

Creating a life to save a life? Reflections on the conception of “Saviour Siblings”

A lecture presented by Professor Eric Blyth, Professor of Social Work, School of Human and Health Sciences, University of Huddersfield, United Kingdom at the Faculty of Medicine, The University of Hong Kong on 2 June 2005.

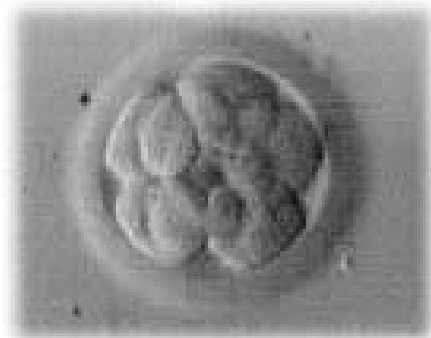
“Saviour Siblings” is a relatively new term. It refers to children whose conception is – at least partially – motivated by the desire of their parents to secure human stem cells to provide treatment for an existing child with a life-threatening illness.

Preimplantation genetic diagnosis (PGD) is an essential step to ensure that the embryo to be implanted to the woman’s uterus is free from the genetic illness that the existing child has. It involves the removal of one to two cells from an embryo created *in vitro* at 8-10 cell stage – about three days following fertilization. DNA from cells derived from biopsy is tested for specific genetic conditions.

Alternative are available to couples knowing they are at risk of conceiving a child with a severe genetic condition for which there is a family history. They may forgo conceiving children with blood ties and pursue parenthood via adoption. There is also the option employing collaborative reproductive procedures such as sperm, egg or embryo donation or surrogacy with the “genetic illness-free” parent being the genetic parent of the child.

Women could also undergo prenatal diagnosis (PND) following conception (fetal testing during first or second trimester of pregnancy). However, there are two considerations here.

One is the risks inherent in the procedure itself. The other is the decision whether to terminate the pregnancy of an affected fetus. PND is well-established and some women have repeatedly terminated pregnancies in an attempt to conceive a child free of the genetic illness in question.



“Removal of 1 to 2 cells from an embryo created in vitro at 8-10 cells stage - about three days following fertilization. DNA from cells taken from biopsy is tested for specific genetic conditions.”

There is certain advantage of embryo screening (PGD) over fetal screening (PND). With PGD, a woman will know from the beginning of her pregnancy that her baby is affected or unaffected by the genetic condition being tested. With such information, the women may decide whether to continue or to terminate pregnancy. Therefore, for physical, psychological and ethical reasons, PGD may be a preferable option.



“PGD is preferable over PND for women to conceive children at risk of having genetic disorders.”

The first application of PGD was first reported in 1989 and, by now, it is currently used to detect over a hundred genetic conditions. The most common uses include (a) diagnosis of single gene conditions e.g. cystic fibrosis, thalassaemia, and spinal muscular atrophy, and (b) determination of sex of an embryo, which has medical application for sex-linked conditions e.g. Duchenne’s muscular dystrophy and haemophilia. The ability to determine the sex of an embryo raises ethical issues on the possibility of using or discarding an embryo simply on the basis of whether it would become a boy or a girl.

PGD together with Human Leucocyte Antigen (HLA) typing (“tissue typing”) could ensure that the embryo is unaffected by a genetic condition(s), but also ascertain that the child would be a tissue-matched donor for an existing affected sibling requiring stem cell transplant. Since the same biopsy undertaken for PGD can be used to test for tissue typing, the embryo is exposed to no additional risk.

Donation of cord blood stem cell is non-invasive, and there is no postnatal intervention involving the “saviour sibling”, and therefore, incur no risk of physical harm.

“Optimum transplant results are obtained from sibling donors.”

A Tale of Two Cases: Hashmi and Whitaker

The Hashmi

The Hashmi couple has five children of which their fourth child, Zain, has β -thalassaemia. The child requires infusions of blood and medications for 12 hours daily. His only hope of long-term survival is a stem cell transplant from a disease-free, tissue matched donor. Since there is a family pre-disposition to β -thalassaemia, Mrs. Hashmi underwent prenatal testing when she was pregnant with the child, but this results gave a false negative. As none of the

child's three elder siblings are potential donors, Mrs. Hashmi subsequently conceived a fifth child but prenatal testing showed the fetus also had the genetic disease so the pregnancy was terminated. She later conceived again. Her new son was unaffected by the disease, but was not a suitable tissue match for Zain.

The U.K. regulatory body, the Human Fertilisation and Embryology (HFEA) gave permission for the Hashmis to proceed with PGD and tissue typing. However, the decision of the HFEA was challenged in the English courts on the grounds that it had no authority to approve PGD and tissue typing.

Dilemmas faced by parents who have a child with a life-threatening genetic condition.

The choice between:

◆ *Decide to take no further risks of a pregnancy, so reducing significantly the chance that a donor would be found for their existing child.*

Or

◆ *Try to conceive another child. If prenatal testing indicates that the child also has the condition, then, the options would be to terminate pregnancy or to give birth to a child whose future health would be in doubt. Misdiagnosis could result in birth of another child with the condition. Omission to perform tissue typing would result in a child who is free of the condition, but is not tissue-matched with the affected elder sibling.*

The Whitaker

Charlie Whitaker has Diamond-Blackfan Anaemia, requiring extensive medical treatment for survival. His only hope of long-term survival is a stem cell transplant. However, his sister is not a tissue-matched.

In contrast to Zain Hashmi, Charlie Whitaker's condition results from a spontaneous genetic mutation and is not hereditary. The HFEA rejected the Whitaker's application for tissue-match only without using PGD for a causative gene. The reason behind the rejections are (a) permitting tissue typing solely to ascertain an embryo's suitability as a potential tissue match undermine its argument in the Hashmi case, and (b) unknown risks of biopsy on an embryo which would itself obtain no therapeutic benefit from the procedure. Therefore, the Whitakers went to the Chicago as a last resort to have tissue typing. Jamie Whitaker was born in June 2003, and Charlie has been successfully treated using stem cells from Jamie's cord blood. In 2004, the HFEA relaxed its policy and permitted tissue typing only i.e. the test it had prevented the Whitaker to use.

Ethical arguments against conception of “saviour siblings”

There are three ethical arguments – wrongful instrumentalization of the child, slippery slope and welfare of the child.

Wrongful Instrumentalization

Wrongful instrumentalization of the child is based on the premise that children should be wanted for their own sake. The notion of wrongful instrumentalization embraces both the idea of selecting the characteristics of children and conceiving them to serve the ends of others. The conception of the “saviour siblings” leads to its being used as a tool, albeit for good ends. If a “saviour sibling” is conceived, s/he must also be treated as an individual in his/her own right. According to Immanuel Kant, it would not be acceptable if the only reason for conceiving a “saviour sibling” was to provide a source of stem cells with which to treat an existing child.

Slippery Slope

There are a several concerns about creating a slippery slope with the conception of “saviour siblings”. What is to stop the conception of entities such as “saviour sons” or “saviour daughters”, etc? Where the line would be drawn – if at all – at the persons in whose favour the proposed donor child is conceived?

“There are three ethical arguments – wrongful instrumentalization of the child, slippery slope and welfare of the child.”

If conception of “saviour siblings” for the donation of cord blood stem cells is permitted, what is to stop donation ending there? There may be an inevitable situation where the donor child will be expected to “donate” bone marrow in the event that the umbilical cord stem cell transplant fails or the sick sibling relapses and requires further treatment.

Given the technology is mature, what is to prevent the conception of children on the basis of other “desirable characteristics e.g. eye colour, hair colour, IQ, personality, etc.

“However, the slippery slope is not inevitable.”

However, the slippery slope is not inevitable. Regulatory bodies in different countries should develop and implement guidelines as to what applications of PGD are and are not permitted after giving due considerations on potential ethical and social implications.

Welfare of the Child

Welfare of the child encapsulates physical and psychological well-being.

There are no current indications of physical harm to the “saviour sibling” at least in the short-term. As for psychological well-being, there is much speculations on both harm and benefits.

There are several factors which may contribute to potential harm to the donor child.

Possible misdiagnosis would make the intended “saviour sibling” afflicted with the genetic condition or unsuitable as a tissue-matched donor. There is the possibility that the donor child’s welfare might be subordinated to that of the older child. A potential consequence is that the donor child may find out that s/he was wanted not for herself, but as a means to save the life of his/her sick sibling. High expectations from the donor child will also cause undue psychological harm. If cord blood transplant failed, the child may be blamed for not fulfilling expectations, especially if the older sibling dies. Alternatively, there may be pressure to donate bone marrow for subsequent transplant.



“There are no current indications of physical harm to the “saviour sibling” at least in the short-term. As for psychological well-being, there is much speculations on both harm and benefits.”

“Saving the life of the existing sibling is also in his/her best interests. This will ensure a happier family (e.g. no grieving parents) from which s/he will benefit.”

While there is potential harm, it is not without potential benefits to the “saviour sibling”. The donor child might derive pleasure from knowing that s/he has saved his/her sibling’s life and would benefit from the saved child’s company. In this respect, it is appropriate to consider the welfare of the donor child within the context of the family since his/her social, emotional and psychological interests depend on the welfare of his/her family.

Saving the life of the existing sibling is also in his/her best interests. This will ensure a happier family (e.g. no grieving parents) from which s/he will benefit.

Conclusion

In summary, there are some necessary conditions for the conception of the “saviour sibling”:

1. Requests should be made on a case-by-case basis. The system must be able to deal with requests expeditiously.
2. Condition of the sick child needs to be sufficiently severe or life threatening, and there should be a realistic chance that treatment will be successful.
3. Embryo should not be genetically modified to provide a tissue match.
4. All realistic alternative treatments and sources of tissue should have been investigated.
5. Parents should be given clear and accurate information about all aspects of proposed procedures, including realistic information about possible treatment outcome.
6. Prior discussion of parents’ attitudes towards “saviour sibling” and how these might be affected by the outcome of treatment.
7. Prior discussion of consequences of an unsuccessful outcome for the parents, the “saviour sibling” and other members of their family.
8. Potential physical and psychological risks to the “saviour sibling” should be assessed. Long-term follow-up should be undertaken. However, families need to be allowed privacy and normal ethical requirements for voluntary and informed participation in research must be maintained.
9. On-going, long-term support should be provided, whatever the outcome of treatment.

Reporter and Photographer: Simon Lee, Medical Ethics Unit, Faculty of Medicine, HKU (sbhlee@hkucc.hku.hk).

Photograph of embryo taken from Professor Eric Blyth’s presentation.