

Is conceiving a child to benefit another against the interests of the new child?

M Spriggs

Saviour siblings are not harmed

An application of in vitro fertilisation (IVF) allows parents to select an embryo free from serious genetic disease and simultaneously select for a tissue match so that the umbilical cord blood of the resulting baby can provide stem cells to treat a seriously ill sibling. The procedure which involves preimplantation genetic diagnosis (PGD) together with tissue typing has been carried out successfully in the USA, where private fertility clinics are unregulated, and has been approved in Australia and the UK.¹⁻⁴ The procedure is generally justified on the grounds that it benefits the new baby by selecting against a hereditary disease.

REQUEST FOR PGD AND TISSUE MATCHING REFUSED

In August 2002, the UK's Human Fertilisation and Embryology Authority (HFEA) refused a request for PGD and tissue matching by Michelle and Jayson Whitaker, the parents of Charlie, a child suffering from Diamond-Blackfan anaemia.⁵ The request was refused because the HFEA will only allow a cell to be tissue typed if it has been taken to test for illness. As there is no genetic test for Diamond-Blackfan anaemia, "it could not be argued that PGD was necessary to select embryos free from the condition".⁵ Charlie, the Whitaker's existing child, but not the new baby, would benefit from the procedure.⁷

Diamond-Blackfan anaemia is a rare condition that requires painful treatment. Charlie requires blood transfusions and painful daily injections to keep him alive. The only cure is a transplant of stem cells that are a perfect tissue match.⁷ The Whitakers had a one in four chance of naturally conceiving a child who would be a match for their sick child but that could be increased to around 98% with PGD and tissue typing.⁸

JAMIE WHITAKER, A PERFECT MATCH SIBLING, IS BORN

After the HFEA refused the procedure, the Whitakers sought treatment in the USA at the Reproductive Genetics Institute in Chicago, Illinois. Michelle

Whitaker has now given birth to a baby named Jamie, who was genetically matched to their existing child, Charlie.⁴ Tests have shown that the baby is a perfect match but further tests are needed to see if he is free of the disease.⁹ There is a small chance, a one in fifty chance, that Jamie may have the disease. The Whitakers must wait six months to know for sure.¹⁰

"DESIGNER BABY" DEBATE RE-IGNITED

The birth of Jamie has re-ignited debate about babies created to help their sick siblings. According to the father of Charlie and Jamie: "All we did was change the odds from a one-in-four chance of a tissue match to a 98% chance".⁴ The British Medical Association has "applauded" the Whitakers' actions:⁷

As doctors we believe that where technology exists that could help a dying or seriously ill child, without involving major risks for others, then it can only be right that it is used for this purpose.

The welfare of the child born as a result of the treatment is of crucial importance. But in our view this is not incompatible with allowing selection of embryos on the basis of tissue type.

Jayson Whitaker's comments give weight to the BMA's view; that allowing PGD with tissue typing is not incompat-

ible with the welfare of the child created. After Jamie's birth, he said, "There are blood tests being carried out now to see if Jamie is a perfect tissue match and we will know in a few days, but at the moment we don't want to think about the stem cell blood." He also said: "The night before [Jamie] was born I didn't even care about the cord blood. I just kept thinking, 'I hope he's all right.'"¹¹

Opponents of the technology argue in terms of dignity and the idea that using the new child for the benefit of another is morally objectionable. According to John Smeaton, director of the Society for the Protection of Unborn Children³:

While our hearts go out to everybody involved, and we welcome Jamie Whitaker's birth, there are profound issues of concern here ... Human beings who were not the perfect match were simply discarded and a child has been created with the primary purpose of benefiting this elder brother. This does not conform to Jamie's human dignity.

Britain's fertility pioneer Lord Winston opposes the treatment and asks: "Can you think of any other medical treatment which you would expect anybody to undergo without informed consent for somebody else's benefit?" He also raises concerns about the position of a child such as Jamie Whitaker: "This child has the spectre of being born for somebody else's benefit throughout his whole life."⁷

It is worth looking at arguments opposing the creation of Jamie Whitaker more closely to see if they reveal something not compatible with his welfare or whether some moral principle has been transgressed.

HUMAN DIGNITY

First of all, it is not clear how Jamie's "human dignity" has been or will be compromised or why his dignity is of such magnitude that it is more important than his brother's life. We have to

Abstract

Conceiving a child by way of embryo selection and tissue matching to benefit a sick sibling is generally justified on the grounds that as well as the potential to save the sick child, there is a benefit for the new baby. The new baby is selected so he or she will not have the disease suffered by the first child. It is not possible, however, to select against conditions for which there is no test and Jamie Whitaker's birth is a case where the process of in vitro fertilisation with tissue matching is viewed as being of benefit only to a third party—the sick child. Some people object to using the technology for this purpose. There are also good reasons to argue that the technology should be used to save a sick child, and that it would be morally remiss for Jamie's parents not to consent to the use of his cord blood.

wonder what this notion of dignity consists of and whether it is something that should be protected at all costs. It might be thought that Jamie is harmed if his dignity is violated or compromised and the moral significance of the harm hinges on the fact that Jamie was created to make some kind of sacrifice—that in resorting to PGD and tissue typing, the Whitakers have taken something from Jamie or compromised him in some way. And the thing that is missing or compromised is his human dignity. As we can see, there is a kind of circularity in arguments which defend human dignity and it is not clear why the protection of this vague notion, the value of which seems unable to be clearly articulated, should trump the life (and presumably the dignity) of another child. Appeals to human dignity tend to be based in religion—not in reasoned argument.

We might think that those who are concerned about Jamie's human dignity would support therapeutic cloning if that could provide the stem cells Charlie needs. The Whitakers would not need to create an extra child—although if they wanted another child they could still have another child and without being criticised for compromising the child's human dignity. Nevertheless, recommending therapeutic cloning is unlikely to appease all critics of PGD and tissue typing. Concerns about human dignity are likely to resurface in relation to the destruction of embryos in the cloning process. In other words, appeals to human dignity reduce to an argument for the moral standing of embryos. Appeals to human dignity are very often religious views in disguise.¹²

LACK OF CONSENT

Lord Winston's concern about lack of consent distracts us from more important issues. The lack of consent is not morally significant in this case. Newborn babies are simply not equipped to give consent. Jamie's parents have the authority to make decisions for Jamie and for his cord blood. Unless donating Jamie's cord blood is not consistent with his welfare there is no reason to challenge their decision.¹³ Taking stem cells from the umbilical cord poses no risk and no inconvenience

to the new baby. Nevertheless, some people might think it morally problematic that the intervention is for the sake of a third party and they might think Jamie's parents have a conflict of interest. Generally we don't allow medical interventions to be carried out on one person for the sake of another but when we think of medical interventions we usually think of procedures that are invasive and risky, or at the very least inconvenient. But that is not the case here. Not even a hair on the head of the new baby has been touched. Lord Winston's question about comparable situations, about undergoing treatment for someone else's benefit without informed consent, is easy to answer. If comparable situations exist, they should proceed—even without informed consent. A comparable situation might be—using a stored tissue sample to assist someone suffering from a life-threatening condition.

CONCLUSION

The interesting thing about this case is that it demonstrates that there is more than one kind of situation in which a parent's consent on behalf of their child is justified. Consent is sometimes considered valid only when the intervention consented to "serves the best interests of the child" but there is another situation where consent is within acceptable limits. Another standard is consent to an intervention that is "not against the interests of the child".¹⁴ Parental consent for some non-therapeutic research on children fits this category—for example, allowing extra blood to be taken during diagnostic or treatment procedures for "legitimate research purposes" involving no additional risk or discomfort.¹⁵ In a situation that requires an intervention involving no sacrifice and no inconvenience by one child to save the life of another child, parental consent is morally acceptable. It may even be morally required.

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Response to Spriggs: Is conceiving a child to benefit another against the interest of the new child?

M Delatycki

Preimplantation genetic diagnosis—the risks are unknown and human dignity could be compromised

Merle Spriggs argues that there are no good reasons to prevent a couple utilising preimplantation genetic diagnosis (PGD) when the sole aim of the procedure is that the resultant child is a compatible umbilical cord blood donor for a sick sibling.¹ I agree with much of the argument to support this, however, I believe Spriggs has omitted one important point and underplayed another.

The risk of PGD to the child born as a result of this process has not been fully studied. Therefore the parents are exposing the child to potential risks without benefit to that individual. This differs from the situation where PGD is done and a genetic disease is excluded as well as tissue matching. In this instance, the child benefits from being free of a genetic disease and also can act as a cord blood cell donor to his or her sibling.

What is known of the risks of PGD? PGD involves in vitro fertilisation (IVF) and intracytoplasmic sperm injection (ICSI) and much more is known about the risks to a child born as a result of

IVF and ICSI. More than 4000 PGD cycles have been performed resulting in 1416 PGD embryo transfer cycles in Chicago plus 1670 transfers at other centres.² This has resulted in 338/1416 (23.9%) and 309/1670 (18.5%) clinical pregnancies and 539 children being born who are unaffected by the condition tested for. Importantly, multiple pregnancies occurred in about 33% of these. On the basis of these very small numbers there have been no deleterious effects attributable to PGD. IVF and ICSI have been studied extensively and a number of the negative outcomes exceed rates seen in naturally conceived pregnancies.³ These include risks associated with multiple pregnancies, prematurity, in utero growth retardation, and disorders of imprinting, particularly Beckwith–Wiedemann syndrome.⁴

An area I believe Spriggs has dismissed too lightly is “human dignity” and the assertion that “appeals to human dignity tend to be based in religion—not in reasoned argument”.¹ Suppose the sick sibling receives the umbilical cord cell transplant from the

child born after PGD but dies despite this. In this situation it is conceivable that their family would mistreat the child who donated the cells as a result. It is possible that the child would be blamed for his or her sibling’s death. This is not a religious view of human dignity as suggested by Spriggs, but a view of possible parental psychological responses in an unusual situation.

At the end of the day, where a child will die without a haemopoietic stem cell transfer and no matched donor is available, my view is that the process outlined in the case of the Whitaker family¹ should be allowed to proceed. It is important, however, that the parents of the sick child contemplating PGD are aware of the potential risks to their planned offspring. It is also essential that they receive appropriate counselling to explore issues of the donor child’s place in their family.

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