BBC NEWS

Should baby be risked for sister?

By Vivienne Parry
Radio 4's Inside the Ethics Committee

Catherine is a little girl condemned by genetic disease to a gruelling regime of treatment.

She could be released from it by a sibling, but the sibling is not yet conceived.

And can one child's health ever be put at risk to save another's?

When Catherine, the first child of Charles and Clara, was born in 2001, she seemed healthy - but not for long.

"She was very listless and would fall asleep in the middle of a feed," said her mother.

"When she was 11 weeks old, she was pretty much pure white, you couldn't even see her lips. We took her into A&E."

Tests revealed that Catherine had virtually no red blood cells.

She was eventually diagnosed with Diamond Blackfan Anaemia (DBA), a genetic disease in which few if any red blood cells are produced by the bone marrow, producing anaemia.

DBA can be treated with day long monthly transfusions.

However, every transfusion adds iron to the body which will cause irreversible organ damage unless removed.

Removal involves giving a drug given as a continuous transfusion through a needle, all through the night, five nights a week.

"Catherine hated it, screaming 'I don't want it, I don't want it'," said Clara.

"She got used to it, but often said: 'Why can't I be normal'."

Risk of early death

DBA carries a one in four chance of early death because of organ damage and an increased risk of childhood cancer.

"Once we saw what her quality of life was and the problems that she might have in the future, we started saying is there something else we can do?", said Clara.

A bone marrow transplant was the only option.

One from an unrelated donor carried up to a 30% risk of death for Catherine, one from a related donor a 5% risk.

Charles and Clare had intended having another baby anyway and hoped that a baby brother or sister would be a tissue match.

With each pregnancy there is the same one in four chance of a match.

But it is possible to use a technique normally used in pre-implantation genetic diagnosis (PGD), in which a cell from the three-day-old embryo is taken to screen out serious genetic disease, for tissue typing, to guarantee that a sibling is a tissue match, before being replaced.

The uncertainty of IVF gives a one in 10 chance of successful pregnancy with such a match.

Spontaneous mutation

There was however a major problem: DBA can be inherited or arise as a spontaneous mutation.

Which sort did Catherine have?

This is not preventing harm to a child, this is creating a sibling for someone else - is that sufficient moral reason to go ahead?
Deborah Bowman
Kings College Hospital

There was no family history of the condition. Tests on Catherine showed she didn't have any of the known mutations that cause DBA, but there are some as yet uknown.

It meant that no-one could test whether another baby had the condition or not.

Not being able to rule out DBA was a major ethical issue.

So Clara and Charles decided to have a baby naturally. But the new baby wasn't a match.

By this time, Catherine was three and the couple were acutely aware that her condition was deteriorating.

She had to have a transplant before she became too sick to survive the procedure.

They decided to go for tissue typing. To do this they needed to have a licence from the Human Fertilisation and Embryology Authority.

But at the time, the HFEA only allowed PGD to be used for tissue typing where a disease could be screened out. This was not possible in Catherine's case.

So the couple went to the US, where it was permitted. But two attempts failed.

They were psyching themselves up for a third attempt, when they read about a UK couple in the same situation as themselves, who had been given a licence by the HFEA following a judicial review.

They decided to try for a 'saviour sibling' using PGD.

Devastating blow

The procedure of taking stem cells for a bone marrow transplant would not harm Catherine's sibling, because they could be obtained from cord blood at birth.

When baby sister, McKenzie was born, not enough stem cells could be collected for a transplant.

It was a devastating blow - but at least she was free from DBA.

"Every picture I took of them together had added meaning because Catherine was looking at her lifeline," said Clara.

A much more invasive collection of bone marrow from McKenzie involving 90 minutes of general anaesthesia was now required.

There is no benefit to the donor, and McKenzie was not able to provide consent.

The chances of success for Catherine were getting less as time went on, but the younger McKenzie was, the greater the risks of anaesthesia for her.

Competing interests

Here the ethical issues are the competing 'best interests' of the sisters.

There is also the issue that the donation will only cure Catherine's symptoms, not rid her of the condition.

There is a good chance it could fail. How would McKenzie feel later knowing that her donation failed to save her sister?

And should Catherine's kidneys fail, then once again, McKenzie would be the first choice of donor.

The Clinical Ethics Committee decided that the bone marrow transplant should go ahead. It took place 18 months ago.

It was a success and Catherine continues to do well.

*The case will be discussed on Inside the Ethics Committee will be broadcast on Wednedsay 6 August at 2000 BST on BBC Radio 4, and for seven days on **BBC iPlayer***

Your Comments:

As a mum, I feel for the couple. I would chop my own legs off for my daughter if it came to saving her life. However, I don't think "saviour siblings" are ethical or fair on the child being born to "save" the other. They have no say in what is done to their body for someone else's benefit. Why should a healthy baby have to go through that? At what point do they get the right to say no?
Karen Reekie, London, UK

It's disgusting that anyone can be forced to be a donor of any part of their body without their consent. If I found out that my parents had used me in that way I would be full of loathing for them. The "saviour sibling" is being put at risk, for no benefit to themselves, before they can even understand what's going on. Babies are people, not raw materials.
Gabriel, Leicester, UK

If I had a child with Diamond Blackfan Aneamia,or any other fatal childhood illness, I would try everything to cure him or her and I'm confident it'd be the same with any parent. Realistically if someone told you there was a cure for your dying child you'd take it, regardless of the sketchy ethics involved. In regards to the point that this will not "cure" Catherine it is important to note that the symptoms themselves are incredibly dangerous. It is like arguing against Chemotherapy which doesn't cure cancer, but instead treats the symptoms.
Ryan Mclean, Leeds, UK

As a bone marrow donor myself, I find this dilemma interesting and heartbreaking at the same time. I cannot imagine the impossible situation these parents found themselves in. However, I do find it hard to accept that it is moral to "produce" a child to order, to save another, reducing its status to that of a laboratory animal. The risks to the donor child are great, and there is the chance of losing both of them. If a donation goes ahead and fails, the parents are left with trying to love the donor child without allowing the failure to cloud their feelings. I wish the whole family continued good health and hope other cases are small in number.
Julie Fenwick, Gateshead, UK

Faced with the same situation, I would have pursued the same course of action. Mckenzie would never feel bad if things turned out differently to expectaions. It is better to know that you saved your sister

from certain death, or at least tried to do something for her. Ethics are there but they do not always put things into pespective.
Jessica m Thole, Lusaka, Zambia

This is a really difficult matter. I do not honestly know how I would decide. Yet I know that as long as one believes in the individual and his or her rights, it cannot be right to have another child only to save the first one. The difficulty arises in the fact that this is never the only reason. If Catherine is doing well, if the treatment was a success, then the justification for the procedure is there - but too late! If the sibling is willing to help (and able to understand this), then there is no problem. But the parents must realise that the sibling is not just a source of aid.
D. Fear, Heidelberg, Germany

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