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The family of the future[1]

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The life of Zain

What would you do if you had a three-year old child (Zain) whose bone marrow does not produce enough red blood cells? Consequently his health is very poor, with a need for daily drugs and regular blood transfusions in order to stay alive. Normal life could be restored by a transplant of stem cells (cells which can give rise to more cells) from a donor who has compatible tissue. The chances of finding that donor are very low. But medical technology can help. A human embryo can be produced by fertilising an egg with sperm outside the body. A single cell can be removed from that embryo and tested for genetic disorders (medically termed "pre-implantation genetic diagnosis" or PGD). At least in the United States, that single cell can also determine tissue compatibility and, if so, the child conceived from that embryo will have stem cells which can cure Zain. Ethicists describe such a child as the "saviour sibling".

Is it right to bring about the birth of a child by use of modern medical techniques in order to save the life of an already existing child? Is this simply using one child as a means rather than seeing each child as an end — unique and special? Who should decide what to do and what should be the basis for the decision?

Who should decide?

On 28 April 2005, in *Quintavalle v Human Fertilisation and Embryology Authority*[2] the House of Lords was asked to provide an answer in Zain's case.

The United Kingdom Parliament set up the Human Fertilisation and Embryology Authority (HFEA), a regulatory committee, in 1990 primarily to oversee the production of embryos outside the human body. The HFEA must have a lay chairperson (neither medically qualified nor engaged in embryo production or research) and a majority of lay members. Therefore HFEA embraces social, legal, managerial, religious, and philosophical experience as well as medical and scientific expertise). It is a criminal offence to bring about the creation of an embryo or use an embryo, except pursuant to a licence from the HFEA. The activities which the HFEA can licence include practices designed to ensure that embryos are in a *suitable condition* to be placed in women or to determine whether embryos *are suitable* for that purpose. The HFEA authorised use of the procedure to create a "saviour sibling" for Zain.

Ms Quintavalle, who brought the case to Court, is a director and founder of a group which believes in absolute respect for the human embryo. Ms Quintavalle wanted to limit the HFEA licences only to processes testing embryos for their own viability (capable of proceeding to birth) and nothing else. Ms Quintavalle's main concern was that once testing of cells from embryos is generally licensed, there will be nothing to stop testing for sex or desired physical attributes and, possibly in the future, athletic ability or intelligence — the so-called "designer baby".

The "saviour sibling" situation was not foreseen in 1990 when the HFEA was set up. The "designer baby" situation was foreseen, but not prohibited. The House of Lords decided that, because Parliament did not prohibit either activity, the HFEA had the power to decide the "saviour sibling" and "designer baby" situations on a case-by-case basis. The House of Lords indicated that it was unlikely the HFEA would "actually allow" selection of embryos based on gender or social grounds.

In New Zealand, s 11 of the Human Assisted Reproductive Technology Act 2004[3] (the Act) sets out the law: selecting embryos purely on the basis of their sex for reproductive purposes is an offence (with a maximum penalty of one year in prison or a $100,000 fine or both) *unless* it can be proven the selection of an embryo on the basis of sex was to prevent or treat a genetic disorder or disease.

The "saviour sibling" is not therefore prohibited. The Act also provides for the *Advisory Committee on Assisted Reproductive Procedures and Human Reproductive Research*. Its functions are to issue guidelines and advice on assisted reproductive procedures and research and to advise the Minister on, for example, the need for further prohibitions or for a moratorium on some procedures. Until this Committee is established, the Act provides that the Minister of Health may approve interim guidelines for up to three years from November 2004.

The National Ethics Committee on Assisted Human Reproduction (NECAHR) is a body set up by the Ministry of Health to advise the Minister and fertility clinics on the ethical issues of assisted human reproduction. Early this year, it published proposed guidelines on PGD in New Zealand. Those guidelines provide that creating embryos and testing them for use as "saviour siblings" may be undertaken, but only if approval is given by NECAHR on a case-by-case basis.

Basis for decisions

NECAHR will give approval to create a "saviour sibling" where:

(i) The affected child has a gene disorder which has been identified within a family. There must be a "high risk of serious abnormality" because of the gene disorder. (By contrast, other countries state a higher threshold. In Sweden it must be a "hereditary disease leading to premature death for which no treatment or cure is possible". In France it must be a particularly severe genetic disorder, known to be incurable at the time of diagnosis.) Zain's disorder satisfies this lower New Zealand threshold.
(ii) There must be a 25-50 per cent risk that the embryos created are affected by the particular genetic disorder within the family. (There are no conditions which presently have a 50-99 per cent risk.) There is a 25-50 per cent chance an embryo created from Zain's parents' eggs and sperm would have his condition.
(iii) All other possibilities for treatment and sources of tissue for the affected child have been explored.
(iv) The intended recipient is a sibling of the potential child.
(v) The expressed intention is to take only cord blood for purposes of treatment, and not other tissue or organs.
(vi) Additional counselling will be provided to the couple undergoing treatment.

Zain's situation satisfies the NECAHR guidelines, so permission would be given in New Zealand to create and test for a "saviour sibling".

What about Charlie?

Charlie is three. He suffers a rare form of anaemia where the bone marrow produces few red blood cells. Charlie is pale, has an irregular heartbeat, and heart murmurs. Charlie gets irritable and tired and faints a lot. His condition needs intensive therapy such as painful, day-long blood transfusions and daily injections of life-saving drugs. There is no cure, but bone marrow transplants give a 90 per cent chance of recovery. If Charlie's parents could have another child whose tissue matched Charlie's, then this child's cells could help Charlie's body to create red blood cells.

Like Zain's parents, Charlie's parents said they wanted to have another child anyway, not *purely* as a "saviour sibling". But there was one difference between Zain and Charlie. Charlie's condition is "sporadic", not hereditary. The chance of his parents having another baby with the disease are no greater than those present in the general population (five to seven per million live births). The embryos created by the Charlie's parents were not likely to have the same defect as Charlie. The HFEA in England therefore rejected the application on the basis that the embryo testing procedure would be performed *solely* to find a match for Charlie and not to check whether the embryos themselves carried a genetic disorder.

The same result would be reached under the NECAHR guidelines in New Zealand, because of the requirement that there be a 25-50 per cent risk that the embryos to be implanted carry the disease. Because there is no "benefit" to the embryos by testing, permission would be denied. Yet, if those embryos were to be tested and found to have a disorder, they would be destroyed or used for research. Is it really a "benefit" to be destroyed? If benefit to the embryos is the basis for distinguishing Charlie from Zain, we should ban all PGD. The embryos that "benefit" are those that do not have a genetic disorder and are then implanted. From this perspective Zain's and Charlie's situations are therefore the same and should be treated as such.

Overriding principles

Section 4 of the Act sets out principles to guide decisions in situations like Zain and Charlie's. These principles are all things to all people.

In s 4(a) the health and well-being of the "saviour siblings" is an important consideration and some may say that

their health and well-being is at risk because they were created as a means to saving others. But are children ever really created as an end in themselves? They are often conceived accidentally or to save a flagging relationship or so that little Johnnie can have a brother or sister or because two people simply want to be parents. We do not ban the creation of children in these situations. There is no clear evidence their health and well-being suffers.

In s 4(b) the human health, safety, and dignity of present and future generations should be preserved and promoted. Zain and Charlie are of the present generation — their health will be promoted by the creation of "saviour siblings".

In s 4(f) the needs, values and beliefs of Maori are to be considered and treated with respect. In Zain and Charlie's cases, treatment would be performed by removing cord blood from the umbilical cord of the "saviour sibling". If the umbilical cord is seen as a taonga and subject to special treatment that must be respected when Maori families are involved.

In s 4(g) the different ethical, spiritual and cultural perspectives in society are to be considered and treated with respect. Those who share Ms Quintavalle's beliefs would want the least interference with the human embryo. Others will see no problem with using medical science to test embryos for a range of conditions. There is no simple knock-down argument to show who is right between these two groups. In New Zealand NECAHR (an ethics committee) will decide what they think is right.

Conclusion

Zain and Charlie are very sick children. There is a medical procedure available which their parents want to use to create children with the right genetic material to make Zain and Charlie better. Do we really need the edifice of an Ethics Committee to make fine distinctions between whether the testing of the embryos is solely to find matching cells or to eliminate a genetic disorder (with the ancillary but desirable outcome of finding matching cells)?

There are major moral dilemmas involved whenever a child is concerned. Should this couple have a child? Are they able to be good enough parents? Have they thought about the well-being of the child? Yet we do not have regulatory ethics committees in every home, checking to see that all children are conceived as wanted children. It would certainly be an interesting job!

The future Zains and Charlies will certainly appreciate having a brother or sister whose cell donation can improve their health dramatically. The real moral issue here is whether PGD will be available on an equitable basis or will it only be available to those who can afford it??

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2 *Quintavalle v Human Fertilisation and Embryology Authority* [2005] UKHL 28.

3 Part 1 of the Act came into force on 22 November 2004. The rest of the Act comes into force on 21 August 2005.