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Semen donors' curiosity about donor offspring and the barriers to their knowing

Abstract

The article reports qualitative research findings which explored the meanings of kinship and genetic knowledge of fifteen pre-1990 semen donors in the UK. This is presented in the context of public and academic debates about the regulation of access to genetic information, genetic information as intellectual property and kinship knowledge, and the multiple ownership of genetic information. Semen donors in the UK traditionally were expected to take no interest in what became of their donations and those who did were considered to be unsuitable as donors. However, this research reveals that men who donated in the past hold varied attitudes, including curiosity, about how donor offspring have fared and what they look like. Whilst some donors would welcome direct contact with donor offspring, there are practical and emotional obstacles to satisfying their curiosity. Donors' views reflect the varied understandings in the UK about the implications of genetic relatedness and the time and energy required to maintain and sustain relationships.

Keywords: semen donors, anonymity, relatedness, UK DonorLink.

Introduction

The men who donated semen in the UK before 1990 were usually expected to take no interest in the outcome of their donations and strongly discouraged from doing so (Speirs 2007a). The stereotypical donor was a young medical student who donated in return for cash or other material benefit, and who was presumed to have no interest in whether there would be long-term effects on themselves and the people conceived with their donated semen (Snowden & Mitchell 1983). Clinic practices were geared towards avoiding long term medical and perceived emotional implications, by recruiting men who were thought unlikely to pass on disease or genetic defects to offspring, and by ensuring that donations were anonymised. Some clinics practised sperm-mixing so that paternity could not be traced (Ciba Foundation 1973), and requests from patients to use the semen of a donor known to them were refused (Brudenell et al. 1976). Keeping donors in obscurity by preventing any connections between them and the semen recipients was thought necessary to ensure that donors would not be able to intrude upon the relationship between a donor-conceived child's parents, a possibility which has been of concern since the practice of donor insemination (DI) was developed in the UK (Barton et al. 1945). The idea that semen donors and the mothers of donor offspring would be attracted to each other in an adulterous fashion if they had social contact, reinforced an insistence by infertility treatment providers that donors must remain anonymous. Moreover it was thought that donors might interfere with the upbringing of their donor offspring if they knew the family (Brudenell et al. 1976), and therefore keeping apart the parties involved – donors, recipients and donor offspring – was seen as essential.

The provisions of the family laws in the UK jurisdictions until the 1980s meant that donor-conceived children were illegitimate even if their genetic mother was married and her husband consented to the procedure (Cusine 1988). The outcome of enquiries into DI such as the Feversham Report (Feversham Report 1960) and the Peel Report in 1973 (British Medical Journal, 1973) noted the problem of the legal status of the practice: donor conceived children were illegitimate, the semen donor and recipient were at risk of being accused of adultery and the donor was thought to be financially liable for the children. Legislation passed in 1987 (Family Law Reform Act 1987) provided that in England and Wales gamete donors were not to be treated as the legal father of a child conceived from their donations, and the Human Fertilisation and Embryology Act 1990 (HMSO 1990) provided similarly for this throughout the UK if the donors donated at a licensed clinics. However this provision was not retrospective and in Scotland, a donor conceived person retains a legal and prior right to inherit from the gamete(s) donor, should the biological link be proved. The Human Fertilisation and Embryology Act 2008 (HMSO 2008) legitimised the exchange of identifying information between donors and their offspring. Although not retrospective in their application, these changes have continued to cause concern amongst some infertility treatment providers about the possibility of unsought for involvement by donors in the families of donor-conceived people (Speirs 2007b). This article describes views held by donors about their interest in donor offspring and suggests that the uncertainty of the donors' position and their concern for the welfare of both their own and the recipients' families, is a restraint on the expression and satisfaction of their curiosity about their donor offspring.

Methods

Between 2002 and 2006, doctoral research on social aspects of anonymous semen donation was carried out, focussing especially on what it meant to pre-1990 semen donors that they had donated anonymously. The aim was to explore the meanings of kinship and genetic knowledge to semen donors in the context of contemporary public and academic debates about the regulation of access to genetic information, genetic information as intellectual property and kinship knowledge, and the multiple ownership of genetic information. Unstructured interviews were conducted with fifteen men who had donated between the late 1960s and early 1980s, eleven of them when they were medical students who had donated at clinics in NHS (state-funded) hospitals in England or Scotland or at privately-run profit-making clinics mostly in London. Interviews were not all recorded but notes were made during and after them.

Additionally key documents relating to historical debates about the law and provision of donor insemination services were examined in addition to participation in conferences about their development and regulation. Research informants were recruited using strategies of convenience, opportunistic methods and snowballing (Atkinson & Flint 2001). Introductions were arranged by mutual friends and colleagues, and by other donors interviewed already, and an advertisement was placed on the website of Doctors.net (a network of GMC authenticated doctors in the UK used for communication, information and education). The essential criterion for recruitment was that potential interviewees had donated before the implementation of the Human Fertilisation & Embryology Act 1990 which introduced regulations governing donor insemination. Data collection and analysis were structured by multi-sited ethnographic methods (Marcus 1995; Franklin 1997; Rapp 1999).

Findings

Fourteen of the donors were married at the time of the research and all but one of them stated that they had told their wives about having donated, usually before they had married. Some had informed their children. The unmarried donor had informed his parents and siblings. In contrast to the intention that donors should forget that they had ever donated, it was clear that knowledge of their having donated was often widespread in their social and professional circles because donors had shared the information. None of the donors had been told the number of babies, if any, conceived from their donations. However, some had made assumptions according to the number of times that they had donated and the policy of the clinic, if it had one, about limits to the number of children per donor. Apart from the unmarried donor, all interviewees said that they now had children and some had grandchildren. Three had experience of raising step, foster or adopted children in addition to biological children of their own. Some donors said that after donating they had not thought about it again until hearing about or reading of my call for research participants. Others had thought about it from time to time, especially when particular circumstances, or the actions of others, had prompted them to do so. These included discussions with their children about sex and reproduction, and socialising with friends and colleagues who knew that they had donated. Donors had also been prompted to reflect on having donated in the past by media reports of the adoption law review in England and Wales and by public debate in the UK about donor anonymity.

The donors conveyed a wide range of thoughts about having donated, including the circumstances of being recruited as a donor, concern for the welfare of donor offspring, and the implications should donor offspring find them. One donor and his

wife have a young son but the donor told me that he often thinks of ‘possible other sons’ that he might have ‘somewhere’. Another donor mused that his donor offspring might have children themselves now, and so ‘there might be grandchildren out there’. Curiosity about what donor offspring might look like was often expressed, and one donor was so curious to know about this that he wished that he could meet them all and hold a party for them. Another donor was sure that if a donor offspring were to make contact with him, it would be impossible for him not to invite the person into his family if there was a physical resemblance.

Prevalent also was a willingness to share genealogical and medical information about the donor’s family directly, and even in person, with donor offspring, and a view that it was understandable for donor offspring to want more information about their origins. Two donors stated that they would warmly welcome a ‘knock on the door’ from donor offspring and would treat them as additions to the family. In neither case, apparently, had concerns about this been expressed by these donors’ family members. In general, donors who thought of donor offspring imagined themselves reacting spontaneously if donor offspring made contact, with statements such as:

‘If he came to the door and was in trouble I would invite him in. Or her.’

‘If she came to the door and looked like my family I’d invite her in’.

‘If they turned up I’d just invite them in for a coffee’

‘If they turned up, I would just invite them in – “join the family” ’

Some of the donors had been paid cash for their donations, some had received payment in kind (such as new shirts for the university rugby team), and others had

received no payment or reimbursement of expenses at all. There did not seem to be an association between payment and thoughts about donor offspring, but several donors expressly regretted having been paid and considered that their own children might not approve if they found out. One donor who had not informed his children that he had been a donor thought that it was because he was now ashamed that he had been paid. Another donor who had been paid was adamant that he and his friends had been taken advantage of, because in hindsight he judged that they had donated without properly informed consent, given their immature age and financial need at the time. Overall, attitudes of donors who had been paid in cash or in kind ranged from feeling that they had been exploited, scorn for the doctors running the DI clinics, to wry embarrassment, including relating the jokes and innuendoes made by themselves and their fellow donors about the business of being a paid donor.

There was a tendency for donors who insisted that there might have been no conceptions from their donations to claim that they had not thought over the years about donor offspring. They had not been informed of the results of their donations and furthermore, the practice of sperm-mixing allowed donors to believe that it might not have been their sperm which had actually enabled conception to take place. They did not know if they had donor offspring and perhaps would never be able to find out. Donors recognised that this absence of information means that there might be unwitting incest between their children and their donor offspring, although they played down this possibility, not because they believed that it was unimportant but because the chances of it occurring were considered to be unlikely. However one donor said that he and his wife had advised their teenage daughter not to fall in love with anyone who looked like her and ‘not to go for anyone aged over twenty eight’.

For donors who donated before the introduction of regulations and whose donations enabled conceptions before 1st August 1991, there is no record of assisted conception births held by the Human Fertilisation and Embryology Authority (HFEA), and no way of donors finding out information or registering their willingness to be contacted by any donor offspring through the HFEA. They can contact the clinic where the donations were made but it may have destroyed its records, or ceased to operate. Alternatively they can register with the voluntary contact register UK DonorLink which helps to link donors and their donor-conceived children who were born before 1991 by means of DNA testing. One of the donors interviewed for my research had done so, because of his firmly held views:

It's important to know about your origins. I know mine. It gives you more control if you are allowed access to information about yourself. Donors' primary responsibility is to look after the people's needs.

Several donors thought that an organisation such as UK DonorLink was a good idea because it ensured that donors and donor offspring could retain control if contact between them was a possibility. It would avoid the situation of donor offspring 'turning up' without warning, leaving the donor uncertain as to how to deal with the situation. The concept of control was important to a number of the donors, especially those who were concerned about donor offspring making contact. Two of these donors explained that they did not have enough time and energy to deal with such an event. One of the two added that donor conceived people 'are strangers to me'; the other thought that registering with UK Donorlink 'would be quite an active thing to

do and it is not where I want to spend a lot of energy. Or any energy really'. He was also concerned that contact with donor offspring might divert his attention from his wife and children.

Discussion

Previous research has shown that even when semen donations were anonymised, donors were interested in what became of their donations, thought about possible donor offspring and might be willing to meet with them (Daniels 1989). More recent research into past donors' views on donor recruitment, information sharing and offspring found that 84% had thought about their donor offspring although many only fleetingly. Reasons for thinking about possible donor offspring included wondering if there were any, how they had fared, what their personality is like, whether they are healthy and what it would be like to meet them (Daniels et al. 2005). Research into public attitudes towards DI has found that people assume that being genetically connected is important and expect that semen donors will be interested in what happened to their donations (Edwards 2000). Fundamentally, although there are various ways in which people can become kin to each other, for example by sharing food or growing up together (Edwards 2009), connection by 'blood' or now 'genes' is a defining characteristic of EuroAmerican kinship. Moreover, physical resemblance is taken as evidence of a genetic link between people especially children and their birth parents (Astuti 2009). For the donors in this study, the idea of such connection was part of a curiosity to know about the outcome of their donations.

A significant barrier to satisfying curiosity is the perceived risk involved. Marilyn Strathern suggests that in the context of kinship, new knowledge is not neutral in its

impact. Acquiring it has ‘built in effects’ (Strathern 1999) and this explains why people may be reluctant to look for further information about genetic relatives. Knowledge of how one is connected to persons can lead to relationships with them, turning genetic kin into social kin. However these new relationships might have a detrimental effect on existing ones (in this case between donor-conceived people and their fathers, and donors with their wives and children) partly because, as a number of research studies have demonstrated (Carsten 1997, 2000; Edwards & Strathern 2000), and as several donors in this study suggested, making and maintaining kinship involves constant work in the form of time and energy.

Finally, when donors are uncertain about their place in the lives of donor offspring, and vice versa, this reflects the lack of agreement as to what is generally meant by ‘father’ in the UK (Sheldon 2005). As the public debate about anonymity and the responses to the public consultation about it revealed (Department of Health 2003), there is ambivalence about encouraging connection between genetically related people amongst some policy makers and infertility treatment providers in the UK. This is reflected in the attitudes of donors of the past and the absence of encouragement to them to satisfy their curiosity about donor offspring (Speirs 2007a). However the provisions in Section 31ZD (3) of the Human Fertilisation and Embryology Act 2008 (HMSO, 2008) are an acknowledgement that some donors may wish to obtain non-identifying information about donor offspring. Nevertheless there is anxiety about a perceived risk to the parental bonds in families created by donor assisted conception, as though a genetic relationship will automatically be stronger than a social one, and particularly in the case of DI that donor offspring will abandon the father who raised them in favour of the genetic fathers, the donors.

Conclusion

The barriers for donors to satisfying their curiosity about donor offspring are practical and emotional. Only one of the donors in this study had registered with UK DonorLink although there is a recognised need for advice, support and counselling and an intermediary service provided by a voluntary registry for people affected by donation made before August 1991 (British Infertility Counselling Association 2003). However for some donors, actually registering may be too big a step at the moment. In addition, lack of information about how reunions between people separated by adoption are managed contributes to donors' uncertainty about taking the initiative. What comes across is a sense that these pre-1990 donors interviewed in this study would prefer to be found, rather than actively to seek.

The donation of semen in the UK was characterised from the beginning by strategies to ensure that donors would remain unrevealed to recipients and to any offspring born after successful conception. Therefore it is unsurprising that donors recruited in that environment find the idea of taking action to satisfy their curiosity a challenging one. They were not supposed to be revealed as donors, and not to give a second thought to having donated. However that has not prevented their curiosity about the possible people created from their donations, even for those who have not felt it appropriate to take their curiosity further.

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Ethics approval

This was granted by the School of Social and Political Studies of the University of Edinburgh. The research methodology complied with the Ethical Guidelines for Good Research Practice of the Association of Social Anthropologists of the UK and the Commonwealth.

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