

Saviour siblings

By Caroline Berry and Jacky Engel

Giving up something to help a fellow human being is a noble action. Donating blood or bone marrow are classic examples of this sort of altruism. However, a new avenue of debate has opened now that techniques of assisted reproduction allow doctors to select an embryo that will have the potential of growing into an ideal tissue donor for an existing person. Is this process turning people into commodities, or is it a wise use of medical technology?

In 1990, Winston and Handyside reported the first successful pregnancies where the genetic status of the embryo had been ascertained before it was transferred to the mother's uterus.¹ The family had an X-linked mental disorder and 50% of male children would be affected. Doctors therefore placed only female embryos in the mother.

Further developments in DNA technology now allow technicians to determine a pre-implantation embryo's histocompatibility leukocyte antigen (HLA). This pre-implantation genetic diagnosis (PGD) lets doctors select embryos that could be ideal donors for existing children, opening the possibility of creating so-called 'saviour siblings'. In the first place, stem cells would be collected from umbilical cord after the baby is born.

The desire to do this comes from a deep sense of compassion. Certain incurable diseases, particularly the anaemias where the bone-marrow does not produce healthy red blood cells, can be treated by using either a bone marrow or stem cell infusion. If the donated cells are compatible with the recipient, they settle in the bone marrow and produce healthy cells. This often results in a permanent cure of the anaemia, though there are risks and occasional failures.

While there are banks of tissues and cells and records of potential donors,

sometimes doctors can't treat a patient because they can't find a suitable match. The people most likely to have an identical tissue type to the patient are their brothers and sisters. On average one in four full siblings have the same tissue type as the affected child. In large families there is a reasonable chance of a matching sibling already being present. Where this is not the case parents sometimes consider having further children in the hope that one will match.

Selecting embryos is another option. The first reported use of this technique was in the USA in 2000 when Adam Nash was born with a tissue type that matched his sister Mollie. She had a rare but fatal condition, recessively inherited Fanconi anaemia. His birth required the creation of 30 embryos and four attempts at *in vitro* fertilisation (IVF).²

While the biology is relatively straightforward, there are genuine questions about the morality of its use.

People have questioned the ethics of having children in order to provide a donor for a sick child ever since it became apparent that parents were doing this using normal biological means.³ With the arrival of PGD, secular ethicists such as Robert Boyle and Julian Savulescu reviewed the issues. In their opinion no-one would be harmed by the procedure, so if IVF and PGD were both acceptable, they concluded that 'it is

reasonable to use them to both bring a new person into the world and to help save an existing life'.⁴ Can Christians go along with this conclusion?

Embryos

The status of the human embryo is obviously a key issue in this debate and has been extensively debated elsewhere.^{5,6,7,8,9} In brief, many Christians believe that since a new human life begins with the fusion of sperm and egg, embryonic human life should be given the same respect as any child or adult. Or that, if its status is uncertain, the embryo should at least be given the benefit of the doubt. Given this, pre-implantation diagnosis and subsequent disposal of unsuitable early embryos is unacceptable. The use of the techniques for 'saviour siblings' would be particularly wrong in view of the large number of embryos destroyed.

Other Christians, however, see embryo disposal as morally acceptable in some circumstances. These people then have to consider what circumstances justify embryo selection and disposal.

Additional factors

Some frequently used ethical arguments draw on secular thinking. It is worth

seeing how well they work and how they relate to Christian-inspired thought.

Means and ends

Opponents of saviour siblings, Christian and secular, often argue that it is wrong because the child is being created as a 'means to an end' rather than 'an end in itself'. A form of this idea has been debated at least as far back as Augustine (354-430 AD) and Thomas Aquinas (d.1274).

The current use of the phrase rests more on philosopher Immanuel Kant's (1724-1804) duty-based concepts of how people should treat each other. Kant wanted to show that human reason alone, with no reference to revelation or a divine being, was the supreme tool for ethical thinking. As part of his work he created a set of 'categorical imperatives', the second of which states: 'Act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means, but always at the same time as an end'.¹⁰ This argues that each person should be an end in him or herself, not purely a means that we can use to achieve someone else's ends.

It's worth remembering that parents have many reasons for having children, including fulfilling their desire to be parents, wanting an heir, or needing someone to care for them in old age.

The question then is whether a saviour sibling would be treated 'simply as a means'. This seems most unlikely. Part of living in a human society is that we constantly make use of other people's labour, abilities and resources. We value people partly because of their contribution. This still leaves room for them to be an end because they will also lead their own lives, and a Christian would add that each human life has intrinsic value in itself.

In addition, parents who have used this technique display as much love and affection for the new child as do any other parents. Some argue that they have more affection in light of the saviour sibling's donation, as well as the lengthy process they have been through to create him or her.

Despite initially appearing to cast

doubt on the practice of creating 'saviour siblings', Kant's imperative gives no grounds for prohibiting its use.

Good to exist

There is also a debate about whether it is ever wrong for someone to exist. In his book *Reasons and Persons*, philosopher Derek Parfit discusses the implications of this 'Non-Identity Problem'. Parfit argues that if your particular sperm had not arrived at that specific egg, or been beaten to it by another, then you would not be here. Either no one, or a person of a different genetic constitution, would have been born. Thus no one can say 'I wish I'd never been born'.¹¹

The 'good to exist' argument does not mean that every possible embryo should be brought into existence. Rather it relates to those that *already* exist. It suggests that once anyone exists, that person is a good thing. It does not imply a duty to create, but that even if you have reservations about the means by which a person is created, that person is still 'good' and could not have existed any other way. In relation to a saviour sibling, a child that would not have existed any other way, can therefore only be grateful for his or her existence.

Christians would also add that any human being, however conceived, has intrinsic value because he or she would be known and loved by God. While this recognises the value of any saviour sibling it does not, on its own, argue in favour of the procedure.

Born by design

But are we at liberty to create 'made to measure' children? Isn't this the ultimate commodification? Opponents of the technique say that we should not design children to our 'wants' but rather accept them as they come, as a 'given'.

Scripture, however, is full of people who are born for a God-given purpose; John the Baptist,¹² Samuel,¹³ Jeremiah¹⁴ were all born to live out specific tasks. In a real way, Christians also believe that everyone is born with a purpose in God's mind. While in each of these cases it is God who chooses the purpose of a

life, could you argue that he might delegate that responsibility to humans?

The question is how far we as God's servants are permitted to join in his designing activity? After all, Christians believe that a vital part of being human is to be made in God's image and as such that we are given responsibility to shape and control many aspects of creation.

Others say that we do the designing and shaping all the time; such as in our choice of schools, or in our establishing of notions of discipline and teaching religious and societal values. In these cases, however, the shaping is happening to a child who already exists, rather than in deciding 'who' we are going to allow to exist.

Many Christians believe that we should accept the children we are given as mysterious gifts from God, rather than selecting or creating children with specific characteristics that satisfy our own wishes, however noble or caring the motivation.

Motivation

In general Christian teaching stresses the importance of individuals serving one another. Jesus gave healing high priority, stressing that it was of greater importance than other duties such as observing the Sabbath minutiae. He also seems to have had particular compassion for sick children and their parents.¹⁵ Healing and helping others are Christian ideals and we are expected to use available means to heal and to help. But is choosing the tissue type of the unborn taking this too far?

Potential problems

As with any medical technology there are potential problems.

There is the possibility that the selected embryo fails to provide the hoped for ideal tissue, which raises the potential risk that the parents may have difficulty fully accepting the new child.

While initial treatment options involving saviour siblings call for the use of cells harvested from umbilical cords, the saviour sibling could be asked in the future to donate other tissues. Even if

legislation were enacted to remove any legal compulsion to donate, the child could feel under enormous pressure to perform this sacrificial act. Some people suggest that this amounts to a new form of child abuse. Again, is this really new? A sibling born after normal sexual intercourse may find him or herself an ideal donor for a sibling and feel under pressure to donate and this could include kidneys and other organs.

Now the question is whether this is an unduly burdensome position to create deliberately, and whether the new child is now just a commodity created to serve another's needs. This question arises partly because we are used to looking at things from the point of view of protecting an individual's rights, and not looking for ways that people can help and serve each other.

Slippery slopes

The first uses of this technique have involved desperate parents who did not choose to be in this position. But it is easy to see how the idea could snowball. Couples wanting to 'replace' a daughter who had been tragically lost in a fire could call for sex selection. Others may wish to supply whole organs or tissue samples that require the pain and risk of invasive surgery to harvest.

When appealing to wider ramifications, we often engage in a version of the 'slippery slope' argument – expressing our fears about what will follow on from a handful of saviour sibling cases. We must ask ourselves, 'how well founded are these fears?'

Family factors

There is a potential risk that focusing so much time, money and emotional energy on PGD and the illness could damage relationships within the family. Again, this is not a new issue. All families are dysfunctional in some way. What is new, however, is the route by which the situation is brought about.

Further, if saviour siblings are permitted, what of 'saviour children', 'saviour grandchildren', 'saviour nephews or nieces' or 'saviour cousins'? Where should the line be drawn?

To select an embryo

A few days post fertilisation when each embryo consists of a cluster of eight cells, a technician removes a single cell and analyses its DNA. Only embryos with the desired genetic make up are placed in the mother. The technique was first used for the single gene disorder cystic fibrosis,¹⁶ but could now be applied to 20-30 different single gene conditions.¹⁷ The stem cells are harvested from the umbilical cord after delivery.

All PGD procedures in the UK have to be authorised by the Human Fertilisation and Embryology Authority (HFEA). Each test requires a separate licence. The HFEA is expected to limit testing to serious disorders, but deciding what constitutes 'serious' will always be contentious.

Practicalities

It is important not to underestimate the difficulties associated with this entire procedure:

Laboratory

The technical aspects are demanding. A single cell is exquisitely delicate, and contamination with extraneous DNA is a constant hazard. Consequently the selection procedure is not error free. The chance of error is around 1 in 20, and varies between tests. It would be discussed with the parents in the pre-test counselling.¹⁸

The parents

Large numbers of embryos are needed so that doctors can select the desired criteria. In a case like the Hashmis (see box, page 4), where selection involves both freedom from thalassaemia and the correct tissue type, on average three of every 16 embryos should fulfil the criteria. Where the primary condition is not genetic (as with the Whitakers and the Fletchers) and only HLA-typing is required, one in four embryos should be suitable. Inevitably even those selected may be unsuitable for other reasons.

Collecting the large number of eggs requires hyper-stimulation of the woman's ovaries and laparoscopic egg collection. Both are unpleasant procedures and can have severe side-effects. In addition, many IVF cycles may be needed to obtain a child. Success rates are carefully monitored and less than one third of IVF cycles result in a baby. PGD results are similar to those of standard IVF.

IVF is stressful and many couples find it more than they can cope with. In a follow-up study on couples using PGD to avoid the birth of an affected child, 41% of the 67 couples questioned rated the procedure as extremely stressful and although 76% would choose PGD in a future pregnancy the remaining 24% would choose either prenatal testing (16%) or have no further pregnancies (8%).¹⁹ It was the low success rate that gave rise to most stress.

No such information is available for the few couples who have used PGD for tissue typing. The motivational aspects – the parents' desire to save their sick child's life – can be a very powerful drive leading to great self-sacrifice and a willingness to discard embryos.

Safety of PGD

PGD has only been used for a relatively short time and worldwide only about 1,000 PGD children have been born. IVF pregnancies in general have a higher risk of prematurity and associated complications. This is mainly due to the frequency of multiple births and the age and poor fertility of many mothers. These latter factors will not necessarily apply to the PGD pregnancies.

It was the concern about risks to the child that prompted the HFEA initially to ban testing solely for HLA-typing, as the risk was not balanced by any benefit for the child. The change of policy rested on new reports indicating that PGD posed no additional risk. It is important to remember that the small numbers and short time since the technique was first used adds an element of uncertainty. More subtle side-effects might be discovered later and there is a real need for good long term paediatric monitoring of these children.

Safety of stem cell transplantation

In more conventional transplant procedures a small proportion of patients do not survive the treatment, and others survive, but the treatment is ineffective. Many need long term treatment with immuno-suppressive drugs that leave them at increased risk of infection and cancer. It may be that some of these risks will apply to transplantation of stem cells from a saviour sibling, and parents will need careful counselling before embarking on this line of treatment.

And what if the donor child was affected by the PGD procedure (see box) or the recipient died of, or was harmed by, a side effect of the treatment? Could parents be left with profound feelings

of guilt. Or what if the procedure is simply unsuccessful? Although adding stress to the family's life, it may enable parents to feel they did everything they could for their child.

UK case histories

2001 Hashmis

Doctors requested a licence for saviour sibling PGD for Raj and Shahana Hashmi, whose son Zain (born Oct 2000) had thalassaemia, a recessively inherited severe anaemia.²⁰

A licence was given²¹ but deemed unlawful²² when Comment on Reproductive Ethics (CORE) won a High Court Judgment in December 2002 on grounds that PGD must only be used in the interests of the child to be conceived.

This High Court decision was subsequently overturned in the Court of Appeal on 1 April 2003.²³ The ProLife Alliance has lodged an appeal in the House of Lords to review the Court of Appeal decision. In January 2005 the case was still pending.

In 2004 the Hashmis ceased treatment after a number of failed attempts. This was partly due to concerns over Shahana's age (she was 39 by the time they were able to begin treatment). At that point they still had two frozen embryos from previous treatment cycles.²⁴

2002 Whitakers

Michelle and Jayson Whitaker sought help for their son Charlie (born 2000), who had Diamond Blackfan Anaemia (DBA), a severe form of anaemia.

A licence was refused on grounds that the unborn should not be exposed to hazards of PGD when

there is no direct benefit to the child itself. This case differed from the Hashmis because PGD was not required to test for an inherited disorder - DBA is rarely familial.

A daughter, Emily, was born naturally, but wasn't compatible as a donor.

The Whitakers travelled to Chicago for PGD treatment. Two embryos were implanted and a son, Jamie, was born in June 2003.²⁵

Charlie was given a stem cell infusion in July 2004 and is recovering well. Doctors cannot say for certain that he is 'cured' until a year after the transplant.²⁶

2004 Fletchers

In April infertility expert Mohammed Taranissi announced that he would launch a legal challenge on behalf of the Fletchers, whose son Joshua (born in 2002) had DBA.

In July 2004 the HFEA officially 'relaxed' the rules licensing saviour sibling PGD to allow for Whitaker-type cases. Each case will be looked at on individual merit and parents will be expected to exhaust all other possible avenues before proceeding with PGD.

In September 2004 Taranissi was granted a licence for the Fletchers.²⁷

pre-implantation genetic diagnosis is only relevant to a few families. Also it may only be a temporary measure, because improvements in tissue donor registries and better sources of compatible stem cells should become available in the future.

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Conclusion

This is never going to be an issue where all Christians reach the same conclusion.

For those who accept the use of reproductive technologies that involve embryo selection and disposal, there is good reason to believe that these children could be greatly valued for themselves as well as being a means to help others.

While Christians will once again differ on their conclusions they should be in a position to discuss the subject clearly and with compassion for all involved. In any case, saviour sibling

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