

Ethical Reflections on Germline Genome Editing

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Lecture Outline

- ▶ Introduction
 - ▶ Issues surrounding Gene Editing - He scandal, multiplicity of ethical statements
 - ▶ Scope of lecture
- ▶ The Ethical Debate
 - ▶ Arguments For
 - ▶ Arguments Against
- ▶ Underlying Ethical Principles and Approaches
- ▶ Conclusions

Introduction

- ▶ Debate has intensified after ‘rogue scientist’ He Jian-Kui claimed (probably falsely?) that he had created the first CRISPR babies, but there was already widespread discussion of the ethics of CRISPR
- ▶ In the past three years at least 61 official reports and statements have been published from 14 different countries - 7 from the UK and 14 from the USA!
- ▶ CRISPR is being widely used in trials on humans, other animals, and plants, both with somatic cells and with germline cells, but the scope of this lecture is on the ethics of *human germline (heritable)* genome editing only

The Ethical Debate -1

- ▶ Arguments for Allowing Research, followed by Clinical Applications
 - ▶ *Medical Benefits*- many severely disabling heritable conditions could be prevented, e.g. breast cancer, heart disease
 - ▶ *Unmet Clinical Need* - couples unable to have a child because of genetic risks, e.g. Huntington Disease (mitochondrial replacement therapy an example, but this is not CRISPR)
 - ▶ *Enhancement* - some authors (e.g. Julian Savulescu) advocate for this as a parental right (or even a duty!), enabling offspring and their descendants to be cleverer, stronger, taller, etc
 - ▶ Authors promoting these developments argue for strict regulation and monitoring over a long term

The Ethical Debate - 2

- ▶ Arguments Against Permitting Germline Editing
 - ▶ *Immediate Risks* - off-target effects (some evidence of this already)
 - ▶ *Longer term harms* - impossible to know what effects could show up one or more generations later, hence we are committing our descendants to a set of risks to which they have not consented (comparisons might be made with global warming against which schoolchildren all over the world are now protesting)
 - ▶ *Discrimination: economic*, given the likely high costs; and *social* against those with disabilities
 - ▶ *Ineffectiveness of regulation/legislation* to prevent 'rogue' operators (He Jian-Kui is a prime example, as what he did is against the law in China)
 - ▶ Opponents of germline editing argue for either a *moratorium* until clearer evidence of benefit and risks, or for an *outright ban*, given the unavoidable unknown long-term effects

Underlying Ethical Principles and Values

▶ Consequentialist Arguments

- ▶ These are the most commonly used in official statements, but the problem is how to balance risks and benefits. Thus, the argument can go either way - too risky to proceed, or irresponsible to prevent possibly massive preventative and therapeutic gains.

▶ Duties and Rights

- ▶ Here the notion of *reproductive autonomy* is often invoked, with the claim that the state should rarely, if ever take away the right to reproduce, and that banning CRISPR is putting a major obstacle in the way of some couples to have a healthy child. (However, for many of the examples given of the benefits of CRISPR there are alternatives, e.g. PGD). In terms of duties, as noted above, it can be argued that we have a duty not to impose harms on future generation, if these can be avoided.

▶ Justice

- ▶ Distributive justice implies a core principle of *equitable distribution of benefits and harms*. Opponents of CRISPR argue that given the major crippling inequities in health status throughout the world, it is a poor use of limited resources (scientific and financial) to focus on this area of medical research.

Conclusions

- ▶ There is every sign that this debate will continue, despite the 61 reports already published! A majority view among scientists at present seems to be for a moratorium, but there are also those who argue that this is not justified, and in any case will be ineffective. Some advocate a total ban, while others want a cautious and highly regulated set of limited experiments.
- ▶ More public awareness and well planned public consultation seems to be a priority to prevent people becoming the victims of the kind of misleading hype and false claims that have dogged the stem cell initiatives.
- ▶ In my view, the arguments concerning justice, non-discrimination, and our duties to future generations are the strongest ethically.
- ▶ This means that germline, that is *heritable* gene editing, is a path we should not go down, now or in the future.

Thank You

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