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**[A Mitochondrial Story: Mitochondrial Replacement, Identity and Narrative.](#)**

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# 1 A MITOCHONDRIAL STORY: MITOCHONDRIAL REPLACEMENT, IDENTITY 2 AND NARRATIVE

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## 13 Keywords

14 mitochondrial replacement,  
15 identity,  
16 narrative,  
17 mitochondrial donation

## Abstract

Mitochondrial replacement techniques (MRTs) are intended to avoid the transmission of mitochondrial diseases from mother to child. MRTs represent a potentially powerful new biomedical technology with ethical, policy, economic and social implications. Among other ethical questions raised are concerns about the possible effects on the identity of children born from MRT, their families, and the providers or donors of mitochondria. It has been suggested that MRT can influence identity (i) directly, through altering the genetic makeup and physical characteristics of the child, or (ii) indirectly through changing the child's experience of disease, and by generating novel intrafamilial relationships that shape the sense of self. In this article I consider the plausibility and ethical implications of these proposed identity effects, but I focus instead on a third way in which identity may be affected, through the mediating influence of the wider social world on MRT's effects on identity. By taking a narrative approach, and examining the nature and availability of identity narratives, I conclude that while neither direct genetic nor indirect experiential effects can be excluded, social responses to MRT are more likely to have a significant and potentially damaging influence on the generation of MRT children's narratives of identity. This conclusion carries some implications for the collective moral responsibility we hold to ensure that MRT, if implemented, is practised in ethically justifiable ways.

## 37 MITOCHONDRIAL REPLACEMENT 38 TECHNOLOGIES

39 The novel techniques of mitochondrial replacement cur-  
40 rently being researched and developed, and the subject of  
41 this special issue, are intended as therapies for women  
42 affected by mitochondrial disease. Mitochondria are sub-  
43 cellular organelles with important functions in generating  
44 cellular energy. Conditions classed as mitochondrial dis-  
45 eases are most commonly due to an abnormality within  
46 the small amount of autonomous DNA carried by each  
47 mitochondrion (mtDNA), and present with a highly vari-  
48 able array of symptoms and prognoses. The most severe  
49 forms lead to death of a child prenatally, or to devastating  
50 physical or cognitive impairment and, often, early death.

Mitochondrial diseases are maternally transmitted 51  
through the mitochondria in the cytoplasm of a woman's 52  
ovum. The aim of mitochondrial replacement technologies 53  
(MRTs) is to enable affected women to have children that 54  
are free of mitochondrial disease by transferring DNA 55  
from the nuclei of the intending parents' gametes into an 56  
enucleated egg provided by an unaffected donor<sup>1</sup> replacing 57  
the mitochondria in an affected woman's egg.<sup>2</sup> Although 58

<sup>1</sup> E. Haimes & K. Taylor. Rendered invisible? The absent presence of 59  
egg providers in UK debates on the acceptability of research and therapy 60  
for mitochondrial disease. *Monash Bioethics Review* 2015; DOI 10.1007/ 61  
s40592-015-0046-7. 62

<sup>2</sup> There are a number of disputes about terminology within MRT, 63  
including the use of 'donation', 'replacement' or 'transfer', and whether 64  
the mitochondria or the nuclear genome should be seen as being mobile 65  
(see Haimes and Taylor, *op. cit.* note 1, for further discussion). In this 66

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1 numerous recent publications have discussed their clinical  
2 and epidemiological details,<sup>3</sup> in comparison with condi-  
3 tions caused by mutations in the nuclear genome mito-  
4 chondrial diseases and the peculiarities of their  
5 inheritance patterns are relatively unfamiliar both to bio-  
6 ethicists and the general public.<sup>4</sup> Nevertheless, if as has  
7 been claimed roughly 1 in 400 people in the UK carry a  
8 disease-causing mitochondrial mutation,<sup>5</sup> with around 9  
9 in every 100 000 clinically affected by mitochondrial dis-  
10 ease,<sup>6</sup> then mitochondrial conditions may present a signifi-  
11 cant health burden, and MRTs are set to become a new  
12 biomedical technology with major ethical, policy, eco-  
13 nomic and social implications.

14 The development of the two most promising techni-  
15 ques of mitochondrial replacement (maternal spindle  
16 transfer, MST, and pronuclear transfer, PNT)<sup>7</sup> has been  
17 paralleled by growing international discussion of the  
18 ethics of their use. In the UK, the academic and policy  
19 examination of MRTs' ethical and public acceptability  
20 has involved several years of discussion, professional  
21 consultations carried out by the Nuffield Council on  
22 Bioethics<sup>8</sup> and the Human Fertilisation and Embryology  
23 Authority (HFEA),<sup>9</sup> as well as public consultations run  
24 by the HFEA<sup>10</sup> and the Department of Health.<sup>11</sup> All of  
25 this led in 2015 to revision of the Human Fertilisation  
26 and Embryology Act 1990, as amended in 2008, so that

70 article, for simplicity I will use the conventional terminology of  
71 'mitochondrial replacement' and 'mitochondrial donor' or 'provider'.

72 <sup>3</sup> S. DiMauro. A history of mitochondrial diseases. *J Inherit Metab Dis*  
73 2011; 34: 261–76.

74 <sup>4</sup> P.F. Chinnery & G. Hudson. Mitochondrial genetics. *Br Med Bull*.  
75 2013; 106: 135–59.

76 <sup>5</sup> N. Manwaring, M.M. Jones, J.J. Wang et al. Population prevalence of  
77 the MELAS A3243G mutation. *Mitochondrion* 2007; 7: 230–3.

78 <sup>6</sup> A.M. Schaefer, R. McFarland, E.L. Blakely, L. He, R.G. Whittaker,  
79 R.W. Taylor, P.F. Chinnery and D.M. Turnbull. Prevalence of mitochon-  
80 drial DNA disease in adults. *Annal Neurology* 2008; 63: 35–39.

81 <sup>7</sup> L. Craven, H.A. Tuppen, G.D. Greggains, S.J. Harbottle, J.L. Murphy,  
82 L.M. Cree, A.P. Murdoch, P.F. Chinnery, R.W. Taylor, R.N. Lightowlers,  
83 M. Herbert, and D.M. Turnbull. 2010. Pronuclear transfer in human  
84 embryos to prevent transmission of mitochondrial DNA disease. *Nature*  
85 2010; 465: 82–85; M. Tachibana, M. Sparman, H. Sritanaudomchai,  
86 H. Ma, L. Clepper, J. Woodward, Y. Li, C. Ramsey, O. Kolotushkina, and  
87 S. Mitalipov. Mitochondrial gene replacement in primate offspring and  
88 embryonic stem cells. *Nature* 2009; 461: 367–372.

89 <sup>8</sup> Nuffield Council on Bioethics. *Novel techniques for the prevention of*  
90 *mitochondrial DNA disorders: an ethical review*. London: Nuffield Coun-  
91 cil on Bioethics; 2012.

92 <sup>9</sup> HFEA. 2011. *Scientific review of the safety and efficacy of methods to*  
93 *avoid mitochondrial disease through assisted conception*. London: Human  
94 Fertilisation and Embryology Authority; HFEA. 2013. *Scientific review*  
95 *of the safety and efficacy of methods to avoid mitochondrial disease*  
96 *through assisted conception: Update*. London: Human Fertilisation and  
97 Embryology Authority; 2013.

98 <sup>10</sup> HFEA. 2013. *Mitochondria replacement consultation: Advice to gov-*  
99 *ernment*. London: Human Fertilisation and Embryology Authority.

100 <sup>11</sup> UK Department of Health. *Mitochondrial donation: A consultation*  
101 *on draft regulations to permit the use of new treatment techniques to pre-*  
102 *vent the transmission of a serious mitochondrial disease from mother to*  
103 *child*. 2014. London: HMSO; 2014.

MRTs could be offered therapeutically to women 27  
affected by mitochondrial disease once (or if) they have 28  
been shown to be safe and effective. 29

30 Several of the ethical problems identified in both the  
31 professional and public bioethical discussion are very  
32 familiar from other biomedical contexts.<sup>12</sup> High on the  
33 list are safety considerations (the ethics of using an inno-  
34 vative technology which by necessity lacks a track record  
35 of clinical safety; the cost/benefit balance of the intrusive  
36 follow-up of children born by MRTs that will be needed  
37 to evaluate longterm safety). Extensive discussion has  
38 also been given to whether mitochondrial replacement  
39 constitutes a germline modification, and if so whether  
40 the near-universal consensus against human germline  
41 genetic modification applies only to the nuclear and not  
42 to the mitochondrial genome. A further highly conten-  
43 tious question is whether the desire of affected people to  
44 have healthy children<sup>13</sup> to which they are genetically  
45 related is a compelling enough reason to warrant the  
46 investment of time, funding and other resources that will  
47 be needed to make MRTs a clinical reality.

48 But MRTs also have some distinctive technical features  
49 that take us into less well trodden ethical territory. A per-  
50 son born through MRT will have nuclear DNA from the  
51 gametes of their father and mother, as in standard fertil-  
52 ization, but will also have additional 'third party'  
53 mtDNA from the mitochondrial donor. This is unlike  
54 other currently used methods of assisted reproduction,  
55 which involve only two sets of genetic material, and  
56 raises the question of whether third party mtDNA will in  
57 some way affect the identity or 'essential character-  
58 istics'<sup>14</sup> of the person born after MRT.<sup>15</sup> The potential  
59 effects on identity are hypothesised to come about  
60 through two essentially separate pathways. The first is  
61 *directly*, through the genetic component contributed by  
62 the donor mitochondrial DNA; the second is *indirectly*,  
63 through the novel family relationships set up by mito-  
64 chondrial replacement.

65 In what follows I want to contribute to the debate on  
66 MRTs and identity. The central ethical questions are not  
67 just whether MRT effects a change in identity, but  
68 whether any such change will be great enough to be  
69 morally significant, and finally whether any significant

104 <sup>12</sup> J.B. Appleby The ethical challenges of the clinical introduction of  
105 mitochondrial replacement techniques. *Med Health Care Philos* 2015;  
106 18: 501–514; R. Dimond. Social and ethical issues in mitochondrial dona-  
107 tion. *Br Med Bull* 2015; 115: 173–182; F. Baylis. The ethics of creating  
108 children with three genetic parents. *Reproductive BioMedicine Online*  
109 2013; 26: 531–534.

110 <sup>13</sup> That is, children unaffected by mitochondrial disease. People born  
111 through MRT will remain as vulnerable to disease and disability in gen-  
112 eral as anyone else.

113 <sup>14</sup> A.L. Bredenoord, W. Dondorp, G. Pennings, and G. De Wert. Ethics  
114 of modifying the mitochondrial genome. *J Med Ethics* 2011; 37: 97–100.

115 <sup>15</sup> A. Wrigley, S. Wilkinson S, Appleby JB. Mitochondrial replacement:  
116 ethics and identity. *Bioethics* 2015; 29: 631–638.

1 change in identity would actually be undesirable. To  
 2 address questions of identity change it helps to be as  
 3 clear as possible about what identity is, and it is disap-  
 4 pointing that much of the public and some of the  
 5 academic debate has not done so. What we mean by  
 6 identity is dependent on specific background theories of  
 7 the self, and how selfhood is formed and maintained  
 8 over a lifetime; whether and in what way MRT is consid-  
 9 ered to change identity depends on which background  
 10 theory of identity is being deployed. In this discussion  
 11 my main focus will be on a third route to changing iden-  
 12 tity, through effects on social identity, and in particular  
 13 how that is influenced by narrative. First, however, I out-  
 14 line some current thinking about identity and its consti-  
 15 tution, and the concerns that have been raised about the  
 16 two pathways to altering identity I just mentioned. My  
 17 argument is not that these other factors influencing iden-  
 18 tity are unimportant, but that bioethics' neglect of social  
 19 effects on the emerging sense of self has hampered its  
 20 examination of MRT's potential (and that of other  
 21 reproductive technologies) to influence personal identity.

## 22 GENETIC IDENTITY

23 Given that mitochondrial replacement is an essentially  
 24 genetic intervention, many commentators have focused  
 25 exclusively on the potential direct identity effects of the  
 26 change in mitochondrial genetic constitution. By defini-  
 27 tion, any manipulation of the genome, however trivial,  
 28 results in an organism with a different *genetic makeup*;  
 29 whether that corresponds to a different *identity*, and  
 30 whether the change is materially and morally significant,  
 31 is less obvious. For some people, any change in genetic  
 32 makeup per se is wrong because there is something  
 33 intrinsically valuable about an individual's genome as it  
 34 is; heavyweight justification is needed before it can be  
 35 right to 'interfere' with it. Few bioethicists today find  
 36 this a compelling argument, however, especially since the  
 37 genetic diversity that we know exists naturally among  
 38 humans makes it hard to see how simply introducing a  
 39 genetic difference is ethically wrong.<sup>16</sup>

40 An altered genetic composition could also directly  
 41 affect identity through the associated phenotypic changes.  
 42 Directed mutation of the human genome has of course  
 43 been extensively discussed by bioethicists, but as changes  
 44 in the nuclear genome. The question here is whether  
 45 mtDNA affects any 'identity-forming characteristics' of  
 46 the resulting individual, which are usually considered to  
 47 be things like facial features, physique, cognitive capaci-  
 48 ties, personality traits and so on. One influential line of  
 49 thinking concentrates on the evidence that all mtDNA

93 <sup>16</sup> Nevertheless, in the HFEA's public consultation there was some evi-  
 94 dence of a minority of the public having concerns about 'violating the  
 95 integrity of nature' through changing the mitochondrial DNA.

50 does is provide essential components for cellular energy  
 51 production: this is clearly important to the organism's  
 52 survival, but it isn't what we normally think of as an  
 53 identity-forming characteristic. According to this argu-  
 54 ment, mtDNA is *qualitatively* irrelevant to the child's  
 55 identity because of the kind of features it codes for. In  
 56 addition, because the nuclear DNA contributed by the  
 57 parents provides over 99.9% of the total genetic material,  
 58 the contribution of the mitochondrial donor has been  
 59 considered *quantitatively* irrelevant to identity-forming  
 60 characteristics. The qualitative and quantitative insignifi-  
 61 cance of mtDNA has been prominent in both profession-  
 62 al and public debates, and was used in the HFEA's  
 63 arguments justifying the first licences for preclinical  
 64 research on MRTs. Nevertheless, it can be challenged.  
 65 Although the current consensus is that mtDNA has noth-  
 66 ing to do with essential functions other than cellular  
 67 energy metabolism, scientists also acknowledge that our  
 68 understanding of mitochondria is far from complete and  
 69 that consensus may change.<sup>17</sup> In that case, the function of  
 70 mtDNA might no longer be irrelevant, and the amount  
 71 involved could become highly significant.

## 72 THE ILLNESS EXPERIENCE

73 The idea that identity is predominantly to do with traits  
 74 directly determined by genes is roundly rejected by most  
 75 commentators today as a discredited genetic essential-  
 76 ism,<sup>18</sup> replaced by a more nuanced view in which perso-  
 77 nal identity is shaped by life experience as well as genetic  
 78 input. From this perspective, modifying the mitochon-  
 79 drial genome affects the identity of the recipient not  
 80 because of changes in the DNA sequences or in identity-  
 81 forming characteristics, but through the resulting  
 82 transformation of that person's experience of health.<sup>19</sup>  
 83 Successful mitochondrial replacement will produce a  
 84 child who does not suffer the well documented, devastat-  
 85 ing effects of mitochondrial disease,<sup>20</sup> and 'a person  
 86 without a mtDNA disease will have a different life expe-  
 87 rience, a different biography and perhaps also a different  
 88 character' from one who does experience mtDNA dis-  
 89 ease.<sup>21</sup> He or she may well be considered to be a  
 90 'different person'. The genetically produced change is  
 92 intended to affect the mtDNA recipient's life for the

96 <sup>17</sup> D.R. Thorburn, H.H. Dahl, K.K. Singh. The pros and cons of mito-  
 97 chondrial manipulation in the human germ line. *Mitochondrion* 2001; 1:  
 98 123–127.

99 <sup>18</sup> R. Dimond R. Social and ethical issues in mitochondrial donation.  
 100 *Br Med Bull* 2015; 115: 173–182; 177.

101 <sup>19</sup> A.L. Bredenoord et al., *op.cit.* note 14, p.5.

102 <sup>20</sup> P.N. Ossorio. Inheritable genetic modifications: do we owe them to  
 103 our children. In *Designing our descendants: the promise and perils of*  
 104 *genetic modification*. A.R. Chapman and M.S. Frankel, eds. Baltimore  
 105 and London: Johns Hopkins University Press; 2003; 252–71.

106 <sup>21</sup> A.L. Bredenoord et al., *op.cit.* note 14, p.5: 99.

1 better, by preventing disease; since it is not ethically trou- 33  
 2 bling to intervene in other ways to prevent individuals 34  
 3 going through disease experiences, then disease preven- 35  
 4 tion by itself cannot be a reason to reject the use of 36  
 5 MRT.<sup>22</sup> 37

## 6 **FAMILIAL EFFECTS, OR ‘THREE- 38** 7 **PARENT BABIES’ 39**

8 A different route to possible identity change is through 42  
 9 alterations in the dynamics of relationships within families 43  
 10 using MRT. These have sometimes been described as psy- 44  
 11 chosocial effects; I will refer to them as familial effects on 45  
 12 identity to distinguish this more intimate family arena 46  
 13 from MRT’s broader social context, which I will be dis- 47  
 14 cussing in more detail.<sup>23</sup> Just like the experience of illness, 48  
 15 these (putative) effects are the consequence of changing 49  
 16 the genetic constitution, but not an unmediated one. 50

17 People who would be born through MRT are often 51  
 18 described as ‘three person’ or ‘three parent’ children, or 52  
 19 more accurately as having three genetic parents<sup>24</sup> or three 53  
 20 genomic contributors.<sup>25</sup> The slippery terminology high- 54  
 21 lights the feature of MRT that many people find the 55  
 22 most disturbing. Having three (social) parents is histori- 56  
 23 cally not unusual; being born as a result of reproductive 57  
 24 input from three separate individuals through gamete or 58  
 25 embryo donation, although statistically unusual is not 59  
 26 unprecedented; but having contributions from three 60  
 27 genomes *is* novel.<sup>26</sup> The question is whether the novelty 61  
 28 of this arrangement could have a significant effect on the 62  
 29 child and future adult’s sense of self. 63

30 Although the phrase ‘three parents’ has been criticized 64  
 31 for suggesting that the sheer provision of mitochondrial 65  
 32 material is equivalent to parenthood, it has nevertheless 66

70 <sup>22</sup> It follows from this is that if the avoidance of the disease experience is 68  
 71 the most salient form of identity change, then in terms of the ethics of 69  
 72 identity it doesn’t matter whether this happens through a change in the 70  
 73 mitochondrial DNA makeup of a person or through a change in the 71  
 74 nuclear DNA makeup. Altering mitochondrial DNA prevents a person 72  
 75 experiencing disease, and the effect on that person’s identity is the same 73  
 76 as if a modification of the nuclear genome had done the same thing. This 74  
 77 conclusion makes the distinction between nuclear and mitochondrial 75  
 78 DNA less clear, and that in turn has implications for the legitimacy of 76  
 79 heritable nuclear DNA modification. I don’t discuss this further here. 77

80 <sup>23</sup> Note also that some authors separate the ethics of MRT identity 78  
 81 effects from the ethics of ‘having 3 genetic parents’. However, since both 79  
 82 the intrafamilial relationship dynamic and the social framing of this 80  
 83 genetic relationship and family structure are important in forming the 81  
 84 child’s sense of identity, both are also highly relevant to the debate on 82  
 85 MRT identity effects. 83

86 <sup>24</sup> F. Baylis. The ethics of creating children with three genetic parents. 84  
 87 *Reproductive BioMedicine Online* 2013; 26: 531–534. 85

88 <sup>25</sup> E. Haines and K. Taylor. Rendered invisible? The absent presence of 86  
 89 egg providers in UK debates on the acceptability of research and therapy 87  
 90 for mitochondrial disease. *Monash Bioethics Review* 2015 DOI 10.1007/ 88  
 91 s40592-015-0046-7. 89

92 <sup>26</sup> Nuffield Council on Bioethics, *op.cit.* note 8, p.3. 90

proved extremely persistent in the popular media and 33  
 parliamentary discussion. The debate over terminology 34  
 reflects the ongoing uncertainty over exactly what kind of 35  
 contribution the mitochondrial replacement makes.<sup>27</sup> Will 36  
 this unprecedented direct genetic link between three 37  
 adults and a child disrupt the ‘normal’ parent-child rela- 38  
 tionship(s) and so cause damage to the psychological 39  
 wellbeing, and by implication the emerging identity, of 40  
 the child? Perhaps the child’s emerging sense of self could 41  
 in some way become confused through knowing that a 42  
 third person was involved in their conception, unlike their 43  
 peers; children might not be able to understand why the 44  
 mitochondrial donor is not included in family events and 45  
 communications; tensions may develop, if the child wants 46  
 more information about the mitochondrial donor than 47  
 parents are able or willing to provide.<sup>28</sup> It’s worth remem- 48  
 bering that problems might also arise even if the child 49  
 does *not* know how she came to be born, if the parents’ 50  
 or family’s knowledge that MRT was used affects how 51  
 they relate to her; for example, if an unwanted character- 52  
 istic of their child is attributed to the influence of donor 53  
 mtDNA. However, against these projected concerns can 54  
 be set the range of experience gained since the 1970s 55  
 from other forms of assisted reproduction that have pro- 56  
 duced family structures and relationships that were, ini- 57  
 tially, equally unfamiliar. Accumulated anecdotal and 58  
 some empirical knowledge suggests that family structures 59  
 are flexible, and familial networks resilient enough to 60  
 accommodate a wide variety of parent-child relationships 61  
 without causing psychological damage. Recent empirical 62  
 studies of children born through gamete or embryo dona- 63  
 tion show no evidence of any distinctive psychological or 64  
 emotional harm due to their unconventional family struc- 65  
 tures.<sup>29</sup> Use of donor gametes, particularly donor insemi- 66  
 nation, has caused difficulties in some families, but these 67  
 seem principally related to secrecy rather than the use of 68  
 donor gametes per se.<sup>30</sup> Of course, at the moment there 69

27 J. Cohen & M. Alikani. The biological basis for defining bi-parental 93  
 or tri-parental origin of offspring from cytoplasmic and spindle trans- 94  
 fer. *Reprod Biomed Online* 2013; 26: 535–537. 95

28 The proposed HFEA regulations stipulate that licensed clinics will 96  
 disclose only non-identifying information about the donor to a child 97  
 born through MRT who seeks that information after the age of 16. 98

29 E. Basatemur & A. Sutcliffe. Follow-up of children born after ART. 99  
 Placenta 2008; 29: 135–140; E.C. Iloi & S. Golombok. Psychological 100  
 adjustment in adolescents conceived by assisted reproduction techni- 101  
 ques: a systematic review. *Human Reproduction Update* 2015; 21: 84–96; 102  
 C.S. Hahn. Review; psychosocial well-being of parents and their chil- 103  
 dren born after assisted reproduction. *J Pediatr Psychol* 2001; 26; 104  
 525–538; K. Wagenaar, J. Huisman, P.T. Cohen-Kettenis & H.A. 105  
 Delemarre-van de Waal. An overview of studies on early development, 106  
 cognition, and psychosocial well-being in children born after in vitro fer- 107  
 tilization. *J Dev Behav Pediatr* 2008; 29: 219–230. 108

30 E. Lycett, K. Daniels, R. Curson & S. Golombok. Offspring created 109  
 as a result of donor insemination; a study of family relationships, child 110  
 adjustment, and disclosure. *Fertil. Steril* 2004; 82: 172–179; E. Lycett, K. 111  
 Daniels, R. Curson, & S. Golombok. School-aged children of donor 112

## A Mitochondrial Story

1 are no MRT children and therefore no equivalent data on  
 2 the psychological health of post-MRT children and their  
 3 families. Moreover, the existing studies focus on psycho-  
 4 logical health and family functioning and not directly on  
 5 identity formation. Still, these data provide some reassur-  
 6 ance that the identities of children within MRT families  
 7 will not be different from, or more dysfunctional than,  
 8 those of ‘normal’ children.

### 9 SOCIAL IDENTITY

10 The discussion of MRT and identity has been dominated  
 11 by the effects of gene action and family dynamics, both  
 12 of which are relatively small-scale, narrowly focused  
 13 processes. But what about the ways in which the develop-  
 14 ment of selfhood is mediated through broader social fac-  
 15 tors extending beyond the individual and family? In this  
 16 section I will give a (necessarily brief) sketch of what it  
 17 means to have an identity formed *within* and *by* the  
 18 social world, and take one approach to analysing socially  
 19 mediated identity – through the action of narrative – to  
 20 consider how MRT might influence a person’s sense of  
 21 self.

22 Social theorists and an increasing number of philoso-  
 23 phers of the self argue that it is impossible to conceive of  
 24 any aspect of a human individual developing or existing  
 25 in isolation from society.<sup>31</sup> As much as materially and  
 26 genetically influenced features (such as the physical char-  
 27 acteristics that indicate their sex), a person’s identity is  
 28 formed by the cultural forces that define which features  
 29 of a person are important for knowing who and what  
 30 they are (e.g. that sex and gender are worth noticing),  
 31 and what these features signify in a particular social con-  
 32 text and relational network (e.g. whether or not a woman  
 33 is dressed appropriately according to prevailing norms).  
 34 Identity features are markers for a variety of ontological  
 35 and social categories, and among the most basic of these  
 36 are to do with family relationships. My understanding of  
 37 myself as a person with a mother and a father, or a  
 38 mother and a stepfather, or two mothers, or (potentially  
 39 through MRT) three genetic contributors, is acquired  
 40 from everyday experiences (the things that happen  
 41 between me and these family members), and also from  
 42 the accounts my family and the communities around  
 43 provide about who these people are and what my rela-  
 44 tionship to them is. Whether Moira sleeps at my house,  
 45 if others refer to her as my mother, whether she is invited  
 46 to school parents’ evening or has her name on my birth  
 47 certificate, all contribute to my understanding of myself  
 48 as her daughter. So any examination of MRT’s identity  
 49 effects also needs to address the questions of whether

98 insemination; a study of parents’ disclosure patterns. *Hum. Reprod* 2005:  
 99 20; 810–819.

100 <sup>31</sup> S. Lawler. *Identity*. Cambridge: Polity Press; 2008; 5.

*socially mediated* identity will be affected at all by the use  
 of the technology, and if so whether any resulting change  
 in identity could be harmful to the child, its family or  
 even society in general.

### NARRATIVE IDENTITY

Social models of identity deploy a range of theoretical  
 frameworks and emphases. Some highlight the manage-  
 ment of a person’s multiple identities across their various  
 social roles, or the formation of one identity through  
 opposition to others. Some emphasise socio-political  
 structures that shape the development of selves, others  
 the ceaseless microinteractions between individuals in  
 daily life. Feminist approaches are notably sensitive to  
 the power dynamics of social categories and the con-  
 straining or liberating effects of gendered relations on  
 identity. Nevertheless, tracing how social structuring ‘gets  
 into’ the individual sense of self is not easy, requiring as  
 it does some analytic traction on multiple macro, meso  
 and micro influences coming together. Since the later  
 twentieth and early twenty-first century, the ‘narrative  
 turn’ in several disciplines<sup>32</sup> has provided a powerful lens  
 through which to conceptualise identity as derived from  
 the stories told by ourselves to ourselves, ourselves to  
 others and others to us.<sup>33</sup>

A personal sense of self accumulates out of the ascrip-  
 tion and recognition, by ourselves and others, of narra-  
 tive fragments drawn from a slowly evolving cultural  
 repertoire of identity-forming stories. Stories tell us how  
 families are made and behave, what a good parent does,  
 the paths a son’s relationship with his mother might  
 take, and so on. The narrative construction of identity is  
 therefore deeply socially embedded, and moreover the  
 options that people have are limited by the materials  
 available at that time and in that place. An important  
 point that theories of narrative tend to underemphasize  
 is that identity narratives aren’t coherent literary con-  
 structions: they are necessarily fragmentary and incom-  
 plete accretions over time out of available tales that  
 more-or-less work. If my partner dies, for example, my  
 new identity might draw on the broad elements of the  
 narrative of widowhood that have long been understood  
 throughout my community, but the story options open  
 to me (staying single; remarriage; partnership without  
 marriage, etc) and the precise way in which I negotiate  
 them as an early twenty-first century, mixed-race woman,  
 which bits I find resonant and which I leave behind, are  
 what make my version distinctive. Ultimately, when I  
 make an identity claim through a story I tell about

<sup>32</sup> R.J. Berger & R. Quinney, eds. *Storytelling sociology: Narrative as  
 social inquiry*. Boulder, CO: Lynne Rienner Publishers; 2005.

<sup>33</sup> M. Somers. The narrative constitution of identity: a relational and  
 network approach. *Theory and Society* 1994; 23: 605–649.

1 myself, the plot or characters need to be familiar enough  
2 that others recognize my claim as plausible; the identity  
3 ascribed to me through others' accounts, similarly, must  
4 appear to me to be a reasonably accurate description of  
5 who I feel myself to be. From this perspective, identity is  
6 not to be found in the genome alone, nor in lived experi-  
7 ence as such, but 'in the world in which we live and the  
8 stories we construct and are able to maintain'.<sup>34</sup>

9 The narrative turn has proved both conceptually and  
10 methodologically rich. It is not that a narrative approach  
11 is the only or best way of conceptualizing how identities  
12 form within the social world, but that it provides a useful  
13 and relatively straightforward analytic framework with  
14 which to explore how political structures and social insti-  
15 tutions, cultural resources and personal biography all  
16 interweave to generate a meaningful subjectivity. A nar-  
17 rative approach also has the advantage of conveying a  
18 feel of the *dynamism* of identity and its potential for  
19 change over time, as well as the limits to such change.

20 The ethical significance of identity narratives lies in  
21 their effect on some morally relevant aspects of a per-  
22 son's life. Theorists interested in the ethics of identity  
23 have particularly focused on the connection between  
24 identity and the capacities for agency, autonomy and  
25 authenticity. Philosophers like Hilde Lindemann,<sup>35</sup>  
26 Marya Schechtman<sup>36</sup> and Paul Benson<sup>37</sup> have different  
27 takes on this, but share the essential view that the sense  
28 someone has of themselves as subjects of their lives is  
29 fundamental to self-determination; 'agency' is the word  
30 we use for the activity of our identities in the social  
31 world. That is, in order to be agents 'present or engaged  
32 in their actions as free agents are, [people] must have a  
33 sense of who they are, and that sense of selfhood must  
34 be capable of being disclosed in their conduct':<sup>38</sup> we need  
35 to have a view of ourselves as the kind of person who is  
36 competent to make moral and other decisions. But in  
37 order for that to happen, according to Benson and  
38 Lindemann, those around us must afford us the power  
39 to act autonomously, and we have to have self-trust in  
40 our ability to do so.

41 Being forced to take on an identity that is disvalued or  
42 marginalized – a damaged identity, in Lindemann's terms  
43 – can result both in direct constraints on agency (if I as a  
44 disabled person am not able to attend school), and indi-  
45 rect effects, through the psychological harm to the indi-  
46 vidual that can follow from a lifetime of being treated as

marginal or of less value (if I as a disabled person believe  
myself to be less knowledgeable than others). And if cer-  
tain identities are marginalized, disvalued or neglected,  
this will be reflected in the forms of identity narratives  
made available to them (see Lindemann Nelson<sup>39</sup> for a  
fuller treatment). Thus, false or 'toxic' narratives that are  
used to assemble an identity will fundamentally damage  
agential capacity.

However, in addition to overtly negative narratives of  
disvalued identities, it is also possible for an identity nar-  
rative to be simply absent from the cultural repertoire,  
with similarly damaging effects on agency. A prime  
example would be when a new social position or role  
emerges so rapidly that the resources supporting an  
account of it are still rudimentary: the provision of a  
story that can be incorporated into a personal sense of  
self lags behind the appearance of the role itself. Past  
examples where this has happened are often to do with  
rapid and contested social change. In the recent history  
of the UK this could include the emergence of a black  
middle class, or of same-sex parents. It seems plausible  
that a person born through mitochondrial replacement  
will face similar difficulties, at least when MRT is first  
used. Her novel birth history, and the distinctive situa-  
tions and problems she may confront, will not (yet) be  
present in the narratives of identity circulating within her  
community. She and her family may lack a vocabulary to  
match some crucial areas of her experience that arise out  
of the special way she was conceived, and a story that  
enables her to make sense of those aspects of her life and  
eventually to describe and account for them to others.<sup>40</sup>

It follows from this that an important question when  
evaluating the impact of MRT on identity is what kind  
of narratives of conception, birth, parentage and health  
status will emerge for the child born through MRT and  
his or her family (and donor) to use. The origin and  
identity stories told by parents and other kin to the child,  
the stories circulating within communities, and the wider  
cultural representations of 'kinds of people'<sup>41</sup> in a soci-  
ety, are mutually constitutive, and so inherently tending  
towards conservatism and at the same time open to  
change. Cultural representations circulate and are passed  
between generations through everyday speech, anecdotes,  
jokes, songs, family tales, written memoirs and other for-  
mal depictions. In contemporary society it is also clear  
that the 'stories that are made into other stories' are effi-  
ciently propagated through the mass information and  
entertainment industries, including online and print

34 F. Baylis. Black as me: narrative identity. *Developing World Bioethics* 2003; 3: 142–50; 142 p 142).

35 H. Lindemann Nelson. 2001. *Damaged identities, narrative repair*. Ithaca, NY: Cornell University Press.

36 M. Schechtman. *The constitution of selves*. Ithaca, NY: Cornell University Press; 1996.

37 P. Benson P. Free agency and self-worth. *Journal of Philosophy* 1994; 91: 650–668.

38 Ibid: 661.

39 H. Lindemann Nelson, *op.cit.* note 35, p.16.

40 J.L. Scully. 2008. *Disability Bioethics: moral bodies, moral difference*. Lanham: Rowman & Littlefield: 115–131.

41 I. Hacking I. Kinds of people: moving targets. 10<sup>th</sup> British Academy Lecture, 2006. Available at: [http://nurs7009philosophyofinquiry.weebly.com/uploads/6/0/4/0/6040397/hacking\\_20071.pdf](http://nurs7009philosophyofinquiry.weebly.com/uploads/6/0/4/0/6040397/hacking_20071.pdf) [Accessed 6 January 2016].

## A Mitochondrial Story

7

1 media, cinema and television, alongside the more tradi- 49  
 2 tional literary and dramatic forms. In what may turn out 50  
 3 to be the early days of MRT, there are as yet no fictional 51  
 4 representations of mitochondrial disease or MRT in liter- 52  
 5 ature, cinema or television; the best we can do at the 53  
 6 moment is to extrapolate from the cultural representa- 54  
 7 tions of other modes of assisted conception. 55

8 Surveying the cultural representations of assisted con- 56  
 9 ception and the related research literature, it is striking 57  
 10 that apart from some publications on cultural representa- 58  
 11 tions mostly dating from the earlier days of assisted con- 59  
 12 ception, there is little academic research in this area.<sup>42</sup> 60  
 13 Although there are now a number of novels, feature films 61  
 14 or television dramas featuring some aspect of assisted 62  
 15 conception, in practice they share features that suggest 63  
 16 their role in the development of novel narratives of origin 64  
 17 is restricted and potentially problematic. The existing 65  
 18 narratives tend to take as their central theme a difficult 66  
 19 and painful aspect of assisted conception, such as the 67  
 20 emotional distress of infertility, or tensions between 68  
 21 intended parents and a surrogate. In these representa- 69  
 22 tions, assisted conception is the problem that drives the 70  
 23 drama. If we exclude technologies that are still science 71  
 24 fiction (such as the routine genetic profiling and selection 72  
 25 of the 1997 film *Gattaca*), one of the commonest themes 73  
 26 is the anonymous gamete donor seeking or being sought 74  
 27 by the resulting child. For example, the film *The Kids are* 75  
 28 *Alright* (2010) charts the disruption in the lives of a les- 76  
 29 bian couple and their two children when one child con- 77  
 30 tacts his previously anonymous donor father. *Leon the* 78  
 31 *Pig Farmer* (1992) is a comedy about a Jewish man who 79  
 32 discovers that his biological father's job is exactly as 80  
 33 stated in the title. These and similar examples are narra- 81  
 34 tives of crises that arise solely from the manner of the 82  
 35 child's conception. They are about a search for identity 83  
 36 in the sense of finding a character's 'real' parent. In 84  
 37 doing so, however, they dramatize rather than normalize 85  
 38 the process of being conceived through donor insemina- 86  
 39 tion, and they fail to offer a useful strand of identity nar- 88  
 40 rative for those donor children who do not want to 89  
 41 know the identity of their donor. Films with this theme 90  
 42 may even make donor conceived children assume that 91  
 43 they *should* be experiencing an identity crisis and that 92  
 44 there is something wrong with them if they don't. (This 93  
 45 is potentially even more problematic: stories may primar- 94  
 46 ily *reflect* how people's lives go, but the very availability 95  
 47 of a handy story can also mean that these narratives 96  
 48 become the obvious paths for a life to follow.) 97

89 <sup>42</sup> See for example S. Franklin S. Postmodern procreation: a cultural 90  
 91 account of assisted reproduction. In *Conceiving the new world order: the* 92  
 93 *global politics of reproduction*. F.D. Ginsburg and R. Rapp, eds, Berkeley 94  
 95 and Los Angeles: University of California Press; 1995; 323–345; more 96  
 97 recently J. Maher. Something else besides a father: reproductive medi- 98  
 99 cine in recent Hollywood film. *Feminist Media Studies* 2014; 14:  
 100 853–867.

The paucity of fictional representations of assisted 49  
 conception, the children born from them and the families 50  
 they are born into, has several possible explanations. It 51  
 could be that the technologies have already become part 52  
 of the 'new normal' of family life: so effectively normal- 53  
 ized that they are no longer felt to merit special (artistic 54  
 or other) attention. However, this explanation becomes 55  
 less plausible, I think, if we consider the lack of examples 56  
 in which assisted conception is a purely incidental aspect 57  
 of the plotline. The only coming near to this I could 58  
 identify are in soap operas where, because characters 59  
 tend to be presented for months or years, an initial plot- 60  
 line about the use of assisted conception can become 61  
 peripheral as the story of that family is carried on (eg in 62  
 the UK, the television programmes *EastEnders*, *Corona-* 63  
*tion Street* and *Emmerdale Farm* have all at different 64  
 times included characters who consider using IVF).<sup>43</sup> 65  
 Beyond the distinctive narrative structures of soap opera, 66  
 however, the lives of children born by assisted conception 67  
 do not seem convincingly integrated into the normative 68  
 narrative stock.<sup>44</sup> 69

Parallels can be drawn with the popular media repre- 70  
 sentations of ethnic or sexual minorities, or disabled peo- 71  
 ple. In these cases it has been argued that characters in 72  
 film, theatre or television dramas are usually black, gay 73  
 or disabled only if their ethnicity, sexual orientation or 74  
 disability forms a central feature of the story. A character 75  
 is deaf because the film is about deafness, not as one 76  
 part of that character's profile.<sup>45</sup> Similarly, for assisted 77  
 conception normalization would mean that a drama 78  
 could involve a child whose best friend was born through 79  
 IVF, a fact mentioned in passing, in the same way that a 80  
 character's employment or hobbies might be; their orig- 81  
 ins are an interesting but peripheral part of their char- 82  
 acter in a story about something else entirely. 83

Collective narratives may also draw from sources other 84  
 than fiction, such as policy documents, public consultation 85  
 materials and similar grey literature. Although not provid- 86  
 ing material that can straightforwardly be adopted as 88

43 <http://www.digitalspy.com/soaps/eastenders/spoilers/a308882/kat-and-alfie-make-a-decision/>; [http://www.thebabywebsite.com/article.3144.Whos\\_The\\_Legal\\_Mother\\_in\\_Coronation\\_Street\\_Surrogacy\\_Story.htm](http://www.thebabywebsite.com/article.3144.Whos_The_Legal_Mother_in_Coronation_Street_Surrogacy_Story.htm); <http://metro.co.uk/2014/03/22/emmerdale-ruby-and-aligo-to-desperate-lengths-to-achieve-their-baby-dream-4673258/>. 96  
 97  
 98  
 99

44 Complete normalization would also require openness within and 100  
 beyond families about their use of ART. Although the HFEA and infert- 101  
 ility support organizations encourage people to be honest with their 102  
 children about their origins, the available evidence suggests that, 103  
 although becoming more common, this does not always happen. I have 104  
 also been told by three fertility specialists independently that their goal 105  
 is for patients to be able to 'forget this [ie IVF] ever happened'. 106  
 107

45 A. Enns & C.R. Smit, eds. 2001. *Screening disability: essays on cinema* 108  
*and disability*. University of America Press; P.A. Darke. 2004. The chang- 109  
 ing face of representations of disability in the media. In *Disabling bar-* 110  
*riers, enabling environments*. J. Swain, S. French, C. Barnes, & C. 111  
 Thomas, eds. London: Sage: 100–105. 112



1 narratives, these sources contribute language, imagery and  
 2 empirical material so that policy can be revised and  
 3 reshaped accordingly. In the case of MRT, official commu-  
 4 nications have been careful to frame it as a vital therapeutic  
 5 procedure intended to support the birth of normal,  
 6 healthy children within normally functioning families. The  
 7 almost exclusive use of ‘donation’ and ‘mitochondrial  
 8 donor’ (rather than ‘transfer’ or ‘replacement’) in these  
 9 sources resonates with the generally positive attitude of the  
 10 UK public towards tissue donation, and connects to exist-  
 11 ing social narratives about the virtue of organ and blood  
 12 donors. Nevertheless, it is still unclear how immediately  
 13 influential these sources are compared to popular media  
 14 references. Likewise, the place of empirical studies in the  
 15 development of cultural understandings of novel identities  
 16 is, to my mind, still very uncertain. These forms of aca-  
 17 demic data clearly do contribute to the thinking that pro-  
 18 duces appropriate policy, on healthcare or child welfare for  
 19 example, but since they are primarily directed at profession-  
 20 al expertise it seems unlikely that empirical psychological  
 21 or sociological studies play a major role in shaping public  
 22 opinion, at least in the short term. This suggests that the  
 23 focus of attention should be on more informal and popular  
 24 representations than on academic data.

25 In the immediate future the most important influence  
 26 on the development of master narratives of MRT will be  
 27 factual news and social media. Here, it has to be  
 28 acknowledged that the current discourse around MRT in  
 29 these domains is pretty disappointing. Although media  
 30 reporting of MRT always mentions its positive therapeutic  
 31 goals, the other prominent themes are the technol-  
 32 ogy’s novelty and the ‘3-parent children’ it will create,  
 33 despite the deliberate efforts of governmental and regula-  
 34 tory bodies, and by scientists, clinicians and ethicists, to  
 35 explain the inadequacies of that description.<sup>46</sup> The lan-  
 36 guage of the 3-parent child positions MRT children and  
 37 their families as so unusual as to be morally suspect, and  
 38 possibly even ‘monstrous’, and could conceivably lead to  
 39 the emergence of severely damaging narratives of iden-  
 40 tity, particularly since the number of people using MRT  
 41 is likely always to be much smaller than the numbers  
 42 using more familiar forms of assisted conception.

### 43 IMPLICATIONS

44 Looking carefully at different models of how identity is  
 45 formed and maintained indicates that mitochondrial  
 46 transfer could indeed have a significant effect on the

identity of the child (and his or her family) born through  
 MRT, but not through the routes that have so far  
 received most bioethical attention. Mitochondrial trans-  
 fer will certainly modify an embryo’s total *genetic compo-*  
*sition*, but this purely genetic change has little to do with  
 what we normally think of as a person’s identity. There  
 is no scientific evidence at present that a switch of  
 mtDNA will alter other identity-forming features,  
 although that may change in the course of future  
 research, nor do we know whether or in which cases any  
 change would be significant, and whether it would be  
 harmful or beneficial. However, we *can* say that if MRT  
 works as hoped, it will change the identity of the result-  
 ing child in a profound and highly beneficial way by *pro-*  
*tecting it from mitochondrial disease*. Meanwhile,  
 although as yet there is no possibility of evidence about  
 MRT’s effect on identity through *family relationships*,  
 longer experience with other forms of assisted conception  
 has given no indication of obviously harmful outcomes  
 specific to their use. It is impossible to know at this stage  
 if the same will apply to children born from MRT. How-  
 ever, since at least the first cohort of these children will  
 have long term health follow-up, it would make sense to  
 include in this an effort to detect any difficulties with  
 identity that do emerge, and where possible indicate ways  
 of compensating.

I have argued that it is the *social processes* that form  
 and maintain identity, through the narratives that the  
 family and wider community adopt, that present the  
 most likely route for MRT to have a significant effect on  
 the child’s sense of self. Families who have undergone  
 MRT in order to have a healthy child are likely to favour  
 the most positive accounts. In the wider community,  
 however, attitudes to new biomedical technology are  
 unpredictable and are strongly influenced (positively or  
 negatively) by media reporting, especially of particularly  
 newsworthy cases that may not be representative of the  
 technology as a whole. What matters is whether a society  
 treats children born through MRT as worryingly anom-  
 alous bearers of an ‘artificially constructed identity’,<sup>47</sup> or  
 whether the story that comes through is of being just  
 part of the ‘new normal’ of family life, which to a certain  
 extent has happened for families generated through more  
 familiar forms of genetic and reproductive technology.  
 Concerns that society would view children born from  
 MRT with suspicion, as well as the converse belief that  
 MRT will eventually be accepted ‘as new advances  
 always are’,<sup>48</sup> were also expressed by a few respondents  
 to the HFEA open consultation, although given in the

96 <sup>46</sup> Numerous examples are available, for example: ‘Three parent babies  
 97 explained: what are the concerns and are they justified?’ *The Guardian*, 2  
 98 February 2015; ‘UK becomes first country in the world to legalise three-  
 99 parent babies after Lords approves controversial IVF technique’, *Mail*  
 100 *Online* 24 February 2015; ‘Three parent babies could risk the future of  
 101 the human race, warn 55 Italian MPs’, *Express* 21 February 2015.

47 Participant quoted in Office for Public Management. *Medical frontiers: debating mitochondria replacement*. Report to HFEA. Annex 1: Summary of evidence. 2013, p.12.

48 Participant quoted in Office for Public Management. *Medical frontiers: debating mitochondria replacement*. Report to HFEA. Annex 1: Summary of evidence. 2013, p.10.

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1 context of discrimination rather than identity. It is possi-  
2 ble that the present media emphasis on MRT as produc-  
3 ing healthy but unnatural embryos, children and families  
4 will persist, and may culminate in resistance to the tech-  
5 nology and, crucially, a failure to elaborate positive nar-  
6 ratives of identity that are familiar to and accepted by  
7 the general public.

8 If identity is created in part through cultural narra-  
9 tives, and can be damaged in a morally significant way  
10 by the lack of a 'good story', then ensuring that such  
11 good stories are available to MRT children and their  
12 families becomes a collective moral responsibility. This  
13 conclusion carries implications for what the state, public  
14 health policymakers, healthcare providers, regulators,  
15 patient groups and society as a whole might need to do  
16 in order for MRT to be introduced in an ethically  
17 responsible way. For example, it may become necessary  
18 to establish a form of systematic monitoring to follow  
19 how the media and other social institutions discuss MRT  
20 children and families, and engage with these agencies to  
21 counter potentially hurtful, harmful or limiting identity  
22 stories with more nuanced ones based on accurate empir-  
23 ical knowledge. A consciousness of what stories can do  
24 for and to people leads to the question of whether  
25 narratives of identity can be manipulated strategically to  
26 create a more accurate repertoire for people born

27 via MRT to choose from, in the way that disability  
28 activism led over time to the creation of new narratives  
29 of disability. Which methods are needed to satisfy  
30 this collective responsibility in practice, whose task it  
31 would be and how it would be resourced, are questions  
32 that call for more extensive exploration involving all  
33 stakeholders.

34 There are also wider implications for bioethics as a  
35 whole. The question of identity arose early in the discus-  
36 sion of MRT because it involves an actual, heritable  
37 genetic change, but if our thinking about the bioethical  
38 significance of identity expands to include the ways in  
39 which it can be shaped by culturally validated narratives  
40 as well as through a person's experience of illness and  
41 disability or family dynamics, then it becomes clear that  
42 a variety of other medical and biotechnological contexts  
43 also, unexpectedly, raise issues of personal and social  
44 selfhood and self-determination. An ethically responsible  
45 approach to innovative research requires noticing not  
46 just how scientific ideas and interventions change peo-  
47 ple's lives in the most obvious ways, but also how they  
48 change who people think they are (or should be), and  
49 the stories that they tell about themselves.

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