

Missing links: identity issues of donor conceived people

By Geraldine Hewitt

Introduction

My biological father is a sperm donor. He donated his semen between 1982 and 1984. He has blonde hair, blue eyes, an average build, is 5'8", his blood group is O+ and he is Caucasian. My list of what I don't know about my genetic father easily exceeds my list of what I do know, and the information that I have about him is questionable. The person who gave me life is as much a mystery to me as the three half siblings – one male and two female – I have who were conceived from his sperm. And all three are apparently about the same age as me. Our parents all sought fertility treatment at the Royal Hospital for Women, Paddington in Sydney, Australia.

I have known that I was conceived following donor insemination since the age of 5½ years. My parents' decision to tell me the truth about my conception was unusual, because even now, 13 years later: 'Nine out of ten parents whose children were conceived using donor sperm have not told them the truth about their parents' (Golombok, 2001).

My parents had not received any form of counselling throughout their fertility treatment and there was no literature or support services available to them, which would have made the process of disclosing my conception to me a lot more difficult for them.

Growing up, I was reminded of the special way that I had been conceived through frequent family discussions. My parents developed an environment within our family unit which was conducive to honesty and openness about everything, especially about donor insemination. I've been very fortunate.

I have wanted to know about the man who enabled me to be conceived, my biological father, since the age of 12. Before that it hadn't really sunk in that the 'very nice man', my donor, was actually a real person. It hadn't really occurred to me that there could be other children that were genetically my half siblings. There seemed a lot that I hadn't really thought about.

My parents had been writing to the hospital where I was conceived and born since August 1995, to try and find out non-identifying information about my donor. They had been told emphatically that all records had been destroyed. Even though my mum and dad had been telling me since I was 5½ that there may not been any information about my donor, this news upset me very much. It felt incredibly unjust that the doctors had just ripped up my donor's records and not cared. I thought that if I wrote to them myself it might help. It didn't.

I was 14 and had just arrived home from school. Mum came into my room and told me that we had received a letter from the hospital. They had some information. In the space of five minutes I had one half brother and two half sisters. It felt like I'd been severely winded while the ground underneath me was breaking up. It seemed so cruel that the hospital waited for three years to tell me this news, and they couldn't even do it to my face. It got me wondering what other kinds of information would just mysteriously pop up. My life contained a sense of uncertainty that I really didn't need.

To a large extent the sense of uncertainty and anxiety in my life has dissipated since, at the age of 17, I was told that the hospital does have my donor's records. The fact that they are incomplete seems beside the point. Those records had been there the whole time and it could have saved me from feeling like a human yoyo for most of my adolescence, if the hospital had told me that the records existed but that they were partially destroyed.

My purpose in researching the identity issues of donor-conceived people for my final year high school project was to find out whether personal identity issues were experienced by other donor-conceived people - which would not only help me to make sense of my own experiences and feelings, but also contribute to increased understanding about the experience of being conceived through donor insemination.

Donor-conceived people's experiences

The 47 participants in this study came from Australia (34), New Zealand (1), the United Kingdom (5) and the United States of America (7). The Donor Conception Support Group of Australia and the Internet proved to be vital resources in recruiting participants, distributing questionnaires and collecting completed questionnaires.

I had originally chosen to only include donor-conceived people above the age of 13 in my study, as I believed that it is onwards of 12 that identity development takes place. However, I later decided to incorporate donor-conceived children as young as 11, on the premise that their parents believed that they were mature enough to comprehend and answer my questionnaire.

Current age of participants:

- 10-14 years: 11
- 15-19 years: 15
- 20-24 years: 11
- 25-29 years: 3
- 35-39 years: 2
- 40-44 years: 1
- 45-49 years: 2
- 50-54 years: 1
- 55-59 years: 1

31 (66%) of the respondents were female and 16 (34%) were male. Given that available evidence of the outcome of DI indicates a more or less equal proportion of male and female births (Human Fertilisation and Embryology Authority, 2000), the evident gender imbalance between female and male participants in my study means that my research is an incomplete representation of the experiences of donor-conceived people.

Given the results of earlier studies (Cordray, 1999/2000; Turner and Coyle, 2000; Golombok, 2001) and individual accounts (Donor Conception Support Group of Australia, 1997), I was surprised that such a high proportion of participants in my study had been told about the nature of their conception prior to adulthood. Nevertheless, almost 1/4 were misinformed about their true genetic history until they were adults.

Age at disclosure:

- before age 4: 7 participants
- 5-9 years: 15
- 10-14 years: 10
- 15-19 years: 7
- 20-24 years: 3
- 30-34 years: 2
- 35-39 years: 2
- 40-44 years: 1
- No response: 4

In addition to the age at which donor-conceived people had learned about the nature of their conception, previous research and individual accounts indicated that the circumstances surrounding the disclosure might also impact on their identity development. The questionnaire, therefore, sought to establish:

- who had informed them of their conception
- what the circumstances preceding the disclosure were
- whether those circumstances impacted on the experience
- how the participant recalled feeling after the disclosure.

These questions were specifically directed towards donor-conceived people who were told about their conception at an 'older' age, i.e. after the age of 13, particularly those who found out about their conception later in adult life. I wanted to include these questions because I felt that the reaction towards disclosure could be indicative of their feeling about their status as a donor-conceived person, whether as a positive or negative attribute, and whether they experienced any issues about their personal identity.

Method of disclosure:

- mother: 23 participants
- father: 5
- both parents: 12
- foster sister: 1
- TV programme: 1
- Unsure: 1
- No response: 4

Circumstances where the sole discloser was the mother were described sometimes as:

'41 years of dysfunctional relationship between me and my mother'

'I sensed that my social father wasn't my biological father and I began asking questions'

'It was after the death of my younger DI brother, one year after the death of my father'

'My father died. My mother said my father made her promise not to tell us'.

When asked whether the circumstances surrounding the disclosure had impacted upon their experience, participants responded with:

'It changed my life'

'No not really...I wish I'd known earlier though, say around 7 or 8 years old.'

'Yes because it made it a very negative experience. It also did lasting damage to our relationship'

'Yes because I felt very special in a way'

'Yes instead of grieving the loss of my dad, I was very angry at him for not telling us the truth. I was also upset that I never got to talk to him about DI'

'We were a close family before the disclosure, and afterward we became even closer because we shared a special bond'

'Being told early allowed it to be a 'normal' kind of thing - there was no sense of distrust in my parents as being told late often causes...it freed Dad and I up to have a great relationship with each other'.

The act of disclosure has the opportunity to be either a positive or a negative experience for all parties involved. The younger the age at which disclosure took place, the more positive the experience was likely to be for the donor-conceived people and their parents. Donor-conceived people who were told about their conception at an 'older' age, that being above 13, quite often expressed a wish to have been told earlier.

When asked about how they felt after the disclosure, the answers were incredibly diverse. Through this particular study it is apparent that the younger the donor-conceived person was at the time of disclosure

the less negative the reaction to the news is likely to be. A few comments made by donor-conceived people about how they felt after the disclosure included:

'Very shocked and really upset for a few days'

'I knew I was still loved. But I think I felt like "who am I?"'

'At first I was shocked. Then I felt sad, knowing that my dad was not my biological dad. Then angry, because I felt that I didn't know myself. And then happy because I was told I was special because they went through a lot to have me'

'... As I found out more about donor insemination I became angry and frustrated at the medical profession for the secrecy and my lack of rights'

'I felt incomplete but at the same time I knew I was special'

'It doesn't bother me at all. I just live life like I would've if I wasn't a "donor sperm" person'

I also included a list of possible responses that participants were able to indicate as to whether they applied to their own personal experience.

Table 1: Disclosure brought a sense of:

	Number	%
Curiosity	32	68
Confusion about Identity	27	57
Sadness	24	51
Disbelief	17	36
Helplessness	16	34
Sense of isolation from society	17	36
Anger	15	32
Anger towards medical profession	15	32
Grief	15	32
Relief	15	32
Loss	14	30
Anger towards parents	13	28
Bewilderment	13	28
Anger towards government	12	26
Anxiety	12	26
Excitement	12	26
Resentment	11	23
Distrust of family members	8	17
Happiness	4	9
Anger towards siblings	3	6

17 participants reported other consequences. These included:

'Self-love and self-acceptance for the first time ever'

'Untroubled'

'Injustice, discrimination, betrayal, a sense of being used, I felt like a commodity that had been commissioned. My best interest had been sacrificed for the benefit of others. I had been bought and paid for like a slave. Where is the dignity in having a financial value? I genuinely felt that I am different to other people'

'I was happy that they told me'

'Scared - because if I marry someone that they could be related to me - have deformed children'

'It felt surreal - like things like that didn't happen to real people when they're 19. It only seemed like something that would happen in a movie or a book'

'I wished that my dad could have kids and that he was my biological father.'

33 participants felt disadvantaged with regards to information on which to base identity. However, only 16 thought that this compromised their ability to form trusting, open, honest relationships with others. 11 indicated that this applied to people in general, 10 to peers, 10 to family and 6 to partners.

37 participants felt disadvantaged with regards to access to genetic information.

35 participants felt disadvantaged with regards to information about their donor's social history.

40 participants wanted information about their donor. Supplementary information provided in response to this question showed that 1 respondent had already met her donor while another has been able to write letters to him. The remaining 5 participants that did not want information about their donors did clarify their response.

Table 2: Information sought about donors

	Number	%
Medical history	40	85
Physical appearance	39	83
Family history	35	74
Personality of donor	35	74
Social history	34	72
Non-identifying information	30	64
Reason(s) for donation	30	64
Hopes for the future	26	55

It is also important to remember that 2 participants had already had the opportunity to have these questions answered by their respective donors.

Table 3: Identity of others to whom participants were comfortable in disclosing the circumstances of their conception

	Number	%
Close friends	40	85
Parents	39	83
Doctor	36	77
Siblings	29	62
Friend's family	22	47
Grandparents	20	43
Peers	20	43
Acquaintances	13	28
Colleagues	13	28

Some participants expanded on their answers to this question giving reasons why they felt comfortable discussing their conception with certain individuals only, based on their previous personal experience. These included some revealing comments e.g.:

'I attend a Christian school, I could never tell - it's a sin what my conception is!'

'I don't mind sharing it. It is what I am and I am not afraid of judgement'

'They [my grandparents] don't want to know about or confront the reality of DI. They'd rather I just forget about it - but I won't.'

I included a question about participants' comfort or discomfort with their physical appearance, as I have always felt unsure about the origins of my own physical characteristics, and I wanted to know whether this corresponded to the experiences of other donor-conceived people. 34 respondents were unconcerned about physical appearance, 13 indicated some feelings of discomfort, and of these 12 were aged over 18.

But even though 3/4 of participants stated that they were not uncomfortable with their physical appearance, a few clarified their opinion with statements like:

'Not anymore! I did when I was younger!!'

'Only sometimes'.

The statement from one participant exemplified responses of participants indicating concern about their physical characteristics:

'Cos I don't know who I'm like. I'm a stranger in my family - an identity crisis!!'

Nearly two thirds (30) of respondents felt that a piece of their identity was missing. A participant who responded that he had not experienced identity issues stated:

'I have never articulated that feeling, although I suspect that I do have thoughts about myself which you might describe in that way.'

Participants were asked how frequently they experienced feelings of an incomplete identity:

- occasionally: 16
- frequently: 13
- rarely: 5

This suggests that if donor-conceived people do experience a sense of incomplete personal identity, this would occur on a frequent to occasional basis.

The primary focus of my investigation into the experiences of donor-conceived people was their experience with regard to identity issues. Within Western society an individual's occupation is regarded as an integral aspect of their personal identity. Some people in society define others by their profession, and it was this concept that led to my questions about difficulties experienced by donor-conceived people when deciding on a career path.

My hypothesis was that if a donor-conceived person had experienced identity issues, they could also experience difficulties in identifying themselves to society through an indicator such as their job. 28 had had these experiences; of these, 20 were over the age of 18 at the time of this research. However, nearly 1/4 of participants were aged 10-14, and so would not be in a position to comment on career choice.

Conclusion

The identity issues experienced by donor-conceived adults and children have not been adequately brought to the attention of society through academic research and the media. It is poignant that this study is, to date, the largest international study of the individuals who have been conceived through donor insemination.

This void in academic and medical research into the implications for the person created by reproductive medicine exemplifies the attitude of some members of the medical community towards the issues of donor conception. This attitude has been encapsulated by Shenfield (2001) who states:

'There is nothing to say that children have to know their genetic parents; it's not a human right [and] there's absolutely no evidence that it's important'.

The lack of research into the issues that deeply concern donor-conceived people, and the resulting lack of education of the medical community and society in general, has allowed comments such as these to be accepted as valid. As long as this attitude prevails, the long-term repercussions of assisted conception will continue to be ignored and the best interests of the individual created through reproductive technology will not be considered.

The experiences of the donor-conceived adults and children who participated in this study hold relevance for lawmakers around the world enacting legislation to govern reproductive treatments such as DI, as well as procedures like IVF when donor egg, sperm or embryo are involved. This study could potentially be relevant when considering the implications of human cloning for the resulting individual.

It is extremely disconcerting that of the 47 donor-conceived people who took part in this study, only 3 had not experienced identity issues which they identified as being a result of their conception through anonymous donor sperm. Most indicated that the insufficient information about their donor which past DI providers were prepared to make available to them and, in particular, lack of a complete and updated medical history for their donor, was an issue of deep concern and frustration.

Of slightly less importance to most participants was the inaccessible social histories of donors. Many were interested in finding out details of the donor's life beyond a basic and fairly impersonal physical description. There was an evident interest in knowing their donor as a person, a fellow human being. None indicated that this would mean the establishment of a father/child relationship; there was adamant denial of such a media-stereotyped aspiration.

There was a considerable difference between the number of male and female participants in this study, which is a result of the limited number of donor-conceived people who have been made aware of the circumstances of their conception and the difficulty in contacting donor conceived adults and children who were willing to discuss their very personal experiences with being born through assisted conception. Also, bearing in mind that a quarter of participants were aged between 10 and 14, and had possibly not yet experienced issues with their personal identity, this research is further limited in its scope.

Further academic research is required if the importance of the complex issues which arise for the individual created through donor insemination are to be recognised and rectified.

References

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At the time she wrote this paper, Geraldine Hewitt was studying combined Arts/Science at the University of Sydney. The research on which this paper is based was conducted in 2001 for a Personal Interest Project at East Hills Girls Technology High School, Sydney, Australia.