

## Commentary

# A moral case study for discussion: designer babies and tissue typing

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### Abstract

We discuss the ethical aspects of designer babies in an answer to Dr Martin Johnson's commentary.

**Keywords:** *designer babies, ethics, pregnancy termination, preimplantation diagnosis, prenatal diagnosis*

The strong social effort to promote health led to the permission of pregnancy termination, prenatal and preimplantation diagnosis, although these are not intended to correct a defect but terminate the life of an embryo or fetus. Preimplantation diagnosis is considered to be a major advance as the object of selection is the affected preimplantation embryo and not the fetus. In 1997, we established the technique in Portugal, and now it is recognized for implantation failure, recurrent abortion, cases whose parent background confers an increased risk of transmitting a severe, potentially fatal or disabling disease to their children, and HLA selection when sick children have no other source of transplant.

However, society may decide that ageing, cancer, respiratory, cardiovascular, nervous, immunological, rheumatological, metabolic, endocrine and other diseases, be included. This will come as new gene-causing defects are established and genetic conditioning enable a better outcome when facing the effects of education, habits and the ambient. This will also include tissue typing for future availability of transplants, as intended to correct a defect and save a life. We also predict that society will allow selection of advantageous characteristics, such as longevity, beauty, stature, sex, physical power, emotional and technical intelligence and skills. In fact, we are a product of technological dominance and transformation over nature, including basic life events such as water supply and quality, food, clothes, housing, sewage, refrigeration, education, disease prevention and health assistance. It is thus correct to admit that the ultimate goal will be an improved species. Simultaneously, our societies have consolidated democracy and thus these changes should remain a free matter of choice. Finally, our societies have established as a human right the equal access to health and thus those indications should be available to all and if impossible to afford, no one should be an exception.

Personally, we believe that instead of selecting we should accept, understand and correct, as we do with living beings. In that eutopic society, families would freely wish not to use prenatal diagnosis and pregnancy termination, nor preimplantation diagnosis. In this case, families with disabled

and sick children would need a very well organized social assistance, research and treatments would be focused on genetic cures, and human evolution would stay outside eugenics.

However, in the real society we live with, many families prefer the free use of prenatal diagnosis and pregnancy interruption, as well as preimplantation diagnosis, because they do not want to have a disabled or sick child. For those, we professionally respect their individual choices and thus we agree that all types of selection should be allowed if directed to do no harm to others.

We presented this special case to medical students, psychologists, biologists, internists, geneticists, forensic doctors, social assistants, lawyers and judges. They all indicated that this case should not be allowed, based on the following major points: selection of a preimplantation embryo or fetus should be restricted to known severe pathologies; tissue typing of brothers would impose a moral constraint in case of transplant need; it would aggravate economic differences, as it would be impracticable by the state in the case of a large populational request; and it would open an irrefusable request to other types of selection.

Technically, we do not agree with these points of view. First, any pathology is undesirable, and thus why not to prevent other less severe cases? Second, families in general behave to protect each member, and thus moral constraints already exist and do not interfere with a final individual decision. Third, these special cases are not related to basic healthcare assistance and social inequalities are already the present rule in our societies. For example, in our present days some families have superb housing and cars whereas others do not, but everyone accepts this as a normal thing. Fourth, we should not have a fear of opening the era of human genome manipulation, as it may be necessary to scale up the evolution of humankind and secure the survival of our species, while it is not expected this will decrease populational diversity. Finally, the important thing is that all the choices be made on a free basis (not imposed by the State or others) and always directed to do no harm to others.

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## Reference

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# Commentary

## Babies by design: a response to Martin Johnson's moral case study on tissue typing

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### Abstract

This commentary was written in direct response to the moral case study on designer babies and tissue typing published in the October issue of *RBMOnline* (vol. 9, no. 4, p. 372). It adds another viewpoint to a difficult ethical conundrum.

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Fortunately, I am not a clinician. Hence, I can spare myself the embarrassment of conveying to Mr and Mrs Smith that according to the rulings of the Human Fertilisation and Embryology Authority (HFEA) I am not permitted to comply with their request. However, suppose the case of the Smiths is brought before the clinical ethics advisory committee as most cases are these days. Having been a member of various ethics committees, I can easily imagine the reactions of its members. The medical doctor would probably say: 'Assisting the Smiths would be indefensible. After all, there is simply no medical indication that would justify performing a preimplantation genetic diagnosis (PGD) for tissue typing.' The lawyer would remind us that the Smiths' petition requires the creation and destruction of early human life: 'Although human embryos may not be entitled to the same moral and legal protections as human persons, they ought to be accorded some respect in virtue of being human life. Creating and destroying a perfectly healthy embryo simply because it does not qualify as a potential source of donor cells decidedly vilifies the value of human life'. And, finally, the progressive theologian, deliberately avoiding any talk of 'God' or 'Divine Providence', will possibly appeal to Immanuel Kant's famous 'Categorical Imperative' and insist: 'Human beings are ends in themselves. They must never be treated as a mere means to someone else's ends. Allowing the Smiths to select embryos which could, one day, serve as a stem cell donor for one of their siblings, would clearly violate the moral respect that is owed to each and every human being.'

As far as I can see, none of the objections is conclusive. Do the Smiths really lack a medical indication? Obviously, the answer entirely depends on what we mean by medical indication. Strictly speaking, a medical indication requires that an individual undergoing a diagnostic or therapeutic procedure has a condition that calls for medical help. According to this definition, the Smiths certainly lack a medical indication. Neither the mother undergoing IVF nor the embryo subjected to PGD have a condition that calls for medical help. It is important to note, however, that on this definition, numerous medical services currently offered are likewise rendered unjustified. If a medical procedure can only be performed on an individual suffering from a medical condition, we would, for instance, no longer be authorised to offer immunizations, live donations, intracytoplasmic sperm injections, or ultrasound-assisted liposuctions, to name only a few routinely performed procedures. More importantly, not even the HFEA-approved cases of PGD for HLA matching would meet the strict requirements of this narrow definition of a medical indication. Thus, we are inevitably prompted to adopt a much wider definition. However, once we use the term medical indication more loosely so as to accommodate currently offered procedures, it is virtually impossible to deny that the Smiths have a medical indication. After all, prevention is a generally acknowledged and fully legitimate end of medicine.

As to the second objection, is it morally impermissible to create and to destroy a perfectly healthy human embryo simply because it does not qualify as a potential stem cell donor?

Evidently, the answer depends on the moral and legal status we are willing to accord to human embryos. Fortunately, we do not have to get into a lengthy debate about this notoriously controversial issue. Given that the HFEA already permits the creation and destruction of human embryos to provide a tissue match for a family member, we only have to inquire whether the HFEA's decision to restrict the use of preimplantation tissue typing to couples having an afflicted child is ethically justifiable. The press release does not specify the HFEA's reasons for limiting the service of PGD for HLA typing. However, it can safely be assumed that its decision was based on the following consideration. According to the Warnock Committee, whose report led to the Human Fertilisation and Embryology (HFE) Act, the 'embryo of the human species ought to have a special status'. The special status requires that the HFEA sets a strict limit on the morally permissible uses of human embryos. In cases where the creation and destruction of human embryos is the only way to provide a life-saving treatment, the use of embryos may be regarded as ethical, if only as a last resort. Hence, while it is sometimes morally acceptable to use embryos to help children who *are* suffering from a life-threatening disease, it is morally unacceptable to do so to help children who simply *may* suffer from a life-threatening disease. In other words: the special status of the human embryo constitutes a claim which can only be overridden in the event of an *imminent*, not in the event of a merely *hypothetical* threat to life and limb of a person.

On the face of it, this looks like a persuasive argument. But is it? No! The Warnock Committee's statement that the embryo of the human species ought to have a special status never implied that human embryos may only be used for the purpose of saving lives. It merely implied that human embryos should 'not be used frivolously or unnecessarily'. Since preventing a child from suffering a life-threatening disease is neither frivolous nor unnecessary, the special status of the human embryo does in no

way rule out complying with the Smiths' request. Besides, treating the Smiths does not have to involve the destruction of human embryos. If only reluctantly, we could insist that we are only willing to offer tissue typing on the condition that the Smiths agree to donate the remaining embryos to infertile couples.

What about the third objection: Would Mr and Mrs Smith's future children really be degraded to a mere commodity and treated solely as a means to someone else's ends if they were only brought into existence after being tissue typed? I do not think so. Couples have children for all kinds of reasons – to give their life meaning, to enjoy watching them growing up, to provide a companion for an already existing child, to save a marriage, to run the family business, to take care of their parents once they become old and grey, or to perform the parents' funeral rites which are deemed to be sacramental. No doubt, some of the reasons may be more laudable than others. Still, the indisputable fact that couples ordinarily pursue their own ends in having children does in no way imply that their children are treated as a mere means. If we were to insist that children must never be conceived for a purpose, couples would not even be allowed to have children to extend their love for each other. More importantly, Kant's often quoted, yet highly elusive categorical imperative does not even apply in the case of the Smiths. Given that they are determined to have three more children anyway, these children are simply not used as a mere means to someone else's ends. All the Smiths are asking for is the permission to give their children the best possible start in life. If the Smiths' concern for the well-being of their future children is not an expression of the moral worth owed to each and every human being, then what is?

## Reference

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## Commentary

# Martin Johnson's moral case study: a reply

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When I read the case from Martin Johnson (Johnson, 2004) my first reaction was to say – yes, why shouldn't the mother go for preimplantation testing? I think, however, that

Johnson did not take into account another aspect that should be discussed under these circumstances.

What about the children who will discover that they are born to be a potential donor for any kind of tissue or organs? What is the pressure which is built up by the parents upon these children? Are the children really free to choose whether they want to donate organs or tissue to their siblings in case of a severe or malignant disease?

Of course it seems to be a clear situation from an ethical point of view: in the case that your brother or sister has a severe disease, you are prepared to donate – if you can. But every human is free to make this choice although this freedom is apparently lost in cases where one selection criterion before uterine implantation and birth is HLA testing. Until now the problems discussed by the Human Fertilisation and Embryology Authority (HFEA) as well as in the USA were related to donation of blood or even only umbilical cord blood. In this case in contrast, we talk about the potential to donate kidneys etc.

What will be the accusations against a child, who has been chosen for its HLA system but who declines to donate in the

case of a non-malignant disease suffered by its siblings, e.g. a case of alcohol toxic liver disease or cases of smoking-induced lung cancer? Or is there an obligation to donate organs or tissue?

I can understand and accept the parents' choice to test an embryo for the HLA system in case of a present disease of an already born child. However, with respect to the arguments listed above I cannot vote in favour of the presented case.

Ethics always come late. But we have to take care that they are not too late. We have to be careful with every step we take in such a direction. I would not take this forward step.

## Reference

Johnson M 2004 A moral case study for discussion: designer babies and tissue typing. *Reproductive BioMedicine Online* **9**, 372.