

This response was submitted to the call for evidence by the Nuffield Council on Bioethics on *Emerging techniques to prevent inherited mitochondrial disorders: ethical issues* between January 2012 and February 2012. The views expressed are solely those of the respondent(s) and not those of the Council.

Mitochondrial Donation: Ethical Issues - Call for Evidence

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1. Kinship Issues

Perhaps one of the most fundamental questions which arises from the use of Maternal Spindle Transfer and Pronuclear Transfer is the fact that more than two individuals are participating in the creation of human life. From this perspective, and although pronuclear DNA is extremely important in the creation of a being, it is impossible to just reduce the concept of creator parenthood to the persons who contributed to this DNA.

This is because without an emptied egg or fertilised egg from another couple, no new life would ever have existed. From an ethical perspective, pronuclei by themselves have no real value. They only become ethically meaningful if they are transferred into an emptied egg or fertilised egg and left to develop.

In this regard, all those participating in the process of creating life may be considered, in some form and to varying degrees, as the 'real' creators of the creature. They may then also experience some or all the corresponding aspects of parenthood bonds and mutual belonging which arise between creators and their creatures.

In the case of pronuclei transfer, it is not only what is being used that is important (and whether DNA, cytoplasm or any other material is considered) but the amount of individual participation in the creative process. A participation which could then also give rise to creator-creature (parent-child) bonds.

With natural reproduction, the 'real' creators and the DNA providers are the two same persons. However, with a number of new fertility procedures, such as the one being proposed by the Newcastle scientists, the identity of the 'real' creators becomes very complex and may vary quite considerably. Thus, a real risk exists that the future child may be confused as to the manner in which he or she understands who his or her creator parents really are. This may be important for his or her sense of identity.

A broad societal discussion concerning the relationship between being a creator and parenthood while trying to understand these parent-child bonds is, therefore, necessary when the creation of human life by novel means is contemplated. After all, it is because these creator-creature bonds are seen as extremely important by many couples that they are seeking fertility treatment and making sure that they have a child 'of their own'.

Thus, in addressing the issues raised by the regulation of assisted reproduction, it is very important to examine the deep bonds that exist between parents and their offspring. For example, many parents, as the responsible partners in the creation of life, know intuitively that they belong to the child and that the child, in receiving life, belongs to them, i.e., there exists a sort of mutual belonging.

The deep sense of loss or incompleteness felt by parents who are unable to be directly responsible for the creation of life in their child is an underlying reason that many seek assisted reproduction rather than adoption. In other words, the fact that prospective parent even consider, let alone undergo, expensive procedures for artificial reproduction indicates the importance they attach to the biology of creation. Such parents are aware, even if subconsciously, that the lack of biological connection may prevent them from feeling a sense of belonging with the child or the child with them.

It should also be noted that assisted reproduction is not risk-free for the woman giving the eggs since egg retrieval procedures may risk ovarian hyperstimulation syndrome following aggressive hormonal treatments¹.

In addition, it may be the case that parents who use dubious forms of assisted reproduction may be bringing a child into the world for their own sakes without fully considering what the wishes of the future child may be. That is, the child may want to have a relationship with all his or her biological parents. Though the social or chromosomal parents may concede to tell their child the truth when they are older, they would then have to understand that the child may wish to see and know his or her gametal parent(s) (the donor(s) of the eggs or the fertilised eggs) and express a sort of a 'love' or affection which he or she may already experience. The child may also experience difficulties towards his or her chromosomal or gametal parents with the possibility of feeling a sense of rejection.

Therefore, the possibility of promoting chromosomal transplantation in order to address mitochondrial disorders should not be envisaged until the two following issues have been satisfactorily addressed:

- the wish most couples express for a child of their own, and
- the important bonds that exist between the biological parents and the child.

2. Creation of Human Embryos for Research is Contrary to International Law

It is noted that in the case of Maternal Spindle Transfer and Pronuclear Transfer, embryos are being created, at this stage, solely for research purposes.

In addition, from a UK legal perspective, two further embryos are destroyed in Pronuclear Transfer to create a third, recombined embryo with new, healthy mitochondria.

This is because the **UK Human Fertilisation and Embryology Act 2008** defines an embryo in Article 1: (1) as:

- (a) *embryo means a live human embryo and does not include a human admixed embryo ..., and*
- (b) *references to an embryo include an egg that is in the process of fertilisation or is undergoing any other process capable of resulting in an embryo.*

The creation, however, of embryos through Maternal Spindle Transfer and Pronuclear Transfer would be contrary to international law if they are produced for research since the **Council of Europe** (47 Countries) **Convention for the Protection of Human Rights and Dignity of the Human Being with Regard To The Application of Biology and Medicine** (ETS – No. 164, Entered into force on 1 December 1999)² indicates that:

Article 18: The creation of human embryos for research purposes is prohibited.

In this regard, the Explanatory Report for Article 18 mentions that:

116. The article does not take a stand on the admissibility of the principle of research on in vitro embryos. However, paragraph 2 of the Article prohibits the creation of human embryos with the aim to carry out research on them. 3

¹ Delbaere, A., G. Smits, O. Olatunbosun, R. Pierson, G. Vassart, and S. Costagliola. New insights into the pathophysiology of ovarian hyperstimulation syndrome. What makes the difference between spontaneous and iatrogenic syndrome? Human Reproduction 19: 486-489, 2004.

² This is a legally binding document when ratified by a country. So far, 29 Member States have ratified this Convention with another 5 signing their intention to ratify. The UK has not signed or ratified this Convention.

3. Seeking to Modify the Genome of a Human Person Before he or she Exists is Contrary to International Law

Any intervention seeking to modify the human genome of a person before he or she is created is contrary to international law, including the two following legal instruments:

(A) The United Nations Education, Scientific and Cultural Organization (UNESCO) - *Universal Declaration on the Human Genome and Human Rights* (Adopted on 11 November 1997) indicates that:

Article 24: That 'germ-line interventions' could be considered as a practice that would be 'contrary to human dignity'.

(B) Council of Europe (47 Countries) - *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard To The Application of Biology and Medicine* (ETS – No. 164, Entered into force on 1 December 1999)³ indicates that:

Article 13 – Interventions on the human genome

An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants.

In this regard, the Explanatory Report for Article 13 mentions that:

91. Interventions seeking to introduce any modification in the genome of any descendants are prohibited. Consequently, in particular genetic modifications of spermatozoa or ova for fertilisation are not allowed. Medical research aiming to introduce genetic modifications in spermatozoa or ova which are not for procreation is only permissible if carried out in vitro with the approval of the appropriate ethical or regulatory body.

92. On the other hand the article does not rule out interventions for a somatic purpose which might have unwanted side-effects on the germ cell line. Such may be the case, for example, for certain treatments of cancer by radiotherapy or chemotherapy, which may affect the reproductive system of the person undergoing the treatment.

³ This is a legally binding document when ratified by a country. So far, 29 Member States have ratified this Convention with another 5 signing their intention to ratify. The UK has not signed or ratified this Convention.