

Fertility Tourism: Too Many Choices, Too Little Support?

Oh for the good old days!

The good old days –

- when UK patients seeking fertility treatment universally turned to – or were referred to - the local clinic licensed by the HFEA,
- when the idea of being treated in India, Spain, South Africa, the USA or even Eastern Europe would have seemed an unbelievably risky venture,
- when authorised material from clinics was seen as more reliable and informative than posts on web forums, and
- when the main issue to confront in donor treatment was “to tell or not to tell”.

Now when fertility patients face a blizzard of information and a mind-bending range of options, I'd be surprised if the session in the counselling room to consider “implications” isn't a more demanding occasion than ever. It is a truism that choices provide opportunities for guilt: every selection made, every option rejected, makes space for worry, regret and, of course, divided views between couples on all these impossible decisions.

Of course there is no going back. People cannot be prevented from going abroad for fertility treatment, cosmetic surgery or hip replacement. Years ago medical and surgical services were seen as a domain dominated by professionals whose only interest was to do the best for their patients. Now this is a consumer-driven, highly commercial, and hugely profitable market.

We should remember that fertility tourism is not just a phenomenon confined to UK women travelling abroad. Many women from overseas – from the Middle East and elsewhere - come to the UK for treatment. German, Swiss and Italian women cannot receive egg donation in their home countries since it is illegal there and they are obliged to travel abroad. Denmark has a history of sperm donor recruitment and of attracting Swedish couples for DI treatment. And Spanish clinics have successfully marketed themselves across Europe for the low cost and availability of IVF and donor treatment. Despite the imminent EU

Directive on tissues and cells, the laws on many aspects of fertility treatment differ in many member state of the EU. Within the EU however there is freedom of movement of citizens, and it was of course the “free market in goods and services” that allowed Diane Blood to export to Belgium her deceased husband’s sperm - which could not have been lawfully used to inseminate her in the UK.

Hard facts and figures about this market are few and far between. Anecdotal evidence tells us that a lot of fertility tourism is going on. A news agency report earlier this year stated that 20 IVF clinics in Greece and Spain reported treating over 2,000 women with donated eggs in 2005 for between \$3,300 and \$8,000 per cycle. According to ESHRE European IVF Monitoring data for 2003, UK clinics performed 2,027 egg donation cycles, while Spanish clinics performed 2,711 and Greek clinics 316. But we do not know how many UK patients are actually travelling abroad, where they went, what were their principal motivations in choosing a clinic (cost, combining treatment with holiday, success rates, availability of donors, wish to avoid donor identifiable donors), how they arrive at those decisions, or how satisfied they are with the services they receive and the decisions they make.

Against this however, one can surmise that among UK women, going abroad is still very much a minority sport. UK clinics are by no means short of business and the number of IVF treatments performed in the UK is gradually rising – even if DI treatments have continued a steady decline, partly as a result of the rise of ICSI, partly as a result of what we all hope is the temporary donor sperm shortage. But many of the couples presenting for treatment in the UK may have considered the option of going abroad. The anecdotal evidence suggests that the majority of those going abroad are going for donor treatment – mainly egg donation.

The Donor Conception Network has a strong guidance note about the issues to consider before going abroad for treatment, and so does the HFEA. The latter starts by advising people to find out about the standards and regulations applicable in the destination country – but that is by no means easy. You’d have to search long and hard, and know the various languages in which regulatory material will be written to do this. Naturally – and rightly – the HFEA draws attention to the UK regulatory regime, the rules, and the inspection and monitoring of clinics and invites people to consider whether these standards will be met elsewhere.

The standards of confidential record keeping, and the fact of a central register of treatments is also seen as a feature of the UK regime. What may happen to clinical records in other countries? Who can access them? How long are they kept? What might happen if the clinic closed down?

And of course access to counselling, which is mandatory in the UK, may not be available at all, let alone in good English, at a foreign clinic.

But it is in the area of donor treatment that most differences are to be found – and donor anonymity or lack of it is the most significant. In Europe, apart from the UK, only Switzerland, the Netherlands, Austria and Sweden have ended anonymity, and these are not high on the list of destinations for UK women. Of course the UK central national register of donors and treatments is a significant feature unmatched elsewhere in the world so far, together with clear legislation on parental rights.

Then there are other ethical issues in using a foreign donor. First, and currently quite controversial, is the limit on remuneration of UK donors. This is designed to ensure that there is an appropriate ethical framework for donation – that men and women are not exploited to sell their reproductive material. The EU Tissues Directive demands that donation be voluntary and unpaid except for compensation for expenses and inconvenience. In the UK we have taken the view that donor payments should be limited to actual expenses, and these subject to the maximum applicable in another area of which demands a degree of public-spiritedness – namely jury service. In Spain however the guidelines of the Spanish National Commission on ART and of the Spanish Fertility Society offer between 600 – 1,000 Euros per donation as reasonable for the time spent, the risks undertaken, time off work, and other expenses. In a study of 100 egg donors in Seville presented last year, only 22% said their motivation was altruistic, while 35% said financial, and 43% said both.

Spanish clinicians, perhaps reacting to rumours of the financial exploitation of egg donors in Spain, are insistent that women donating in their clinics are mainly Spanish and not being exploited or inappropriately induced to donate. But where the blanket of secrecy covering anonymous donation continues and central

regulation is light, it is difficult to be sure what is actually going on. Two years ago, following reports of the exploitation of Romanian women who had donated for the benefit of a UK clinic, the European Parliament adopted a resolution expressing concern about the trafficking in human eggs, and demanded that the Commission investigate.

As far as donor treatments in the UK are concerned there is a limit of ten families per donor – but there has been no attempt to harmonise this across Europe, and of course there is nothing to stop a foreign sperm donor coming to the UK and donating again here. His overseas donations will not count towards the ten family limit.

Of course by contrast the USA has no regulations and no limits on donor remuneration. Egg donors can receive between \$5,000 and \$10,000 depending on educational qualifications, while sperm donors are paid around \$100 per donation. South African egg donors are paid around SAR 5,000 = £360. Against this, US and South African donors provide much more information about themselves than is made available by UK or Spanish clinics.

Regulators and professional bodies

The HFEA advises those travelling abroad to obtain legal advice on the enforceability of contracts with foreign clinics, but frankly this is pie in the sky. There are very few UK lawyers who are competent to advise on our own legislation, let alone on those of other countries. There is a real need for European and other regulators, including the HFEA, to exchange authoritative information about the laws and regulatory regimes operating in different countries and to make this available to their citizens. If there is to be a cross-border market, let it at least be one where the basic facts can be communicated.

And what about the professional bodies – the British Fertility Society and the Royal Colleges? Is there not a greater leadership role for them to liaise with their counterparts in other countries to ensure that cross border activity is appropriately managed, that patients are properly protected, that patient concerns or complaints can be investigated, and that neither they nor donors are exploited financially or otherwise.

But for the patients looking at long waiting lists for donor treatment in the UK, what does all this mean? For those whose age is against them, who have a history of unsuccessful treatments, and who feel that time, not to mention money, may be running out, how can they put all these factors into the balance – along with all the others they will have been considering, such as:

Do they really want children? (Both of them?) Are they comfortable, both of them, with the idea of donor treatment, and non-genetic relationships in the family – and non-family genetic relationship with a donor? Do they foresee difficulties with other members of their families? And now, what are the consequences of going abroad? Do they deliberately want to obtain an anonymous donor? Or is their preference for an identifiable donor, but getting an anonymous donor is the price for getting pregnant at all? And what about worries that the donor may have been an uneducated woman pressurised by members of her family or by financial worries to sell her eggs? And what if the child turns out to have 20 or 30 half siblings in a variety of different European lands?

And how to explain these decisions to a future child? We know that many donor conceived people – but not all – are very anxious to have the right to access information about the identity of their donors – and half siblings. That was the basis of our change in the law. We can recall that in the debates on this subject, there was some support for a “twin track” approach – allowing patients to choose between anonymous or identifiable donors. The Government rejected this notion, wanting to see equal rights for donor conceived people – at least those conceived in the UK. But now the fertility tourism market has brought this twin track option within reach of many. So how many of the donor conceived children born (as opposed to conceived) in the UK will in fact have the right to the identity of their donor? And if they do not, will they blame their parents for the decision that they took to opt for treatment abroad with an anonymous donor?

It falls to the infertility counselling profession – along with the voluntary patient groups such as INUK and DCNetwork, to help people make some sense of this heady mix of choices, both before, and particularly in the case of our Network, after, they have made these decisions. We know that the desperate, overwhelming urge to have a child will drive women and couples to do, literally, almost anything to fulfil their desire. They can be oblivious to what

the pursuit of this desire is doing to their relationship, their finances and their health, let alone to the prospective well-being of their future child. This latter inevitably comes way down the list of risks, when way up at the top is the awful prospect of not having a child at all.

I mentioned that we in the Network see and hear from donor conception families as their children grow up, and as their families develop. The most distressing calls we receive are from those who regret the decisions they made, or who just failed to address the implications. Last week a woman who has an egg donation boy of six conceived at a UK clinic called us. She wants to tell her child about his origins, but her husband will not hear of it. How we wonder did this couple not confront this issue with a counsellor before going ahead with treatment? A couple conceived using a known donor, but it is now apparent – as relations both in the couple and with the donor are confused and tense – that these issues were not addressed in counselling at all. A woman who had expressed fears about whether she could bond with an egg donor baby now finds these anxieties have become real with her child reaching two. Two women who contacted us in recent months had both been to Spain for egg donation, had been assured of a physical match, but were horrified to find that they had given birth to obviously “Spanish looking” babies.

Some of these worrying examples (and I am afraid we have many more) relate to potentially poor counselling in the UK, or maybe lack of counselling at all – it is difficult to be sure. Many fertility tourists will make arrangements direct and may not go near a counsellor in the UK. Some UK clinics however have referral arrangements with overseas clinics and start the drug regime work-up in this country before patients travel. This clearly constitutes the sort of treatment that attracts duties of care on the part of the UK clinicians, including in my view a duty to provide counselling. Those travelling abroad may be in most need of the chance to talk through the implications of what they are about to undertake, and counsellors may need to make their voices heard within clinics to ensure that they are available to meet the needs of this group.

So I see real challenges ahead for members of this association as more and more people travel independently abroad for treatment. First, how can you make yourselves relevant and available to

women and couples considering treatment abroad? Will the fact that many of you are linked to UK clinics be seen as off-putting? While not becoming experts or advisers on overseas practices, can you gather enough information to provide counselling that is relevant to the situation of those who are having treatment abroad?

The second challenge is to make yourselves accessible to those who may not have consulted anyone before going abroad, but find themselves in desperate need of support when they return. Nursing anxieties, maybe guilt, and sometimes divided attitudes within the couple, these people can feel they have nowhere to go. Some may find us in the Network. Others, if they have decided not to tell their children about their origins and have not told friends or family what they have done, may see our commitment to telling off-putting. So the availability of independent counselling from those with experience of infertility issues is a vital resource. For some of course, their therapeutic needs go well beyond what a counsellor can reasonably expect to provide, and they need specialist referral. But then where are the specialists with the understanding to help families like these? Few indeed.

So to sum up. We know few firm facts about fertility tourism, but quite enough to know that while it may provide solutions for some, it may pose problems for others. To minimise these problems, UK clinics, regulators, professional bodies and indeed the European Commission need to recognise and accept greater responsibility for this increasing trade in fertility services. EU harmonisation of laws and standards is in its infancy, and then there is the USA, South Africa, India and what may be burgeoning markets in Eastern Europe and other parts of Asia. This may offer a bewildering range of choices and decisions for those desperate for a child - choices and decisions they surely need help to confront both as they face them and after they have made them.

We in the Donor Conception Network want to do everything we can to support you and your colleagues in the very major challenges this brings for us all.

Walter Merricks
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