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Should Mitochondrial Donation Be Anonymous?

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Currently in the United Kingdom, anyone donating gametes has the status of an open-identity donor. This means that, at the age of 18, persons conceived with gametes donated since April 1, 2005 have a right to access certain pieces of identifying information about their donor. However, in early 2015, the UK Parliament approved new regulations that make mitochondrial donors anonymous. Both mitochondrial donation and gamete donation are similar in the basic sense that they involve the contribution of gamete materials to create future persons. Given this similarity, this paper presumes that both types of donor should be treated the same and made open-identity under the law, unless there is a convincing argument for treating them differently. I argue that none of the existing arguments that have been made so far in favor of mitochondrial donor anonymity are convincing and mitochondrial donors should therefore be treated as open-identity donors under UK law.

Keywords: *anonymous, donation, gamete, gene, mitochondria*

I. INTRODUCTION

Currently in the United Kingdom, anyone donating gametes has the status of an open-identity donor. This means that, at the age of 18, persons conceived with gametes donated after April 1, 2005 have a right to access certain pieces of identifying information about their donor (United Kingdom Parliament, 1990, section 31ZA; HFEA, 2015a).[1] However, in early 2015, the UK Parliament approved The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015 (United Kingdom Parliament,

2015), which amend the Human Fertilisation and Embryology Act 1990 (United Kingdom Parliament, 1990). On October 29, 2015, these amendments came into force and allow the Human Fertilisation and Embryology Authority (HFEA) to license clinics to use two mitochondrial replacement techniques (MRTs) on humans: maternal spindle transfer (MST) and pronuclear transfer (PNT) (United Kingdom Parliament, 2015). The intent behind this legal change is to allow intending mothers to be able to clinically access MRTs in order to avoid passing on serious mitochondrial diseases to their genetically related offspring.[2] Although MST and PNT are different techniques, each requires the use of donor eggs from "mitochondrial donors" (as it is the healthy mitochondria from a donor's egg that is used in place[3] of the diseased mitochondria from an intending mother's egg). However, Regulation 11 of the HFE Regulations 2015 makes mitochondrial donors anonymous.[4] This paper considers whether or not mitochondrial donors should be treated differently from gamete donors and instead be given the status of anonymous donors under the HFE Act 1990 (as amended).[5]

Both mitochondrial donation and gamete donation are similar in the basic sense that they involve the contribution of gamete materials to create future persons. Therefore, this paper begins with the presumption that, given this similarity, mitochondria donors should be open-identity donors under UK law as gamete donors are. If regulators wish to treat mitochondrial donors differently under the law and make them anonymous, then a convincing argument must be provided to overturn the initial presumption that both forms of donation should have the same open-identity status. A "convincing argument" must explain both why the two forms are different and why this difference matters with respect to making donors anonymous or not. I argue that none of the existing arguments that have been made so far in favor of anonymity are convincing enough to overturn the above initial presumption of sameness. Therefore, throughout this paper, I argue that mitochondrial donors should be treated as open-identity donors under UK law in the same way that gamete donors are currently treated.

Although this paper is focused on discussing the status of mitochondria donors in the United Kingdom, many of the same key concepts, arguments, and debates that I discuss are also likely to emerge in regulatory debates surrounding mitochondria donation in other countries. As a result, the bioethical analysis in this paper is of international relevance to those working on both the ethics of mitochondrial and gamete donation specifically, as well as those with a general interest in reproductive donation and genetics.

This paper consists of five sections. First, a brief scientific overview is given to explain the nature of mitochondria, MRTs, and mitochondrial diseases. Second, I outline what I call the Quantity Claim and the Quality Claim. Each claim describes a type of biological difference between mitochondrial donation and gamete donation; however, I argue that neither claim is a sufficient reason for treating the two forms of donation differently. Third,

I consider the argument that both forms of donation should be treated differently because mitochondrial donors are not "third parents" and gamete donors are. I analyze this claim across several different interpretations of "parent" and find that there appears to be only a single instance where gamete donors might be considered "parents" and mitochondrial donors would not. It is then argued that this instance is not a convincing reason to warrant treating both donor types differently. Fourth, I consider the "sense of self" argument, which states that mitochondrial donation should be treated differently from gamete donation because being mitochondrial donor-conceived (MDC) will have less significance for an individual's sense of self than if an individual had been gamete donor-conceived (DC). I find that this argument is based on a number of mistaken views about DC persons and it is not a convincing reason for treating both forms of donation differently.

Finally, in the fifth section of the paper, I consider four arguments about why treating mitochondrial donors the same as gamete donors could bring about unwanted consequences: first, there might be a shortage of mitochondria donors if regulators require open-identity donation rather than anonymous donation; second, some parents may not want to use an open-identity donor and may therefore be forced to travel abroad for treatment in order to access an anonymous donor; third, requiring open-identity mitochondrial donation could "devalue" the contributions of gamete donors; and fourth, requiring open-identity mitochondrial donation reinforces the social attitude or view that donors should be seen as an important part of their children's lives when in fact regulators should be emphasizing the significance of the child's parents instead (by making donors anonymous). I reply to each of these arguments and explain why they are not convincing reasons for treating mitochondrial donation differently from gamete donation. Therefore, I maintain the position that mitochondrial donors are not significantly different from gamete donors, and in the absence of a convincing argument for treating the two donor types differently, both forms of donation should be made open-identity.

II. MITOCHONDRIAL DONATION AND MITOCHONDRIAL REPLACEMENT TECHNIQUES

Mitochondria are cellular organelles, which contain their own genome (i.e., separate from nuclear DNA) and produce energy for cellular functions. However, if high concentrations of mitochondria in the human body accumulate harmful DNA mutations, then serious mitochondrial DNA (mtDNA) diseases may occur. Serious mtDNA diseases (e.g., Leigh syndrome or MELAS—mitochondrial myopathy, encephalopathy, lactic acidosis, and stroke-like episodes) can be painful, debilitating, and often shorten the lives of those who suffer from them (Bredenoord et al., 2008, 23; Nuffield, 2012, 21).

The prospective clinical use of MRTs could help reduce the risk of mothers transmitting serious mtDNA diseases to their offspring.

As mentioned earlier, the HFE Regulations 2015 permit the licensed clinical use of two in-vitro techniques: MST and PNT. The process of MST involves removing the nuclear DNA from an intending mother's egg (carrying diseased mitochondria) and transferring that nuclear DNA into an enucleated donor egg (carrying healthy mitochondria). The reconstructed egg is then fertilized. Similarly, PNT involves removing the nuclear DNA from an embryo created with sperm and the intending mother's egg (carrying diseased mitochondria) and inserting that nuclear DNA into an enucleated embryo that was initially created using sperm and a donor egg (carrying healthy mitochondria). The result is a reconstructed embryo that carries the nuclear DNA contributions from an intending mother and father (or a sperm donor), as well as the healthy mitochondria (and mtDNA) inherited from the egg donor. The egg donors used in MST and PNT are referred to as "mitochondrial donors."

III. THE QUANTITY CLAIM AND THE QUALITY CLAIM

Within the debate about whether or not mitochondrial donors should be anonymous, there are two central claims that are often made about the differences between mitochondrial donation and gamete donation. The first is what I refer to as the *Quantity Claim* and it states that mitochondrial donation is different from gamete donation because there is a much smaller *quantity* of genes in the mitochondrial genome (approximately 37 genes) than there is in the nuclear genome (approximately 20,000–30,000 genes) (DH, 2014, 9). The second is what I call the *Quality Claim* that states that mitochondrial donation is different from gamete donation because mitochondrial genes are different in *quality* from the nuclear genes involved in gamete donation. Here the term *quality* is used to refer to the various different genetic qualities (i.e., those that can be expressed by genes to serve different functional roles in cellular processes) that make mitochondrial genes different from nuclear genes. For example, nuclear DNA is responsible for some of our personality traits and physical characteristics (e.g., eye color, hair color, and other phenotypic traits) and mtDNA is by contrast primarily dedicated to mitochondrial energy production.

Although both the Quality Claim and the Quantity Claim describe differences between mtDNA and nuclear DNA, neither of these claims constitute arguments that are sufficient on their own to warrant treating mitochondrial donation differently from gamete donation. As they stand, what both claims lack is a persuasive account of why they are of normative significance for the purposes of determining whether mitochondrial donors should be anonymous. Therefore, as I discuss in the following sections of this paper, the Quality Claim and Quantity Claim are often used

as part of more elaborate arguments in favor of treating mitochondrial donation differently from gamete donation.

IV. MITOCHONDRIAL DONORS AS PARENTS?

Some argue that mitochondrial donors should be treated differently from gamete donors because mitochondrial donors would not be the "third" parents of any children they help to create, and gamete donors, by contrast, could be considered parents to the children that they help to conceive (as discussed in HFEA, 2013, 21, 24; DH, 2014, 35). However, the term "parent" carries a number of different possible meanings, and in this section of the paper, I consider how, if at all, different concepts of "parent" can be applied to gamete and mitochondrial donors, respectively. I argue that it is only in discussions about "biological parenthood" that the language of "parent" can be accurately applied to gamete donors and not mitochondrial donors. Nevertheless, this difference is not a convincing reason to treat both forms of donation differently by making mitochondrial donors anonymous.

In the debate surrounding whether or not mitochondrial donors should be treated differently from gamete donors, the language of "parent" has been used when describing someone who is a child's "biological parent" (DH, 2014, 35 and as discussed in Nuffield, 2012, 46). However, what is meant by the term "biological parent" in the context of this debate? The term describes an individual who contributes an egg or sperm cell to create an embryo, and who is therefore also responsible for contributing approximately half of the resulting embryo's nuclear DNA. As mentioned earlier, the embryo's mitochondrial genome is inherited from the biological parent who contributes the egg (i.e., the intending mother); however, when an MRT is used, the embryo's mitochondrial genome is inherited from an egg donor. Therefore, some argue (DH, 2014, 35) that the term "biological parent" should only be used to refer to individuals whose eggs or sperm have contributed half of an embryo's nuclear DNA and that only contributing mtDNA is not sufficient for someone to be considered a biological parent. According to this account of biological parenthood, gamete donors are biological parents and mitochondrial donors are not. The argument that biological parenthood is only attributable to nuclear DNA contributors (i.e., gamete donors) and not mtDNA contributors (i.e., mitochondrial donors) appears to be based primarily on two kinds of biological differences that are identified by the Quantity Claim and the Quality Claim.

First, the Quantity Claim can be used to describe the view that mitochondrial donors are not biological parents because mitochondrial donors contribute only a very small quantity of inheritable genes to an embryo and gamete donors by contrast provide a very large quantity of inheritable genes. A similar argument that reflects the Quantity Claim can be found in the UK

Department of Health Response Document that discusses why mitochondrial donors are not biological parents and should therefore be made anonymous:

> . . . the Government's view remains that a child born following mitochondrial donation would have two biological parents, who provide 99.9 per cent of their genes and that any relationship between the child and the mitochondrial donor is remote. (DH, 2014, 35)

This example demonstrates how the Quantity Claim is a useful way of explaining a key biological difference that can be used to distinguish those who are considered biological parents (i.e., gamete donors) from those who are not considered biological parents (i.e., mitochondrial donors). However, if biological parenthood is going to be the basis upon which an argument is made for treating mitochondrial donors differently from gamete donors, a more robust and convincing explanation must be provided about why certain biological differences (e.g., the Quantity Claim) between donors types are important for determining whether mitochondrial donors should be anonymous.

Second, the Quality Claim is also used to argue that mitochondrial donors are not biological parents because the mitochondrial genes contributed to an embryo are of a different quality than the nuclear genes contributed by gamete donors. For example, in discussing biological parenthood and the status of mitochondrial donors, the UK Department of Health Response Document also claims that:

> . . . evidence of the sequencing of the whole mitochondrial DNA genome (the Revised Cambridge Reference Sequence of the Human Mitochondrial DNA) indicates that all of the mitochondrial DNA genes are involved in mitochondrial energy production and none are involved in governing personal characteristics and traits. (DH, 2014, 30)

By contrast, nuclear DNA does govern significant personal characteristics and traits. This difference in the role of mtDNA and nuclear DNA could be used to argue that there is an important difference between the two forms of donation.

For example, it could be argued that a gamete donor's contribution of nuclear DNA to an embryo is somehow "unique" because replacing it with any other nuclear DNA would result in the embryo developing into a different person with different traits and characteristics. In contrast, an embryo carrying mitochondria with diseased mtDNA could have its mitochondria replaced with *any* healthy donor mitochondria and the effect on the embryo would essentially be the same (i.e., because all healthy mitochondria fulfil the same biological function of facilitating normal cellular energy production). Hence, we might say that mtDNA is fungible in a way that nuclear DNA is not. Therefore, the Quality Claim can be used to argue that gamete donation is different from mitochondrial donation because of differences in

the fungibility of the genes contributed by each form of donation.[6] These differences are another reason why gamete donors are considered biological parents whereas mitochondrial donors are not. However, what is missing from the above Quality Claim-based argument (as with the previous Quantity Claim-based argument) is a convincing explanation as to why these biological differences that restrict biological parenthood to gamete donors are also important ethical differences that should warrant society treating gamete donors differently from mitochondrial donors with respect to anonymity. As I argue later in the paper, even if it is accepted that some persons think that "knowing who one's biological parents are" is a good reason for wanting identifying information about one's donor, it must also be accepted that this is only one of many legitimate reasons for wanting donors to have an open-identity status and it is not a sufficient reason to justify making mitochondrial donors anonymous under the law.

Therefore, it does not appear that the above account of biological parenthood is a good basis for making a convincing argument that regulators should treat gamete and mitochondrial donation differently. Furthermore, using the language of "parent" (as in "biological parent") to distinguish one donor type from another may cause unnecessary confusion, especially because referring to a gamete donor as a biological *parent* could be misinterpreted to imply that the donor is a legal parent,[7] that the donor occupies a parental role, or that the donor is perceived to be a parent (by their DC children or others). For the sake of clarity in this debate, it would therefore make sense to replace the language of "biological parent" with "biological progenitor" in order to avoid any confusion about the implications of mitochondrial donors not being biological parents.

The term "parent" can also be used to describe a person with a parental role in someone's life. However, are either mitochondrial donors or gamete donors necessarily parents in this sense? To start with, in the United Kingdom, neither gamete donors nor mitochondrial donors are legal parents, nor are they legally bound to occupy a parental role in the lives of any persons resulting from their donation (United Kingdom Parliament, 1990, 2015). Therefore, child support cannot be claimed from mitochondria or gamete donors, and MDC or DC offspring are not the legal heirs to their donors.[8] Furthermore, parenting arrangements are often influenced by a myriad of social, economic, and cultural factors (Nuffield, 2012, 47) and there is no available evidence to suggest that a gamete donor, rather than a mitochondrial donor, would be more likely to occupy a parental role in a DC person's life.[9] Therefore, it appears that there is no difference between either type of donor with respect to this sense of "parent" as a person who occupies a parental role.

Finally, the term "parent" might be used to refer to someone who is perceived to be a parent by their offspring. Is there any reason to believe that gamete donors are more likely than mitochondrial donors to be perceived to

be parents by DC children? To begin with, children do not need to be genetically related to an individual with a parental role in order to view him or her as a parent, as is evidenced by years of research on adoptive families and DC families (Nuffield, 2012, 47; Blake et al., 2013).[10] The available social science evidence suggests that many DC persons do not typically view their donors as parents (Blake et al., 2013; Nuffield, 2013). Therefore, even in light of the biological differences between mitochondrial and gamete donation (as described in earlier discussions involving the Quality Claim and the Quantity Claim), there does not appear to be any convincing reason why either form of donation is different with respect to how likely it is that donors will be perceived to be parents (Blake et al., 2013; Nuffield, 2013).[11]

This section has considered a variety of different ways that the concept of "parent" could be interpreted and applied to the contexts of mitochondrial and gamete donation. However, it does not appear that any of the above "parent"-based distinctions (of which there appears to be only one clear instance—i.e., "biological parents") between either form of donor would be a convincing reason for treating these forms of donation differently.

V. THE SIGNIFICANCE OF "SENSE OF SELF"

Considerable discussion has also surrounded what I refer to as the "sense of self" argument in relation to the question of whether or not gamete donors should be treated differently from mitochondrial donors (as discussed in Nuffield, 2012; PET, 2012; HFEA, 2013). This argument states that mitochondrial donation should be treated differently from gamete donation because being MDC will have less significance for an individual's sense of self than if an individual had been gamete donor-conceived.[12] This difference in sense of self is argued primarily to result from the differences (i.e., those differences attributed to the Quality Claim and the Quantity Claim) between both forms of donation (as discussed in HFEA, 2013, 24). I consider this argument, explain why it is based on several mistaken views, and show that it is not a convincing reason for why mitochondrial donation should be treated differently from gamete donation.

In order to proceed with this discussion, it is important first to clarify what is meant by the concept of "sense of self" in the context of this paper and in the literature to which I refer. According to Dan Brock, a person's "sense of self" ". . . consists of the properties or qualities that an individual considers important to who he is, to what kind of person he is, to what properties of himself he identifies with" (Brock, 2002, 314).[13] This description by Brock is an accurate reflection of what the term "sense of self" refers to when it is used in this paper. Of course, how a person comes to describe the properties that he or she identifies with is dependent on that person's self-knowledge (e.g., nationality, physical appearance, being donor-conceived, or who their

donor is) and how that person attributes significance to different pieces of knowledge in relation to his or her sense of self at different times in life (Lillehammer, 2014). For example, I may know that I carry a gene with "mutation X," but that knowledge of "mutation X" may be unimportant to me and have no significant bearing on how I think of myself. In the analysis that follows, I discuss the significance of different kinds of information, such as genetic information, for the development of the sense of self of DC and MDC persons. I also elaborate on how we should think about the concept of sense of self in relation to DC and MDC persons and argue that knowledge of information about the nature of one's genes (i.e., that detailed in the Quality Claim and Quantity Claim) is not always significant for the development of one's sense of self. To begin, the sense of self argument relies on three views about how DC persons understand scientific facts about their genes in relation to their own sense of self.

The first view is that one of the main reasons why some persons feel that being donor-conceived has significantly impacted their sense of self is because they have inherited genes of a particular quantity and with particular functional qualities (e.g., personality or physical trait affecting) from their donors. Based on this view, it is then assumed that future MDC persons will not feel that their sense of self has been significantly impacted by the mitochondrial genes they have inherited from a donor because those genes are of a different functional quality (i.e., the mitochondrial production of cellular energy) and quantity than nuclear genes.

The second view is that DC persons have a sense of self that is significantly determined by the knowledge they have of their genetic makeup. In other words, the sense of self argument assumes that the genetic makeup of DC persons plays a major role in shaping how they think about their sense of "self" and "who they are." This can be described as a highly "geneticised" perspective of how persons think of themselves because it views genetics as an essential and dominant influence over one's sense of self (Nelkin and Lindee, 2007, 41–9).[14] From this, it is argued that in the case of mitochondrial donation, the mitochondrial genes donated are of a quality and quantity that will not significantly impact on an MDC person's sense of self.

The third view is that one of the most important reasons why DC persons want to know identifying information about their donors is because these DC persons have inherited nuclear DNA from their donors, and this particular nuclear genetic connection is significant for their sense of self. Because MDC persons do not inherit nuclear DNA from their donors, it is assumed that MDC persons would not want to know identifying information about their donors. Importantly, the soundness of the sense of self argument relies on the empirical integrity of the above views about the nature of how gamete donation and mitochondrial donation impacts on individuals' sense of self. Next, I critique the sense of self argument by showing that the three views I have outlined above are mistaken and that the sense of self argument

is therefore not a convincing reason for treating mitochondrial donors and gamete donors differently.

First, the sense of self argument assumes that the main reason that being donor-conceived significantly influences some persons' sense of self is because they have inherited genes (i.e., nuclear genes) that are of a particular functional quality from their donors. It is not clear that this aspect of the sense of self argument is an accurate reflection of the available social science evidence. It is possible that for some DC persons it may be relevant for their sense of self that they have inherited nuclear genes that afford them some similarities with their donors with respect to their character or physical appearance. However, the evidence also suggests that other DC persons search for their donors, meet them and then find that they do not have much in common with their donors or share much physical or character resemblance (Freeman, Appleby, and Jadva, 2012). Since some DC persons may not resemble their donors, it is therefore not relevant in this case whether or not MDC persons are likely to physically resemble (or perceive themselves to resemble) their donors.

Second, the sense of self argument mistakenly assumes that one of the main reasons that being donor-conceived significantly influences some DC persons' sense of self is because they have inherited nuclear genes that are of a *particular* quantity from their donors. This claim is not clearly reflected in the available social science evidence. Although there is some evidence to suggest that some DC persons find that their sense of self is influenced to some extent by having a "genetic connection" to their gamete donor (Jadva et al., 2010; Nuffield, 2013, 55), there is little indication that DC persons generally think about this genetic connection in terms of *sheer numbers of genes*. For example, we might expect some DC persons to say that their sense of self is influenced by sharing nuclear genes with their donors;[15] however, we would not expect DC persons to say that their sense of self has been significantly influenced as a result of sharing *approximately 10,000–12,500 protein encoding nuclear genes* with their donors. Therefore, it is not necessarily the *size* of the genome or the *particular* quantity of shared genes that matters to some DC persons' sense of self. Instead, what appears to matter to some DC persons is that some form of basic genetic connection exists and that this genetic connection has come to take on some form of meaning in relation to his or her sense of self (Turner and Coyle, 2000). Therefore, contrary to the sense of self argument as used to date in the debate regarding mitochondrial donors, it does seem possible that some future MDC persons could also find that the genetic connection they share with their mitochondrial donor is of some significance to their sense of self.

As the Quality Claim suggests, nuclear genes and mitochondrial genes do serve different physiological functions in the body. However, it is a mistake to argue that the mitochondrial genes inherited from a donor will not impact the phenotypes of persons in a way that could significantly affect their sense

of self. The HFE Regulations 2015 require that MRTs only be used in cases where there is a *particular* and *significant risk* that an egg or embryo would develop into a person with a serious mtDNA disease (see Regulations 5 and 8 of United Kingdom Parliament, 2015). Therefore, some MDC persons may feel that the inheritance of healthy mitochondria from their donors is significant to their sense of self because their donor helped their parents conceive children who have not physically suffered from a serious mtDNA disorder (Bredenoord et al., 2011). Had their donor not provided mitochondria via an MRT, a different person may have come into existence and developed a different sense of self.[16]

In addition, the HFE Act (United Kingdom Parliament, 1990, section 31ZA) currently allows DC persons to access identifying information about their donors regardless of whether or not those persons look like or feel as though they may resemble their donors. Furthermore, the HFE Act does not require that DC persons feel as if their sense of self has been significantly affected by the inheritance of a donor's nuclear DNA before they can be granted access to identifying information about their donors. Therefore, the question arises as to why MDC persons should not be given the same legal rights to access identifying information about their donors, even though they may feel similarly to some DC persons in this respect (i.e., both MDC and DC persons may or may not attribute significance to their donor's genes in relation to their sense of self). Accordingly, the current use of the sense of self argument in the debate on mitochondrial donation is based on a mistaken assumption about the extent to which the functional quality of inherited genes has a significant impact on DC persons' sense of self. Therefore, it is not a convincing reason for treating mitochondrial donation differently from gamete donation.

There is also the mistaken assumption that DC persons are for the most part focused on genetics with respect to how they think about their sense of self. Although this may possibly be the case for some DC persons, there is no evidence to suggest that this is the norm. DC persons do not grow up with a "fixed" sense of self based on knowledge about having donor DNA of a particular quantity or quality, and as Richards argues, genetic information " . . . is not a kind of molecular essence of personhood" (Richards, 2014, 37). Furthermore, even if most DC persons were aware of the particular quantity and quality of nuclear genes that they inherited from their donors, there is an important difference between (a) a person having knowledge and understanding about having a certain quality and quantity of genes, (b) whether that knowledge about having a certain quality and quantity of genes is something that actually becomes successfully integrated into the narrative of that individual's sense of self, and (c) whether that knowledge about having inherited genes of a certain quality and quantity from a donor forms a *significant* part (if any) of their sense of self. For example, it would be a mistake to assume that simply because DC persons have inherited genes from a donor, steps (a) through (c) will automatically follow. A fundamental

problem with the current use of "sense of self" in this argument is that it confuses the existence of an individual's *objective biological properties* (e.g., the number and nature of the genes that they have in common with a donor) with that person's existing or potential *psychological understanding* of their sense of self.

A further issue with the sense of self argument is its assumption that the main reason why DC persons typically wish to have identifying information about their donors is because they feel it is important for their sense of self. This reason is treated as if it is trumps all of the other reasons that persons might wish to access identifying information about their donors. The available social science evidence does suggest that a person's sense of self is one possible reason for wanting to know a donor's identity, but it is not necessarily the only reason or the main reason for that matter.[17]

For example, a study by Jadva et al. (2010) surveyed 127 persons who had used the Donor Sibling Registry (DSR) to search for their sperm donors and asked them why they had searched for their donor.[18] These respondents provided a broad range of reasons (beyond the reason of "sense of self"), which included the desire to find out the donor's motivation and a desire to thank the donor (Jadva et al., 2010).[19] There appears to be no obvious reason why these additional examples of important reasons for having identifiable gamete donors would not equally apply to the case of MDC persons. Importantly, there are a number of reasons why (as discussed above) a DC person or an MDC person might want to have identifying information about their donors, and it would be a mistake to assume that "sense of self" is the most common reason or the only important reason.

It is also important to give adequate consideration to the additional social and cultural factors that may result in some MDC persons wanting to know the identities of their donors. First, the initial few generations of MDC persons will likely be voluntarily subjected to sustained long-term medical monitoring and follow-up research (by both clinicians and social science researchers, respectively). In fact, the importance and intent to pursue this monitoring and research (which could be encouraged by the HFEA, clinicians and researchers, but could not be made compulsory) (Nuffield, 2012, 65; HFEA, 2013, 5; DH, 2014, 42) is stated clearly in the Department of Health Response Document (DH, 2014, 42), the HFEA Mitochondria Report (HFEA, 2013, 26), and the Nuffield Mitochondria Report (Nuffield, 2012, xv).[20] Subjecting MDC persons to such voluntary research would potentially emphasize the significance of having a mitochondrial donor for some MDC persons.[21]

Second, the HFEA is currently recommending that any future MDC persons be disclosed to about the nature of their donor-conception at an early age (HFEA, 2013, 36), similar to the HFEA's Code of Practice guidelines for early disclosure to DC children (DH, 2014, 33; HFEA, 2015c, T63(a)). This means that MDC persons who have been disclosed to[22] will grow up knowing that

they have a mitochondrial donor and some MDC persons (and their parents) may then wish to obtain identifying information about those donors.

Third, it is possible that some of the first MDC persons born following the use of MRTs may be subject to considerable media and cultural attention,[23] similar to the first IVF baby in 1978, Louise Brown (Brinsden, 2009). When MDC persons are old enough to reflect on the cultural and scientific significance attributed to having been one of the first few generations conceived via MRTs, this may also result in some of these MDC persons wanting to know identifying information about the donors involved. At this point, it is impossible to know for certain to what extent social and cultural factors may influence the desire of some MDC persons to know identifying information about their donors; however, it would be a mistake to overlook the fact that there will likely be many social and cultural pressures in the lives of future MDC persons which may result in some of those persons wanting to know identifying information about their mitochondrial donors. Therefore, one must appreciate the potential significance of the social and cultural contexts into which future MDC are likely to be born.[24] As I have argued extensively in this section of the paper, the "sense of self" argument does not appear to be a convincing reason for treating mitochondrial donation differently from gamete donation and making mitochondrial donors anonymous.

VI. NEGATIVE CONSEQUENCES OF ALLOWING OPEN-IDENTITY MITOCHONDRIAL DONATION?

Finally, I respond to four reasons why some might argue that allowing open-identity mitochondrial donation could have negative consequences and why this form of donation should be treated differently from gamete donation. I begin with the first reason (as discussed in House of Commons Science and Technology Committee, 2014, 11) that there might be a shortage of mitochondria donors if regulators require open-identity donation rather than anonymous donation. This same reason was often heard (BioNews, 2005) prior to amendments being made to the HFE Act 1990, which prohibited anonymous donation and required all donations from April 1, 2005 to be made by open-identity donors (United Kingdom Parliament, 2004).[25] However, donation statistics recently released from the HFEA demonstrate that following the removal of donor anonymity in 2005, the number of donors actually increased rather than decreased (HFEA, 2014, 10–14). Therefore, if anything, evidence from the United Kingdom suggests that within recent history (e.g., past 10 years) there are more gamete donors willing to donate on an open-identity basis than on an anonymous basis, and there is little reason to believe that this will not also be the case for women donating their eggs for mitochondrial donation. If there are concerns about shortages of donors, then the most appropriate response would be to argue that both forms of donation should be treated the same.

The second possible reason is that some prospective parents may not want to use an open-identity mitochondrial donor and could therefore be forced to travel abroad to a country where it is legal to access fertility treatment using an anonymous donor.[26] However, this is an objection that could also be made toward the United Kingdom's current policy of requiring open-identity egg, sperm, and embryo donors. Moreover, given the large scale on which gamete donor-conception takes place, as compared with the projected small scale of mitochondrial donor-conception (e.g., estimated to be around 10 cases per year in the United Kingdom), this is probably a much bigger problem for gamete donation than it would be for mitochondrial donation (DH, 2014, 38). Therefore, if there were concerns about travel abroad it would make sense also to make gamete donation anonymous in the United Kingdom; however, this is highly unlikely considering the UK government's removal of anonymous gamete donation in 2005.

A third reason, as discussed in the Department of Health Response Document, is that:

> . . . according a mitochondrial donor the same status as a gamete donor could 'devalue' the position of gamete donors, who have a significantly greater link to the child and whose situation provides much greater justification for identifying information about the gamete donor being made available to the child (at age 18).[27] (DH, 2014, 35)

This is a speculative claim and any response is likely to involve some degree of speculation. However, the problem with this argument is that it is not immediately clear how or why treating mitochondrial donors the same as gamete donors would "devalue" the position of gamete donors. What is of particular concern is that this objection could, in turn, be perceived as downplaying the seriousness of the need for mitochondrial donation, which arises from mitochondrial disease. Of course, this would be unfortunate and it is worth avoiding such an argument for this reason.

For example, consider the case of an MDC person or their mother (i.e., someone carrying a serious mtDNA disorder), who finds out that their mitochondrial donor was given a different legal status with respect to information sharing because regulators considered that it would "devalue" the status of other gamete donors if mitochondrial donors were afforded the same value or significance (by making them open-identity). It is possible that such an MDC person and their family (especially the mother) could come to see this policy position as disrespectful and disparaging in relation to the seriousness of the medical condition the MDC person has avoided and from which the mother potentially suffers. Therefore, the argument about devaluing gamete donors appears to be an unattractive and potentially offensive means of attempting to justify treating mitochondrial donation differently from gamete donation.

A final possible reason to treat mitochondrial donation differently from gamete donation is that requiring open-identity mitochondrial donation reinforces the social attitude or cultural view that donors should be seen as an important part of their offspring's lives, when in actual fact regulators should be emphasizing the significance of the child's parents instead (DH, 2014, 29). As with the second argument discussed above, anyone making this claim must equally take issue with the fact that the HFE Act 1990 (as amended) currently requires open-identity gamete donors. It is also not clear that by making mitochondrial donors open-identity it would necessarily reinforce or influence anyone's attitude that donors should be seen as an important part of their offspring's lives. The chances are that parenting practices and the influences that the children are exposed to during their upbringing are the main factors that will influence how DC persons come to attribute importance (or unimportance) to the role of donors in their lives (Blake et al., 2013). In any event, claims that treating both forms of donation the same way will noticeably reinforce unwanted attitudes and cultural views about the importance of donors are at best speculative. Similar to the other three arguments discussed in this section, this argument also fails to be a convincing reason to warrant treating mitochondrial donation differently from gamete donation.

VII. CONCLUSION

In this paper, I have argued that anyone wishing to treat mitochondrial donation differently from gamete donation (i.e., making the former anonymous and the latter open-identity) must offer a convincing argument for doing so. I began by explaining the nature of MRTs, mitochondria, and mitochondrial diseases, and then I identified two key claims that are used in the context of the debate over mitochondrial donor anonymity: the Quality Claim and the Quantity Claim. Next, I considered two different arguments in favor of mitochondrial donor anonymity. Each argument offers a different reason as to why mitochondrial donation is different from gamete donation: first, mitochondrial donors, unlike gamete donors, are not third "parents" and second, unlike gamete donation, mitochondrial donation will not have a significant impact on the sense of self of MDC persons. Finally, I considered a set of four arguments about why allowing open-identity mitochondrial donation could have negative consequences and should therefore be made anonymous. Each of these arguments is incorrect or misleading, and therefore, none of them successfully provide a convincing reason for making mitochondrial donation anonymous under UK law. Furthermore, there do not appear to be any unique disadvantages (as compared to gamete donation) to allowing open-identity mitochondrial donation.

In the light of the arguments discussed in this paper, the UK Parliament should amend the HFE Act 1990 (as amended) so that mitochondrial donors are required to be open-identity donors. Following through with this recommendation would ensure that the law is more likely to take into account the interests of future MDC persons, and it will also help to ensure that the HFE Regulations 2015 are based on consistent use of arguments and evidence in this area of research. In addition, as the international debate surrounding mitochondrial donation grows, the analysis from this paper is also of significance for regulatory and bioethical discussions beyond the United Kingdom.

NOTES

1. Persons conceived on or after April 1, 2005 can access the following information collected by the HFEA about their donors: ethnicity; marital status; medical history; year and country of birth; physical description (hair and eye color, height, weight); identifying information (last known address, donor's name, and date of birth); number of children, if any, and their gender; and a goodwill message, if provided (United Kingdom Parliament, 1990, s.31ZA; HFEA, 2015a). Although the same identifying information is collected from each donor, there may be some variation in the amount of biographical information offered by different donors. Anonymous gamete and embryo donation ended on April 1, 2005. For a detailed discussion of open-identity donation in the United Kingdom, see Appleby (2016).

2. Mitochondrial diseases are maternally inherited. Examples of serious mitochondrial diseases include NARP (neurogenic muscle weakness, ataxia, retinitis pigmentosa) and Leigh syndrome (Bredenoord et al., 2008). For an interesting discussion of the social value of MRTs, see Rulli (2016).

3. In the next section of this paper, I discuss how the process of MRT actually involves more than replacing mitochondria—that is, everything except the nuclear DNA from intending parents is replaced by an enucleated egg or embryo (depending on whether or not MST or PNT is being used).

4. However, the HFE Regulations 2015 do not require mitochondrial donors to maintain their anonymity and they can make themselves known to the recipient family. Regulation 11 of the HFE Regulations 2015 modifies section 31ZA of the HFE Act 1990 (as amended by United Kingdom Parliament, 2008) by inserting subsection 2A after subsection 2, in order to prohibit the release of identifying information about mitochondrial donors to MDC persons, thus making mitochondrial donors anonymous (United Kingdom Parliament, 2015). For further explanation, see also HFEA (2015b). Also, for the remainder of this paper, I refer to women who donate eggs for use in MRTs, as "mitochondrial donors." A practical reason for doing this is because "mitochondrial donor" is the language that has been predominantly used to date in ethical and legal debates surrounding MRTs.

5. The main UK sources of discussion to date surrounding mitochondrial donor anonymity are found in three key reports: from the UK Department of Health (DH, 2014); the HFEA (2013); and the Nuffield Council on Bioethics (Nuffield, 2012). Hereafter, these will be called the Department of Health Response Document, HFEA Mitochondria Report, and Nuffield Mitochondria Report, respectively. All three of these reports recommend that mitochondrial donation be made anonymous under the law. For a more detailed analysis of these reports and debates surrounding them, see Appleby (2015).

6. Following on from this argument, some have argued that mitochondrial donation is comparable to organ donation (as discussed in HFEA, 2013, 22). However, this comparison has been dismissed by others (DH, 2014, 29) on the basis that mitochondrial donation is different from organ donation—that is, mitochondrial donation involves germline modification.

7. For further details on legal parenthood in the United Kingdom in the context of donor-conception, see United Kingdom Parliament (1990, sections 33–56).

8. For a detailed account of legal parenthood in relation to donor-conception, see Nuffield (2013) and McCandless and Sheldon (2014). For a detailed discussion of the moral significance of genetic ties and why some DC persons may wish to search for their donors, see Appleby and Karnein (2014).

9. It is impossible at this time to know with any certainty whether or not the biological differences identified in the Quality Claim and the Quantity Claim might lead to different cultures of parenting which

tend to involve one type of donor more than another, if at all. Such evidence will not be available to use for comparative purposes until MDC families are created and research on these families is undertaken and published.

10. If some DC persons come to view their donors as parents, then this could be based on a variety of reasons, including how closely they are genetically related, but also potentially because the donor had a causal role in bringing them into existence. See Blake et al. (2013, 425–37) and Nuffield (2013).

11. In addition, the evidence also suggests that of the DC persons who are interested in acquiring identifying information about their donors only a small minority tend to be interested in establishing some form of parental relationship with the donor (Blake et al., 2013; Nuffield, 2013).

12. A similar argument has also been made by the Progress Educational Trust (PET) (2012), and the significance of MDC persons' "sense of self" as a reason for treating mitochondrial donation differently from gamete donation has been discussed by HFEA (2013) and Nuffield (2012).

13. In this instance, Brock clarifies that "sense of self" is being used in a psychological sense rather than a numerical sense.

14. For a detailed discussion of genetic essentialism in the context of reproduction, the family and individuals' sense of identity, see Nelkin and Lindee (2007, 41–49, 151–55).

15. For example, there is evidence of this kind of language being used in a 2000 study by Turner and Coyle.

16. For a detailed discussion of the implications of MRT use on numerical identity, see Wrigley, Wilkinson, and Appleby (2015) .

17. It must be noted that the available relevant empirical social science evidence in this field remains limited with respect to the number of studies published. However, this body of evidence is valuable and relevant and should be given further consideration by anyone considering this topic of debate.

18. The DSR is a US website that assists DC persons and their families make contact with donors and donor-siblings (Jadva et al., 2010).

19. Many DC children are generally quite curious to meet their donor (Jadva et al., 2010; Nuffield, 2013). This evidence is corroborated by additional evidence cited in Nuffield (2013).

20. Similarly, an Institute of Medicine (part of the National Academy of Sciences, Engineering, and Medicine) report titled *Mitochondrial Replacement Techniques: Ethical, Social, and Policy Considerations*, commissioned by the US Food and Drug Administration (FDA), recommends that MDC children should be followed-up as part of a long-term monitoring plan (Institute of Medicine of the National Academies, 2016, 15).

21. The risk of inheriting a medical disorder from a donor is very low as a result of the clinical screening of donors in the United Kingdom. Therefore, the risk of inheriting a medical disorder from a donor is often not commonly viewed as a reason for providing identifying information about donors (especially because UK clinics maintain identifying records of donors in case the donor needs to be identified and contacted as a result of any medical complications from the donation). For a detailed discussion of the regulation and medical screening of donors and the risk of inheriting health complications from donors in UK clinics, see Appleby (2016) and Nuffield (2013). For a discussion of these issues in the context of the United States, see Cahn (2009, 52–64). However, it is nevertheless possible that some DC persons may wish to know the identity of their donor in case they have inherited a medical disorder from their donor that was not detected by medical screening of the donor.

22. Given the fact that MDC persons will likely be subjected to the kind of research and follow-up monitoring mentioned above, it is also likely that their parents will disclose to those children.

23. The Nuffield Mitochondria Report emphasizes the considerable amount of media and cultural attention the use of MRTs has attracted. See (Nuffield 2012, 78).

24. Additionally, some prospective parents might anticipate that there are a number of reasons (e.g., general curiosity or to understand the donor's motivation) why their MDC offspring may want to know identifying information about mitochondria donors; it is possible that this may lead some prospective parents to prefer using open-identity mitochondrial donors.

25. Regulation 2(3) of The Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004 came into force on July 1, 2004 and amended Section 31 of the HFE Act 1990 so that persons conceived with donations made after April 1, 2005 could request identifying information about their donors from the HFEA (United Kingdom Parliament, 2004). These amendments have been included in Section 31ZA of the Human Fertilisation and Embryology Act 2008, which amended and updated the HFE Act 1990 (United Kingdom Parliament, 2008).

26. Similar concerns were raised in debates about gamete donation before gamete donor anonymity was removed (BioNews, 2005). Also, traveling abroad to access treatment with anonymous mitochondrial donors would only be an option if MRTs use were legally available.

27. This type of claim was also discussed in HFEA (2013).

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