 who had actually told their offspring said that they had not met with an encouraging attitude from the staff. In other words, not all, but a majority, of those who had been encouraged to tell their child/ren had done so. In addition, almost half of those who had told their child/ren had not been encouraged by staff to act in this way.

Need for guidance and support

Since the majority of the parents in the study had already told their child/ren about the DI treatment, most did not express any need for guidance and support regarding whether or not to tell. However, many stated that they really had had, or even still had, a need for assistance and advice concerning *when* and *how* to share information about DI with the child/ren. The parents described the necessity of being offered professional

counselling and support given, for example, by a child psychologist or social worker, and some had also themselves made such a contact. Apart from professional counselling, 42% of the women ($n = 8$) and 29% of the men ($n = 5$) highlighted how important it would have been to get in contact with other couples/families in a similar situation. Furthermore, many complained about the lack of books and video films as resources to help them when talking with children of different ages.

Parents' viewpoints and advice to staff

All women and men told that they had been received with kindness partly or fully during the period of infertility investigation and treatment. At the end of the interview they were, however, asked to formulate some advice to staff that meet and treat couples trying to achieve a pregnancy through DI. Some decision points were brought up:

- (i) *You want to be treated as a couple and not an ovulation. . .*
- (ii) *The dilemma has a lot to do with views about masculinity . . . one's whole self image is called into question . . . I don't know any other men in this situation. . .*
- (iii) *. . . give more support when delivering the diagnosis. . . x (the husband) was given the information in a cold and unfeeling manner.*
- (iv) *More openness to the outside world is needed. . . the clinic should inform the childcare centre! They think that there are only biological and adopted children. I have had to teach the childcare centre about this!*
- (v) *Collect reference families who can be there and talk to others, they know what it's like.*
- (vi) *More guidance is needed and the opportunity to meet other parents or specialists . . . it is left up to us to try and figure out when to tell the child.*
- (vii) *Social workers and counsellors are needed, psychology is behind most things . . . not just medical decisions and treatment.*
- (viii) *More responsibility is needed from the healthcare sector. . . we're talking about a third party.*
- (ix) *The staff should be rooting for the child. They should be aware that what they are doing is more than giving medical treatment. It is about creating a life someone who will grow up to be an adult individual with rights and possibilities.*

Discussion

For investigating complex phenomena such as the factors that influence parental decision-making regarding information sharing in families where DI had been used, semi-structured in-depth interviews were found to be the most suitable method (Starring *et al.*, 1997; White, 2004). In the current study, the interviews were conducted by telephone in order to create the best possible conditions for the responders to arrange a suitable time and an undisturbed setting for the interview session. In addition, it was a way of avoiding dropout of participants, in view of the fact that several years had passed since the initial questionnaire study was performed and

interviews in person would have been exceptionally difficult to arrange because families had moved all over Sweden, and one had even gone abroad. A participation rate of almost three quarters of those who had indicated interest in taking part in the follow-up study could, therefore, be regarded as high. However, it must be kept in mind that the sample size is small. It could be argued that the small number is not adequate for generalizations. But given that this study is a qualitative one where the focus is on trying to understand the meaning that people attach to their decisions, the design gives important indications of information that have not previously been known regarding Swedish DI parents. Conducting interviews over the telephone has both advantages and disadvantages. Some participants may feel that it is easier to be open on the telephone than in a face-to-face interview, whereas others may react in the opposite way. From the interviewer's point of view, it may be a greater challenge to have a keen ear and move to a deeper level on the phone, as no body language can be registered.

For ethical reasons, there is, unfortunately, no possibility of approaching the quarter of the sample who declined to participate in the follow-up interview in order to obtain information about the frequency of disclosure among them. However, there are no grounds for assuming that the design of the study attracted only those who had already shared information about their family building history with their offspring, and therefore assume that the participants who dropped out had *not* told their children, since more than a third of the participants had not yet told their children, and even some who were against openness joined the study.

In four families, the child had received information about the DI a short time prior to the interview. This could be a coincidence or it may reflect that receiving the request to participate in the study could have influenced the parents to tell the child/ren. If so, this may serve to reveal the parents' need to talk to someone familiar with the issues when you have told or are going to tell the child. On the whole, having a participation rate of 73% 4 years after the first questionnaire study had been performed, could be seen as both remarkable and a revelation of a need to share experiences and thoughts.

The present study provides insights into the parents decision-making concerning telling their children about how they were conceived and their possibility of gaining information about their genetic origin. Although the sample of parents cannot be considered representative of DI parents in general, the findings do indicate that a marked proportion of parents recognize the importance of sharing DI information with their children. Moreover, the findings also provide further insight into why parents may continue to be opposed to disclosure, despite the Swedish legislation, which gives the offspring the right to know about the DI as well as the identity of the semen provider (SFS, 1984; SFS, 2006). Those parents who were open with their children gave the following reasons for their decision:

- (i) To avoid accidental discovery
- (ii) The desire for openness and honesty within the family
- (iii) The fundamental right of the child to know his/her genetic origin

Those parents who were inclined to disclosure generally gave the same reasons as those who had already disclosed the DI. A large proportion of those in favour of disclosure were afraid of the child discovering something accidentally. They feared that their child/ren would discover their genetic origin through disclosure by friend and/or family members who were aware of the DI treatment, and preferred to tackle the issue of disclosure themselves to reduce the psychological distress that accidental discovery could have on the child/ren. There is supporting evidence for this view according to some previous studies on detrimental disclosures after the death of a sibling or the father, in connection with the parents' divorce or the revelation of different blood groups (Turner and Coyle, 2000; Hewitt, 2002). In the present study, the parents' worries were legitimate since the risk of accidental disclosure was certainly high in view of the fact that almost all the parents had told someone in their vicinity.

The second reason for sharing information regarding the DI conception with the child/ren was an essential desire to be open and honest with them. Those who had already told their child/ren said they felt a great relief from the burden of keeping a secret whereas those who had not yet told the child/ren described a certain negative impact on their partner relationship. Some were also worried that their child/ren sensed that a secret was being kept from them, which several anecdotal reports have confirmed, published by various donor conception networks, for example, the Donor Conception Network in UK (www.dcnetwork.org, 2006).

The third main reason for telling was the conviction that children have a fundamental right and need to know their genetic origin. The couples who had already disclosed the DI conception to the child/ren had generally found this experience uncomplicated and relieving. In whatever way the children had been told about their DI origin, the information was initially met with little curiosity or even interest.

Among the women and men intending to tell their child/ren, the main hindrance to openness was that it was difficult for them to find the right occasion and the right age for both their oldest and youngest child. This group of parents thought that the most appropriate age was when their oldest child had reached the age of 12 years, which in turn meant that the youngest sibling would be about 8 years of age. The corresponding ages for children who had already been told were 5 and 3.5 years, respectively. In other words, those who had not been told about the DI, would have to wait, at least, until they had become more than twice as old. This, however, is not in line with opinions among the offspring themselves. From children conceived by DI, there is emerging confirmation that those who learnt about the DI later in life experience uncertainty and confusion and take some time to adjust to this information, whereas early disclosure prevents disturbance in identity development (Triselotis, 1993; Turner and Coyle, 2000; Daniels and Thorn, 2001; Daniels and Meadows, 2006). In addition, not sharing information about DI with the children can have a negative impact on the parents, which in turn may become destructive for the children (Lycett *et al.*, 2004). One successful way of reducing parents' worries regarding when and how to tell their children is by offering them

pretreatment counselling as well as group sessions with couples who have already told their offspring (Thorn and Daniels, 2003), as was mentioned by several of the respondents in the present study. Furthermore, booklets and videos about telling and talking about donor conception could be of great importance (www.dcnetwork.org, 2006).

When comparing the prevalence of openness about the DI in the same sample in the primary questionnaire study performed about 4 years previously (Gottlieb *et al.*, 2000; Lindblad *et al.*, 2000), it was found that more than half of those who had told their offspring in the present study had not yet told their child/ren at that time. This could be explained by the fact that some of the children were then very young, but it could also reflect a general trend towards openness as regards different ways of building a family. In addition, having answered a questionnaire dealing with feelings and thoughts regarding a child's right to know about her/his genetic origin could in the long run have had a positive impact on several parents.

Regarding reasons cited by parents who were not inclined towards disclosure of the DI, the parents generally responded that they considered it to be a private matter, and they wanted to keep it secret in order to protect the family, and especially the child, against the possible negative attitudes and opinions of others. These hindering factors have also been highlighted in earlier studies (Golombok *et al.*, 1996; Nachtigall *et al.*, 1997a; Blyth 1999; van Berkel *et al.*, 1999; Lindblad *et al.*, 2000; Brewaeys, 2001). Finally, an additional factor involved in the wish to 'protect' the child from knowing about the DI was connected with the father's fear of being rejected by the child and no longer regarded as her/his 'real' father since they were not genetically related to each other. In other words, trying to 'protect' the child from awareness obviously had just as much to do with trying to protect the man. One has to remember that the underlying reason for DI treatment is male infertility, which is still seen as a taboo topic and often makes men feel stigmatized (Nachtigall *et al.*, 1997b; Greil, 1997; Daniels, 1999, Daniels 2004). When breaking bad news concerning fertility it is, therefore, of crucial importance for physicians and staff to facilitate a positive resolution of the trauma in order to prevent long-lasting crisis reactions (Lalos, 1999). Interestingly, the women and men who did not intend to tell in the present study seemed not to have thought of the possible damage that secrets and lies may impose on the offspring, as well as on the couple, nor the risk of accidental discovery by the child—or later as a teenager or an adult. Thus, in contrast to those who had told their child/ren, this group of parents seemed to consider themselves to be in control of the information about their use of DI as well as trusting their confidants not to disclose anything to their offspring. This has also been reported in some previous studies (Brewaeys, 1996; Golombok *et al.*, 2002).

Regarding telling offspring, when mature, about their right to obtain information about the semen provider's identity, the present study has shown that this may not be as natural as telling the child about DI in general terms. Among the parents who had disclosed the DI to their child/ren, less than two-thirds had also told them about their right to obtain

information about the identity of the semen provider. However, among the rest, all except one intended to inform the child/ren in the future. The underlying causes for postponing or hesitating to share this legislated right with the offspring would be an interesting focus for future studies, since these seem to have crucial impact on how parents act. Therefore, a second study is in preparation, which focuses particularly on parents' attitudes and thinking regarding their children's right to information about the identity of their donor.

As regards healthcare staff, it was found that their attitudes and standpoints had had a great impact on the couples' decision about whether or not to inform their child/ren about the DI. A great majority of those who had been encouraged by staff to tell their child/ren had also done so, but when disclosure was not consistently encouraged, the willingness to inform the child/ren was found to be lower. However, in total more than half of the parents stated that they had not been encouraged to be open. Furthermore, it was not uncommon for the partners within a couple to receive unclear advice and even conflicting messages from staff, and a great majority said that they had just been told to do as they wished. Thus, it seems that staff should be more educated in the implication of the legislation and trained to provide a congruent and positive attitude vis-à-vis disclosure. However, the fact that almost half of those who had already told their child/ren reported that they had not been encouraged by staff to act in this way could be a result of a general positive trend towards openness among the parents as well as the effect of an almost imperceptible influence from the staff.

The data obtained in the present study may have practical implications for clinics, for example, in the provision of counselling pre- and post-treatment. This may be particularly valuable for parents who are unsure about whether, how and when to share information about the DI with their offspring and what possible outcomes and reactions they may face. The study has shown that (i) it is common for parents to feel alone and forlorn when deciding to tell the child/ren about the DI and their right to obtain information identifying the donor, (ii) among those who had told their child/ren, most had decided to do so at a very early stage (often before the DI), (iii) the longer the parents postponed the decision to tell the child/ren the more difficult it became and (iv) almost every parent who had not told his/her child/ren had told someone else. Consequently, the healthcare staff can play a key role in guiding and supporting these couples. Their knowledge, insights and attitudes can be of crucial importance for the couples' reasoning regarding openness towards the offspring. Furthermore, staff can provide access to other DI families and networks.

To conclude, the present study has shown that compliance with the current Swedish legislation must be regarded as low even though more than half of the participating parents had shared informed about the DI with their child/ren. It has become obvious that there is a wide divergence between the intentions of the legislation and how parents act in relation to them regarding telling children about their DI conception. In order to increase compliance, it is crucial to organize education, support and stimulate ethical discussion for the professionals. In addition, parents, and parents-to-be, need to be

offered counselling and support, along with the opportunity to share experiences with other DI families through group sessions, videos and booklets. Thus, for the purpose of increasing awareness of the value of openness towards children and to find adequate methods to facilitate this approach, the DI recommendations must be evaluated and followed up. It is not sufficient merely to change the law; it also has to be implemented.

Acknowledgments

The Swedish National Board of Health and Welfare supported this study.

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Submitted on October 11, 2006; resubmitted on January 31, 2007; accepted on February 15, 2007