Ethics, legal, social, counselling

Gamete donation – where is the evidence that there are benefits in removing the anonymity of donors? A patient’s viewpoint

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Abstract

The Department of Health has recently initiated a consultation exercise seeking input on the subject of removing gamete donor anonymity. This paper examines the case for disclosure alongside that of providing additional non-identifying information. The author questions the availability of scientifically based research to demonstrate that children’s best interests can only be served by the provision of identifying information. The author also questions whether all the possible implications of legislative change have been identified and debated. The paper states that the harmful effects of disclosure on the lives of other interested parties, an inevitable downward trend on donor numbers, and a negative emotional impact in the event of a mismatch in expectations between donors and donor offspring guard against the identification of gamete donors. It is proposed that egg share schemes without anonymity, possibly the only reliable source of donor eggs, would become impractical in the UK. It concludes that given the far-reaching and irreversible impact of disclosure, the removal of anonymity should be considered only when research provides unequivocal proof that improved levels of non-identifying information are insufficient for the well-being of donor offspring.

Keywords: anonymity, egg donation, egg sharing, legislation, welfare of the child

Introduction

Following the announcement that the Department of Health (Blears, 2003) is to extend a consultation period in order to seek further views on the subject of removing the anonymity of egg donors, I decided to add my contribution to the debate. I have a son conceived through donor insemination and have donated both altruistically and as an egg share donor. The strong vocal support of some unrepresentative groups in infertility circles creates the feeling that there may be an unrelenting tide in favour of disclosure. However, this is not evidenced by the facts. My major concern is that while various interest groups have articulated their respective stances, the real drive for change and the far-reaching implications that would arise from that change have yet to be sufficiently debated in the public domain. There is a lack of verifiable evidence that disclosure is in the best interests of the child; conversely, there is also no evidence to suggest that the lack of disclosure is potentially harmful to the donor offspring. Collectively, this suggests that the proponents of legislative change are motivated by paternalism rather than realism or pragmatism. In this paper, I aim to highlight some of the wide-ranging potential implications of disclosure on a practical, rather than a theoretical, level.

Changing nature of donation

I believe that identifying donors would change the whole nature of gamete donation and create a new type of donor. Today, the donor’s role is to help create a family; in the future, the donor could become part of that family. The only comparison between adoption and donation today is that at least one of the parents does not have a genetic link to the child. In the case of adoption, there is a history, with many different, often complex, reasons why the child was given up for adoption. With donation, the motivation is much clearer.
Donation is either motivated by an altruistic desire to help infertile couples or, for egg share donors, is combined with supporting their own quest for a family. Without anonymity, donation would simply become an alternative type of adoption. We would be creating life to adopt, rather than adopting children who need homes. The donor would become the equivalent to the birth parent, traceable once the child comes of age. Currently, in the donor scenario, there are only ever two parents. In the future, at least subconsciously, there would always be more than two parents in the relationship. As with adoption, the relationship may remain psychological or it may become a reality.

Possible consequences of removal of anonymity

If there were a change in the law, all donor cycles would be embarked upon in the full knowledge that the child would be able to trace the donor. So if everyone is aware of this, is there a problem? I can envisage the emergence of practical issues for all interested parties, including those very children at whom the legislation is aimed.

Children

Advocates of change quite rightly refer to the ‘rights of the child’. However, this does need to be qualified, as surely what we must focus on are society’s obligations to consider the best interests and the well-being of the child. We must be absolutely sure that the outcome of any change represents a genuine step forward for those born through donor conception, not just to fulfil an idealistic concept of what is their ‘right’.

The crux of the problem is that naming a donor would create a perceived emotional link between the child and the donor that currently does not exist. By offering the child knowledge of the donor’s identity, society would be indicating that there is a significant relationship between donor and child. This would inevitably create a greater curiosity, a greater significance of the donor in the mind of the child, and therefore a greater drive to trace them. What does society expect children to want from their link to the donor? I think it is for them to have the ability to ask questions about their genetic ‘roots’, to understand ‘where they come from’. However, do we really know what kind of expectations would develop in the mind of the children? What kind of relationship would they expect? I believe they could develop a range of expectations: (i) of a one-off contact, in order to ask questions about their origin; (ii) of irregular contact, just to remain in touch with the donor and their family; (iii) of being part of the donor family (as in the birth mother scenario), as well as their real family; and (iv) of being part of the donor family exclusively.

The first two scenarios may be perceived as natural and healthy curiosity. Yet they may lead to the third and fourth scenarios, which have more serious implications. Donors, while aware of the chance of being traced, would undoubtedly have different views about an appropriate level of contact. Inevitably there would be some donors who would want to avoid any kind of contact, perhaps young medical students who may still donate without fully thinking through the implications. While the majority of donors who donate ‘with their eyes open’ would be comfortable with the first two scenarios, few would want the third, while some may ultimately accept it. A child is unlikely to find a donor willing to accept the fourth, and indeed the motivation of anyone donating in the hope or expectation of this outcome is questionable.

Major practical issues arise when the donor’s views on the level of contact do not match the child’s expectations. It would not be a rare occurrence for a child to expect to be accepted into the donor’s family, while the donor is prepared only for a one-off or irregular contact. Society would have implied that the child has a significant relationship with the donor by providing them with the means to make contact, only to find that the donor does not perceive the same significance. In these circumstances, the child would experience feelings of rejection when the response they receive does not match the one they have built themselves up to expect.

While the donation process matches on vital physical and genetic features such as blood group and race, there is no match on background and home environment. How would the child who has been brought up in a relatively poor environment feel when it becomes clear that their genetic mother has a far more affluent background? Would they perhaps feel jealous or cheated? In the case of an egg share donor would they ask ‘what if the eggs had been shared differently?’ How would this affect their relationship with their own parents? A child in these circumstances, far from benefiting from understanding their genetic roots, may find the knowledge raises many complex and negative emotions.

Twenty years ago, fertility treatment was a taboo subject. Today, while there is still some reticence in discussing infertility, the situation has changed considerably. Now so many people are aware of someone who has had IVF treatment that the mystique surrounding it has greatly reduced. It was my hope that egg share, by increasing the level of public exposure to donor conception, would result in greater awareness and have a similar positive impact as the expansion of IVF has had on fertility treatment in general. Unfortunately, the inevitable outcome of disclosure would be to reduce the number of donation cycles. The stigma associated with donation, far from being removed, would be perpetuated. The result of this may be that in the future fewer children are informed that they were conceived with donated gametes. There is also the danger that those children who are told that they were conceived with donated gametes may suffer emotionally as a result of this stigma.

Donors

So what would be the impact on altruistic donation? I believe that the altruistic donor, whose motivation is simply to help childless couples, would largely disappear with the removal of anonymity. It requires an incredibly special individual to donate in the ‘post-anonymity’ world. They need to be prepared to accept the donor offspring and, while recognizing their genetic link, also positively reinforce the true parental relationship. It is only in this way that the destabilizing factors on both family units could be kept to a minimum. The key characteristic for a donor in the ‘post-anonymity’ world, it seems to me, is to be involved but remain detached.
For those who would still be prepared to donate eggs, what are the potential issues they may have to confront? Firstly, they and their family would face years of uncertainty about whether the child would decide to trace them. A far more worrying prospect, however, is the situation in which a donor’s family circumstances have changed since they donated. If the donor has remarried, for example, their second family may have totally different views about the donation, perhaps even strongly opposed to gamete donation on religious grounds. Even more disturbing is the possibility that a donor may have a family prior to donating but then lose a child. The emotional impact of being traced by the donor offspring in these tragic circumstances would be simply horrific. Morally, we cannot just dismiss this possibility on the grounds that the donor knew at the outset that the child could trace them legally. Altruistic donors donate for no personal gain other than the knowledge that they are giving another couple that precious chance to experience parenthood. They do not deserve to face such unimaginable emotional distress as a result of circumstances beyond their control. If the anonymity of donors is removed, it is hard to see how donors could be protected from this nightmarish situation.

There is always debate about the importance of genetics over environmental influences. Whatever the conclusions of the debate, not many will dispute that the environment in which a child is brought up has a significant effect on their development and the type of people they become. Disclosing the identity of donors would bring added complications. A donor would be expected to introduce into their family a child who may have been brought up in a totally different environment, perhaps with totally different values. The possible impact on the child has been discussed, but it isn’t difficult to see the possible implications on the donor’s own family. Who would prepare the donor for how to deal with these difficult situations? One counselling session 18 years earlier would not help them to address the reality. This all seems so much to expect of any individual or family. It takes donation way beyond the altruism asked of an anonymous donor today.

Egg share schemes are relatively new and were not prevalent when the consultation process was first discussed. My second son was conceived on an egg share scheme, and I believe that such schemes are the perfect win-win scenario for infertile couples. However, I have to question the viability of such schemes in the ‘post-anonymity’ world. Inevitably, the number of potential donor couples who take up egg share would diminish for all the same reasons as for altruistic donors. Concern about future contact is understandably higher in this group, due to uncertainty over their own future chances of having children, but at the same time there is also a greater incentive to donate. Many willingly accept their only chance to have a child and are pleased if they can also help someone else at the same time. Egg share donors would have to balance the chance of having a child against three unknowns: (i) whether the recipient will achieve a pregnancy; (ii) whether the child will be told they were conceived from donated gametes; and (iii) whether the child will decide they want to trace the donor.

It is unrealistic to think that some couples, even if they are uncomfortable with the prospect of being traced, will weigh up the pros and cons carefully and decide to take the risk. The complete desperation that can develop from years of dashed hopes would inevitably drive some to make a decision that may cause them very real emotional distress in years to come.

Today, when an egg share donor fails to conceive and the recipient achieves a pregnancy, neither party learns the outcome of the other’s cycle to avoid potential emotional trauma for both couples. I question the use of this practice if donors are no longer anonymous. Living with the uncertainty for an altruistic donor would be hard enough, but for the willing egg share donor it would be harder still. Is it really fair to inflict that uncertainty upon them, even when the recipient has not conceived? If a child was conceived, shouldn’t they have advanced warning in order to prepare themselves? The ultimate nightmare scenario, I believe, is one in which the egg share donor fails to conceive, the recipient is successful and the donor ultimately remains childless. Wilcox (2001) writes that couples are ‘comforted by the thought that even if their treatment is ultimately unsuccessful others have been given their chance’. From my personal experience that is an accurate assertion, but I question whether such an outlook would endure when that chance could ultimately lead to the couple’s childlessness being re-emphasized through contact with the donor’s genetic offspring.

An enormous responsibility would be placed on counsellors to ensure that couples take on board the full implications of their decision, including this nightmare scenario. Nevertheless, couples who ultimately choose to pursue egg share do not do so in the expectation of remaining childless, and of finding themselves in the situation I have described. It is impossible to predict how often this would happen, but as it would, I disagree with the concept of disclosure being applied to any forms of egg donation, including egg sharing.

Today, all non-egg-share donors are totally altruistic, because payment is illegal and generally not wanted. Other than the pleasure of helping a couple to achieve a pregnancy, there is nothing to be gained by the donor. I fear that if anonymity is removed, there is the potential for what I would describe as ‘less than altruistic donation’. By this I mean a situation, for example, in which a woman donates as an ‘insurance policy’ against not having her own children. She may donate in the knowledge that she could become a part of the child’s life at a later date and experience their weddings or grandchildren. This may happen rarely, but I believe it would happen and would be a totally unwelcome and possibly dangerous result of the removal of donor anonymity.

**Donor recruitment**

One reason for the Department of Health’s extension of the consultation period was to examine ways of recruiting donors in the future, so it is clearly accepted that this change in legislation would have a damaging effect on the number of donors coming forward. I have been involved in attempting to recruit donors in the past. I have spoken about my experiences from the perspective of an altruistic and egg share donor at several recruitment events. I have written articles on the subject and agreed to speak to anyone who contacted CHILD (The National Infertility Support Network). I do feel incredibly strongly about egg donation and have tried to promote it in every way possible. If anonymity were removed,
I would no longer feel able to promote egg donation actively. I could not be party to encouraging anyone to donate when I am fully aware that it may ultimately cause them personal emotional distress at a later date.

It is already notoriously difficult to recruit altruistic egg donors. This legislative change would only exacerbate the dreadful shortage of donors that already exists. The new type of donor needs to be involved but remain detached, be prepared to accept years of uncertainty, and be willing to accept the potential issues of accepting a child into their life at a later date. The number of people who would be willing to donate in the full knowledge of these facts must be very limited. Inevitably the number of donors would drop, the question is purely by how much. Waiting lists for couples requiring donated gametes would undoubtedly lengthen in the wake of a change in the law.

The only options that I can see to address the shortfall in donors are to recruit donors abroad or to offer payment for donation cycles. I believe that neither of these are acceptable options and I can envisage complications arising from each. To recruit abroad presupposes that race or background is not an issue. This goes against the current trend in adoption. If mixed race adoption is not perceived to be appropriate, I fail to understand why this is different for donation. It seems inconsistent that on all other points people promoting legislative change are aligning donation more closely to adoption, but on this point they are prepared for donation to fly in the face of adoption trends that look to place children in ‘racially compatible families’. If genetics are so important that we must identify donors, do we really want our children to discover that their genetic link is to Scandinavia or to a different race, for example? Has the emotional impact of this been considered?

I have never believed in paying any donors anything beyond reasonable expenses. One of the strengths of the British system, I feel, is that donation is in general altruistic, and that recipients are aware that the donor’s motivation was purely to help them conceive. I have always felt that the gift of life should be willingly and unconditionally given. If donors were offered payment to encourage them to come forward, the motivation of gamete donation would be blurred by the potential financial gain. This would inevitably have a negative impact on how donor conception is perceived. Donors could be encouraged to donate a large number of times in order to earn money, thus exposing themselves to regular high doses of drugs, taking potential, as yet unproven, risks. I was advised to stop donating after five cycles; however, if I was refused by one clinic, presumably I could have approached another to continue this income stream. Who would regulate this unwelcome and potentially dangerous practice? I ask myself if the individual who has donated purely for financial gain is as likely to treat the child who traces them with the same level of compassion as the person who has donated altruistically? My feeling is that they would not. How would I feel as a child to discover that my genetic parent donated her eggs in order to pay off a debt?

Recipients

What is the impact on those couples who cannot achieve a pregnancy with their own eggs or sperm? Their only choices are gamete donation, adoption or remaining childless. When a couple opts for donation it is usually their final option and is not a decision taken lightly. Many people choose donation because adoption isn’t an option, as they fail to satisfy the criteria of their local authority. Donation may be the only way a couple can hope to have a baby or a young child. Others choose donation because they want to have their own family and adoption is more like having a child ‘on loan’, as the birth parents can still become a significant part of the child’s life. If anonymity is removed, donation would be little different to adoption in that sense. Yet donation is not the same as adoption; there is no question of ‘why was I adopted?’ in the same sense as ‘why was I adopted?’ for the child to ponder over. Today it is clear, in the past a donor donated with the motive of helping a childless couple.

While the numbers of recipients would undoubtedly fall for similar reasons as for donors, the desperation of childlessness would still drive many couples to use donated gametes to overcome their fertility problem. I believe disclosing donors’ identities would have undesirable results that go against the objectives of those organizations actively advocating disclosure. I believe it would lead to more secrecy, rather than less. Rightly or wrongly, couples would be less likely to inform the child that they were born through donated gametes if the child was able to trace their genetic parent. Some couples may decide to go abroad for treatment and would spend even more money in countries that have less regulation than here. This would lead to an even greater variation in the race and social background of the donor and recipient couple. Sperm donation, in particular, may go ‘underground’, with couples resorting to DIY donor insemination to get around the law. There are well-understood issues here, which led to the implementation of regulations in the first place.

Extent of the impact of anonymity removal

How wide could be the impact of legislative change? As the law would not be applied retrospectively, would it affect only those couples or donors who entered into donation after the changes became law? I do not believe this to be true. The impact of the change would extend beyond this finite group to anyone touched by infertility in the past and those who will be so in the future.

The change in legislation is likely to lead to a poorer public image of infertility and its treatment. The importance of this image to infertile couples should not be underestimated. I went through my treatment during the period that Mandy Allwood (who conceived eight babies after taking fertility drugs) was regularly in the press. The media backlash added significantly to the stress of my treatment. It was part of the reason I never felt able to discuss the problem with anyone outside the medical profession. Even now, when my family is complete, press reports portraying a negative image of infertility affect me personally. Stories written in an uninformed and sensationalist manner damage the public perception of the way my children were conceived. That matters to me greatly.

It has become apparent to me in my involvement with infertility support groups that couples do now feel more
comfortable in sharing fertility problems with family and friends. This great stride forward is because IVF is now seen in most circles as just another form of treatment to overcome a medical problem. I believe we face the unwelcome prospect of returning to the days in which couples underwent treatment in isolation because of the public image of fertility treatment. There is a real danger of this if donation becomes seen, for example, as an income stream for donors, and once the media circus begins to report on examples of 'less than altruistic donation' or specific human interest stories relating to problems resulting from donor offspring tracing their genetic 'roots'.

**Personal perspective as an egg donor and egg sharer**

I donated eggs to help couples escape the heartache of infertility, having experienced it myself. I wanted to help another couple to create their family, not to have another child for myself. It was never my intention to bring a half-brother or -sister into my own family. If society decreed that for me to offer these couples hope it would be necessary to create an extended family for myself I know I would not have come forward. I felt very strongly about helping couples to conceive, enough to donate five times. Altruism is one thing, but I know I could not have become one of the new type of donors, involved but detached. I could not have coped with the years of uncertainty, and I would not have been prepared to risk destabilizing my family by bringing in a new 'member' from a totally unknown background.

I would never have donated as anything but an anonymous donor; however, I have tried to consider how I might have felt if I had donated with the prospect of being traced. There were twins born from my donation and I fear that I could have begun to resent them knowing that they could at some point 'intrude' on my own life and family. Inevitably I would have passed these negative feelings onto them if they did make contact with me. Alternatively, I may have developed an emotional bond with the twins in my mind in the knowledge they could become a real part of my life. There would then be an almost tangible link between us rather than a purely genetic one. I think of them now as another couple's children. I am proud to have helped them to become a family: I think about them as just that, a family. However, in the 'post-anonymity' world my outlook may have changed. I would always be conscious that meeting them may become a reality and I am sure I would wonder about them, what they would be like and the kind of relationship they would expect. I think with this at the back of my mind for so long, by the time they were eligible to trace me I may be waiting - perhaps hoping - that they would contact me. Yet I know I would be very concerned about the impact on my family. These are potentially complex emotional mind games for a donor, who only wanted to help another infertile couple!

My husband and I decided early on that adoption was not an option. It's desperately hard for me to say that, as it feels like I am betraying my son. What he has given us over the last 6 years, and what I'm confident we have given him, is immeasurable. If I ask him in 10 years time whether he would have traded his life for knowledge of the identity of his donor, I wonder what he would say. If his answer to this question was 'yes', then clearly we would have failed in some way as his parents, and then I could see some justification in the stance of the pro-removal lobby.

**The case for a change in legislation**

The case for the provision of non-identifying information is now, I believe, well accepted. The case I am considering in this paper is one of disclosure of identifying information rather than provision of greater levels of non-identifying information. I'm not a scientist, a sociologist or a psychologist, and I'm certainly not a politician. I am a business analyst, and I develop business cases. I have to demonstrate that the benefits of any action outweigh the costs and represent the most appropriate option in the circumstances.

There is evidence that children benefit from the knowledge that they were conceived with donated gametes. There are now enough children born through sperm donation to testify to the fact that this knowledge leads to a level of curiosity about the donor and their background. However, do we actually know what the information needs of donor offspring are? What controlled research has been undertaken to develop this needs assessment, and what conclusions have been drawn? Have the information requirements that represent the best interests of the child been established, recognizing that these may not entirely match what he or she believes they want? Without such a clear understanding of these needs, how can we determine whether any given approach is appropriate? If we press on with change without this knowledge, is the question posed by Ahuja and Symons (2001) not pertinent: 'Is it right to experiment with a child's psyche?' I have yet to see clearly articulated what perceived benefits there are to be gained from disclosure over and above that which can be gained through an expansion of non-identifying information. I have not yet seen any verifiable evidence in support of the main thrust of the proposed change in legislation.

I believe we still have greater scope in providing donor offspring with additional information, within the bounds of anonymity, by being more creative in our approach. As a donor I wrote a brief pen portrait for the child to receive at a later date. We should encourage all donors to write and regularly update such pen portraits and provide them with guidance about what to include in them. We could introduce a 'mailbox' type system, managed by an organisation such as the Human Fertilisation and Embryology Authority (HFEA), offering the child the facility to ask more searching non-identifying questions, such as 'do you ever think about me?'. By expanding the non-identifying information that the children can obtain, I believe we can satisfy the child's natural curiosity without threatening the donor's anonymity.

Some costs of change have been outlined in this paper. The most fundamental cost for the child is the raised expectation of their relationship with the donor and the real risk that this will not be reciprocated. For donors the key point is the unknown
practical issues they would have to face, such as one in which the expectation of the child does not match their own. The nightmare scenarios described earlier for altruistic and egg share donors would happen from time to time and would be such a sad legacy in return for offering the gift of life. Potential recipients would clearly be affected by the reduction in the number of donated gametes available.

I am conscious that in this paper I have raised many unanswered questions. I do not believe that to date all the potential costs of change have been identified, let alone considered.

Conclusion

The need of a child to trace the donor is an idealistic concept as yet unsupported by scientifically based research. In such circumstances, it is imperative that idealism is tempered by realism and that the least risk option is taken. In this case, the least risk option is to refrain from disclosing the identity of donors until there is unequivocal evidence available to show that children’s needs can only be served by the provision of identifying information. I do not, therefore, feel that a change in the law is either wise or justified at this time. There are still sufficient options open to us to improve the level of information available to donor offspring, which do not require full disclosure. We should only consider taking such a far-reaching step once all these avenues are exhausted and scientifically researched evidence has been collected to establish the true requirement.

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A dedicated surrogate mother

News reports recently identified Carole Horlock as about to become pregnant for the ninth time, to produce a surrogate child. Her dedication to the sufferings of others is immense, especially so since she delivered her eighth surrogate baby only 12 weeks ago. She will receive expenses for donating one of her eggs and then carrying the baby to full term. Press reports indicate she has received reasonable rewards for all her efforts. She has two daughters of her own, and joined Childlessness Overcome Though Surrogacy (Cots) in 1994, joining Kim Cotton, the UK’s first surrogate mother. At the time, Kim Cotton’s venture into surrogacy stimulated UK legislation that accepts the procedure provided only ‘reasonable expenses’ are paid to the surrogate (Speed, 2001).

This high number of surrogacy services was seemingly unplanned, but Ms Horlock felt so low after her first pregnancy that she felt she had been made redundant from her job! Her principle motive remains helping childless couples and she often meets her surrogate offspring, referring to them as nieces and nephews. A retirement age of around 40 will suit her fine, although she does not promise to end there. Such dedication on the part of women was not predicted in the early days of IVF, and goes to show that the most unexpected events can arise as the advancing field of biomedicine enters society.

This news item coincides with data from an ongoing study by Jadva et al. (2003) showing that the great majority of surrogate mothers had no misgivings about handing over the babies to their ‘mothers’. Any emotional difficulties were seemingly soon over, and many surrogates happily embarked on the same procedure all over again. The report by Jadva et al. (2003) will strengthen the case for surrogacy by embryo transfer. Some of the issues raised by objectors in its early years have simply not come through as yet. Caution will remain essential but it will now be tinged with optimism.

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