Gamete donation and anonymity

Should offspring from donated gametes continue to be denied knowledge of their origins and antecedents?

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This paper presents the case for a change from the current practice of anonymity and secrecy in the use of donated gametes in medically assisted conception. It does so by describing history of the practice, various committees of enquiry over the years, their recommendations for consideration of the children created and the need for follow-up of the outcome; presenting the evidence from outcome studies both about child development and family relationships where secrecy is maintained about the child's origin and those where the practice is openly to acknowledge their origins. This is followed by an analysis of the experience and views of these children once they are adults. In discussion of the composite findings recurring themes emerge. From this it is concluded that offspring from donated gametes should not continue to be denied knowledge of their origins and antecedents. In the public debate, four schools of thought are identified. Possible practical scenarios to implement change are discussed. This paper argues that the fundamental issue regarding any of these remains—that priority in decision-making should be the lifelong well-being of the children being created.

Key words: anonymous gametes/child welfare donor offspring/family secrets/origins and antecedents

Development of medical provisions

Artificial insemination by donor (AID) for humans was introduced into medical practice in the 1930s. It developed furtively over four decades because of disapproval on moral and religious grounds. One of the commissions of enquiry (Archbishop of Canterbury, 1948) considered it should be a criminal offence. It was also considered tantamount to adultery.

The first published reports about the practice were in 1945 (Barton et al., 1945) and 1953 and 1955 (Jackson, 1953, 1955). Jackson developed a DI clinic copying the already established veterinary practice in animal husbandry. Between 1940 and 1980 there were 480 births from her clinic. Donors were anonymous, assured of confidentiality. Recipients were encouraged to keep AID secret and not to tell the child.

Donors were recruited through personal contacts. Frequently medical students were used. One donor used by Barton was described as a ‘champion’ after his first 100 births (DI Newsletter No 14, 1999–2000). Another from this period claims being responsible for 100–200 pregnancies (Beeney, 1999). How far the clinics routinely kept records is uncertain.

Relevant for contemporary debate is the question of follow-up studies. Concern was expressed about the outcome for the children (Archbishop of Canterbury, 1948). The Feversham Report (1960) commented: ‘To be born in this way could only
be considered a handicap: the practice involves suppression of the truth.’

The Peel Report (1973) agreed to the practice being carried out under the National Health Service but argued for follow-up studies (Peel Report, 1973). The discussions at a CIBA Foundation Symposium (1973) are evidence of the views at that time. Practitioners described selecting healthy, intelligent donors and matching physical characteristics to that of the male recipient (CIBA Foundation Symposium, 1973). Questions about origins and genetic histories and records were not seen as an issue.

As insemination had been so quickly and successfully established in animal husbandry with no adverse effects, its use in humans was considered to be equally problem-free (McLaren, 1973). That no children from AID were reported in the psychological or psychiatric literature was used to indicate that the procedure was ‘problem-free’.

Medical procedures and the screening of donors on medical and genetic grounds have become more sophisticated. Since 1991 such procedures have been regulated in the UK by the Code of Practice of the Human Fertilisation and Embryology Authority set up by the Human Fertilisation and Embryology Act 1990.

In respect of the recruitment of donors, the Code of Practice (Human Fertilisation and Embryology Authority, 1991, 1998) follows the recommendations of the British Andrology Society to include screening details of family health and genetic histories so as to exclude major problems. However, the argument about secrecy (or privacy), confidentiality and anonymity about donors and their personal and family backgrounds continues as before and mirrors or has resonance with the stance adopted twenty or more years ago.

Oocyte and embryo donation have been added to the repertoire of medical interventions. Whether oocyte donors should be relatives or anonymous strangers was debated at a seminar of the Voluntary Licensing Authority at the King’s Fund Centre in London in September 1988 (Gunning and English, 1993) The consensus was to favour anonymous strangers. In relation to screening, the recommendations for good medical practice largely follow those already developed for sperm donors but allowing for the ‘differences between egg and sperm donations in terms of availability and method of collection’ (Aird, et al., 2000). It is argued that ‘it may not be appropriate for the same criterion to be applied in each case’... ‘in particular because of the major shortage of eggs’.

There have also been legal changes. Where previously registering the child as the child of the social father was breaking the law, since 1987 it has been legal to do this (Family Law Reform Act, 1987). As a result of the Human Fertilisation and Embryology Authority (HFEA) Act (Human Fertilisation and Embryology Act, 1990) all births from donated gametes should be registered with the Authority set up in 1991 under the Act. The Act was not specific about how much information should be recorded about the donor, although both the Warnock Report (The Report of the Committee of Inquiry into Human Fertilisation and Embryology, 1984) and the White Paper prior to legislation had been specific. The HFEA has evolved its practice about this. The form currently in use about donors gives name, date and place of birth, physical characteristics and ethnic group, together with what the donor may offer as a personal anonymous profile. Although this affords the possibility of considerably more donor information than the pre-1991 practice, a survey of clinic practice showed considerable variation in the general approach to donors about this and how much is offered and thus recorded (Blyth and Hunt, 1998). A limit on the number of live births allowed from each donor has been set at 10, except where the same donor is requested for the creation of siblings when the number can be exceeded. Non-identifying information from this register can be released to the offspring when they reach the age of 18, or when younger with their parents’ consent, in particular circumstances, for example, at 16, to ascertain if anyone they are considering marrying was also from DI, or in special medical situations.

It is how this question will be implemented generally when the children born post-1991 reach 16 (when they may marry) or 18 (when they reach majority) that has caused a refuelling of interest and concern about the question raised in the title of this paper. The information is there, but will it be made available to those adults who request it? Will the information be anonymous or give identifying detail about the donor?

Although this paper is set in the UK context of regulation and practice, the questions about access to information about the donor are currently being debated elsewhere in the world, for example, Canada, Australia and USA.

Two aspects relevant to this question and currently also being debated in the UK are counselling provision and the implementation of the ‘welfare of the child’ clause in the Human Fertilisation and Embryology Act (1990), Chapter 37, Section 13(5). How this clause is interpreted is controversial. Does it refer to protecting against possible harm to the potential but not yet created child, or does it include the lifelong well-being of any potential child following the well-established principle in child care legislation in the UK that paramount consideration should be given to the welfare of the child throughout his/her growing up years? [This is currently spelt out in the Children Act (England and Wales) 1989 and the Children (Scotland) Act 1995]. Is this second interpretation likely to be served by a continuation of the current practice of secrecy about the child’s conception and lack of information about the child’s paternal and/or maternal origin? What evidence is available from research about this? Could this be used to influence practice and counselling?

Outcome studies

Research studies about outcome fall into two broad groups:

Those that address the psychomotor, behavioural and emotional adjustment and development of the children in their early years. The tests used to ascertain this are standardized measures based on the norms for a particular age and stage of child development.

Those that look at the quality of interpersonal family relationships and explore emotional and psychological aspects relating to infertility, parenting and child-rearing. These use qualitative research methods and, in particular, interviews and
life histories for the collection of data. It can be argued that such an approach has particular relevance when exploring new areas of complex human interactions. These different but potentially complementary research approaches should be borne in mind when reading this review of published studies.

Child development studies

Studies about DI children have been mainly follow-ups from specific clinics of the psychomotor, behavioural and emotional development of the children in their early years. Reviews (Brewaeys, 1996, 1997; Kovacs, 1997) came to the conclusion that the children were progressing ‘normally’ and showing no indication of any behavioural or emotional problems.

Exceptions to the general conclusion were reports of hyperactivity in a proportion of DI children, a small group of DI fathers having problems in relating to their children (Kovacs et al., 1993) and a study (Manuel et al., 1990) which reported DI parents having an anxious over-investment in their children resulting in increased vulnerability in the children.

The comparative studies (Golombok et al., 1995, 1996) have been much quoted. Four groups of children all aged between four and eight years were involved: DI, IVF, adopted and naturally conceived. All the children were singletons and those with disabilities were excluded. Standardized tests and observational procedures were used. The most important finding was that the quality of the parent-child relationship in DI families, IVF families and adoptive families emerged as better than in the control group of families with children conceived naturally. No significant differences, however, were found in the social and emotional development of the children. The authors concluded that the presence or absence of a genetic link between parent and child was less important to the family relationship than a strong desire to have children. None of the children in the studies of Golombok et al. (Golombok et al., 1995, 1996) knew about their DI origins. A similar study has been added with donor oocyte families with similar conclusions regarding the genetic links (Golombok et al., 1998).

From Golombok et al. the conclusion has been drawn that ART children are likely to have as good or better self-esteem and to be happier in later childhood and in adult life than those naturally conceived. However, doubts about this as a legitimate forecast have been raised. Brewaeys (1997) urges caution about these findings, arguing that, although the secrecy may not have a negative effect at the early stage of the child’s development, this may change when the children are older (Brewaeys, 1997). Brewaeys observes that young children do not have the capacity for abstract thought by which they would be able to decode the signals regarding their own origins. She comments that further large-scale studies at adolescence and later are needed. However, she also stresses the need for a way to be found to deal with the high degree of non-participation of heterosexual DI families in the published follow-ups. In Golombok’s European study (Golombok et al., 1996) the response rate for DI families was 47% and in the UK study 62%, which was similar to the naturally conceived children but lower than the IVF (95%) and adopted (76%).

Research by Snowden and Snowden (1998) raised a similar issue. The non-response rate increased markedly as the children in their study became older (Snowden and Snowden, 1998). This suggests that the longitudinal studies sought may be more problematical in practice than is currently assumed, an opinion also shared recently by Golombok in the Times Higher Education Supplement (Times Higher Education Supplement, 6 October 2000).

There are also aspects of the studies by Golombok et al. which merit comment. Fathers were not part of the original observational procedures used—these were confined to mothers. This may have been inevitable but is regrettable in the light of the earlier finding in some studies that some fathers were experiencing difficulty in relating to their children.

The studies by Golombok et al. are based on attachment theory—the assessments and findings thus rely heavily on the emotional environment. Using attachment theory as a predictor of the future is controversial. It inevitably excludes other conceptualizations of adult-child interaction (Vasta, 1992) and has been questioned (Clarke and Clarke, 1999). These researchers draw on previous studies (Rutter, 1989; Schaffer, 1992) as well as their own. They comment: ‘Theories ascribing overwhelming, disproportionate and predetermined importance to the early years are clearly erroneous’. ‘There is no suggestion that what happens in the early years is unimportant. For most children, however, the effects of such experiences represent no more than a first step in an ongoing life path which may be straight or winding, incremental or decremental, depending on the two-way relationships between individuals and their contexts.’

Also, a reliance exclusively on attachment and the emotional environment side-steps the question of the relative weight to be given to nature and nurture. After a long period of silence on such matters, studies relating to this issue have recently been extensively reported and reviewed (Plomin, 1995; Rutter, 1999). They clearly have relevance for any discussion regarding the use of donated gametes. Plomin reports: ‘Research and theory in genetics (nature) and in environment (nurture) are beginning to converge... It is time to put the nature/nurture controversy behind us and to bring nature and nurture together in the study of development in order to understand the processes by which genotypes become phenotypes.’

Howe, writing recently on the same subject (Howe, 1995), but again relevantly in relation to the use of donor gametes, comments on recent reviews in this area that: ‘Current estimates suggest that genetic influences account for anything between 30 and 70% of the variation between individuals.’

In spite of these reservations and comments by other researchers, the realities of medical practice have been that Golombok’s studies are welcomed by clinicians as validating proof that the established practice of ‘using donor sperm to complete a family where the husband is sterile is a very realistic option with a good prognosis’ (Kovacs, 1997).

The research studies described below belong to the qualitative group already described and suggest a different scenario, although in respect of the children being wanted and reported as much loved, the findings are similar, certainly in the children’s early years.
Social and family relationship studies
Research by various authors (Snowden et al., 1981, 1983; Baran and Pannor, 1989; McWhinnie, 1992, 1995, 1996a,c, 1998a,b, 2000) deal with the social, psychosocial and emotional aspects of parenting children created by the use of donated gametes.

The study by Snowden et al. was based on the records of the Jackson clinic over the period 1940–1980, during which time 480 children were born (Snowden et al. 1998). The general analysis of the 40 years of such practice, and letters of follow-up about the children, was combined with interviews with 57 parents from the sub-group of parents whose children were of pre-school age. This group offered the best opportunity to establish a research interview contact combined with the possibility of a later follow-up contact. This was done when the children were aged 10–13. However, almost 50% declined to be interviewed. Some gave as the reason that they feared the secret of DI would be revealed; others that they never thought about the recourse to DI and to do so in a discussion was ‘unsettling’.

An American study (Baran and Pannor, 1989) gave access to the perspective and experiences of 171 people directly connected with donor insemination; 70 partnerships with children from babies to 3–5 years; 14 single women with children; 37 donors and 19 donor offspring aged between 16 and 68 years. The authors describe their study as exploratory. Data collection was by interviews and group discussions.

McWhinnie’s study provides empirical data from the parents’ perspective of their experience of learning of their infertility, attending a medical clinic and/or unit and achieving parenthood following IVF and DI. The data collection covered both the intimate and personal relationship issues and the wider sociological aspects of family, kinship, social networks and the communities in which they live. The study is of 54 families, 31 from IVF/GIFT (where both parents are the biological parents) and 23 from donor insemination, bringing up a total of 101 children, 74 from ART and 27 either step-children, adoptees or children conceived spontaneously, in most cases following the birth of ART children. Details of the methodology of the study, access to participants, the basis for recruitment and the composition of the sample have been published elsewhere (McWhinnie, 2000). Reports were lodged with the Economic and Social Council (R-000-12–1463). The basic conceptualisation of the study was developmental, both with regard to the infertility process (McWhinnie, 1992) and the parenting (McWhinnie, 1995, 1996, 2000). The latter was based on the recognised stages of child development charted by research and clinical practice by paediatricians and psychologists (Sheridan, 1973; Bee, 1981; Cohen and Westphues, 1990; National Childrens Bureau, 1982) and the corresponding changing tasks of parenting in relation to each developmental stage (Erikson, 1959, 1965, 1980; Boulton, 1983; McWhinnie 1985; Kellmer-Pringle, 1986).

The knowledge of communication patterns in relation to emotional, social and cognitive development and about children’s understanding of abstract concepts, such as the passage of time, death and questions about ‘Where did I come from?’ derives from the extensive psychological, psychiatric and educational literature in this area. A child’s particular understanding of substitute parenting, i.e. psychological or social parenting being different from biological parenting, but not necessarily in the nurturing aspects, derives from the retrospective life histories of adult adoptees, foster and step-children, and the considerable international literature about this (McWhinnie, 1967, 1969; Triseliotis, 1973; Raynor, 1980; Boul, 1987; Brodinsky and Schechter, 1990; Hoopes, 1990). A major contribution to the specifics of this understanding has been made by the research of Brodinsky et al. (1984).

The aim of the study was to gain access to the participants’ perspective and to ascertain what were the particular issues that were important to them. The use of a questionnaire would have pre-decided what was important. By using in-depth, non-directive interviews, combined with a retrospective life history approach, the parents set the agenda and so were able to describe the realities of the parent/adult attitudes, relationships and feelings involved in this new way of family building. This was followed by a second much more structured interview to achieve comparability of data and full social and biographical data.

Using this approach based on stages of child development and changes of appropriate parenting responses, the research aimed to recruit IVF and DI families with children at the different development stages. This was done by using a sample drawn on the basis of the date of birth of the children. In the DI families the age range was 0 up to 10/12 years and in the IVF families up to 5/6 years. These age ranges were determined by the length of time the participating clinics/units had been operational. A comparison between biological parenting and the use of high technology (IVF) and mixed biological/social parenting with the use of low technology (DI) became possible.

Each of the three studies in this section contributes to our understanding of a personal world where the conception of children has been achieved not by the aeons-old method of sexual coitus but by medical intervention, either in a Petri dish or by the use of a syringe. The use of donor gametes, whether anonymous or known, adds the other dimension.

In all three the parents had opted for secrecy. There is evidence that parental satisfaction with DI is high, that parents have no regrets in spite of the strong moral disapproval of an earlier period or of their religious group (Snowden et al., 1983; McWhinnie, 1996a, 2000). The secrecy is central to these families’ functioning and their relationships with each other and with their wider family and friends. In all three studies it emerged that the secrecy is maintained or ‘managed’ by denial of recourse to DI. DI is never talked of even between the parents in private conversations. Talking to the researcher was the first time it had been discussed since before the birth of the child (McWhinnie, 1995). Baran and Pannor (1989) described DI as a ‘cover-up’ for the man’s infertility. They found that ‘Most sterile men... who utilise donor insemination... do not deal with the emotional and psychological effects of sterility.’ Such men are likely to be insistent that the child must never be told about their origins (Baran and Pannor, 1989). In McWhinnie’s study, the interviews with the fathers revealed unresolved feelings about infertility, leading in some
cases either to an over-concern and involvement of the father for, and with, the child or a distancing from taking on a full parenting role. An important aspect of whether secrecy is planned and is maintained is that to the outside world this is a fecund partnership with children. The woman has been seen to be pregnant and a child is born to a previously childless partnership, perhaps childless for many years. If attendance at a DI clinic has been kept a secret, as it is in many cases, when will it be possible or easy to explain the truth about the child’s origins? Experience shows that once a partnership has presented the child to their family and friends as a child of the partnership, they maintain the secret. It is hard to turn back.

But how easy or possible is it to maintain the secret in reality? In McWhinnie’s study, although all the parents were keeping DI a secret, three were considering telling the child later. There was disagreement about this in another family. The majority were managing their role as DI parents competently. For ~40%, however, there was a range of problems evident, some directly attributable to DI, in others it was a contributing factor. Whatever their level of competence as DI parents, the issues that all these families face and which the parents of the older children were beginning to experience or recognize through incidents in their daily lives relate to the consequences of 50% of the genetic and family history of the child being unknown to the parents. This raises issues about the health and development of the child and presents an immediate problem on being asked at hospital or GP’s surgery consultation. ‘Is there anything of this in the family?” The mothers report having to lie or give evasive answers but realize there could be life or death situations or serious medical conditions when they would have to tell the child. They also realize, however, they have no detail to give them. The other issue that constantly confronted parents was comments about differences in appearance, for instance, eye colour, height, aptitude, etc. ‘Who does he/she look like? Who does he/she get that from?’ Some parents could find answers; others evaded answering (McWhinnie, 1992, 1996b, 2000).

In general the majority of the families interviewed in Snowden’s and McWhinnie’s studies present themselves to the outside world as cohesive and ‘normal’. The denial of the recourse to DI makes it possible for them to mimic any other heterosexual partnership. The reality, however, is that the basic secret can be exposed by external events or comments which to the parents may seem trivial. McWhinnie’s study highlights these; shows how they arise in the daily lives of the families; the questions the child brings from school; the observations and comments from relatives and others. The dilemmas and evasions last a lifetime. The reported experiences of the DI adults show how these same issues are also part of their experience and the consequences of this for them. The experiences from families who tell their children about DI show how they deal openly with the same kind of questions and discussions brought to them by their children which those practising secrecy evade answering or convey misinformation.

The experience of families where parents tell their children about DI

Some parents have decided to tell their children about DI, frequently because they have seen how upset adopted children became when they learned unexpectedly from an outsider that they were adopted. There has also been a gradual change among medical practitioners towards being more open with their patients about the possibility of telling their children about their origins. Some even now advise it, eg, (Cooke, 1993; Neuberg, 1994) and Craft (Comment on BBC1 television current affairs programme ‘Words with Wark’, November 1998). There is no accurate estimate to date of how many actually follow this advice. The assumption has been that such a policy of non-secrecy will deal with any difficulties that may arise. However, the experience of those who have decided from the start to acknowledge openly their recourse to DI is that it solves some questions but it raises others. It does not solve the problem of how to deal with the questions that the children and others raise about the donor. Requests for details of health and family history again arise as a major cause for concern. The children themselves can raise very specific queries about whether talents or interests they have are similar to those of the donor. When there are siblings created from different donors, sibling rivalries and quarrels can become rivalries over the alleged attributes of their respective anonymous donor.

As the years have gone by the parents who have been open about DI remain certain that it was right to tell the children. ‘I couldn’t have lied to them.’ But it is ‘not an easy option’. And it is not an option that is dealt with in one episode of telling the children. It has to be dealt with for a lifetime and the need for explanations can arise at any time. As their children grow older the parents’ anxieties focus on ‘What will I say when as adolescents or adults they ask for specific details about the donor?’ They have no information and little is available to them even if they return to the DI clinic where the insemination was carried out.

So DI parents in the UK can be seen to be in a ‘no-win situation’. If they do not tell the child there is the risk of traumatic disclosure; if they do tell they have no information about the donor to answer their children’s questions. Their experience, and the kind of conversations between them and their children, has been used as the basis of a book discussing telling or not telling the child (McWhinnie, 1996b). Parents who decided on openness about DI have formed a support group in the UK called DC Network (Donor Conception Network, previously DI Network). They hold regular meetings which the children also attend, have a newsletter and play a recognized public role in the contemporary debate about change. Their activities are mirrored elsewhere in the world, eg. Infertility Network in Toronto, Resolve in USA, Donor Conception Support in Australia.

The life experiences of DI adults/donor offspring

Because of the extreme secrecy over the 60 years of this practice, it has not been possible to undertake any kind of systematic study of DI adults and their experiences. However, by scanning the findings from small studies available and the literature about personal biographies in newsletters and elsewhere, it is possible to gain access to the experience of approximately 80–90 DI adults. That number is continuously

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rising as more and more adults are willing and able to talk about their experiences. Through an international network of support groups and the Internet, a focus has become available whereby they can talk with other adults created in a similar way. For them this can mean that years of isolation can end. They find that there are others with similar experiences, anguish, frustrations and anger. This form of contact too can be established without involving parents or wider family, many of whom might view their attitudes as disloyal to those who brought them up. But donor offspring themselves also found that they could not talk about their feelings earlier because of a feeling of disloyalty to their parents and, of course, revealing the parents’ secret about their infertility.

From this search of published material, there appear to be three groups in relation to being told or learning about their origins:

- Those who learned about their DI origins following a family disagreement, divorce or from a step-parent.
- Those who were told on the initiative of their parents because of some other event in the family, e.g., a severe inherited illness of the social father, (telling the child was seen as relieving them of anxiety that they might inherit the same condition) or when their social father died.
- Those who asked because there was something in the family relationships that had puzzled them for years—some evasions or some unanswered questions or that they felt their father was very distant from them. ‘Perhaps my mother had had an affair?’ For some the question posed was, ‘Is it somehow my fault that I feel so different from him?’

No matter how they found out about their DI origins, the reported reaction was anger, resentment at the lies and deceit, loss of a sense of self and of their identity. ‘My story was destroyed. It was taken away. I felt I was in a vacuum. Who else knew?’ (man, aged 46). ‘I was not the person I thought I was’ (woman, aged 44). ‘I feel like there is a line drawn down the middle of me, and one side I know well, but where did the other side come from?’ (aged 53). ‘We trusted our parents to tell us the truth, but they had been told to deceive us’ (man, aged 54)

All wish they had been told much earlier. They want to have information about their donor, what he looked like, what he was like as a person, his education and interests and especially details about his health and family health record. Some want to meet him, at least once. It is a source of great frustration and anger that this will never be available to them. For some, the quest for information about their donor father pre-occupies them. They wish it solved so that they can get on with their lives. A recurring comment about their anger and frustration is that no one thought them important enough to keep records about their donor father and that the system was set up intentionally to deceive them and to make it impossible for them ever to know. Even their birth certificate is a lie. It says they are the child of the parents who brought them up. But the father on the certificate is not their ‘real’ father in the biological sense. So how can they find out who their biological father really is? And how many half-siblings are out there that they don’t know about as well as uncles or aunts? If they are from the Jackson clinic, i.e. one of 480 children mainly from the same geographical area, perhaps they live in the same village or even in the same street. If from a London clinic there could be hundreds of half-siblings somewhere in the UK and elsewhere. Once sperm samples arrive in the UK from an international commercial sperm bank in Copenhagen, as has recently been agreed, these children could have half-siblings in many different countries (O.Schou, personal communication, Cryos International Sperm Bank, Denmark regarding the international recruitment of donors and number of births per donor permitted in different countries). This is already a possibility in other countries where there are no regulations regarding such a commercial approach.

If they have children, they too want details about the donor, his health, interests, etc. As the adult daughter of a 44-year old DI adult said, ‘After all, he is my grandfather. What can I tell my own children about him?’ From this perspective the issue has many ramifications and involves a whole network of other people in relationships with the DI adult. It has consequences into the next generation and the one after that. Many ask why has it been ignored for so long?

These observations, drawn from several sources, have been confirmed in a recent publication of a study of 16 donor offspring aged between 20 and 55 in the UK, USA, Canada and Australia. The conclusion from this study was that it was withholding information about their conception which had the most important impact on these adults. Whatever their individual differences, what was common to this group was mistrust within the family; lack of genetic continuity; poor self-perception and frustration at being ‘thwarted in the search for their biological father’ (Turner and Coyle, 2000). The authors acknowledge the selectivity of their sample. Participants were recruited from support groups in different countries. It can be argued that only those needing to talk join support groups; further selection could be attributed to the fact that inclination and time was needed in order to be a participant. Nonetheless, the data and findings are valuable. They offer insights into the areas which could bring DI adults to seek therapeutic help. They also add to the slowly developing body of knowledge and awareness about how donor conception can be experienced by those who result from it. Since the majority of donor offspring have not been told, they are not able to contribute openly to any such knowledge base.

As individuals, donor offspring emerge as competent, intelligent, articulate and thoughtful about others and about their own predication. The words they use can express sadness and wistfulness, frustration and resentment, anger and puzzlement at the indifference of others. Whatever their individual experiences and the words they use to describe it, they all make clear that they consider they have been done a serious injustice and they wish the matter rectified. The following quotations illustrate this (Speaking for Ourselves, 2000): ‘I long to know who my biological father is, and to meet and speak with him at least once. I search for my half-siblings in other people’s faces. I want to know the missing part of my family history, but more than anything I need to know the other half of my ethnic background. Now that some of us are adults and, in fact, older adults, it is time for our voices to matter. We have a right to know our identity and to grow up
in truth’ (woman, aged 42). ‘They created me in the same way as they breed pigs. All I know, and am allowed to know about my father, is that he masturbated his ‘sample’ for a sum. Yes, you could say I’m angry.... DI adults must be allowed to speak, and must have rights and access to information on our genetic heritage’ (man, aged 33).

**Discussion**

This paper has reviewed how medical practice has developed the use of donated gametes and improved aspects of that in relation to screening of donors for serious medical conditions, while still adhering to the original concepts that were seen as essential to the practice, i.e., anonymity of donors, confidentiality and secrecy/respect for the privacy of the infertile adults. The evidence from outcome studies regarding the development of the children has shown them, on the whole, to be developing normally.

The social and family relationship outcome studies show the impact on family relationships where one of the parents is a social parent and there is secrecy and lack of information about the true biological parent. The impact on the parents is to deny this reality and its consequences. The issues involved in this form of family building have been presented: First, where the parents have not told their children about their origins; second, where the parents have told their children about their DI origins but have no information about the donor; and third, in the life histories of people who have experienced growing up in such families.

The incidents described in these three different situations frequently concern the kind of everyday situations, questions and queries that can arise in any family, in any discussion with peers at school, in biology lessons when, for example, Mendelian laws about the inheritance of eye colour are learned, with grandparents and other kin and with complete strangers meeting the family for the first time. They can comment on any obvious differences in physical characteristics between siblings, for instance, the assumption then arises that the children are adopted. Not knowing 50% of your biological origin and antecedents has social consequences and can cause those who experience it great emotional pain, made worse by their awareness that this was no accidental happening but set up intentionally to mask their parents’ infertility and is sanctioned by current legal provisions.

Faced with these comments and reactions, it can be argued that these are the views of a disturbed minority of donor offspring. In reality, however, they mirror exactly the reactions and comments of adult adoptees and other adults who, for whatever reason, have been denied access to accurate information about their origins. Also, more generally, family genealogy is a source of great interest and discovery for many people. Such people researching into their family’s origins are not considered neurotic or pathological, but legitimate and understandable and facilities are provided to facilitate the search in public libraries and elsewhere.

The accumulated evidence presented in this paper represents the perspective of ART children, whether as dependent children or as adults and parents themselves. Their perspective should be part of any debate about the use of donor gametes. On the basis of their perspective and the evidence available, it can be argued that they should not continue to be denied knowledge of their origins and antecedents.

**The public debate**

To debate this subject is not new and there is a considerable literature about it. It was debated in 1993 in the *Journal of Politics and the Life Sciences* under the title, ‘Secrecy and Openness in Donor Insemination’ (Daniels and Taylor, 1993). In 1997 the *Journal of Assisted Reproduction and Genetics* carried a series of papers under the title, ‘Controversies in Assisted Reproduction and Genetics: The Controversy surrounding privacy and disclosure among donor gamete recipients’ (Lopata, 1997). These two titles represent opposite ends of the debate. The openness versus secrecy papers represent those who argue from the perspective of the consequences of creating babies in this way, both for those who become parents as a result but primarily for the children thus created and for their subsequent adult life. The papers in this group use arguments based on what is known as important for good and stable interpersonal relationships, partnership and family functioning and immediate family and kinship. These function best long-term when based on openness, honesty and trust (Imber-Black, 1993). Secrets and deception do not fit well with this. The privacy versus disclosure group is mainly identified with clinical practice and the delivery of services to the infertile. The arguments here are based on concepts from medical ethics, confidentiality, respect for privacy, autonomy of patients, informed consent, beneficence, etc. These two divergent points of view or analysis have to be borne in mind when considering the arguments presented in the following pages.

In practice, four schools of thought have emerged so far in this debate:

First, preserve the status quo until 20 years of prospective studies can reveal the truth about the effect of telling or not telling the children. Meantime, the privacy of the patients/parents must be maintained and any disclosure moderated by their needs and rights and those of the donors. Personal self-esteem and feelings of certainty about identity come from the emotional environment created by being a wanted child. The emphasis on an interest in genealogy and genetic origins is a social construct and should be discouraged. Feminists see it as an example of male dominance and male concern about the continuation of their genes. Arguments, philosophical and otherwise, have been used to justify this approach, or aspects of it (Lockwood, 1997; Shenfield, 1997).

Within the status quo school of thought there are also those who argue on pragmatic grounds: to change from anonymity to known donors would adversely affect the supply of donors and so affect provisions for the infertile. When possible changes to anonymity were reported in the press in 1999 the question of the supply of donors loomed large. Under the headline, ‘This foolish threat to the gift of life’ Winston commented: ’...a change in the law could damage the chances of many people to have a family, and cause more distress than
we need information about their biological parent or parents and that it is not just about helping infertile partnerships to achieve their much-wanted baby. It is also about creating children who will have needs and rights separate from the wishes of their parents. However, it is possible that no donors would come forward. The use of ICSI has replaced DI for some partnerships, but not all, and it does not help where the man is a carrier of a genetic disabling condition. A two-pronged argument has been used here to defend the continued use of anonymity; first, some distressed, infertile partnerships would inevitably be denied the opportunity of having a baby and, second, from the offspring perspective it is better to exist than not to exist. This latter argument is one defended in philosophical terms. However, it negates all arguments that the welfare of the child has to be considered since the concept of welfare is at variance with the concept of mere existence.

Such arguments apart, is it ethical to continue the practice of anonymous donors when it can cause harm and distress to children and adults for a lifetime? An adult DI offspring has opportunity to collect information about the effect of both models is currently used in most donor oocyte programmes in the USA. It was initially introduced because of the difficulty of attracting oocyte donors. The arguments used are that there is a proportion of contemporary donors who already have understood of the future child’s needs. Also, studies of donor motivation from the 1980s onwards, reviewed and commented on by Daniels and co-workers, confirm this (Daniels et al., 1996; Daniels, 1998). Practice from other countries, Sweden, New Zealand and elsewhere, also shows change is possible. It does require, however, that the realities are fully explored with potential donors, i.e. that the children need information about their biological parent or parents and that it is not just about helping infertile partnerships to achieve their much-wanted baby. It is also about creating children who will have needs and rights separate from the wishes of their parents. However, it is possible that no donors would come forward. The use of ICSI has replaced DI for some partnerships, but not all, and it does not help where the man is a carrier of a genetic disabling condition. A two-pronged argument has been used here to defend the continued use of anonymity; first, some distressed, infertile partnerships would inevitably be denied the opportunity of having a baby and, second, from the offspring perspective it is better to exist than not to exist. This latter argument is one defended in philosophical terms. However, it negates all arguments that the welfare of the child has to be considered since the concept of welfare is at variance with the concept of mere existence.

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and scientists as decision-makers, the ‘double-track’ policy for example, most donors opt for anonymity, or only a few do, the degree of choice available to the recipients will diminish.

The fourth and final point of view is that which argues from the evidence presented in this paper. If this is then combined with a ‘rights of the child’ approach, a philosophical argument would be that we are acquiescing in ignoring the rights and needs of dependent children and that they are being used instrumentally to fulfil the needs and wishes of adults. Certainly, not giving, or having available to them, any information about their donor father is flying in the face of the spirit of Articles 7 and 8 of The United Nations Convention on the Rights of the Child (1989). The relevant phrase in Article 7 is ‘as far as possible the right to know...his or her parents’ and in Article 8, ‘the rights of the child to preserve his or her identity’.

It must also be asked whether it is good medical practice to set up a situation where a future patient, that is, a DI child or adult will not have access to half their genetic or family health history and that this is a state of affairs which will last throughout their lives and affect the genetic history of their children (Turnpenny et al., 1993; McWhinnie, 1998a,b).

More generally, as genetic knowledge advances, it seems possible that a full genetic family history will be asked for as well as a general health record for insurance purposes. There already has been discussion about this pointing to the possibility that employment prospects could thus be affected. In the USA a legal prohibition of this has been established. However, in the UK, permission has already been given for insurance policies to be weighted where there is a tested proof of, for example, Huntingdon’s Disease (The Times, 13 October 2000).

There is an urgent need for a wide-ranging debate about all of these concerns and about whether and how to change both medical practice and the law. Detailed discussion of how any changes will or may be translated into practice and into legislation is beyond the remit of this paper. However, in general terms, there are at least three main practical scenarios being presented:

First, arguments that support the status quo. The premise for this comes from the contemporary shortage of donors and the pressures from infertility support groups for more generally available services for all under the National Health Service. Clinicians are satisfied that they have met reasonable demands about genetic histories by the careful screening of donors which is now done. Any other changes will come gradually with changing public opinion and greater openness about infertility. In the meantime, non-identifying information about donors should be seen as adequate.

Second, the double-track policy could be instituted generally without recourse to major changes in the law or regulations.

Third, the provisions and services available in this area should take on board the perspective of the ART child, both as dependent child and as autonomous adult. This would require a shift in priorities and conceptualisation for donors, potential parents, clinicians and scientists. The need for this and the arguments for it have been presented in this paper. This would involve only recruiting donors who were willing to give identifying information about themselves to be registered and stored on a central register. Children could have access to such information as of right when aged 18 or with the parents’ and/or the donor’s consent if under that age. Whether such a register should be kept by an authority such as the HFEA or be part of the central register of all births would need to be debated.

Such a movement towards much greater openness about origins and antecedents is part of a growing perception elsewhere in Europe, in Australia and in Canada that donor offspring’s rights and needs have to be given recognition and not denied or ignored. For those offspring conceived before the 1990 legislation in UK, it is also being suggested that a voluntary register be established where past donors who understand the offspring’s point of view and also any offspring wanting information and/or contact could register. This type of voluntary register has already worked well in adoption. It opens doors to tracing where this is needed or wanted. It could be thought advisable to provide a counselling service as part of the provisions for such a register.

Conclusions

The proposals advocated in the foregoing discussion based on the perspective of the children being created by ART, and that their welfare and well-being should be of paramount importance in decision-making, conform in principle to our society’s views and assumptions, which are that all its transactions operate on the basis of trust and on the assumption of honesty. Contemporary society values openness, transparency in decision-making and access to relevant records. We have accepted the United Nations Declaration of Human Rights and signed up to the UN Convention on the Rights of the Child (1989) with its emphasis on giving children a voice and that their voice should be heard. Donor offspring do not consider their voice has been heard, or their perspective given any consideration, or that they have been treated fairly. While it is legitimate to argue that individuals have a right to privacy about personal matters, such as infertility, in the long-term it is the offspring who have to carry the burden of their parents’ infertility and their secrecy about it and of the clinicians’ earlier interventions and decisions about the use of anonymous donor gametes. The offspring have also to deal with feelings of loyalty to their parents and, particularly if they go public, revealing their parents’ secret infertility.

Medical science has social and human consequences. The results of ART interventions are a striking example of this. This paper advocates a re-think of certain long-held views about medical practice when advocating the use of donor gametes. What may have seemed appropriate when responding originally to the sadness and distress of an infertile partnership needs to be reconsidered in the light of what is now known from follow-up studies and the increased awareness at all levels of the vulnerability of children when adults around them pursue their own agenda without considering the impact on them. This fits well with the present ART scenario where the focus is on meeting the needs and wishes of infertile partnerships but without an equal concentration on the lifetime
consequences for the children who result from these medical interventions. Removing anonymity from the donor background of these children would make a beginning to a realignment of all ART provisions and services to take on board the question, ‘How would this affect the children?’ This takes the argument much wider than just being about donor origins into considering always ‘Will these new procedures affect the quality of the life of any potential children in their childhood and adolescence and as adults?’

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References


1995 – Children (Scotland) Act


Families following assisted conception: what do we tell our child? Department of Social Work, University of Dundee.


