

## Introduction

## Published by

Camporesi, Silvia.

From Bench to Bedside, to Track and Field: The Context of Enhancement and Its Ethical Relevance.

University of California Health Humanities Press, 2014.

Project MUSE. https://muse.jhu.edu/book/124666.



→ For additional information about this book https://muse.jhu.edu/book/124666

## Introduction

This book addresses the issue of human enhancement technologies and their ethical permissibility through a contextual, bottom up approach based on case studies. The first chapter familiarizes the reader with the various definitions that have been put forward for "enhancement," and the arguments for and against. I then argue in favour of a neutral definition of enhancement, where decisions regarding the ethical permissibility of a technology are reached through a contextual analysis aimed at spelling out the values intrinsic in the particular practice under scrutiny. In this first chapter I also discuss the value of distinguishing therapy versus enhancement, and distinguishing absolute versus positional goods.

In the second chapter I discuss the application of genetic technologies from the "bench" (of research on molecular biology) to the "bedside" of clinical trials and experimentation on pharmaceuticals on human beings.

The first part of the chapter is dedicated to the discussion of the objections to genetic technologies aimed at enhancing human capacities and grounded in the resurgence of "eugenics." To answer the question of whether the ethical objections against classical eugenics are still valid against contemporary practices of reproductive genetic choices, I provide a comparative historical overview of eugenics in the UK, the US and Scandinavia. I divide the analysis into three periods: (a) "classical eugenics" (1883-1945), (b) "modern eugenics," from the end of WW II to the first 'test tube baby' (1946-1978), and (c) "contemporary eugenics," from the birth of Louise Brown until now (1978-2014). I highlight similarities and differences between the three periods and address whether the ethical objections to classical and modern eugenics are still valid today, and whether the contemporary use of genetic technologies in the reproductive context to choose children's traits can still be called "eugenics."

The second part of the chapter is dedicated to the analysis of how preimplantation genetic diagnosis and other genetic screening techniques at the

## 2 Camporesi

level of the human embryo raise a conflict of interest between parental reproductive freedom and children's right to an open future and capacity for self-determination. As a case study, in section 2.4 I analyse the case of parents choosing to have deaf children through pre-implantation genetic diagnosis. The expressivist argument that deafness (or other traits traditionally considered disabilities) is "only a difference" is the focus of my analysis in section 2.5.

Genetic technologies impact all stages of life, and in Chapter 3 I analyse how genetic technologies, and in particular gene transfer, are translated directly from the molecular genetics/biology laboratory to "track & field," where they are applied with the goal of enhancing athletic performance, without going through the clinical research step of experimentation of the pharmaceuticals in human subjects.

In the first part of chapter 3 I discuss gene transfer technologies applied to enhance athletic performance. In section 3.1 I analyse the scientific and regulatory context of gene enhancement, and the basis on which these technologies are classified as doping. In section 3.2 I focus my analysis on a real case study of a gene transfer clinical trial aimed at raising tolerance to pain, and discuss its ethical permissibility in therapeutic and professional sport contexts.

In the second part of the chapter (sections 3.3 and 3.4) I discuss the ethical and social implications of the recent boom in direct-to-consumer genetic tests to scout out children's athletic potential. In the last section of the chapter I discuss performance enhancement and anti-doping governance, and analyse the arguments in favour of introducing doping in sport under a controlled and regulated medical context.

In Chapter 4 I discuss how professional sport has always been a laboratory for biomedical and biotechnological innovations regarding the treatment of injury, recovery and training regimes aimed at maximising athletic performance. It is a matter of fact that elite athletes are willing to accept high degrees of risk in exchange for the expected performance enhancing benefits derived from the consumption of prohibited substances, from extreme training regimes or diets, or the experimentation upon themselves of innovative surgeries. In the first part of the chapter (sections 4.1 and 4.2) I propose an alternative way to alter the practice of high-performance athletes discounting future health for current performance, without engaging in doping under a medical context,

by shifting the burden of proof from the regulator to the sponsors, as well as providing the right incentives in the form of penalties to the sponsors whose athletes test positive. In order to do so, I borrow arguments from similar discussions in the sustainability field, where it has long been proposed to shift the burden of proof of damaging the environment from regulators to the private sector. In the second part of the chapter (section 4.3) I tackle the broader question of an ethical justification for research on enhancement, which has been surprisingly neglected in the bioethical debate on enhancement. I argue that even though particular technologies aimed at enhancing human capacities are not ethically permissible in a certain context, it does not follow that research on enhancement *per se* is also not ethically permissible.

Moral disagreement in society about bioethical issues will persist, no matter what philosophical arguments are put forward. The pressing questions posed by enhancement technologies do not allow us simply to acknowledge that moral positions differ and then nonconfrontationally concern ourselves with ironing out internal inconsistencies in the different positions. Rather, they demand a shift in focus from classical philosophical ethics to the realm of political philosophy. This is what I try to do in the last section of chapter 4, where I lay the groundwork for the discussion of how to shift the debate on enhancement technology from the ethical level to a policy level, and to analyse the role for the philosopher in the enhancement debate.

All throughout this work I adopt a casuistic approach to ethics, meaning I deploy different tools from deontologist, consequentialist, principled and virtue-ethics approaches, trying to bring the debate on enhancement out of the stalemate caused by the polarization of proponents and opponents. In each case I discuss the ethical permissibility of a technology in a way that could be used to inform policymaking, and to bring forward the bioethical debate in a productive way. I am aware that the work contained in this book is preliminary and incomplete, but I hope that it will point towards interesting and original directions for research, for example at the intersection of sport, medicine and ethics, where traditional ethical issues in clinical research are exacerbated in the context of elite sports; and in the field of reprogenetics, where the use of genetic technologies to choose children's traits traditionally considered a disability force us to rethink the debate surrounding enhancement and the resurgence of eugenics.