Responses and Dialogue

How To Welcome New Technologies

Some Comments on the Article by Inmaculada de Melo-Martin

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Therapy delayed is therapy denied, and those who oppose the introduction of new therapies that promise to reduce suffering and extend life face a responsibility as grave as do those who would recklessly introduce technologies that might cause more harm than the good expected or hoped of them. The tension between caution and recklessness walks both sides of this street. An example of the progress of this tension is encapsulated by the articles appearing in this journal by Inmaculada de Melo-Martin (IDMM) and me.

IDMM, is I am sure, neither callous nor desperate, but she is just a trifle wrong-headed and much more dangerous than she thinks I am. (For convenience all italicized sections are quotes from IDMM's articles). She asks:

> *Are there good reasons to celebrate this new technological achievement unreservedly? Does Harris offer any of them? "I think not" is the appropriate answer to both questions. Perhaps the reason why Harris is ready for the unqualified embrace of MRTs is that the objections he entertains are not particularly good ones.*

So what, then, are the good objections that I should have engaged with and would, or rather should, they have convinced me of the folly of my ways? Her chief complaint seems to be that MRT therapy does not constitute the highest medical priority and that she can think of better uses for resources. Because the context of the article of mine that she criticizes was to examine whether the chorus of claims that the germline is sacrosanct and should never be altered and that all heritable interventions should be banned, should have any merit, the issue of prioritization of medical resources was not one that I addressed. Before returning to this issue, I will clear away some other bizarre claims.

Identity

> *[Harris] both claims that "no identity-conferring features are transmitted by the mitochondria," and that mitochondrial DNA influences one's "susceptibility to disease and suffering." It seems to me that influencing one's susceptibility to disease and suffering is quite an identity-conferring feature. It is the identity-conferring trait that women who will use these technologies will want to prevent their children from having. As others have pointed out, health and disease are states of being that clearly inform personal identity and, therefore, no matter how small the genetic contribution of the mitochondria, it nonetheless influences one's susceptibility to disease and suffering. Therefore, it seems to make little sense to say that it has no effect on one's identity.*

We could argue about personal identity until the cows come home, and many philosophers have! But in so far as what IDMM says here is part of a plausible conception of identity, it simply dissolves any critical argumentative force that concern with degrees of identity alteration can give. In IDMM's view, all therapy and all disease is identity

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altering "no matter how small" the influence on "one's susceptibility to disease and suffering." Therefore, good diet, vaccination against influenza, and not smoking are identity-changing decisions. In this view, identity is incredibly fragile to the point where a person's identity is constantly changing, or rather people are ceasing to exist and coming into existence in the same body at a bewildering rate. It is true that some people cling to such a conception of identity, yes perhaps in desperation; however, it is doubtful that such a conception is either usable or useful.

IDMM needs, but fails totally to provide, an argument that it is only genetic changes to these susceptibilities that have this effect. She needs to establish this because otherwise she is saddled with objecting to common or garden-variety therapies on the same grounds. This claim, that only genetic identity counts, seems implausible and unsustainable, and it seems to involve a commitment to a form of genetic essentialism that IDMM herself also rightly rejects repeatedly elsewhere in the article. IDMM and I agree that it is not wrong to alter identity in these ways if what is altered does (even *per impossibile*) change identity, so we will move on.

Genetic Essentialism

> *What about the alleged right to know one's genetic origins? I am equally unpersuaded by this concern, but again, not for the reasons that Harris gives….*
>
> *Furthermore, I believe that talk of a right to know one's genetic parentage imbues genetic information with very special significance and thereby contributes to promoting problematic beliefs about genetic essentialism.*

I am happy for IDMM that she manages to find her own reasons for rejecting genetic essentialism, but I do not think that her reasons differ much from arguments I have used since the early 1990s, inter alia in my *Wonderwoman and Superman* in which I also argue extensively for radical skepticism about the sanctity of the human germline.[1] Therefore, I am not at all discomforted that IDDM is unpersuaded. I have no disagreement here.

Safe Enough?

IDMM then ventures to put a gloss on what might constitute evidence that MRT is safe enough for first-in-human use.

> *Therefore, although for Harris it seems clear—unreservedly so apparently—that MRTs are a way to do what is best for future children and generations, all things considered, others might not be so sanguine about it. After all, although Harris takes these technologies to be "safe enough," the evidential grounds for this assessment are pretty flimsy given that not a single human being has been yet born through these particular technologies.*

The test she proposes for "safe enough" requires the consideration of data from children "born through these particular technologies" and she opines that without such data, claims that a technology might be considered "safe enough" to use in humans must be "pretty flimsy" given that "not a single human being has been yet born through these particular technologies." In so far as this bizarre claim of IDMM's has any merit at all, it constitutes a powerful argument against first-in-human use of any technology whatsoever! This is a real Catch 22; one cannot, according to IDMM, create a child using MRT until a child has actually been created using MRT!

IDMM then asks:

> *So, where does this leave those of us who are not particularly excited about MRTs? Are we desperate and callous?*

And answers:

> *Nonetheless, contrary to Harris, I believe that the evidence about the safety of these technologies is at this point completely inadequate, and that, therefore, an "all things considered" decision would actually call for the gathering of more evidence before we proceed.*

I do not think that it is fair or reasonable for IDMM to try to get away with such a flagrantly inaccurate claim about the evidentiary basis of moving current MRT research in the United Kingdom into therapy in humans, particularly without explaining on what her extraordinary claim is based.

Contrary to IDMM"s flippant statement "I believe that the evidence about the safety of these technologies is at this point completely inadequate," MRT has, in fact, gone through just as rigorous an experimentation and trial as almost anything else we move to use in humans for the first time, and has a commensurate perceived risk, or potential for unknowns as other comparable trials. IDMM, and indeed almost all critics who make this argument, do so as though this prior research simply has not taken place and some mad scientist wants to try something totally "on spec."[2]

Legislative and Regulatory Accountability

It is important to be clear that, in addition to the science research, the United Kingdom has a unique and very rigorous procedure for approving any human embryo research at all, and for research to go on to be used in therapy, the process is immensely demanding.

In the case of MRT, use in humans first required, and has in fact secured, a change in the law, a change that had to be approved by both houses of Parliament separately by a vote following a full debate. The approval of Parliament, by a free vote of MPs in the House of Commons, took place on February 3, 2105.[3] After an exhaustive debate, the vote was overwhelming: 382 in favor and 128 against. The matter then required separate consideration by our second chamber, The House of Lords. This took place on February 24, 2015[4] again, after detailed and high level debate (read Hansard),[5] and the majority in favor was massive: 280 votes for and only 48 against. Now that the law has been changed, any therapy in humans will additionally require approval by The Human Fertilisation and Embryology Authority (the HFEA) on a case-by-case basis, with each application requiring a separate license from the HFEA, such licenses only being granted after full consideration of all the evidence presented.

It is vital to emphasize that this process ensures not only scientific evaluation and continuing oversight, but, perhaps more importantly, demonstrates a parliamentary, and therefore national, consensus that the issues have not only been fully examined, but also that the way forward was democratically agreed to by the full Parliament, with publicly accountable elected officials taking personal responsibility for the decision and being accountable to the electorate for the way that they have voted.

If there is a stricter and more exhaustive legislative and regulatory process in the world I would definitely like to hear about it and if IDMM has a better process in mind I am sure the United Kingdom government would wish to hear about it.

It may be that IDMM intended her claim that "an "all things considered" decision would actually call for the gathering of more evidence before proceeding to apply only to possible developments in the United States. Such an intention, although understandable, would be parochial in the extreme, given that she was responding to an English author commenting on a procedure developed in the United Kingdom, the only country in the world that has a robust regulatory regime requiring the licence of individual procedures by a permanent authority charged with licencing and oversight.

Interestingly, as I write these words, the United States National Academies of Sciences, Engineering and Medicine have recommended (on February 3, 2016)[6] that the United States Food and Drug Administration (FDA) should approve clinical trials of a gene therapy technique to create embryos "with genetic material from three people," that is, should approve MRT. In its report, the academy panel suggests limiting the tests of mitochondrial replacement to male embryos as a safety precaution. Because a child inherits its mitochondria from its mother, male offspring would not be able to pass their modified mitochondria to future generations. This would limit any possible unforeseen danger of the procedure being passed on to future generations. The report also recommends several extra safety measures, which include making every attempt to follow the children born as a result of the technique for years and sharing the resulting data with scientists and the public. The idea is clearly that if mitochondrial replacement is proven safe enough in male offspring, it could be expanded to female embryos. I should add that I gave evidence to this panel at their Washington summit in March 2015, and we heard dramatic and heart-rending evidence from women affected by mitochondrial disease. These patients very much wanted this therapy to be approved. We also heard a wealth of scientific evidence as to the rigorous science behind the therapy. I can fully understand why the panel accepted that the therapy is "good to go" and rejected ideas such as those of IDMM. This recommendation by an expert panel of the United States National Academies of Sciences, Engineering and Medicine clearly signals that they do not share IDMM's opinion that "that the evidence about the safety of these technologies is at this point completely inadequate." They think clearly to the contrary, that it is safe enough to begin clinical trials with a view, eventually, to permitting MRT to be used to create both male and female children.

Scientific Priorities and the "Marie Antoinette Manoeuvre"

> *Nonetheless, one might concede that safety concerns might, at some point, be better addressed. And that although it is true that the "proof is in the pudding" when it comes to creating human beings with these technologies, if the benefits are thought to be worthy and we have more confidence about the risks and the uncertainties, the safety objection eventually might have to be jettisoned. Therefore, let us assume for the argument's sake that one is reasonably confident—as Harris clearly is—about the fact that MRTs do not involve excessive risks. Should we embrace these techniques unreservedly?*

To answer this question, IDMM first rehearses a range of (allegedly preferable) ways in which women affected by mitochondrial disease can have children without using MRT, all of which are quite beside the point of my article, the point of which was to challenge the *necessity* of their choosing any alternatives at all. There is something rather patronizing, I believe, about telling a woman who has chosen one reproductive path (a path moreover that has reached the point at which it is likely soon to be offered to affected women in the United Kingdom and now in the United States) that she should use either other reproductive modalities, which entail the denial of her reproductive aspirations, or adopt or foster children instead if she wishes to found a family.

This we might aptly dub "the Marie Antoinette Manoeuvre"; "if the people can't afford bread let them eat cake!"[7] Whether she (or indeed anyone) actually used these words is irrelevant; they nicely capture the flavor of IDMM's confidence about the acceptability of denying MRT on the grounds that there are possible alternatives even if undesired by, and undesirable to, those with mitochondrial disease.

Finally, IDMM does actually engage with my argument again:

> *What MRTs really do is allow women to have unaffected children and genetically related ones. But clearly, although the ability to have genetically related offspring is highly valued by many people, it is implausible to argue that satisfying a such desire should constitute a scientific priority, given the many pressing needs that exist.*

For the record, I have not made any claims about what level of scientific priority MRT should have. My arguments were, and are, all directed to the question of whether there are any valid moral objections to MRT per se. It might well, for example, be permitted only if privately funded, or permitted on some sort of rationed basis. I do have opinions about this, and they are that for the United Kingdom, with approximately 2,500 women affected, the countless progeny who multiply the benefits but not the costs, provide good reasons for the National Health Service (NHS) to fund the procedure; however, I have no space here to argue further for this proposition.

Grounds for Banning a Technology

Again, I seem to need to remind IDMM that the article she criticizes, and other forays of mine into defense of gene editing and other procedures that permanently affect heritability, such as MRT,[8] are directed to the question of their moral permissibility or impermissibility, not to the level of priority they should have, nor to the moral evaluation of particular people's desires to access these technologies.

> *Now, I would like to remind readers at this point that Harris is happy to dismiss at least some strongly held desires. Recall that, although he acknowledges that "many people think that children have a right to know the identity of their progenitors," he does not find this fact particularly compelling.*

It is true that I certainly am happy to dismiss some strongly held desires when they are as wrong-headed as those of IDMM; those, and many strongly held beliefs as well! However, desires that I happen to find compelling, or for that matter misconceived, are not necessarily desires that people should be denied the possibility of fulfilling. In the case of MRT, I have argued that neither the objections to the nature of the intervention, nor its state of safety, are powerful enough to support preventing access to the technology; similarly, with the claim that there is a right to know one's genetic origins. I have argued that the arguments adduced in support of an alleged right to know one's own genetic origins are not sufficient to treat it as a right. It *is* perfectly legitimate to try to satisfy one's own curiosity on that point, anyone can try; but does that person have a right, which other people have a duty to accede to and that is possibly enforceable, to succeed?

It does not follow from the fact that I desire something that I must have it; however, if I have a right to have it that is a different matter! If a child, for example, has a right to know his or her genetic origins, then information about them should be provided, and that would, as I have argued, imply universal paternity testing, because without such testing, that child could never be sure of his or her "true genetic identity" for whatever it is that that is worth. "Motherhood"[9] as it used to be said, "is a fact, whereas paternity, merely a hypothesis." However, a right to knowledge of genetic origins would contravene other equally powerful rights to privacy and family life; therefore, it is difficult to think of it as a right, rather than as a desire that people may try to satisfy, or not, as they choose.

What Is to Be Unreservedly Welcomed?

IDMM has greatly and somewhat repetitively played with my use of the idea that MRT should be "unreservedly welcomed." I must confess to a certain amount of enthusiasm for reducing misery and promoting health where possible, and a treatment that, it seems to me, has been objected to principally on the spurious ground that it involves heritable changes to the germline should not be denied on principle to those who might benefit: the mothers now, and their children in perpetuity for generations to come.

> *Not wanting to accuse Harris of callousness for ignoring the significantly higher benefits that could be achieved by using our scientific resources in other ways, I concede that he might be sympathetic to these concerns. I assume, however, given his unreserved embrace of MRTs, that no matter how sympathetic he might be, ultimately he does not find these objections compelling.*

I am always suitably gratified when, although not being officially accused of callous behaviour, I at least find that someone is willing to introduce the idea that I am callous, while not committing themselves formally to accusing me of it, and yes, I find her objections totally uncompelling and the strategy somewhat disingenuous. There are almost always plausible arguments that higher benefits can be achieved by doing something other than what we are/anyone is doing at a particular moment. This applies, "in spades," to the writing of IDMM's article and even, (unimaginable though this might seem to right-thinking people), to this response! To which the answer is – so what?

The "so what" is that no one is trying to stop IDMM, or me for that matter, from working in philosophy and being published if we can! I certainly would not have bothered to write the article to which IDMM has responded but for the fact that powerful, very powerful, lobbies were trying to get the technology on which it based banned, or to impose moratoria on its use, with the result that unnecessary suffering would be caused and serious disease would inevitable continue to be inherited for generations to come. This is also why I spoke in the United Kingdom Parliament on the eve of the vote that gave the "in principle" go-ahead to MRT in this country. This is why I flew to Washington in March 2015 to take part in the summit to discuss these issues. Our Parliament did not on that occasion discuss what priority MRT should have, neither did the meeting in Washington. Prioritization involves an entirely different set of issues, interesting issues, definitely, but not directly pertinent to this debate.

I "unreservedly welcome" IDMM's article, (IDMM has definitively established that I am a welcoming sort of person). It deserves an airing and is part of an activity, bioethics, that has some significance in the world, although just how much significance is another matter altogether. I would guess that neither of us thinks there are not more important things for us to do, even very much more important things to do than work in the field of philosophy. But that is not a reason not to welcome our modest efforts. What a world it would be if only the most important things got done, or more importantly, were permitted to be done! That is not a world I want either to live in or help create.

Notes

1. Harris J. *Wonderwoman and Superman: The Ethics of Human Biotechnology*: Oxford: Oxford University Press; 1992, especially Chapter 8. See also Harris J, Keywood K. Ignorance, information and autonomy. *Theoretical Medicine and Bioethics* 2001;22(5):415–36. Also Harris J, Sulston J. Genetic equity. *Nature Reviews Genetics* 2004;5(10):796–800.
2. I am indebted to my colleague David Lawrence for helpful advice here.
3. Vogel G, Stokstad V. U.K. Parliament approves controversial three-parent mitochontrial gene therapy. *Science,* February 3, 2015; available at http://www.sciencemag.org/news/2015/02/uk-parliament-approves-controversial-three-parent-mitochondrial-gene-therapy (last accessed 6 Feb 2016).
4. Hannah Devlin, "Britain's House of Lords approves conception of three-person babies". http://www.theguardian.com/politics/2015/feb/24/uk-house-of-lords-approves-conception-of-three-person-babies (last accessed 9 September 2016).
5. Hansard; available at http://www.parliament.uk/business/publications/hansard/ (last accessed 6 Feb 2016).
6. Reardon S. US panel greenlights creation of male 'three-person' embryos. *Nature*, February 3, 2016; available at http://www.nature.com/news/us-panel-greenlights-creation-of-male-three-person-embryos-1.19290 (last accessed 3 Feb 2016).
7. Did Marie-Antoinette really say "Let them eat cake?" History.com; available at http://www.history.com/news/ask-history/did-marie-antoinette-really-say-let-them-eat-cake (last accessed 7 Mar 2016).
8. Harris J. Germline manipulation and our future worlds. *The American Journal of Bioethics* 2015;15(12):30–4. Harris J. Germ line modification and the burden of human existence. *The Cambridge Quarterly of Health Care Ethics* 2016;25(1):6–18. Harris J. Why human gene editing must not be stopped, December 2, 2015 available at file:///Users/mdimsjmh/Documents/JOHN'S%20DOCUMENTS/PAPERS%202016/guardian%20gene%20editing%20Why%20human%20gene%20editing%20must%20not%20be%20stopped%20_%20Science%20_%20The%20Guardian.html (last accessed 6 Feb 2016). Harris J. Rewriting our genes will bring benefits for us all. *Financial Times*, London, January 16–17, 2016, at 12; available at http://www.ft.com/cms/s/0/9fd0529e-bb6a-11e5-b151-8e15c9a029fb.html (last accessed 6 Feb 2016).
9. Motherhood has now also become a rather complicated hypothesis; however, the reasons for that and the degrees of complication are again beyond my purview here.