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Donor gametes: anonymous or identified?

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The practice of gamete donation has, until recently, been shrouded in secrecy. The stigma associated with infertility and, in particular, donor insemination has been the main factor contributing to this secrecy. Over the last 20 years, this secrecy and the anonymity of the gamete donors has been challenged. In the first instance, the challenge came from governments in some countries legislating to abolish donor anonymity. Counsellors, social workers and psychologists advocating for the interests and needs of children and their families, as well as parents who did not wish to keep gamete donation secret from their children, were also instrumental in the change of policies and practice. Those offspring who know that they were conceived as a result of gamete donation are also calling for an end to the secrecy. This chapter reviews the changes that have occurred and which are still occurring, and reviews the research associated with these changes.

Key words: donor gametes; anonymous; identifiable; secrecy.

> 'My sense of gratitude to the donors is profound. I don't think about the donors much, but when I do, I am moved to tears because I wouldn't have these children if it weren't for the gift that the donors gave me. To never acknowledge that seems, to me, so ungrateful at some level.' Susan
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> 'To the donors out there, I would like to say thank you. I owe my life to one of you. I wish I could know more about you. I wish you could be proud of my achievements and me. You gave me the opportunity of life and I have tried to live it to the full in return.' An anonymous British adult offspring[1]

Women and men who provide their gametes so that others may be able to have the family they desire are very significant people. They provide the gift of life to individuals and the gift of family to those who would otherwise not be able to be a family. Due to

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the history of semen donation, and particularly the secrecy that enveloped it, there has been little opportunity for parents and offspring to express their appreciation or to value the special contribution that has been made. Oocyte donation (OD), beginning as it did some 100 years after the first reported case of donor insemination (DI)[2] and at a time when questions were being raised and recommendations made concerning the appropriateness of semen donors remaining anonymous[3], has experienced a somewhat different development. While secrecy and anonymity still tend to characterize OD in most countries, the changes that have occurred and which are still occurring owe a great deal to the changes that began in the attitudes and polices concerning DI some 20 years ago. This issue will be explored in more detail later. What is clear is that parents who have used OD and offspring who have been born as a result, and who know this, express the same type of gratitude and appreciation as those for whom DI has played such a critical part.

This chapter will begin with an explanation of changes that have occurred and which are still occurring in the practice of gamete donation. The underlying culture of gamete donation within assisted reproductive technology (ART) will be discussed in relation to doctors, donors, parents and offspring.

GAMETE DONATION: A CHANGING SCENE

The indigenous people of New Zealand (Maori) have a saying that people walk into the future backwards. This means that people should always be aware of their history and particularly the people who have contributed to their being in the position in which they now find themselves. This awareness of history and the early beginnings of DI are important in helping to set the backdrop against which recent developments must be seen.

The first reported account of the use of DI was in 1909:

> 'Addison Hard was a student of Dr. William Pancoast who, while teaching a class at Jefferson Medical College in 1884, discussed a situation in which the male in a couple was discovered to be azoospermic and the female was found to be perfectly capable of bearing children. The students in the class suggested that a "hired man" be called in to solve the problem. Dr. Pancoast then took a semen sample from the "best looking member of the class" and inseminated the woman without her consent and while she was anaesthetized. The doctor later reluctantly told the husband and was relieved to find he approved of the doctor's actions but suggested that his wife not be told. In 1909 Addison Hard went to New York "to shake the hand of the young man" who had resulted from this procedure. It is speculated that this latter action indicates that Addison Hard was perhaps the student from which the semen sample was collected in 1884, and consequently the genetic father of the worlds' first DI offspring.'[2]

Dewar[4] described DI as 'shrouded in secrecy and silence'. In the above example, this secrecy is operating at three levels: (a) the patient couple not being told by the doctor before treatment and therefore not being offered any choice; (b) the husband keeping the use of DI secret from his wife; and (c) the offspring never being told. It is now most unlikely that secrecy at levels (a) and (b) would occur. At level (c), however, practice is very mixed and debates over the appropriateness of sharing knowledge of the use of DI with offspring are very contentious.[5–8] Parents deciding to keep the use of gamete donation secret means that the identity/anonymity of the person providing the gametes does not become an overt issue for them or their child/ren.

The practice of secrecy in DI has to be seen against the social attitudes of the late 1880s and early to mid 1900s. There was moral uneasiness about couples who utilized DI, as DI was seen as being akin to adultery.[9] The legal uncertainties and implications for offspring, donors and recipients were also reasons for keeping the practice of DI secret.[10]

It was the move from private ordering to public policy[11,12] that signalled the beginning of a shift in the way in which DI was viewed. The birth of Louise Brown in 1978 [the first child born as a result of in-vitro fertilization (IVF)] led many countries in the Western world to establish committees/commissions to report and advise on how developments in ART might be managed. These reviews[13] invariably included DI and as a result there was a focus on this means of responding to infertility. DI had moved in to the public arena and with it a consideration of the secrecy surrounding DI and the anonymity of the men providing their semen for others. Most jurisdictions, however, continued with what was then current practice and professional policy, although concern for the welfare of children born as a result of ART was highlighted in most of the reports.

At the same time as this external review was occurring, social workers and counsellors were being recruited to work in the area of ART, and this was to provide an added impetus to the review of existing policy and practice. McMichael[14], for example, reported that, in Australia, there was one social worker involved in ART in mid 1977, but there were at least six by the end of 1978. Social workers and, to a lesser extent, counsellors and psychologists brought to this area the knowledge gained from the field of adoption and working with children and families. However, it was highlighted by Brandon and Warner[15] that adoption fell within the social services and ART fell within the health services, which meant that knowledge transfer did not occur easily between the two.

Social workers and counsellors draw on a psychosocial model for their work, in contrast to a medical or biological model used by health professionals. They are also likely to be concerned with the implications and issues arising from the treatments being provided. In the case of gamete donation, this means considering issues arising for the families that are built with the assistance of gamete donation, as well as the issues arising for patients at the time of treatment.[1] One of the future issues for parents is the management of information sharing and gamete donation. The pressure on parents in keeping a secret about the use of gamete donation is another factor of significance.[16,17]

Some parents began to share the family building history[1] with their offspring, and as a result, a number of the offspring wanted to access information about ‘their’ semen provider. Susan Rubin[18,19] in the USA was one of the first offspring to raise her concerns in public. She has had a growing number of followers over the years. Again, social workers and psychologists with their knowledge of the importance of psycho-social identity[20–22] became active in advocating for access to information.[8,16]

In 1984, the Swedish Government became the first jurisdiction in the world to legislatively provide for offspring conceived by DI to have access to the identity of the donor when they reached an appropriate age.[23] It was concern for the welfare of the child and their right to know the identity of the donor that led to this change. Since that time, Austria, Switzerland, UK, Norway, The Netherlands, New Zealand and the states of Western Australia and Victoria in Australia have enacted legislation abolishing anonymity for gamete donors, and making provision for offspring to ‘discover’ the identity of ‘their’ donor and to make contact, should they wish.

Legislation will not, of course, change long-established attitudes, but what it does do is signal the beliefs and values of the governments concerned, and highlights that the welfare of children is seen to be a major and, in some cases, paramount concern. We turn now to the changes in attitudes or 'culture' that are beginning to impact strongly on the provision of gamete donation services. Change of the type discussed in this and the next section is never easy and is frequently associated with considerable conflict. The fact that there has been such dramatic change in the space of some 20 years is, in itself, quite remarkable. Managing and responding to that change has, however, been extremely demanding.

GAMETE DONATION: A CHANGING CULTURE

The culture of gamete donation can perhaps be best described as being dominated by the notion of secrecy. So much of what has been practiced, and in many respects continues to be practiced, evolves from this culture. This culture has been so dominant as to lead many to traditionally view secrecy as a 'natural' component of gamete donation. However, this is changing:

> 'I think we were just appalled when we discovered the cloak of secrecy that surrounds that whole thing and we just recognized that this doesn't work when you are raising children. You can't have this big secret.' Greg[1]

For Greg and his wife Susan, keeping knowledge of the use of DI secret from their children was anything but natural; in fact, it was very unnatural. Keeping something secret involves two very powerful dynamics. Firstly, events/issues/things that a person may feel uncomfortable about or, put more strongly, may feel ashamed of are likely to be candidates for secret keeping. The stigma associated with infertility[21,24,25] may lead some people to want to hide this from others who are significant in their networks. It is important, however, to understand the nature of stigma. While others may act and speak in ways that convey stigma, it is only when an infertile person or couple accepts the stigmatizing and begins to behave in a stigmatized manner that stigma comes in to full effect. An infertile person who refuses to accept that they are stigmatized is limiting the impact of stigma. Stigmatizing behaviour and words can be conveyed to someone who may be in a vulnerable position, but it also needs to be recognized that a vulnerable person may believe or expect stigmatizing behavior when none is present.

With the extensive media coverage of new developments in ART, often accompanied by personal stories of successful treatment, the public have become much more aware of infertility. This has almost certainly had an impact on levels of understanding and acceptance. Issues that are not understood are more likely to be subject to uncertainty and stigma.

One of the factors that has contributed to the stigma associated with infertility has been the confusion for many between sexuality and reproduction. It was not uncommon for people to assume that if someone was unable to 'have' children, this was due to sexual incompetence. In this respect, it needs to be recognized that in OD, a woman is giving her eggs to another woman, whereas in DI, a women will receive semen from, most likely, an unknown male. The joining of sperm and oocyte is usually associated with sexual intercourse. For a man who is azoospermic or oligospermic, there is of course no joining of sperm and oocyte.

The second powerful dynamic associated with secrecy is power. Secrecy means that some people have information that others do not. If parents are secretive with their offspring about the use of gamete donation, it means that the parents have made their decision without any involvement of the offspring. Parents have decided for their children, and this means that they have assumed decision-making power. This has the effect of offspring feeling excluded and powerless:

> '[regarding donor anonymity] … clinics are powerful, and the doctors are powerful, and the industry's powerful, and the adults who want to conceive children and can't are powerful. They're a damn sight more powerful than the children who haven't been conceived yet.' Johanna[17]

> 'The decision (destroying of donor records) was made for me before I was even conceived. It has made me incredibly angry and frustrated that all the power had been taken away from me.'[26]

The notions of stigma and power as central components of secrecy are very significant, and impact on the culture of gamete donation and therefore on all of the parties who are involved. These notions are now explored in relation to these different parties involved in gamete donation.

Doctors

It was doctors who began, and have largely maintained until recently, the culture of secrecy. By implication, this meant that they never challenged the stigma. Furthermore, gamete donation does have the potential to enable the infertile to appear to be 'normal' if no one knows about their use of donated gametes. Gamete donation practiced in secret does have the potential for recipients to be 'normalized' instead of 'marginalized', and therefore avoid the possibility of stigma. This may be seen as a desirable goal by some doctors.

Bateman Novaes[27] wrote of the construction of DI as medical treatment saying, 'Increase in technical control over our reproductive processes, and assisted conception in particular, implies entry into a new type of reproductive relationship, loosely defined as therapeutic, in which some reproductive decisions are in fact being transferred to physicians'. Doctors have become the gatekeepers in relation to third party reproduction. They may make decisions over who will have access to their services, which gametes are used for which patients, and what information will be shared with the different parties. Many of the decisions they make will include significant moral and social factors. The debates concerning access by lesbians and single women to DI services is an example of this. The anonymity of gamete donors is yet another issue. Some have argued[28] that increased openness should not be supported because there is no evidence that either anonymity or secrecy causes harm. Such an argument calls for scientific evidence to support the calls for change in relation to secrecy; essentially a moral issue. It also needs to be recognized that no scientific evidence was presented to support the establishment of secrecy when DI began. The doctors providing the service adopted this policy believing it to be in the best interests of all concerned. They were one of the 'all concerned' parties, as there was anxiety that the negative views concerning DI would also be applied to those who carried out this treatment. Haimes[29] asked the question 'Do clinicians benefit from gamete donation anonymity?'. In her paper, she commented on the absence of a systematic consideration of clinicians' views. She suggested that, based on the history of DI, clinicians have supported keeping such practices secret, not just for the protection of donor's recipients and resultant children, but also to protect their own position from the detailed scrutiny of others who have expressed doubts about the practice.

Another area in which policy and practice has been heavily influenced by doctors is payment/compensation for oocytes. Craft and Thornhill[30] are some of the most recent doctors to argue for increasing payment levels in an attempt to attract prospective donors.

While there are still doctors[31,32] who argue that anonymity of donors is necessary to protect all parties and therefore should not be removed, there is a movement towards openness, which is often forced on doctors by government legislation. In 2004, the American Society for Reproductive Medicine[33], the professional body representing staff working in ART, issued a statement supporting disclosure from parents to offspring about the use of donor gametes in their conception. It remains to be seen what impact this policy, prepared by their ethics committee, will have on practice.

Advice to patients not to talk about the use of gamete donation also reflected the position of power held:

> 'The doctor actually said, and he was blatant about it, that we shouldn't ever tell anybody. He said that it would be devastating to tell the child, so we were torn. But the child is something precious and it's the way of handling this precious gift of life that is really wrong. I was ostracized. It was a disgrace, these feelings that I suffered all on my own. No one should have to do this'. Maria[1]

Donors

The culture of secrecy also extended to the anonymity of donors. Finegold said 'It is generally agreed that the donor's identity should be veiled in absolute obscurity'[34], and in 1981, Glezerman wrote that donor semen should be regarded as 'material from an anonymous testis, the donor actually being a non-person'.[35] 'The myth of blood and flesh has to be uprooted and a state of consciousness has to be achieved in which the donor, from the psychological point of view, does not exist.'[35]

Johnston, writing of Australia in the early 1980s, said:

> '…an occasional person will not be considered if he seems unusually interested in the progeny that may be produced from his semen. The absolute anonymity of donor is considered essential in this country and all donors must be prepared to donate semen without any follow up on its use or results.'[36]

The semen donors and later the oocyte donors were seen as a means to an end. Their task was to provide gametes for others. They not only collaborated with the health professionals providing the treatment, but also collaborated in the secrecy as they agreed to remain anonymous and not to ask questions or show any interest in the outcomes of their donation. It has been suggested[37,38] that the payment made to donors in many countries symbolizes this view of donors as a means to an end. The donors, in receiving payment for a 'service' they provided, were likely to see this as the end of the contract/agreement.[39] Payment brought obscurity. In the new and emerging culture of openness and information sharing, there may well be future contact with the offspring, and therefore closure does not come when gametes are exchanged for money.

The language that is used for those providing gametes needs to be noted. Traditionally, the word 'donor' has been used. A donor donates; therefore, if payment is being made, this word is not appropriate. In addition, the word 'donor' has a social value that is not insignificant. Someone who donates, whatever the donation, is usually seen in positive terms because they are acting in an altruistic manner; they are giving.[40] The desire to help and assist is cited frequently as a motive for donating gametes.[41]

The word 'donor' is inappropriate when payment is made. Annas[42] suggested that the word 'vendor' should be used and the present author has suggested the word 'provider'.[43] The word 'donor' is used in this chapter as it is still the term used most commonly in the literature.

Payment is likely to be an incentive for younger prospective gamete donors, whereas for older men and women, especially those who have their own families, money is not an important consideration or a consideration at all.[41] This pattern seems to repeat itself in relation to the wish/desire to remain anonymous. Studies of younger donors show anxiety about and resistance to the possibility of contact with offspring in the future, with many saying that they would not donate if their anonymity was not guaranteed.[44] On the other hand, in countries such as Sweden, New Zealand and Australia, different types of donors are coming forward because of legislative changes or changes in the culture of secrecy. These donors tend to be older, in ongoing partnerships and have children.[41]

There has been widespread concern[45–47] that with legislative changes abolishing donor anonymity, there would be a decline in the number of donors being prepared to come forward. Some of the evidence used to support this argument came from studies of current donors. It is important to note, however, that almost all of those donors were recruited under a system that offered either payment and/or anonymity. It is almost certain that the system and culture they were recruited under will influence their attitude to proposed or actual changes.

The emerging culture of openness and information sharing, based as it is on a lessening of stigma, will require the recruitment of different types of donors. The new donors are more likely to be 'real donors' in the sense that their actions are being taken to assist others, and where altruism is the major motivator. Their age and family status are also likely to be different. This was reflected in a study of semen donors in two clinics in the UK. The younger single men in one clinic were concerned about anonymity and payment in a way that the older men who were in ongoing partnerships and had children in the second clinic were not.[48]

In a follow-up study of some of the men involved in the second clinic, it was found that 56% held the same views concerning the provision of identifying information to offspring as they did at the time of recruitment. Twenty-five percent had changed their views and were more now open to information sharing, while 12% who had previously been unsure now wished to be anonymous.[49]

The ways in which views may change over time are reflected in a recent conversation with a man who donated semen some 20 years ago. He reported that at the time of his donation, his primary motivation was the money he would receive. He was assured of anonymity and was very happy that this was the practice. Twenty years on, however, and with two children of his own, he sees his donation in a different way. He says that having his own children has made him aware of the child's perspective and the possible need for information. He has made several attempts to advise the clinic at which he donated and other authorities of his willingness to provide non-identifying information should this be requested. He does not rule out the possibility of meeting any offspring in the future.

An increasing number of donors, recruited under the anonymous system, are now coming forward to register their names on the few voluntary registers that have been established in some jurisdictions. By doing so, they are indicating that they are willing to supply information, and have possible contact, should an offspring wish this. They clearly recognize the deficits or potential deficits for offspring whom they had a part in creating and who wish to access information. Voluntary registers have been established in Western Australia and Victoria in Australia, in the UK and in New Zealand. The New Zealand system is unique in that it is managed by the Births, Deaths and Marriages Section of the New Zealand Government. It is, therefore, a part of the central government system. The two states in Australia have given the task of managing their registers to government-appointed councils, and a pilot project has been established in the UK by a non-government organization. The project is funded by the UK Government.

While the voluntary registers have an important part to play, they are dependent on donors and offspring knowing of their existence and registering. In New Zealand, an increasing number of young people who have been told of their DI conception are approaching the clinic/s at which their parents were treated in search of information. Most clinics are trying to trace donors, where there are records, and then approaching them with a request for information. Many of these donors would have been young students at the time of donating, but now have their own families. Anecdotal reports suggest that many of the donors contacted are willing to supply the requested information, and some are considering meeting the offspring.

The establishment of voluntary registers has occurred to provide a ‘safe’ means by which donors and offspring may share information, or potentially get to meet each other. This development is designed to respond to those who were involved in gamete donation before the advent of legislation that required donors to be willing to be identified to offspring, should they wish this, in the future. Those jurisdictions which have enacted legislation abolishing donor anonymity are part of the new culture; they have moved to deal with the stigma, secrecy and power that were so much a part of previous policy and practice. The effectiveness of voluntary registers remains to be seen, as their establishment has been recent.

In September 2000, Wendy and Ryan Kramer established the Donor Sibling Registry in the USA. This registry was born out of a belief that ‘donor offspring would have the same curiously as Ryan about his genetic origins. Yet also knowing that sadly no public outlet exists for mutual consent contact between people born from anonymous sperm donation, we started this site as the logical next step to making these connections’.[50]

On 21 April 2006, 8345 members were registered and matches between more than 2114 half-siblings (and/or donors) had been facilitated. This development highlights several factors: (a) that for those who know of the nature of their conception, many have an interest in obtaining more information; (b) that for many offspring, it is important to have contact with others with whom they share a genetic connection; (c) given the difficulty in finding ‘their’ anonymous donor, offspring are turning to half-siblings; and (d) whereas many parents were advised not to tell and donors were usually given an assurance of anonymity, this did not necessarily impact on parents’ telling or, as a result, offspring seeking information about their half-siblings.

Registers, whether formal or voluntary, and whether focused on the donors or on the half-siblings, are a reflection of the changing culture of gamete donation.

Parents

The majority of studies that have examined parents' views about sharing the DI family building history with their children show that most parents have not or do not intend to tell their offspring.[51–53] In one particular study[54] covering four European countries (UK, The Netherlands, Italy and Spain), families who had children via IVF, DI, adoption and natural conception were studied. Not one of the 111 DI families had told their 4–8 year olds and 75% said that they had no plans to do so. Murray[55] suggested that:

> 'The high level of non-disclosure among these families suggests that DI is still not seen as an entirely acceptable route to parenthood in the four countries studied.'[55]

It needs to be noted, however, that most of these parents received their treatment when the culture of secrecy was very strong. In this connection, the results of a study of parental attitudes and behaviour in Sweden is informative.[56] The authors found that 52% of parents had either told the children (11%) or intended to tell them. Many of the children were still quite young at the time of the study. Gottlieb et al highlighted that compliance with the intention of the 1985 legislation can be regarded as low, although the number of parents willing to inform their child is high when viewed from an international perspective. A New Zealand study[57] of 181 parents who had created their families through DI showed that 30% of the parents had already told their children about their DI origins, and of those who had not told, 77% intended to do so. For approximately the last 12 years, New Zealand professionals have been actively encouraging parents to share the family building history with their children.[58] In a study by Golombok et al[59], families in the UK created via IVF, DI, adoption and natural conception were compared. The families who had used DI had been recruited from fertility clinics throughout the country. At the time of the study, the children were aged 4–8 years and none had been told of their DI conception. This can be compared with a recent UK study[60] which showed that, in families with children aged 4–8 years, 39% of parents had or intended to tell the child of their DI conception while 61% did not. All respondents were from the same clinic and that clinic encouraged openness.

DI is being used increasingly by lesbian couples and single women. Brewaeys et al[61] found that virtually all lesbian parents disclose the use of DI to their offspring. The absence of a male parent in the family is likely to be the main reason for the disclosure.

As Andrea said:

> 'It's easier in some ways for us because there is no man here. We can't not tell; there's never been a question about it.'[1]

It could also be that lesbian parents are likely to have experienced stigma as lesbians and, therefore, any stigma associated with the use of DI is a secondary and less important factor.

Over the last 12 years, donor conception support groups for parents (and often including offspring and donors) have started in several countries. They provide a forum for parents who wish to discuss their use of gamete donation with other parents. Such groups provide support, education and advocacy. In relation to the advocacy function, all of the groups that the author is aware of have been lobbying for a more open system that includes the abolition of donor anonymity and the right of their offspring to gain access to ‘their’ donor should they wish. These groups have held conferences, run seminars and publish regular newsletters for their members. The UK organization, ‘Donor Conception Network’, has recently received funding and produced booklets designed for parents who want to talk with their children about their family building history.[62]

The question has to be asked why parents would not be open with their children. Most, if not all, parents want their children to grow up with the values of honesty and truth, and children will learn these values firstly, and most importantly, from their parents. In a study[55] of parents who had used either DI or OD, questions were asked regarding whether children were to be told, and the reasons for parents’ decision were sought. For those who were not going to share information, 49% of DI parents and 69% of OD parents said that their decision was based on a desire to protect their child. A desire to protect the father was also reported, as was a concern about the time and methods of disclosure. Donor conception parents, in contrast to adoptive parents, were often conscious of the difficulty of providing an explanation due to the absence of genetic information about the donor. For 85% of DI parents and 69% of OD parents, there was the belief that there was no need for the child to know.

Any moves to encourage parents to share their family building history with their offspring must take account of these concerns, and should ideally be seen as part of appropriate preparation for this type of family building.[63]

Another important piece of recent research that may impact on parents and their decision making is that reported by Lycett et al[60], in which 46 families with a child conceived via DI and aged between 4 and 8 years were interviewed. Some of the parents had disclosed and some had not. The study found that:

> ‘…the differences that were identified between the two groups of families indicated fewer difficulties among the disclosers than the non-disclosers. Mothers who were inclined toward disclosure reported less frequent, and less severe, arguments with their children. They also considered their children to show a lower level of conduct problems, and to be less of a strain. In addition, disclosing couples viewed themselves as more competent as parents than did their non-disclosing counterparts… With respect to fathers, there were no differences in the present investigation between disclosing and non-disclosing fathers regarding their relationship with their child or their reports of child adjustment.’

This study clearly revealed that keeping secrets regarding DI impacts on family relationships, and this can almost certainly be extended to OD. For parents wanting to build families that are healthy and where family wellbeing is a primary consideration, these results provide an important message about the impact or potential impact of secrecy.

Confidence is required in order to resist any potential stigma and view gamete donation family building in a positive manner. For the last few years, Dr. Petra Thorn and the present author have been offering seminars for those considering the use of DI or those who have just started treatment.[63] The weekend seminars are run using an educational format with information being provided on the medical and legal psychosocial aspects of DI family building. There is extensive sharing of experiences and thoughts between the couples who attend, and they meet and talk with parents who have children conceived as a result of DI. The children usually attend as well. In recent research (Daniels, Thorn and Westbrooke, in press), participants were asked to score their levels of confidence regarding the use of DI at three different times: before the seminar, immediately after the seminar and at follow-up 12–30 months later. In summary, the results show that the confidence levels of participants increased dramatically as a result of attending the seminar and this was maintained at follow-up. Whereas 42% indicated that they would tell or probably tell the offspring, this figure increased to 90% after the seminar.

Based on this research, it is the author's view that the vulnerability which frequently results from the discovery of infertility needs to be addressed as a first step in future family building. This means working to restore and build confidence so that the decision to use gamete donation is viewed as a positive move rather than a reactive one. One of the key elements in these seminars seems to be the opportunity to meet and gain support from others who are in the same situation. The isolation that was previously experienced is eliminated. Meeting parents and their children is also reported as being critical in viewing this type of family building as acceptable and positive. Many of the fears and anxieties concerning the future are removed. It is important to note that while professionals (doctors, lawyers and two social workers) provide input, the main focus is on the social workers facilitating the self-exploration and learning of the participants. This research points the way to assisting parents to parent in an open and positive manner.

While there is a need for preparatory work for would-be parents, as there was with these seminars in Germany, there is also a need for assistance with psychosocial issues that arise during treatment and after treatment, i.e. when the family is growing or if no children have resulted from the treatment. This is not to suggest that such families will experience difficulties, but rather that issues will arise from this different (not better or worse) type of family building and support needs to be available.

Offspring

Arising from the concern expressed by government committees and commissions regarding the welfare of children born as a result of ART, a number of psychologists and social scientists began to study children's development. This was not without its difficulties given the secrecy that surrounded ART treatment.

The studies undertaken by Golombok et al over a number of years have made a major contribution to knowledge and understanding in this area. The results of these studies point to a picture of children who are developing in ways that are no different from other children.[64] Golombok et al also studied patterns of parental interaction with their children, and by comparing families who had used IVF, DI, adoption and natural conception were able to conclude that:

> 'With regard to family functioning, the findings demonstrated that families with a child conceived by assisted reproduction (IVF and DI) obtained significantly higher scores on each of the overall ratings of quality of parenting…'[64]

In a Finnish study[65], it was found that OD and IVF children aged 6 months to 4 years were developing normally. Thirty-eight percent of OD parents and 60% of IVF parents intended to tell the child about the nature of their conception. There have been very few studies of adults who were conceived as a result of gamete donation. What information is available comes from a single source, namely those people for whom gamete donation conception is not a secret. It has, therefore, not been possible to compare adults who know with those who do not know. A study reported in

2000[66] showed that some offspring who had discovered or been told of their DI conception when adults felt some hostility and mistrust in relation to their parents. This reinforces a great deal of anecdotal evidence that has been accumulating from adult offspring who have spoken or written about their experiences. This is not to suggest that major problems are being experienced by this group because of the DI conception, but rather that finding out in adulthood raises issues that do not seem to be present when children grow up with this knowledge.

In a recent follow-up study (Daniels, Grace and Gillett, work in progress) of parents who had used DI, 18% of the parents wanted to tell their offspring aged 15–20 years. They reported feeling pressured by keeping the use of DI secret. While expressing concern about how they would share the information and what impact it might have, they were convinced, for a variety of reasons, that their offspring had a right to know. The parents also had a need to tell. Pettle[67] and Daniels and Meadows[26] recently wrote about the issues to be considered in sharing information with adult offspring. This is an emerging area of practice, influenced no doubt by the lessening stigma and more open approach being encouraged by counsellors, social workers, some doctors and, perhaps most importantly, consumer groups. No evidence is available to indicate if those informed as adults are more likely to want to obtain genetic information or contact with 'their' donors. Nor is there any evidence available regarding whether females are more or less likely to want genetic information, or if there are differences between those conceived as a result of DI and those conceived as a result of OD.

The ways in which offspring think about and understand the nature of their relationship with their parents and their donor is of considerable importance. The same can be said in reverse, i.e. how parents view their offspring and again about how parents and offspring view the donor and vice versa. What is being highlighted is the relative importance and relationship between the biological and the social as the base for family. Early anthropologists[68] who studied family and kinship used the biological relationship as the starting point for their studies. In 1965, Schneider[69] began to challenge biological connectedness as the basic assumption/premise of family and kinship. This area is now a matter of much discussion and is particularly relevant to gamete donation and who and what constitutes 'family'.[70–72] The explosion of knowledge concerning genetics is also highly relevant given that, for many doctors, one of the first questions asked of patients with certain conditions is 'what is your family history?'. The assumption is that family is always biologically connected.

The use of third party reproduction raises issues for offspring and parents about the way in which they view the nature of their connectedness. Is blood really thicker than water?

CONCLUSION

The practice of DI and, to a lesser extent, OD has changed dramatically over the last 20 years. The secrecy that has characterized gamete donation is being increasingly challenged. Some of the early challenges came from government-appointed committees. The most significant change, however, has occurred within the four central groups involved in gamete donation: the doctors, the donors, the parents and the offspring. As challenges have emerged in all four of these groups, the underlying culture of secrecy has started to change. The current climate can perhaps be best described as one that is in transition. This chapter has presented evidence of the increasing moves towards a culture of gamete donation that reflects the values of honesty and openness; values that are basic to the health and wellbeing of the families that owe their existence to the significant contribution of the donors.

Practice points

- the need to affirm donors for the contribution they make
- focusing on relationships with patients on treating infertility and building families
- assisting patients to manage actual or perceived stigma
- remembering that while most families are based on biological connections, this is not so for an increasing number of families
- being mindful of the impact of the language that is used, e.g. normal, natural
- the advisability of working closely with those who have specialist knowledge in the psychosocial domain

Research agenda

- the way in which the views/attitudes of professionals impact on the decisions that parents make about sharing information about the use of gamete donation
- the motivation of gamete donors and particularly their views concerning the children who will result from their contributions
- the experiences and views of donors who meet the children who have resulted from their contributions
- the experiences and views of the donors and parents who meet each other

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