

THE mTDNA OF HUMAN RIGHTS

Introduction

In the context of the development of the technique to create an embryo with the mitochondrial DNA (mtDNA) donated by a third person, Mitochondrial Replacement Techniques (MRT), Turkmendag engages with the question of the extent to which individuals should be able to obtain knowledge of their genetic identity. MRT raises this question in its purest form, because current scientific understanding suggests mtDNA transplantation, unlike gamete donation, has no clearly known effect on the outward identity of the resulting human being. Consequentially, the question is whether there is a right to the information itself, not for the way it could affect how an individual chooses to live their life.

Coherently resolving this question requires us to ask and answer the most fundamental question of human rights thinking: what is the basis on which human rights are held? To be a protected human right it must arise from the defining characteristic of humanity, to which human rights are stated in the UN Universal Declaration of Human Rights (UDHR) and the European Convention on Human Rights (ECHR) to be inalienable (*Pretty v UK* (2002) 35 EHRR 1, preamble to the UDHR).

I will argue that within its decisions on individuals' rights of access to information about their origins, the European Court of Human Rights' (ECtHR) conception of the defining nature of humanity to which human rights attach is apparent. Neither the ECtHR nor the UK courts have considered the rights to information of mtDNA donation recipients. I will, however, show that their understanding of rights supports the current UK position under which identifying information about mtDNA donors is not required to be disclosed, as consistent with the balance that must be struck between the rights of those seeking information and those who would be affected by its disclosure.

The Basis of Human Rights

This basis on which human rights are possessed is not defined in detail in any of the major rights treaties or the judgments of the UK courts or the ECtHR. This hesitancy is deliberate. In order to ensure as many states as possible would sign up to the rights documents, their basis was left

open. By stating only that the human rights contained within the UDHR are “inalienable” to the “inherent dignity...[of] all members of the human family,” or in the Convention are possessed by “everyone,” the drafters avoided stating a specific basis for the rights. This allowed states characterized by fundamentally different political and moral philosophies to agree to the same documents (Glendon 2002).

In spite of their open-ended foundation, Kai Möller (2012) has argued from the core features of modern human rights documents that the underlying foundation of human rights norms is protection for an individual’s capacity for “existential self-understanding.” This characterizing capacity of humanity “involves an element of where one is coming from and where one wants to go”; it encompasses being able to reflect on one’s own personal history, and to make choices which shape one’s identity going into the future (Möller 2012, p.60).

The features of the rights documents from which he triangulates this basis are: the protection of rights for an individual both from interference and to assistance, the increasing scope of rights protection as part of rights inflation, against both the state and individuals, subject to being balanced against the competing rights of others. Although a full evaluation of Möller’s theory is beyond the scope of this commentary, the ECtHR’s case law on access to information about genetic identity supports the basis of rights he identifies.

mtDNA as a crucible for the question of the fundamental basis of rights

As Turkmendag’s paper relates, mtDNA transplants were initially characterized in the media as creating “three parent babies.” This subsided into the more accurate portrayal of the procedure as creating babies with the DNA of three persons, the donated mtDNA forming 0.1% of the body’s DNA. The rules regulating MRT, which determine the extent of the disclosure about their genetic ancestors a person is entitled to, take what Turkmendag describes as a “genetic essentialist” focus on parenthood. A child created through mtDNA transplantation is thus only entitled to non-identifying information about the donor (Reg. 11, Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015/572). In contrast, children born with donated gametes, comprising 50% of the body’s nuclear DNA, have had the right to identifying information about the donor since 2005 (Reg. 2 Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004/1511).

The justification for the distinction is that, under current scientific understanding, compared to nuclear DNA, mtDNA has no clearly-known direct effect for the way in which an individual chooses to live their life, or on the choices with which they may be faced. Whether this distinction complies with the human rights protection the UK is obliged to give, depends on whether it is consistent with the foundational human characteristics that those rights protect. To resolve this question necessitates asking whether the protection of rights is limited only to those aspects of our humanity that affect or are manifested through the choices we make. If the rights are not so based and limited to choice, the question then becomes one of whether distinction between the different amounts of information disclosed to the recipients of mtDNA and nuclear DNA can be justified under that basis.

The ECtHR has not yet ruled upon the existence and extent of a right of access to donor information for mtDNA recipients, nor does any rights document deal with it explicitly. However, the ECtHR has recognized rights of access to information generally and specifically concerning individuals' parents. This case law indicates both that the Court views rights as having the fundamental basis that Möller describes, and consequentially encompasses rights to information for recipients of mtDNA donation.

Case law on access to information about genetic donors

Within the ECtHR's case law there is general support for Möller's claims that at the core of what human rights protect is the human capacity to choose how to live one's life (Möller 2012). The pivotal case of *Pretty v UK*, recognized, as a fundamental part of the "very essence" of what the Convention protects, the capacity for individual choice which was bound up with their "ideas of self and personal identity" [65]. In particular, the Article 8 right to "respect for...private and family life" has been held to encompass an individual's "right to establish details of their identity as individual human beings" (*Goodwin v United Kingdom* (2002) 35 EHRR 18, [90]). The nature of this foundation has also been recognized by the UK courts. In *R (Nicklinson) v Ministry of Justice* [2014] UKSC 38 the Supreme Court identified the capacity for self-determining choice as fundamental to our "humanity," and encapsulated within the principle "that individuals are entitled to be the masters of their own fate" [208].

More specifically, the ECtHR has recognized that this human capacity for choice entails a right of access to information. The Convention rights have been held not only to prohibit unjustified

interference with individual's choices, but also that those choices be facilitated through the provision of information (*Guerra v Italy* (1998) 26 EHRR 357, [58] & [60] and *McGinley and Egan v United Kingdom* (1999) 27 EHRR 1, [99]-[101]). Thus in *Guerra* the Court held that Article 8 required the government disclose information about pollution levels, to facilitate people in making an informed choice whether to live near a factory [60].

This right of access to information has been held to require the disclosure of information about an individual's parents, the source of their nuclear DNA. However, the ECtHR does not view this right as merely grounded in the use the information for an individual choosing how to live, such as whether to make contact with the parent. The right is held to have a foundation constant with the broader capacity for the "existential self-understanding" Möller describes.

In *Mikulic v Croatia* [2002] 1 FCR 720 an illegitimate child challenged the inefficacy of the Croatian legal system in establishing her father's identity by DNA testing. The ECtHR held the Convention protected an individual's right to know details of their "physical and social identity" [53]. The court argued "that an individual's entitlement to such information is of importance because of its formative implications for his or her personality" [54]. Subsequently, the decision in *Odièvre v France* (2004) 38 EHRR 43 went further, stating "...people have a right to know their origins..." [44]. The court held that this was a freestanding right, separate from and in addition to a "right to establish and develop relationships with other human beings" for which information about their origins might be necessary [29]. The ECtHR recognized that knowledge of one's origins was important for an individual's "personal development," and that not only the identity of one's parents was an important aspects of an individual's personal identity [29] & [42], but also that "the circumstances in which a child is born, forms part of a child's, and subsequently the adult's, private life guaranteed by Art.8 of the Convention" [29].

Consistent with the ECtHR's case law, the UK courts in *Rose v Secretary of State for Health* [2002] EWHC 1593 (Admin) recognized individuals have a right "to know about their origins" [28]. The claimant, who was born as a result of artificial insemination with donated sperm, challenged the law's refusal to allow access to non-identifying information about the donor. The court held that the identity of the claimant's father "goes to the very heart of their identity, and to their make-up as [a person]" [33]. Even though the information the claimant sought would not enable the father to be identified, the court felt that individuals had the right to know and understand their origins, as part of their "physical and social identity and psychological integrity" [45].

How an individual came into being and the nature of their DNA are facts of their existence. The judicial recognition of this by the ECtHR and UK courts is consistent with the foundation for rights that Möller puts forward. The humanity defining capacity for “existential self-understanding,” to comprehend and shape one’s own identity underlying human rights, protects more than freedom of choice to act. As the existentialist John-Paul Sartre claimed, identity involves knowing one’s origins, the position from which an individual acts, as well as shaping one’s identity through choices (Sartre 2003).

Implications for mtDNA information access

This basis for human rights that Möller’s theory proposes, and which finds expression in the Convention case law, supports recognition of a right of access to information for recipients of mtDNA donation. Although the decisions discussed above were made prior to the development of MRT, the breadth of the conception of identity they recognize, and the fundamental human characteristic underlying rights implicit within it, indicates that the scope of the right to information encompasses the information that a person had been created using MRT and about the donor. Thus the Convention underpinned by Möller’s understanding of the essence of humanity, “existential self-understanding,” supports the 2015 Regulation’s stance of allowing individuals created using MRT to request information that this process was used in their creation and information about the donor.

mtDNA has only been proven to affect a person’s outwardly observable characteristics or choices in a much more limited way than donated nuclear DNA. Consequently, disclosure of information concerning it could not be as easily justified on the grounds that it facilitated a person to make choices as to how to live their life. However, the ECtHR and UK courts have recognized that the Convention’s protection of identity includes factual information about a person’s origins, even if that information is not instrumentally necessary to make decisions about how to live, and recognized rights to that information.

Is the difference in extent of information disclosure justified?

The regulations governing disclosure of information about those who have donated nuclear DNA since 2005 allow the identity of those who donate gametes be disclosed to individuals born

using them (Reg. 2, Regulations 2004/1511). However, a person created using MRT is only entitled to non-identifying information about the donor (Reg. 11, Regulations 2015/572).

Whether this difference in the protection given to the recipient's right to know of their origins can be justified depends on the balance between the rights and interests of the recipient, the donor, and others affected by the disclosure of information. Article 8, the right most frequently invoked in this context, is not absolute. It can be limited to protect "health or morals, or for the protection of the rights and freedoms of others" (Article 8(2) ECHR).

Turkmenbag describes two interests that counterbalance the desire of a recipient of mtDNA to know their identity, justifying the current limits on disclosure. Firstly, the desire of a donor to remain anonymous; disclosure of their identity against their wishes would interfere with their choice as to how to define themselves to others, and whom to choose to be known to. Secondly, the interests of those wishing to use MRT; it was feared requiring identity disclosure would deter donors, thus limiting the eggs available for those wishing to use MRT. At a more general level, the scientific community also feared that if MRT were perceived to be too radical a scientific development it might be prohibited, thus it was portrayed as more akin to organ donation, for which there is also no disclosure of donor identity.

To assess the coherence of this distinction in the extent of disclosure, it must be scrutinized against the fundamental characteristic of the capacity for existential self-understanding upon which the Convention rights are based. The ECtHR does not require the disclosure of identifying information about the source of an individual's nuclear DNA in all circumstances. In *Odièvre* the court held that the wellbeing of children and mothers justified the practice of anonymous birth and the non-disclosure of the birth mother's identity [44]-[47] & [49]. However, in the similar Italian case of *Godelli v Italy* [2012] ECHR 33783/09 the court held that refusal to give non-identifying information to an abandoned child was an unjustified interference with the child's self-understanding [56]. This shows the ECtHR attempting to strike a balance between the conflicting fundamental self-understanding of those who wish to know of their genetic ancestry, and those who do not wish to be identifiable to those to whom they are genetically related. It shows that the right to know one's genetic ancestors is not absolute.

The 2005 change in UK law to require the identification of gamete donors takes a stance that knowledge of the source of one's nuclear DNA is sufficiently important to self-understanding to

take the risk of a decline in gamete donations. However, this change only applied prospectively. Consistent with the ECtHR's case law, the disclosure of the identity of those who had donated nuclear DNA under anonymity would have been too great an interference with their self-understanding, even though that information would have facilitated both the child's self-understanding and shaping of their identity by opening up choices to them.

Although the current case law indicates that the scope of Article 8's protection for identity encompasses that of individuals created using MRT, the extent of that protection against the competing interests described above is not yet resolved. As with gamete donors, retrospective disclosure of identifying information would be too great an interference with their self-understanding as they have chosen to construct it (*Odièvre* [44]). In terms of whether future donations should be accepted on the condition that identifying information must be given, the balance of rights and interests is a fine one. The importance of identifying information for MRT recipients is less. The source of their mtDNA is a part of their self-understanding, but it does not on current understanding affect their outward characteristics or have direct relevance to future life choices in the way that nuclear DNA does. Thus it is less necessary for their oncoming construction of their identity. But also, the impact on the donor's life of their identity being disclosed where they have only donated mtDNA would be less than with a gamete donor.

The difference between mtDNA and nuclear DNA makes the current distinction coherent with the fundamental nature of humanity, which forms the basis of the Convention rights. The lesser impact of mtDNA on a person's life makes it less important to their self-understanding, justifying Turkmendag's favored solution, where only those mtDNA donors who consent will have their identifying information disclosed. However, were scientific advances to reveal a greater role for mtDNA in shaping an individual's sense of self and the identity defining choices with which they are confronted, the basis of rights in self-understanding, which underpins the current rights case law, could justify removing the option of anonymity for mtDNA donors.

Conclusion

Regard to the defining characteristic of humanity to which human rights attach gives a deeper explanation of what is at stake in the questions of whether, and to what extent, there is a right to know one's own genetic identity. Casting the debate in terms of the existential self-understanding of the recipients and donors of DNA does not provide a clear answer to the balance between the

competing rights at issue, but it does highlight the importance of the debate and gives guidance in what should be valued in deciding the law.

Bibliography

European Convention on Human Rights 1950

Glendon M (2002) *A World Made New*. Random House.

Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015/572.

Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004/1511

Möller K (2012) *The Global Model of Constitutional Rights*. Oxford University Press.

Sartre J-P (2003) *Being and Nothingness*. Routledge.

Universal Declaration of Human Rights 1947

Case Law

Godelli v Italy [2012] ECHR 33783/09

Goodwin v United Kingdom (2002) 35 EHRR 18

Guerra v Italy (1998) 26 EHRR 357

McGinley and Egan v United Kingdom (1999) 27 EHRR 1

Mikulčić v Croatia [2002] 1 FCR 720

Odièvre v France (2004) 38 EHRR 43

Pretty v UK (2002) 35 EHRR 1

R (Nicklinson) v Ministry of Justice [2014] UKSC 38

Rose v Secretary of State for Health [2002] EWHC 1593 (Admin)

Author Biography

Benedict Douglas, Durham Law School, Durham University, Durham, DH1 3LE, UK

Email: benedict.douglas@durham.ac.uk

I am very grateful to Noa Vaisman for inviting me to be part of this project and for her encouragement and support in the writing of this paper. Any errors are my own.