

Screening for genetic disorders: therapeutic abortion and IVF

Michaelis Michael, Stephen Buckle *Princeton University and Monash University, respectively*

Authors' abstract

This paper examines a proposal to make use of IVF techniques to provide an alternative to therapeutic abortion of fetuses with genetic abnormalities. We begin by describing the proposed procedure, and then show that, considered in itself, it is morally on a par with therapeutic abortion. However, once the wider practical implications are brought into view, the proposed new procedure loses its initial appeal. The pros and cons are not sufficiently clear-cut entirely to rule out the IVF procedure, so the paper concludes by indicating some further complications which may follow, should the procedure come to be adopted.

This paper will examine the ethical issues raised by a proposed method of screening for genetic diseases. The method was advocated in evidence given to the Australian Senate Select Committee on Human Embryo Experimentation, a committee set up by the Australian parliament to consider a wide range of issues raised by *in vitro* fertilisation, especially as they bear on the status of the human IVF embryo. In evidence given to the committee, it was proposed that *in vitro* fertilisation together with genetic screening could provide a viable alternative to therapeutic abortion of fetuses with genetic abnormalities (1). We shall first describe the proposed procedure, and then turn to an examination of its major implications.

The proposed procedure

A couple with a high likelihood of producing children with a serious genetic disease would be placed on the IVF programme. A number of the woman's eggs would be collected, and then fertilised *in vitro* with her partner's sperm. The fertilised eggs would then be allowed to develop until about the eight-cell stage. At this stage, a cell biopsy would be performed to test for the relevant genetic disorder (ie the one to which the couple is susceptible). The procedure is as follows. A chemical is injected into the zona pellucida which decreases the stickiness of the cells and thus separates

them. Using a micropipette, one or two cells are withdrawn from each embryo, while the remaining cells (still in their zona pellucida) are frozen. Each of the sample cells is developed into a cell culture. When enough cells have grown, the genetic constitution of the cells – and thus the presence or absence of the disease to which the couple are susceptible – is determined. This determination can be either in terms of gross chromosomal features as in the recognition of Down's syndrome, or smaller scale features – such as the absence of normal alleles, or the presence of deleterious ones – as in techniques proposed for the recognition of haemophilia, thalassaemia and multiple sclerosis. In these latter cases, genetic markers would be used to determine whether or in what form the relevant genetic material appears.

Embryos which show no signs of the tested-for genetic disorder(s) would then be considered for transfer to the woman's womb. If transfer is successfully effected, the woman could then look forward with confidence to the prospect of delivering a healthy IVF baby, and so be spared the trauma of undergoing, or at least having to consider, a therapeutic abortion.

The advantages of the procedure are thus clear. The problem, however, is this: the procedure is based on the expectation that many of the embryos created *will* be diseased, and that these not be transferred to the woman's womb. So the problem of what to do with 'spare' embryos, a question which has already occasioned uncertainty and some controversy for IVF programmes, is here present in an acute form. Further, the fact that the 'spare' embryos are in this case diseased means that there is little likelihood that other infertile couples would be interested in accepting them. Although the procedure creates embryos for the purpose of implantation (2), it is based on the expectation that a great many – in some particular cases, perhaps even all – of the embryos will not be implanted, and, for want of anyone prepared to accept them, will have to be destroyed. For this reason, one of the critics of the proposed procedure has described it as a 'search and destroy mission' (3). The important question is: Does the procedure display an unacceptable willingness to destroy the earliest forms of human life? Not too much of a difference between

Key words

IVF; genetic screening.

copyright:

the proposed procedure and IVF should be seen here, for even in IVF there is a definite tendency to fertilise more eggs than are likely to be implanted, and to reject for transfer any embryos that grow poorly or inadequately.

Considering the procedure: an argument advanced

Although IVF programmes continue to have their critics (4), they are now widely regarded as a morally acceptable method of treating infertility, especially in the simple case where donor gametes are not used. However, the proposed procedure extends the use of IVF technology to *fertile* couples. This changes the function of the IVF programme. Instead of being a means of producing children for people who could not otherwise have them, it becomes a means of producing children *of a certain kind*. Even though the programme's goal – to produce children free from predictable genetic diseases – cannot be faulted, it is nevertheless committed to making what amount to life-or-death decisions about IVF embryos on the basis of their genetic normality. Can we tolerate a procedure that (routinely) makes such decisions? On the other hand, even in IVF quite often several eggs are fertilised and there's selection of one, two or three of the healthiest looking, best developed embryos for transfer to the mother.

It should be remembered that this problem, and more generally the IVF procedure with which we are concerned, arises as an attempt to find an alternative to therapeutic abortion, with all the trauma such an abortion entails. So, if it is allowed that a fetus with a severe genetic disorder can justifiably be aborted, it is then possible to approach the moral problem raised above not by determining what the absolute rights and wrongs may be, but by *comparing* it with therapeutic abortion. That is the approach adopted here.

Let us imagine a hypothetical person who believes that embryo destruction is wrong, but that therapeutic abortions are not. Appearances to the contrary, this person need not be inconsistent. Therapeutic abortions can be, and indeed often are, justified in terms of the health and well-being of the pregnant woman. If this condition is understood broadly, abortion will be justified in those cases where it is judged that the continuance of the pregnancy would have costs for her that she ought not to have to bear. The important question here is how such judgements are to be made; but since the costs in each particular case will reflect what the woman is prepared to bear (remember that we are considering cases where the woman wants a child), there will be no better indicator than whether or not the woman wants to continue the pregnancy (5). Clearly, a justification along these lines enjoys a substantial degree of independence from questions concerning the importance of the embryo, and thus the rights or wrongs of destroying it. So the outlook of our hypothetical person is not obviously unreasonable (6).

Recognising that this is indeed a reasonable outlook makes it possible to defend the proposed IVF programme without denying that embryo destruction, in and of itself, is wrong. The premises needed are the following: that there are cases of therapeutic abortion which are morally justified; and that the standard IVF treatment for infertility (including the creation of more embryos than can be safely transferred on a given occasion) is morally justified. From these premises it follows more or less directly that a procedure for separating out certain types of embryos as inappropriate for transfer to a woman's womb is not a procedure that can be morally censured if the embryos so separated suffer from disorders that are sufficiently serious to ensure that, had they occurred in an embryo *in utero*, they would lead the pregnant woman to seek an abortion on broadly therapeutic grounds.

The argument works because it seeks only to establish that, if a pregnancy can be ended at an advanced stage for a given reason, then it can also be ended at the earliest stage when the same reason obtains. It requires no new (and possibly contentious) moral judgements, but only the recognition that one of our previously established judgements has implications for the new, largely morally uncharted, area of artificial fertilisation. So our conclusion is this: in all cases for which an abortion is justified, for the same cases the proposed procedure introduces no distinctive moral wrong, and so is itself justified. Our argument, it is worth emphasising, makes no reference to the fact that for many people there is an intuitive moral difference between a developed fetus and a pre-implantation embryo.

Considering the procedure in practice

The argument advanced in the preceding section shows that, far from displaying an unacceptable willingness to destroy the earliest forms of human life, the proposed procedure is, in terms of its implicit assumptions about the value of human life, morally on a par with the widely accepted view that abortions performed for broadly therapeutic reasons are justifiable. However, matters of ethical concern do not stop at this point. In this section, the proposed procedure will be put to the practical test, by judging its relative strengths and weaknesses as a therapeutic method. A considerably more complicated moral picture results: a picture in which the proposed IVF procedure can be seen to be rather less attractive than initially imagined.

The chances of a couple each of whom is heterozygous for thalassaemia having a child who is seriously afflicted by thalassaemia is one in four. This means that on average 25 per cent of offspring produced by such couples will be homozygous for the defective allele. If we imagine two groups, each consisting of one hundred such couples, we would expect 25 thalassaemic children in each group. Suppose we applied the current techniques of prenatal diagnosis followed by therapeutic abortion to one

group, and the proposed IVF abortion-bypass method to the other. Which method would be most successful?

To a certain degree, the answer depends on how we gauge success. If success means no more than ensuring that a thalassaemic offspring does not come to be born, then both methods succeed equally well. It is not clear, however, whether the two methods can equally ensure that the couple will succeed in having a child who is not homozygous for thalassaemia. Two factors inveigh here. First, accompanying abortion there are various low probability risks including a small risk of infertility (7). So a woman who has a therapeutic abortion may thereby come to be unable to have another child. Second, and on the other hand, the success rate of IVF and embryo transfer (ET) is something less than 20 per cent for each episode of superovulation and egg collection, so it is not at all certain that couples on the IVF programme will have the child they desire. These are contingent matters which will change as IVF techniques change, but they need no less to be kept in mind (8).

One criterion for judging the success of a medical procedure is to contrast its benefits with its costs. The latter include not only outlays of time and resources but also more intimate costs for the patient, such as emotional trauma (9). It will be instructive if we apply this test to the two alternatives.

Among the prenatal diagnostic techniques currently used to identify the occurrence of the various defects are sonography, amniocentesis, sampling of the chorion-villus, and fetal blood and tissue sampling. We will take amniocentesis as an example. It is not a complicated procedure: it is performed at present at about the sixteenth week of the pregnancy. It does not require a general anaesthetic, and usually is not traumatic. In contrast, IVF and ET appears at present to be associated with a great deal of trauma. It is not clear, however, how much of this trauma can be attributed to the medical procedures themselves, and how much to the anxieties the patients bring with them for other reasons. The principal cause of these other anxieties is the simple fact that, to date, couples on the IVF programme are subfertile, and most of them see the IVF programme as their last chance to have a child of their own. Couples embarking on the programme in order to screen out defective embryos are a good deal less likely to have such a 'last chance' mentality, so there is reason for thinking that, for them, IVF would not be so traumatic.

Nevertheless, the IVF programme would be, for most such couples, more intrusive than the alternative. It would also be substantially more expensive. Following prenatal diagnosis only 25 per cent of the couples with the chance of producing a child with thalassaemia major need undergo therapeutic abortion, whereas every couple on the IVF programme will go through at least one cycle of the programme (10). On the other hand during the comparatively long wait until the prenatal diagnosis is available all of the potentially affected couples are likely to experience

considerable stress in worrying that the baby may be affected. Balancing the ledger is thus a difficult task, since there seems little room to doubt that an abortion, because of both the hopes generated by the pregnancy and the physical impact on the woman's body of a comparatively late abortion, would be a very traumatic event. Conversely non-implantation of an affected embryo is risk-free for the woman. So a great deal hangs on just how traumatic the IVF programme could be expected to be for the couple seeking genetic screening. For unless the trauma of undergoing the abortion is a great deal worse than that incurred on the IVF programme, the proposed procedure is expensive, wasteful and unnecessary.

The lateness of the abortion might give additional cause to hesitate before drawing this conclusion, for the fetus may be at a sufficient stage of development to suffer pain. There are considerable uncertainties surrounding this issue, which make it difficult to draw lines between abortions which can be expected to be (for the fetus) painful or painless. Nevertheless, the more general question of the interests of embryos and fetuses cannot be left aside, and, if interests are (plausibly) interpreted as a function of the level of biological development (11), then the IVF proposal is clearly preferable in this respect. In fact, the IVF proposal was initially advanced in part because of this superiority: it was thought that embryo screening would be more likely to meet with ethical approval than would a late abortion (1). This may be so, but our discussion has shown that the ethical issues are more various than initially supposed, and lead in different and opposing directions.

Further ethical questions can also be raised about the screening procedure itself. The only way to see what effects the procedure causes is to take a sample of apparently normal embryos, perform the biopsy and then implant the embryo. It is reasonable to suppose that this will decrease the chances of a successful pregnancy (12). Exactly by how much is, however, not known.

This raises two problems. The first is: Whose normal embryos and subsequent pregnancy can legitimately be exposed to this risk? It is not clear that anyone's pregnancy can be so treated; and, even if this were not so, there is still the second problem of dealing with the possible undesirable outcomes. Since it is not inconceivable that the various drugs used to separate the cells could have detrimental effects, we might well be faced with having created neonates who are deformed or otherwise impaired. If it occurred, this would be a deeply ironic outcome: a programme instigated to overcome the barriers to having normal healthy children would then be providing new ways of producing impaired children. Since outcomes of this kind cannot be ruled out, it must be concluded that the proposed technique falls short of being the boon to sufferers of genetic diseases that some of its advocates appear to imagine.

Concluding remarks

In our opinion a more complete grasp of the implications of using IVF techniques as a method of screening intending parents suffering from genetic diseases shows it to be of uncertain value. Although the proposed procedure is, considered in itself, morally justifiable, its implementation would, we have argued, generate a cluster of further problems. These appear sufficient to tip the balance against it. The benefits it offers do not appear to provide an adequate return for the costs (emotional and financial) it imposes.

However, the issue is anything but clear-cut, and so it is not impossible that the technique could reasonably be adopted. If this does happen, we can expect that further thorny problems will arise – problems that will have to be faced and, as well as we are able, resolved by us as a community of agents with responsibilities to our descendants. These problems cannot all be predicted in advance, but some can be. For example, we will have to determine the grounds that can count as adequate for refusing to transfer an embryo. Under this general heading, the question of sex selection is almost certain to arise: Is the sex of an embryo an adequate reason for refusing to transfer? This is more than a question of individual choices, because sex selection could have serious consequences for our community as a whole. In many societies, male children are more highly valued than female, such that an effective programme of sex selection in those societies would seriously disrupt the rough equality of the 'sexual mix'. The consequences of disruptions of this kind are uncertain, but it has been argued that the status of women in such an environment could suffer markedly (13). Whether the same preferences, and thus the same dangers, are sufficiently true of our own society is unclear; and the high premium placed on individual choice in Western societies would make effective opposition to discreet sex selection difficult to maintain. Nor is such resistance to regulation, considered from a broader political perspective, a bad thing.

Further issues could be raised, but the discussion suffices to show the underlying moral. It is this: The development or extension of new technologies, especially into the most personal of spheres, is a two-edged sword. Effective biomedical innovations bring not only advantages but also difficult problems that no responsible society can avoid.

Acknowledgement

This work was supported by a National Health and Medical Research Council Special Initiative Grant to Professor P Singer, Professor J Funder, Ms B Gaze and Dr H Kuhse. Our thanks to Peter Singer and Helga Kuhse for helpful comments on earlier versions of the paper.

Michaelis Michael is a Graduate Student in the Department of Philosophy, Princeton University, Princeton NJ 08544, USA. Stephen Buckle is Research Officer in Philosophy in the Centre for Human Bioethics,

Monash University, Clayton, Victoria 3168, Australia.

References and notes

- (1) Evidence given to the committee by Wilton L J. See *Senate Select Committee on the Human Embryo Experimentation Bill 1985* (Official Hansard Report), Canberra, 1986: 38–44.
- (2) Within the Australian state of Victoria, this is crucial to the legality of the proposed procedure. The Victorian law requires that fertilisation of a human egg outside the womb of a woman can be allowed to proceed to or beyond the point of syngamy only where there is the intention to implant the resulting fertilised egg. See *Infertility (Medical Procedures) Act 1984*, section 6 (5), and *Infertility (Medical Procedures) (Amendment) Act 1987*, section 4.
- (3) See reference (1): 74.
- (4) Criticism comes, in the main, from two (very different) directions. On the one hand, the Catholic Church holds that IVF is unacceptable because it breaks the (morally) necessary connection between procreation and the conjugal act. See, in particular, Sacred Congregation for the Doctrine of the Faith, *Instruction on respect for human life in its origin and on the dignity of procreation: replies to certain questions of the day*, Homebush, NSW: St Paul Publications, 1987; 40–47. On the other hand, some feminists object that IVF reduces women to mere objects of scientific research – making their bodies 'living laboratories'. See, for example, Rowland R, *Reproductive technologies: the final solution to the woman question?*, in Arditti R, Klein R D, Minden S, eds, *Test-tube women*, London: Pandora Press, 1984; 356–369.
- (5) It might be thought that this is too broad an interpretation of what can count as therapeutic. If this were granted, however, it would make no difference to the substance of the argument, which would then be based on the common belief that aborting significantly defective fetuses is justifiable. And, if these abortions are not to be classed as therapeutic, it is uncertain how they should be described. A woman would, presumably, seek screening for either therapeutic or beneficent reasons – ie for her sake or for that of the possible future child.
- (6) Of course, these remarks do not constitute a full treatment of the moral issues that may arise when considering cases of this kind. The issue is complicated by the fact that an unwanted *in vitro* embryo need not be destroyed, but can be donated to another. Even in such cases, however, the genetic parents may have reasons for preferring the destruction of the embryo – for example, because, although they do not want the future child, they cannot separate that child's existence from their sense of responsibility for its welfare. Further possible examples are the guilt-based fear that one day they will be faced by their progeny and accused of abandonment (which, if accurate records of embryo donations are kept, cannot be totally discounted), and the possibility of unexpected and unwanted inheritance claims (unless effective legal barriers are built). These examples are more pressing for the standard IVF case than for the case being considered here, however, since embryos which are too defective for their biological parents are not going to be very attractive for other prospective parents on an IVF programme. Unless there are no other IVF embryos available for donation, these embryos will remain unwanted.

- (7) The actual extent of this risk seems to be very poorly understood. It may well be greater for the late abortions associated with this procedure.
- (8) The variations in claimed success rates do not make the task any easier. As Mary Anne Warren observes; 'Estimates of the success rate of IVF treatment range from 4 per cent to 25 per cent. Not surprisingly, the critics of IVF tend to favour the lower estimates, while the proponents favour the higher'. IVF and women's interests: an analysis of feminist concerns. *IVF: the current debate* (Conference Proceedings), Melbourne: Monash University Centre for Human Bioethics, 1987: 149.
- (9) This very general, bland term has been chosen deliberately, in order to accommodate the widest possible range of perceived costs and benefits.
- (10) This is true whenever the disease under consideration is a recessive genetic disease.
- (11) This view would not be accepted by the Catholic Church, for whom, on the whole, the interests of all members of the human species, whether embryos (at whatever stage of development), children, or adults, and whether healthy or even very seriously impaired, are to be regarded as equal.
- (12) See reference (1): 49.
- (13) Warren M A. *Gendercide: the implications of sex selection*. Totowa, N J: Rowman & Allenheld, 1985.
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