Matti Häyry

Playing God

Essays on bioethics

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Essays on bioethics

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Preface

The following chapters record an odyssey – the voyage of an aspiring philosopher through the murky waters of academic life in the 1990s. Steering between the Scylla and Charybdis of conformity and idiosyncrasy, deaf to the Siren song of an easy life outside the academia, daring the Cyclops of bureacracy, he is briefly enchanted by the Circe of external funding. Noticing, however, that the sorcerer has changed his shipmates into swine, he rises to challenge her, and continues his adventures, favoured by some Olympian gods of the scientific community – and censured by others.

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In the early 1990s, just after the completion of my doctoral thesis on bioethics, I spent much time and energy sketching an ethical theory which would be both intellectually and emotionally appealing. The result of my work was a book, *Liberal Utilitarianism and Applied Ethics*, which was written in 1991-93 and published in 1994.

The normative conclusions of that project as regards bioethical work are presented in the opening chapter of this book, where I argue that philosophers should strive for conceptual clarity and intuitive acceptability when they participate in the work of multidisciplinary research groups. My main point is that ethical guidelines, legislation and public policies should not be based on views or doctrines which are unclear, or make appeals to unspecified feelings of approval or disapproval. Moral philosophers should be the ones who detect and draw attention to such flaws.

In the next two chapters, I apply this idea to two classic questions of bioethics, the beginning and the end of life, in the framework of new knowledge concerning latent diseases and disorders. My first question is how adults should react to their impending illness and death, and the second concerns the suffering of children as a result of reproductive choices. These are purely conceptual exercises based on certain simple intuitions, although multiple layers of meaning can be read into them by the champions of more complex views.

In the following four chapters I try to redefine the methodology of bioethics in the context of modern biotechnologies. I start with a critique of some 'categorical' objections to genetic engineering, and go on to point out some of the inadequacies of an alternative, more 'pragmatic', approach. After an examination of the concept of risk, in chapter six, I briefly review the standard ethical responses to the use of gene technologies which may have adverse environmental impacts. The conclusion of this survey is that the recognition of *rights* as protective shields against deliberately inflicted harm probably offers the best device to ensure the ethical soundness of legislative and policy decisions.

In the eighth and ninth chapters, the right of individuals to know about their own genetic makeup when they so wish, and to remain in ignorance when this is what they want, is defended. The tenth chapter, in its turn, can be seen as a plea for the welfare, or rights, of dairy animals against the economic interests of biotechnological companies.

The concluding chapter is an appendix where I recount my adventures in bioethics since 1983. Written in April 2000, this piece is the 'bonus track' of the otherwise retrospective collection of studies on bioethics in the 1990s.

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Earlier versions of most of these chapters have appeared previously in academic journals and edited volumes. The details of the publications have been given at the end of each chapter, where I have also recognised, with thanks, the help many colleagues have provided over the years.

On rare occasions, most notably in the sixth and seventh chapters, there are short passages which repeat almost word by word some points already made. While I apologise for these minor redundancies, I did not find a convenient way to avoid them.

Special thanks are due to Tuija Takala, with whom I have co-authored chapters six to nine, and with whose permission they are reproduced here.

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Doctors, nurses and scientists have often been accused of ‘playing God’ in life-and-death decisions, reproductive medicine and genetics. The tenor of this book is that the same accusation can be extended to ethicists and public decision-makers who refuse to examine the issues analytically before they pass their judgements. In many cases, *they* are the jealous gods who obstruct the voyage of honest philosophers and bioethicists who desperately try to find their home island of intellectual zeal and emotional security in the stormy sea of high feeling and firmly held prejudice.

1. The Role of Philosophers in Bioethical Research Programmes[*]

My aim in this paper is to define the role that professional philosophers can ideally play in bioethical research programmes commissioned and financed by national governments and international bodies. The presentation is divided into three parts. In the first part, I examine the nature of bioethics as an activity and as an academic discipline. In the second part, I describe those characteristics of bioethical research programmes which are relevant to my inquiry. In the third part, I study the proper role of philosophers in these programmes, and in practical ethics in general.

The scope and methods of bioethics[1]

The concept of bioethics, or biomedical ethics, has, I believe, often been defined too narrowly. A 1983 edition of *Webster's*, for instance, defined bioethics as 'a discipline dealing with the ethical implications of biological research and applications esp. in medicine'.[2] The obvious deficiency of this definition is that bioethical studies have been gradually extended to moral problems which are not directly related to biology or biomedicine. Such problems include the dilemmas of nursing and the questions of justice in health care provision.

Other definitions of bioethics, or biomedical ethics, are restricted with regard to methodology rather than to scope. In 1983 Tom Beauchamp and James Childress, for example, defined biomedical ethics as 'the application of general ethical theories, principles, and rules to problems of therapeutic practice, health care delivery, and medical and biological research'.[3] The difficulties of this view include, first, that bioethical studies are not necessarily restricted to the mechanical application of moral theories, and second, that laws and public opinions as well as moral theories should be accounted for in comprehensive bioethical work.

Another methodologically incomplete attempt to define bioethics is related to public decision-making. Medical choices can be called 'ethical' when they conform 'to accepted professional standards of conduct',[4] and many politicians and administrators seem to think that bioethical studies should be confined to this type of ethicalness. For these individuals, bioethics has come to mean the national or international regulation and control of medical practices and health care provision. But although Beauchamp and Childress may have emphasised too strongly the importance of general moral theories in biomedical ethics, their view is at least partly correct. Bioethical considerations cannot be confined merely to the examination of what is accepted or acceptable in terms of professional standards or democratic and bureaucratic decision-making.

My own suggestion is that bioethics should be defined by reference to both its scope and its methods. The definition given in the *Constitution of the International Association of Bioethics* provides a good starting point. In Article 2 of the Constitution, bioethics is defined as 'the study of ethical, social, legal, and other related issues arising in health care and the biological sciences'. In what follows, I specify this general definition both with regard to subject matter and with regard to methodology.

The scope of bioethical studies, as I understand them, can be divided roughly into four fields, which are presented schematically in Figure 1.

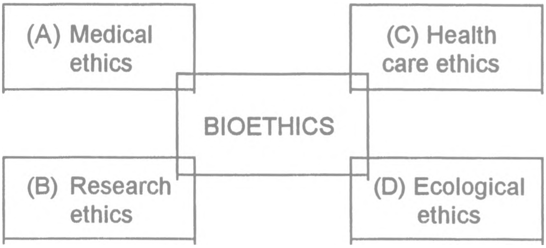

Figure 1: The scope of bioethics

(A) First, medical decision-making which directly concerns the welfare of individual patients forms, historically speaking, the hard core of bioethical considerations. From the Hippocratic Oath to the Declaration of Geneva and onwards, the ethical codes of physicians have centred on issues like professional competence and the definition of malpractice, or medical immorality, in the light of prevailing religious creeds and moral views. Bedside behaviour also plays an important role in the more recent codes of nurses and other health care providers.[5]

(B) Another important field of bioethical interest is created by biomedical research and development. The moral issues of scientific research include the use of human beings and other animals in potentially harmful experiments, as well as questions related to human genetic engineering and biotechnology in general.

(C) The third area on which bioethicists can focus their attention is formed by the provision of health care and welfare services in modern societies. The central questions in this field concern the efficiency and respect for justice and autonomy displayed by the system which is under scrutiny.

(D) Fourth, in addition to the professional, research-related and social aspects of medical and health-care ethics, there are certain global issues to which bioethical studies can be extended. These issues include overpopulation, world-wide justice in the distribution of health, and the protection of our natural environment. Bioethical studies in this field provide, among other things, a global background against which the problems of affluent Western societies can be seen in a different light.[6]

Important as I think that these points regarding the content of bioethical work are, bioethics as an activity and as an academic discipline must be defined with reference to its aims and methods as well as to its scope. There are four approaches to the ethical issues of medicine and health care which are relevant here. These approaches are presented in Figure 2.

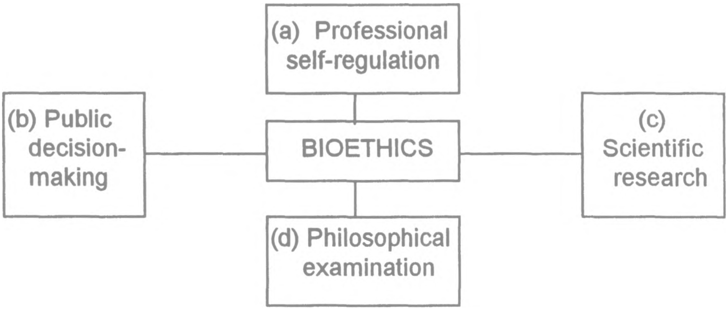

Figure 2: The main approaches to bioethics

(a) The self-regulation of physicians and other health care providers has traditionally been regarded as the most natural way to deal with moral problems in medicine and related areas. The ethical rules and principles that professionals impose upon themselves in their voluntary codes usually serve, however, a dual function, and this creates tensions. On the one hand, the publicly advertised role of the codes is to make explicit the ethical guidelines which are, ideally speaking, respected by the members of the profession and which ensure that the professionals can in their work satisfy the relevant needs and preferences of their clients without inflicting unnecessary harm or causing offence. On the other hand, however, the codes can also be seen as a front which makes it possible for the professionals to seize and maintain undeserved benefits and privileges, and to misuse their expertise and authority to obtain unproportioned shares of social and political power.

(b) Laws and statutes have been increasingly employed in modern societies to regulate medical matters. Preventive measures like quarantines have been enforced by law for centuries, and during the last few decades research ethics and ecological and population problems have caught the attention of the legislators. Criticisms levelled at medical paternalism have also brought the professional conduct of physicians and nurses in clinical situations under closer legal scrutiny. The main difficulty with this approach in the present context is that the relationship between medical law and bioethics is not well-defined. Public decision-makers could regard ethical principles as the ultimate basis of legal work, but usually their idea seems to be that ethical considerations are subordinate to the law.

(c) Political and administrative decisions are often based, at least allegedly, on the results of scientific research. The moral choices concerning the provision of medicine and health care are no exception to this rule. Many social sciences, including epidemiology, psychology and nursing science, have been recruited to gain knowledge concerning different health care systems, and to learn about the effects of these systems and other socio-political factors on the morbidity, mortality and life quality of the population. The facts acquired by scientific methods do not, in and by themselves, yield normative conclusions, but they can certainly be suggestive if they are publicised in a social environment which is not, from the moral point of view, completely numb. Epidemiology and statistics, for instance, can shed light on the questions of justice and equity by examining the quantitative distribution of health, welfare and access to health care in present-day societies. Psychologists and nursing scientists, in their turn, can estimate the impact of health policies on individual patients by assessing qualitatively their physical and mental well-being.

(d) Academic philosophers have for some time now thought that they have something to contribute to bioethics. The supposed advantages of the philosophical approach include impartiality, conceptual clarity, and an unhindered recourse to traditional moral theories. I shall return to the nature and methods of philosophical bioethics in the third part of the paper.

The nature of bioethical research programmes

Bioethical research programmes financed by national governments and international bodies can be generally characterised by examining their actual and potential scope, and by studying their standard approaches.

As regards the scope of publicly funded bioethical programmes, there are, theoretically speaking, no limits. Medical practice, scientific research, health care provision and ecology all embrace questions which can be of interest to political and administrative decision-makers, and which can thus become the subject matter of research schemes commissioned by them. In practice, however, there seem to be areas that attract considerably more attention than others. These areas are usually marked off by at least one of the following features.

First, treatments, policies and medical procedures which are expensive and in some sense extraordinary tend to be more noticeable than those which are inexpensive and commonplace. Haemodialysis has been the object of many ethical studies during the last four decades, whereas, for instance, the ethical dimensions of prescribing aspirin have been far less frequently discussed. Second, technological developments which seem morally suspect, but which can be expected to produce vast economic profits, usually seem to arouse more interest than less lucrative enterprises which are ethically unproblematic. Inquiries into the morality of genetic engineering have, of late, been generously funded by the public authorities, while, say, the ethics of plumbing have been virtually forgotten. Third, issues which are religiously controversial often attract more funding than purely secular concerns. Many committees and concerted action groups have been appointed by political decision-makers to study abortion, euthanasia and reproductive technologies, but few politicians have been keen to finance the study of the underlying, more mundane problems of, say, moralism, paternalism and patient autonomy.

To take a closer look at just one example, it is easy to see that AIDS is a natural topic for publicly-funded bioethical programmes. The treatments are expensive, the development of drugs, therapies and vaccines is economically tempting, and the mode of transmission makes it possible to focus on issues like sexuality, contraception, homosexuality and intravenous drug use. The difficulty here is that the threats and promises involved in the issue can be interpreted in many ways, and it is not always obvious which angle those financing the research would like to choose. For responsible ethicists, the high price of treatments is alarming in terms of equality, because not everybody can afford costly drugs without public support. Those funding the work, however, may expect moral philosophers to justify the exclusion of so-called self-inflicted diseases, along with their carriers, from national health programmes. Again, business executives can welcome the opportunity to develop new drugs and vaccines, while those infected by the HIV can quite legitimately fear that economic duress will force them to become human guinea pigs for the medical corporations. And where liberal ethicists are troubled by the negative impact of AIDS on sexual enjoyment and on the rights of sexual minorities, religious moralists can see the spread of HIV as a warning against what they consider deviant and ungodly behaviour.

The self-evident aim of publicly funded bioethical programmes is to facilitate political and administrative decision-making. In many cases, the main point of these programmes is to assess the prevailing professional codes and practices, and to examine whether or not they need legislative control or support. But the approach assumed by commissioned project groups can seldom be categorised simply as ‘public decision-making’ or ‘professional self-regulation’. Rather, the methods chosen for most bioethical studies are, to some extent at least, scientific or philosophical. This means, among other things, that the recommendations given by the research groups usually lack the normative strength that ethical codes derive from the group solidarity of professionals, and laws and regulations draw from the legitimate authority of democratically chosen decision-makers. The conclusions reached within bioethical programmes can, of course, be expressed in the form of hypothetical norms: 'If these ends are desirable, then those means ought to be chosen.' As far as the results of purely scientific research are concerned, this is, in fact, the only type of normativity that can be reasonably allowed. But philosophical work in bioethics is not necessarily restricted to the creation of conditional norms. Other viable options can, I think, be found by studying the methods moral philosophers can employ in this field.

The role of philosophers[7]

There are four basic ways in which philosophers can examine the moral problems of medical practice, biomedical research, health care provision and ecology. These ways are presented in Figure 3.

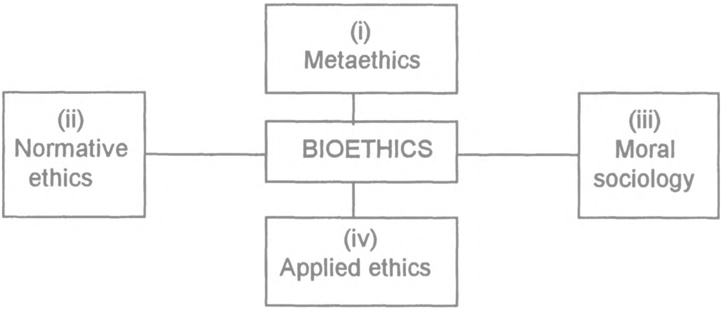

Figure 3: The methods of philosophical bioethics

(i) Metaethics, or 'the study of the meanings of ethical terms, the nature of ethical judgements, and the types of ethical arguments',[8] is a prerequisite for all systematic ethical studies, including comprehensive studies in bioethics. Reliable moral judgements cannot be based on considerations which lack a firm conceptual foundation. Some scholars of the analytical school have thought that linguistic clarification is the only legitimate task for philosophers in practical matters. But the popularity of this view has been steadily on the decline since the 1950s.

(ii) Theoretical studies in normative ethics, in their turn, provide answers to regulative questions concerning the value of states of mind and states of affairs, the rightness of human actions, and the desirability and worth of various character traits. Without the support of normative theories and principles, bioethicists would seldom be able to offer solutions to the moral dilemmas they unearth and analyse. But there are two features which make the straightforward application of any traditional moral doctrine to real-life issues problematical. First, there are situations in which no standard ethical theory can provide an intuitively acceptable and universally valid solution. This is characteristically the case when the basic needs, or basic interests, of individuals or groups are in conflict. Second, even the solutions proposed to less difficult questions by traditional ethical views vary considerably, compelling moral agents to make a choice between the theories. But on what grounds should this choice be made? Is it possible to find fundamental axioms on which all valid moral principles are based? Answers to these questions have divided philosophers for centuries.

(iii) One feasible line of argument is to say that there are, as a matter of fact, no ultimate principles on which moral theories could be founded, and subsequently no valid reasons to prefer one normative theory to another. Early proponents of this view thought that philosophers should forgo their customary ethical speculations concerning the absolute rightness and wrongness of actions, and concentrate instead on the relative rightness and wrongness of actions according to the customs, laws and shared moral feelings that prevail or have prevailed in contemporary or historical societies. This approach, which can be labelled psychological ethics or moral sociology, has many advantages in the study of social and cultural phenomena, as it prevents anthropologists from judging, and thereby distorting, the views of those they observe. But although ethical relativism may be a necessary methodological assumption for descriptive social scientists, it is not a view which could be fully condoned by the majority of today's moral philosophers. Despite the genuine need for toleration towards unfamiliar opinions and ways of life, there are limits beyond which Western ethicists do not usually want to extend their moral acceptance.[9]

(iv) The approach which enables philosophers to present normative solutions to practical issues without evoking all the difficulties of traditional ethical theories has come to be called applied ethics. This method should be kept carefully apart from the mechanical application of moral doctrines to the real-life problems introduced by concerned citizens and public decision-makers. The latter view, the so-called engineering model of applied ethics, is open to many thorny questions regarding the identification of moral problems, the scope of ethical inquiries and the impartiality of professional moral philosophers.[10] Applied ethics proper, on the other hand, can be employed quite successfully to examine controversial practices, policies and situations.

The work of applied ethicists proper can be divided into two closely related tasks, which both involve the assessment of moral responses as well as the analysis of conceptual coherence and logical consistency. I have coined[11] the phrases 'cognitive deprogramming' and 'rational reconstruction' to denote these tasks, which have been outlined in Table 1.[12]

	Cognitive deprogramming	**Rational reconstruction**
Mapping	A survey of some of the prevailing theories and views regarding the issue to be settled.	A survey of some of the potential solutions suggested to analogous issues in the past.
Conceptual and logical critique	The assessment of these theories and views from the conceptual and logical point of view.	The assessment of these potential solutions from the conceptual and logical point of view.
Intuitive and emotional critique	The evaluation of these theories and views in the light of idealised or imaginary examples.	The evaluation of these potential solutions in the light of hypothetical examples.

Table 1: The methods of applied philosophical ethics

All human action takes place in an empirical moral reality, where judgements and assessments are constantly made by public authorities, professionals and ordinary citizens. Consequently, the philosopher's first task in studying real-life moral dilemmas is to uncover the principles and codes which have been applied previously to the issue in hand. The methods employed in this mapping of the prevailing theories and views are similar to those used in normative ethics and moral sociology.

When the mapping of the existent rules and beliefs has been completed, the work can proceed to the stages of conceptual and emotional cognitive deprogramming. By cognitive deprogramming I mean the critical assessment of prevailing ethical views which have their roots in laws and statutes, common-sense morality, personal convictions, religious doctrines, professional codes, philosophical theories and in fragments of scientific thinking. The evaluation may or may not result in changes in these views, as philosophers can sometimes but not always make people unlearn specious models of moral reasoning. The methods by which applied ethicists can try to make other people abandon their previous views are, first, conceptual analysis, and, second, the use of idealised or imaginary test cases.

Conceptual cognitive deprogramming consists of the analysis and critical assessment of the terms and arguments which have been used in the formulation of everyday moral rules and principles. If the terminology in use is ambiguous, or if the inferences made are invalid, the rules and principles in question must be either reformulated or rejected. Emotional cognitive deprogramming, in its turn, centres on the use of idealised or imaginary examples. These examples are normally designed to portray how, under particular hypothetical circumstances, apparently reasonable moral rules and principles lead to actions which have intuitively unacceptable consequences. Imaginary cases cannot normally be employed to establish moral views, or to refute them absolutely, but if they are well chosen they can in many cases provide good grounds for abandoning certain prima facie approvable ethical rules and principles.

Successful cognitive deprogramming may create a momentary moral vacuum, which must then be refilled with new ideals and new rules of conduct. If called upon at this point, applied philosophers can continue their work by trying rationally to reconstruct acceptable ethical principles and theories to replace the previous ones. Rationality in this context means that the norms and rules arrived at must be intrinsically consistent, mutually compatible and on the whole reasonably acceptable. But the criteria of consistency and acceptability cannot always be set from outside, or from above. While conceptual consistency and logical soundness may yield to objective criteria, intuitive acceptability is often a function of the deep values which prevail in the community under scrutiny. The conclusions of the applied ethicist are in these cases ad hominem, or of the form: 'Since your own basic norms, values and beliefs are this-and-this, and you presumably wish to be consistent, you ought to consider it your duty to do, or your right to have, that-and-that.'

Rational reconstruction proceeds in three stages, which are closely analogous to the steps taken in cognitive deprogramming. The starting point is a survey of at least some of the axiological and normative principles which have been applied to relevantly similar cases in the past. When this survey has been completed, the potential solutions must, once again, undergo the tests of consistency and intuitive acceptability.

Summary and conclusions

What, then, is the proper role of philosophers in bioethical research programmes? My answer to this question is based on the foregoing remarks on the nature of bioethics, practical philosophy and applied ethical work. Philosophers are not essentially medical professionals, public decision-makers or social scientists, nor can bioethical problems be solved exclusively by using the methods of metaethics, normative ethics or moral sociology. The proper role of philosophers is, therefore, the role of the applied ethicist.

The task of the applied ethicist in bioethical programmes, in its turn, is easy to describe. After the problem has been identified, there are three questions that should be asked and answered time and again until the replies to all three are satisfactory. These questions are:

(1) What is the best hitherto unrefuted solution to the problem?

(2) Is this solution logically and conceptually consistent?

(3) Is it emotionally and intuitively acceptable?

As long as the answers to questions (2) or (3) are in the negative, the work must go on. But when both questions can be answered affirmatively, the task of the applied philosopher is completed, and the specified solution is valid unless proven otherwise.

Notes

[*] An earlier version of this paper was presented in the 'Philosophy and AIDS Workshop', Paris, France, 12-15 January 1995, arranged by the Commission of the European Communities Biomedical and Health Research Programme Project *AIDS: Ethics, Justice and European Policy*. My thanks are due to the Coordinator of the Project, Professor John Harris, and to the participants of the workshop, for their useful comments. My thanks are also due to Mark Shackleton, Senior Lecturer in English, University of Helsinki, for checking the language of the paper.

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Erin (ed.), *Philosophy and AIDS. Reports from the Centre for Social Ethics and Policy* 1, 1996, 23-30; and it was reprinted, with minor modifications, in *The American Philosophical Association Newsletters* 98 (1), 1998, 111-115.

[1] The contents of this section have been assembled by combining the ideas expressed in two previous articles, namely M. Häyry and S. Karjalainen, 'Academic bioethics in Finland', *European Philosophy of Medicine and Health Care* **3** (nr 1) (1995): 21-30; and M. Häyry, 'Bioetiikka' (in Finnish), in *Fakta 2001 Täydennysosa 1994* (Porvoo: WSOY, 1994), 28-31.

[2] *Webster's Ninth New Collegiate Dictionary* (Springfield, Massachusetts: Merriam-Webster Inc., 1983), s.v. *bioethics.*

[3] T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics*, second edition (New York and Oxford: Oxford University Press, 1983), ix.

[4] *Webster's* 1983, s.v. *ethical.*

[5] Some of the most important ethical codes of medical professionals are reprinted in Beauchamp and Childress 1983.

[6] The term 'bioethics' was probably first used by Van Rensselaer Potter to refer to the moral study of environmental and population problems in his book *Bioethics, Bridge to the Future* (Englewood Cliffs, New Jersey: Prentice-Hall, 1969).

[7] Many ideas put forward in this section have been introduced in M. Häyry, *Liberal Utilitarianism and Applied Ethics* (London and New York: Routledge, 1994), 147-158.

[8] *Webster's* 1983, s.v. *metaethics.*

[9] The dispute between ethical relativism and ethical absolutism is a particularly Western phenomenon. Not many non-Western cultures can claim a similar history of two thousand years of monotheistic evangelization, followed by a series of attempts to reject this tradition.

[10] See, e.g., A.L. Caplan, 'Can applied ethics be effective in health care and should it strive to be?', *Ethics* **93** (1983): 311-319; M. Häyry, *Critical Studies in Philosophical Medical Ethics* (Helsinki: Department of Philosophy, University of Helsinki, 1990), 6-10.

[11] Häyry 1990, 11.

[12] Table 1, and the following explanation of the table, are derived from Häyry 1994, 153-158.

2. How to Make Sense of One's Impending Illness and Death?*

We are all going to die one day. Our hearts will stop beating, our brains will quit functioning, and we shall cease to exist. Some of us will die of old age, that is, of the general inability of the human body to stay alive, even in ideal conditions, for much over a hundred years. Others will die in the midst of life, affected by an unexpected disease or struck by a fatal accident. And still others know in advance that their lives will be shortened by an illness which is, at the present time, latent or at its earlier stages. Whatever the differences between these cases, and the prospects they offer, we are all mortal, and therefore equally confronted by the question: 'How do we make sense of our impending illness, infirmity, and death?'

Two levels of moral inquiry

Moral philosophers can try to make sense of the universal and inevitable human morbidity and mortality in two ways – descriptively and normatively.

At the descriptive level, the initial questions that interest the moral philosopher are: 'How do we, as a matter of empirical fact, react to our own impending illness and death?' 'What do we think?' 'How do we feel?' 'What do we do?' The obvious answer to these questions is that different individuals react in different ways. Some accept the knowledge of their infirmity and death with dignified resignation, even with gratitude. Others are uncomplaining but hope, often secretly, that they could have been spared the information. Still others react violently, accuse themselves and others of their condition, and seek for revenge. In the light of this variation, the real question turns out to be how to explain the similarities and dissimilarities in the prevailing attitudes and ongoing behaviour. Can the pattern of one's reaction be divined by studying the circumstances in which one learns about one's fate? Or should the reasons for the individual's response rather be pursued by examining religious beliefs and other less concrete factors? I shall make an attempt to answer these questions in the first part of this paper.

At the normative level, the basic question is: 'How should we, morally speaking, react to our own impending illness and death?' There are two issues which ought to be dealt with here. First, how should we respond to the *knowledge* that we are going to die sooner than we had thought? It has been argued that it is in our own best interest to know about our condition, because the knowledge enables us to make autonomous and well-informed decisions concerning our lives. But is this argument valid, and if it is, under what circumstances? Second, how should we respond to the *fact* that we are going to die sooner than we had thought? Are some of our possible reactions more justifiable than others, and if they are, on what grounds? These questions will be answered, at least partly, in the second part of the paper.

A note on methodology

Before tackling the more substantive issues, I should add a note on the methodology that I have used. Every observation, remark and comment that I make is based solely on introspection and imagination. I have employed no psychological or sociological theories, nor have I consulted any systematically collected body of empirical evidence regarding mental or social phenomena. In a word, my approach in this paper is purely speculative.

How *do* people react to their impending illness and death?

The first substantive question concerns the significance of the circumstances in which people learn about their impending illness or death. There are four major types of case which ought to be considered.

First, since all human beings are mortal, anyone can at any time become acutely aware of one's eventual fate. Most religions and some philosophical creeds actually feed on the insecurity that people feel in the face of suffering and death, although there are also doctrines which teach that the end of life should not be feared in any way. It is probably safe to say, however, that the majority of people in the affluent West try to ignore their own mortality, and suppress all information that could contribute to the awareness of the fact. This suppression tends to make it difficult for individuals to cope with grave illness when they are confronted by it, and it also tends to make it difficult for others, for individuals who have not been afflicted by serious disease, to provide help and to offer consolation.

Second, even those who are lucky enough to avoid what can be considered premature illness and death will eventually have to become aware of their mortality when their ageing bodies begin to degenerate and their mental activity starts to slow down and fail. Many people who have lived to an old age have met approaching infirmity and imminent death with relative calmness, recognizing the inevitability of the process. But this attitude has by no means been universally shared. Old people have also died reluctantly, filled with fear, anxiety and rancour in the face of their finiteness.

Third, human beings of any age are forced to become aware of their own vulnerability if they are suddenly struck by grave illness or injury. The initial reaction in these cases is often shock, followed by milder astonishment and confusion. More reflective attitudes range from resentment and vengefulness to resignation and concern for others.

Fourth, due to the development of diagnostic techniques many people can nowadays learn about a disease they have while the disease is still asymptomatic or at an early stage. Individuals who are afflicted by multiple sclerosis, or are infected by the human immunodeficiency virus, or are endowed with certain so-called genetic disorders, may be informed of their condition years before they can be expected to fall ill – if, indeed, they can be expected to fall ill at all. People's reactions to the knowledge regarding a latent ailment vary, of course, considerably according to the gravity, present phase and predicted progression of the disease.

The resentment and anger that individuals may feel towards their undesired condition can be projected in various directions, depending on the nature of the disease in question. Those with hereditary problems can, if they so choose, attach the guilt to their parents, while persons with communicable diseases can blame anyone they see as the source of their contagion. If it is conceivable that the ailment could have been avoided by choosing a different life-style, individuals sometimes accuse themselves, and when the origin of the disease is unknown, people often rebuke their bad luck or ill fortune.

The circumstances in which individuals learn about their illness or imminent death seem to have a tangible, but not a decisive, role in the formation of their reactions. People dying of old age, for instance, can be expected to yield to their fate more peacefully than individuals who suddenly fall ill in their prime, but since there are countless exceptions to this rule, and to all similar rules, it is impossible to predict with certainty people's responses to the knowledge merely by referring to their age and general health status.

The similarities and dissimilarities in the reactions towards death and disease can be further elucidated by drawing on two important sources of a person's self-image. These sources are the religious convictions people hold and the opinions they have concerning the fullness of their lives so far. In the Western world, where the dominant religious beliefs are Judaeo-Christian, the two factors can be employed to distinguish between three main types of response to one's fate.[1]

One of the core ideas of Judaism and Christianity is that the universe is created and controlled by a superhuman, benevolent and personal force, God. The existence and continuing presence of this powerful and watchful supreme being guarantees that every human life has, from the viewpoint of eternity, its measure and meaning, and, furthermore, that the lives of individuals will continue after the death of their bodies. In the present context, these points imply that faithful Christians and Jews should not resent too passionately the fact that they are subject to illness, injury and premature death. The gratitude felt for the gift of life should within these religious frameworks outweigh the anxiety possibly caused by the general uncertainty of the human lot.

By saying that religious believers 'should' accept their fate with dignity I do not mean that they are in any absolute sense morally or legally bound to obey the will of God as they see it. What I mean is that persons who firmly insist that they have been treated unfairly by the creator of the universe cannot, conceptually speaking, be regarded as faithful Jews or Christians. Their responses have to be examined in the same category as the reactions of self-confessed atheists and agnostics.

Nonreligious individuals who think that they have already lived a full and significant life can assume a relatively relaxed view towards their own impending illness and death. As depicted in many biographies and several works of literary fiction, people who do not seek consolation from religious beliefs can sometimes find comfort in the notion that a good and timely death completes a good life. In fact, atheists and agnostics who genuinely believe that they have lived a full life should accept their demise as quietly as faithful Christians and Jews.

The only ones who are, according to my analysis, conceptually entitled to full-fledged resentment in the face of illness and death are the nonbelievers who do not think that their lives have been completely fulfilled yet. This attitude is quite understandable, when, for instance, young persons are struck by a fatal disease before they have had the opportunity to experience all the phases that human beings are, according to popular feeling, supposed to experience during their lifetimes. The reaction also seems appropriate in situations where other people's lives and fortunes depend on the contribution of the ones at immediate risk of death. But the limits of this category can be extended far beyond these morally uncontroversial cases, as individuals can always argue that they have not, up to the present time, managed to achieve all the things they have resolved to achieve in their lives. As long as the episodes which are allegedly missing from a person's life are reasonably attainable by human effort, such complaints are conceptually justifiable.

To recapitulate, certain basic religious beliefs, and the views people have concerning the fullness of their lives, can be employed to define three types of response to grave illness and premature death. First, faithful Jews and Christians should see their lives as part of a divine plan, and they should, consequently, accept their destinies with passive obedience. Second, nonreligious persons who believe that their lives have been full and complete, ought to regard a good death as the suitable conclusion to a good life. Third, nonbelievers who think that their lives have not yet been fulfilled, are the only ones who are conceptually entitled to resentment and anger in the face of sudden illness and imminent death.

How *should* people react to illness and death?

Granted that my descriptions and classifications are, to some extent at least, plausible, people's beliefs and opinions, as well as their age and health status, can be employed to explain some of the prevailing attitudes towards illness and death. But, moving on to the domains of prudence and morality, how should individuals react to the knowledge concerning their mortality? What should a person think when his family doctor tells him that his body is infected with a widespread, malignant tumour? How should he feel, when she, the doctor, informs him that his HIV test result was positive? And what should he do if she reveals that he is the carrier of a fatal genetic disorder?

It is possible, and quite natural, that the person's first reaction is evasive and negative. Many people believe that they have a right not to know about their medical condition, especially if the knowledge is unpleasant and emotionally disturbing.[2] Others, however, have defended the view that autonomous individuals have a duty to know about their health status.[3] There are, I think, some sound prudential and moral grounds to subscribe to the latter view in our present context.

As regards prudence, it is obvious that the person's own long-term self-interest can be promoted by the knowledge. Those who know about their condition can make informed, rational choices concerning medical treatment, life-style, and other matters which are pertinent to their continued survival and life quality. Another clear, if less concrete, advantage is that informed individuals can make more realistic life plans than persons who have chosen to remain in ignorance. If one is expected to live less than a year, it is of no use to plan seriously a journey which would take place in two years' time. On the other hand, if there are things that one has always wanted to do, the information regarding one's illness can be seen as a signal to pursue the unfulfilled desires while there is still time.

In the field of morality and moral considerations, as in the realm of prudence, the benefits of knowing about one's health status are manifest. It is widely deemed wrong to inflict harm on other human beings, and knowledge reduces the likelihood that we commit this particular wrong. In the case of communicable diseases, for instance, those who are aware of their infection are often better motivated, and always cognitively better equipped, to avoid passing on the disease to others than those who do not know about their condition. Furthermore, since people's destinies and life plans are inexorably intertwined, decisions made by autonomous individuals, even if designed to influence only themselves, frequently have beneficial or harmful repercussions on other people as well.

Although we 'should', both prudentially and morally speaking, understand that it is good to know about our impending illness and death, the strength of the obligation varies along with the contents of the disclosure. The closer we are to fatal illness and death, the more important it is to us to make well-informed, autonomous decisions concerning our own lives and the lives of those who depend on us. If a person has less than six months to live, her prudential duty to know it, and to arrange her life accordingly, is rather strict. The situation is different, however, when the threat of illness is more remote. Since individuals with genetic disorders sometimes live for years, even decades, without any detectable symptoms, it would be difficult to argue on self-regarding grounds that they have an obligation to acquire the knowledge. If they have a duty to know, this is based on the possibility that they might otherwise pass on the disease to their offspring.

Let me emphasize, at this point, that the obligations that I have evoked here belong to the realms of prudence and individual morality, and that they are subject to social facts and norms regarding prevalent attitudes, the provision of health care, and the legitimacy of the political system as a whole. The duty to know about one's condition is, therefore, at most a *prima facie* moral obligation, which can be outweighed by more serious moral considerations, and which cannot, without further justification, be enforced by law.

Despite the fact that we cannot be legitimately compelled to know about our health status, every day thousands of individuals are informed, voluntarily or involuntarily, of their impending illness and death. Putting the issues involving the duty to know on one side, the question is, how should people react to the fact that they are expected to fall seriously ill, or to die prematurely? What should they do with their lives, and how should they behave towards other people?

If my remarks on the value of informed decision-making are valid, then people who suddenly learn about their untoward fate should try to rearrange, as soon as they have recovered from the shock, their preferences and life plans according to the newly discovered facts. This would in many cases improve both their life expectancy and life quality, and it would therefore be advisable from their own, prudential, standpoint. Seen from the moral point of view, again, individuals who are confronted by premature death should also do their best to guarantee the future wellbeing of those who depend on them, primarily their young children, unwaged spouses, and elderly parents. In more advanced societies, where the material welfare of individuals is publicly secured, this responsibility can in most cases be confined to the provision of emotional support.[4]

Persons who discover that they are fatally ill sometimes blame themselves or others for their condition. If they have fully grasped the nature of their own predicament, and if their notion of the prevailing circumstances is correct, their accusations can in many cases be justified. For example, I can quite legitimately blame myself or my sex partners for contracting a sexually transmitted disease, if the possibilities of other modes of contagion have been reliably ruled out. But there is seldom any point in my doing this. I can, of course, claim that I have been victimized by the earlier carriers of the disease, but since their fate has in the majority of cases been similar to mine, this would not, apart from a few genuinely criminal cases, be either fair or reasonable. I can also, if I so choose, blame myself for making less than considered choices, but it is difficult to see who could benefit from these self-accusations.

Politicians and administrators who are in charge of public decision-making can sometimes be held partly responsible for the prevalence of fatal diseases and lethal accidents.[5] The evil effects of illness, injury and premature death can, furthermore, be aggravated by the same individuals if they uphold unjust social and economic structures. When this is the case, the victims have a right, perhaps even a duty, to reproach those responsible and try to replace them. But this right, or duty, is not confined to those who have suffered from the ill-advised decisions. Every decent person has an obligation to criticize policies which tend to inflict unnecessary suffering on innocent individuals.

Even those who do not blame themselves or others for their misfortune often resent the state they are in due to illness or injury. If they are not fully committed to the idea of benevolent divine guidance, and if their lives have been less than complete, they are, provided that my observations have been correct so far, conceptually entitled to their resentment. Prudence and morality dictate, however, certain limits to the manifestations of the emotion. The most important of these limits concerns the possibility of suicide. Autonomous individuals are prudentially free to end their own lives, but only if they have decided to do so without coercion or pressure in the light of truthful and adequate information. In addition, there are two moral requirements which ought to be met. First, even suicides have to consider the impact of their decision on their dependants. It is not morally right to end one's life if one's family and friends have to suffer the consequences of the deed. Second, rational persons who intend to take their lives ought to make sure that they are not setting an example to those who are not equally capable of assessing the motives and results of their actions. To prompt another individual to commit suicide on insufficient grounds is a moral wrong that should be avoided.

Apart from all these negative and critical duties, people who suffer from fatal ailments may have a more positive obligation to support others with similar problems. This obligation could be based on the fact that people who have to live with a particular type of illness or injury are sometimes better equipped to deal with the specific questions that arise from it than others. It should be kept in mind, however, that even if this special duty to help others can be justified, it cannot be legitimately enforced by law or public opinion.

Facing the facts

In sum, how should we react to our impending illness and death? What should we do when we suddenly learn that our prospects are bleak and our days are numbered? My remarks seem to suggest the following conclusions.

When we are confronted by illness, injury and premature death, we should begin, after the initial shock, by assessing the facts of the situation, including our prognosis and our attitudes towards life, death, and the possibility of an afterlife. We should then try to rearrange our remaining lives, and the lives of those who depend on us, in view of the facts that we have learned. It would be futile to resent the knowledge that our lives will come to an end sooner than we had thought, but it is not necessarily futile to resent the fact that this is going to happen. Our resentment should be directed against the persons and structures responsible for the prevalence of preventable diseases and accidents, most notably negligent public authorities, not against ourselves or those near us. If our condition is hopeless and we are suffering acutely, rational suicide is an option, but only if the choice is well-informed and autonomous, and only if other individuals are not unduly harmed by the decision.

These conclusions, which I have put in the form of duties and liberties, can also be expressed in terms of desirable character traits, or virtues. We are all mortal, and we are all subject to illness and injury.

But if my speculations have any truth in them, we can make sense of our existence and strive successfully for a good life, even in the face of premature death, if only we have three traditionally valued skills and virtues, namely the serenity to accept the things we cannot change, the courage to change the things we can, and the wisdom to know the difference.[6]

Notes

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[1] Since I am not sufficiently acquainted with other cultures, I confine my remarks to Western communities which adhere to Christianity or Judaism.

[2] For a defence of this view in cases where the choice concerns only the persons themselves see, for instance, H. Häyry, *The Limits of Medical Paternalism* (London and New York: Routledge, 1991), 153-155.

[3] For a defence of this view in situations where the knowledge can be used to benefit others see J. Harris, *The Value of Life: An introduction to medical ethics* (London: Routledge & Kegan Paul, 1985), 208.

[4] By 'the more advanced societies' I mean Scandinavian-type welfare states.

[5] An example of what I have in mind is that by preventing the marketing and use of condoms in Catholic countries and in the Third World the Pope on account of his authority makes himself partly responsible for the spread of AIDS.

[6] This list, in the form of a prayer, has been attributed to the American theologian Reinhold Niebuhr.

3. Is It Undesirable that Children Are Born Infected with HIV?*

There are few issues in the context of HIV and AIDS which rouse more emotions than the fact that children can be infected with the virus even before they are born. Many people feel that it is undesirable, indeed intolerable, that grave suffering is inflicted upon innocent newborns and their families, and believe, therefore, that children should not be born with the infection if this can be helped. But what, exactly, does this mean? How can the suffering caused by HIV and AIDS be controlled, and what is required of others if this aim is to be achieved? In what follows I am going to argue that radical changes are needed in popular and official attitudes before the unnecessary suffering of newly born children and their families can be effectively prevented.

The normative starting point of this paper is simply that avoidable suffering should not be inflicted, by acts or omissions, on actual or prospective individuals, unless even greater suffering can thereby be alleviated or prevented. This is a position I share with many contemporary philosophers of the consequentialist tradition.[1] I must emphasise, however, that I do not *automatically* condone the infliction of harm or suffering in cases where greater harm can, as a consequence, be prevented, as some utilitarians do. There are other considerations to be taken into account in conflict situations. But I do believe that harmful actions which cannot even be expected to check comparable harm elsewhere are never justifiable.[2]

There are two ways to secure that children are not born with HIV infection, and thus harmed by other people. The first is to guarantee that foetuses and infants are not congenitally infected with the virus. The second is to make sure that children – or foetuses – who do carry the virus are not allowed to be born. Since the first alternative saves lives as well as spares people from needless suffering, it should clearly be preferred. But many economic and emotional factors prevent governments from enforcing this option.

Preventing HIV infections before conception

The most natural method to decrease the incidence of HIV among newly born children is to ensure that individuals who reproduce do not have the virus. This, in its turn, could probably be best accomplished by providing everybody with information and education, and special groups with free condoms, syringes, needles and other devices which lower the risk of contagion. But three problems arise here. First, many people who are offended by explicit sex education try to keep others, especially children, from knowing about contraceptives and safer sex practices. Second, most governments have difficulties providing intravenous drug users with free and clean syringes and needles, as the unauthorised use of these drugs is illegal. Third, education, hospital hygiene and the testing of blood and blood products is expensive, and cannot therefore be procured unless sufficient resources are allocated to these sectors, which in many countries is not the case.

The other way to prevent individuals from having HIV-infected children is to restrict their right to reproduce by either moral or legal sanctions. This alternative has been opposed for many different reasons, none of which is, I think, good. Some people seem to think that it would be wrong to discourage the deliberate production of even suffering offspring, because all human reproduction is good and should not therefore be intentionally interfered with. Whatever the intrinsic merits of this view, my sympathies towards it are seriously limited by the fact that it advocates openly the promotion of avoidable suffering, which goes against my normative premises in this paper. Others have argued, more feasibly, that legal sanctions on childbearing are wrong, because widely accepted international agreements stipulate that all human beings are entitled to form a permanent relationship and to found a family. Insofar as these regulations are meant to eradicate discrimination, and to give individuals an equal right to have *healthy* children regardless of their nationality, skin colour, health status or sexual preferences, the underlying morality is sound. It is difficult for me to see, however, why these statutes would grant individuals the right to bring about *suffering* children. Equality would certainly not be threatened by a universal ban on the practice, as everybody would have the same obligation to avoid bringing about unnecessary pain.

The reluctance to interfere with people's family lives at all is at least partly based on the extremeness of the measures that would have to be taken to check the birth of suffering infants. But suppose that this could be changed, for instance, by giving everybody a pill that would make them provisionally infertile. Instead of having to deal with individuals who are, as a rule, capable of reproducing unless this capacity is limited, public authorities would face a population that can have children only with the help of the medical profession. Under these circumstances, the regulation would surely be more widely accepted, as evidenced by the prevailing disinclination to select couples with hereditary genetic problems for programmes of assisted reproduction.

Many people think, no doubt, that even in my hypothetical situation individuals should be freely allowed to conceive and give birth to suffering infants, or at least to gamble with the possibility. My moral disagreement with them concerns the degree to which human beings should try to control their lives and the lives of those they are responsible for. I agree that legal sanctions would be an unnecessarily rough method of preventing the existence of suffering newborns in a world where reproduction is not normally restricted. But since I also believe that nobody should knowingly bring about unnecessary suffering, it would, I think, be wrong of medical authorities to actually assist people in conceiving and giving birth to HIV-infected children. And I am inclined to think that it would be, at least *prima facie*, right to threaten the potential parents with moral disapproval and social contempt even in our present world.

Preventing the birth and taking the lives of HIV-infected children

If it is impossible or difficult to prevent the creation of foetuses and infants who would be infected with HIV, the question of ending their lives before birth or shortly afterwards arises. The legally easier solution in many European countries is abortion, which at the official level can be either morally encouraged or legally required. Theoretically speaking, the more obnoxious choice is to let the child be born and then take its life. It is not obvious, however, which option conscientious parents would find convenient in practice. I shall return to this question after a few remarks on the abortion issue.

Those who hold liberal views on social ethics and policy can easily condone certain types of moral encouragement in an HIV-related abortion situation while rejecting other kinds of persuasion along with the idea of legally forcing women to terminate their pregnancies. The acceptable variety of pro-abortion counselling would consist of information and support, whereas the application of any kind of mental pressure upon the decision-makers would have to be condemned. On the other hand, of course, people who oppose abortions on personal, religious or moral grounds would presumably find all encouragement to terminate a pregnancy inadvisable and disturbing.

But when it comes to infants who have already been born, the attitudes of those who reject abortion can become slightly paradoxical. If a child born with HIV is too weak to survive without extraordinary care and attention, some parents who have already refused termination can interpret this as a sign saying that the child ought to be let out of its misery. The idea underlying this kind of thinking seems to be that only positive actions like abortion can be morally condemned. Since a decision to let the infant die does not involve such actions, it cannot be wrong, either. The reasoning here is, I should have thought, blatantly skewed, but people do not always stop to think all that carefully what they are doing in emotionally loaded situations. It should be noted here that many philosophers do, in fact, uphold the view that positive actions are intrinsically different from omissions in the context of medical choices involving life and death.

Nobody would, I believe, seriously consider the possibility of deliberately killing children born with HIV, not at least in the more affluent European countries. Incorrigible liberals like myself can defend active euthanasia in cases where a gravely suffering newborn does not have the capacity to become a person with self-awareness, beliefs and emotions, but infants born with HIV can usually be expected to live a quite meaningful, if often short and painful, life.

To recapitulate, if it is intolerable that children are born with HIV, there are four principal methods to tackle the issue. First, public health authorities can try to ensure that people who conceive children do not carry the virus. This, I think, would be the best policy overall, but people with more conservative moral and economic ideals have, alas, hindered its implementation in many countries. Second, individuals who are infected with HIV can perhaps be morally discouraged when they plan to have children. Legal restrictions are probably too blunt an instrument for this purpose, but displays of moral and social disapproval could, arguably, be *prima facie* justified. Third, pregnancies where the foetus is infected with HIV can be terminated, if the potential parent or parents see this as the right choice. Given that my general premise is valid, moral support can be justifiably provided in favour of the abortion decision, but legal regulations are, once again, out of the question. Fourth, infanticide is only a theoretical option, since nobody seems to advocate it seriously. But it should be kept in mind that if attempts to practice active infanticide are rejected on moral grounds, then the passive forms of ending the lives of newborn babies should probably also be censured.

Contesting the premises

If it is truly undesirable that children are born with HIV, then I conclude that those who oppose the methods I have suggested are inconsistent and immoral. But maybe there is something wrong with my premises: perhaps it is not, after all, genuinely undesirable that children are born with HIV, or perhaps it does not follow from the undesirability that the birth of such children should be prevented. What would people who hold these views have to say for themselves?

One possibility is to redefine the key concepts of the case by referring to an allegedly analogous situation. The line of argument could be as follows. Criminal activities are undesirable, but this does not mean that they should be prevented by the excessive use of public resources. To say that these activities are undesirable is to say that the individuals who are involved in them should be punished by the rest of society. The situation is similar when it comes to women who give birth to HIV-positive babies. The babies are the innocent victims, and they deserve our sympathy, but the women should be legally punished for their irresponsible and immoral behaviour. And so (in case all this sounds too manifestly chauvinistic) should the men who knowingly participate in the conception of HIV-infected children.

The flaws of this view are, I hope, obvious. The retributive theory of justice and correction is, in and by itself, simplistic and illiberal enough, but the analogy drawn between deliberate criminality and the misfortune of having one's child infected with HIV is appalling. This is clearly not the adequate answer to my question concerning the necessity of preventing the occurrence of undesirable states of affairs.

Another way to escape my conclusion is to state that to have children who are HIV infected is undesirable only in the mild sense that we should all sympathise with the parents, not in the more demanding sense that we should do what we can to prevent such events. For the other members of the family, the birth of a potentially ill child gives an opportunity to re-evaluate their lives, and for the child itself to have a life which is comparatively short and painful is still better than to have no life at all.

I have no quarrel with the idea that when people are confronted with an unpleasant and inescapable situation they can and should reassess their lives and try to adjust themselves to the novel conditions. But the question is, is the birth of an afflicted child inescapable? If the measures I have suggested are taken, this is far from obvious. People can in the majority of cases abstain from having children, and when they can, they are not, I think, entitled to a great deal of sympathy for their choice to burden themselves and others by bringing into existence a suffering human being. Besides, the most important moral consideration here is not the psychological welfare of the family but the well- or ill-being of the child. Many people seem to take for granted the idea that even a short and painful life is better than no life at all. But this axiological, or metaphysical, assumption is not self-evidently valid.

According to the prevailing, essentially Judeo-Christian, view human life is always good. It is, other things being equal, better to have a happy life than to have a miserable life, but even a miserable life is better than nothing. If a good life is, on a scale from zero to ten, worth the full ten points, a miserable life is worth at least five points, and only total non-existence credits none. But it is also possible to see the comparative values of existence and non-existence in an entirely different light. Stoic philosophers, for instance, believed that life can become so unendurable that death, understood as an utter emptiness, is a better alternative. In these cases the Stoics themselves advocated the practice of rational suicide. On a ten-point scale, their theory could have stated, for example, that a good life is worth up to five points, non-existence nothing, and a miserable life down to minus five.

If the Stoic axiology is even remotely plausible, as I think it must be, then decisions to conceive and to give birth to HIV-infected children cannot be unquestioningly condoned. If non-existence can be a better alternative than a miserable life, it cannot always be right to bring suffering human beings into this world. More likely, it is *never* right to do so.

Discrimination and moralism

Two tentative charges can be brought against the conclusions of this paper. First, my remarks can be seen as an instance of discrimination against individuals who decide to have children despite the risks of HIV and AIDS. With proper medication, only about one out of ten infants of HIV-infected mothers contract the virus during the pregnancy or in birth. Yet greater risks are regularly taken by healthy, or apparently healthy, individuals and couples in reproductive matters. Many genetic diseases can cause inordinate suffering, and even healthy children can lead unhappy lives if they are not adequately cared for. Why, then, pick on HIV carriers?

I agree that it would be wrong to single out HIV carriers, and blame only them for bringing suffering children into existence. I do not, however, wish to restrict my comments to them. Everybody who intentionally or negligently allows avoidable suffering in reproductive matters is equally guilty, be the source of suffering medical, social or hereditary. The reason why I concentrate on children born infected with HIV in this paper is that their predicament is caused by the illiberal attitudes of religious and public authorities more clearly that the fate of individuals who are faced, say, with genetic disorders. Hereditary diseases cannot be eliminated by simple policy choices regarding sex education, contraception and drug use, whereas HIV infections could.

The second charge against my remarks is that social disapproval and moral contempt are harsh instruments of control, and should not be used lightly. If individuals are socially stigmatised merely for offending the sensitivities of others, in this case presumably my own, then greater suffering is inflicted on them in order to alleviate lesser suffering – which would be wrong according to the principles I committed myself to at the outset of this paper.

But this seemingly critical point works, as a matter of fact, in favour of my suggestions, not against them. My foremost recommendation is, namely, that HIV-related suffering should primarily be prevented by giving up all moralistic regulations concerning sexual relations and intravenous drug use. Since genuine harm could be checked by liberal sex education and the free provision of clean syringes and needles, it would be wrong to respect the sensitivities of those who regard some forms of sex and drug use as immoral. An additional policy suggestion, based on a comparison of social pressures, is that the pro-natal attitudes prevailing in most parts of the world should be briskly contested. There is no reason to believe that people would actually prefer having children to not having them had they not been indoctrinated from childhood into thinking that marriage and children are intrinsically involved in the notion of a full human life. The induced sense of inadequacy and the social disapproval experienced by childless individuals and couples is definitely a factor in many reproductive decisions in the face of possible future suffering. In this situation, the suggested pressure against having children whose lives would be short and full of suffering could be seen as a countermeasure to the already existing mental coercion.

Here, however, my *prima facie* argument for creating moral pressures against individuals who knowingly or negligently bring into existence suffering children runs into slightly paradoxical difficulties. Their decisions can be condemned only if they are free and uncoerced, but this is not the case in a world which favours the production of offspring regardless of the circumstances. To punish them for succumbing to the prevailing attitudes would be unfair, as this would inflict suffering on them in order to prevent suffering on their offspring, which is not unproblematically acceptable within my normative framework. This means that subjecting parents of HIV-infected infants to social disapproval and moral contempt would be justified only in a world where they would not be under pressure to reproduce, that is, in a world where they would probably not want to create suffering children in the first place. My argument can be pre-empted by holding on to the unethical pro-natal indoctrination.

But be that as it may, I conclude that if my analysis is correct, it *is* truly undesirable, indeed intolerable, that children are born infected with HIV, and we do have every reason to try to prevent this from happening. The methods which can be employed in this preventive work depend on the ability of religious and public authorities to put their own moralistic prejudices on one side and to start doing what is necessary to decrease the amount of avoidable suffering in this world.

Notes

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which resulted in a near-total rejection of my arguments in the Prague meeting.

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[1] E.g., P. Singer, *Practical Ethics* (Cambridge, New York and Melbourne: Cambridge University Press, second edition 1993); J. Harris, *Clones, Genes, and Immortality: Ethics and the Genetic Revolution* (Oxford and New York: Oxford University Press, 1998).

[2] My position is more fully explained in M. Häyry, *Liberal Utilitarianism and Applied Ethics* (London and New York: Routledge, 1994).

4. Categorical Objections Against Genetic Engineering – A Critique*

When new genetic technologies are examined and assessed within an ethical framework, two general types of objection are usually presented. First, some theorists appeal to the predictable consequences of employing gene technology. The core idea of the objection is to claim that the evil probably produced by genetic engineering exceeds the benefits probably flowing from its use. This approach has been dubbed in the literature as 'pragmatic' or 'consequentialist'. Second, there are theorists who reject the first approach as amoral, and argue that ethical evaluations should always proceed from purely ethical considerations. Arguments of this second type can be labelled as 'categorical' or 'deontological', and they range from complex theological accounts to simple commonsense expressions of disapproval.

Although I think that genuinely pragmatic reasons for and against gene technology are decisively important, I shall say virtually nothing about them in this paper. It is the second, deontological type of objection that interests me here, because it is in a sense more fundamental than its consequentialist rival. What I mean by this is that if deontological theorists are right, they can establish the moral status of human activities – such as genetic engineering – quite independently of the expected consequences of those activities. One valid deontological objection against gene technology would be enough to put all consequentialist moralists out of business in this field.

New genetic technologies include a variety of practices from the manipulation of plants and animals to attempts to alter the human chromosomes. The categorical and deontological arguments have, however, mostly been restricted to human genetics, and I shall focus on this aspect of the issue. There are three major forms of human genetics that have been regarded as morally dubious, and it is to these that I shall confine my attention. They are somatic cell therapy, germ-line gene therapy, and the project to map the human genome. The medico-biological aim of these practices is to identify the genes which cause known diseases, and to cure these diseases by recombinant DNA techniques.[1] Somatic cell therapy is intended to cure only the individuals who are actually being treated, whereas germ-line cell therapy is expected to rectify hereditary disorders both in the patients themselves and in their descendants. The project to map the human genome is related to these therapeutical applications in that reliable knowledge concerning the chromosomal structure of human beings would be quite invaluable to medical personnel when diagnoses are being made.

Is genetic engineering dangerous?

The difference between 'pragmatic' and 'categorical' arguments can be illustrated by studying one basic objection against the use of biotechnology, namely the apparently simple statement that 'genetic engineering is dangerous'. Two interpretations can be given to this objection.

First, the point of the argument may be that the genetic engineering of human beings is physically dangerous to certain identifiable individuals. For instance, many experimental animals lose their lives in biotechnological research. Human embryos and pre-embryos are also subjected to scientific experiments, and their lives are in similar danger. And although the embryos subjected to therapeutical gene manipulation would have the status of patients, their chances of survival would still be rather low until the treatments have developed beyond the experimental level. Even adult patients, embryo patients who survive the therapy, and the offspring of these groups may be in peril, since the manipulation of genes can cause new diseases as well as cure existing ones. Finally, genetic engineering as a whole is an expensive high tech enterprise which will possibly benefit only multinational corporations and a handful of affluent Westerners who suffer from obscure ailments. If scarce medical resources are primarily allocated to the development of gene therapy, more important projects such as sanitation and social security may have to be abandoned, and vast masses of people, especially in the Third World, will be endangered.[2]

The distinctive feature of all objections based on these and similar claims is that their structure is conditional. Genetic engineering, according to the objections, is dangerous only if at least one of the claims concerning its undesirable entailments is valid. Put the other way around, this implies that unless at least one of the remarks and predictions about present and future evils is true or reasonably probable, there is no tenable objection against gene technology. It is this possibility that makes objections based on physical danger pragmatic or conditional as opposed to absolute or categorical.

Second, however, the point of the argument may also be that genetic engineering is dangerous in some moral or symbolic rather than physical sense. Many theorists and a number of lay persons seem to think that gene technology is somehow inherently and irrevocably 'immoral', either because it violates the rules set by the human community, or because it is against the higher laws of God or Nature. The objections based on these ideas are genuinely categorical, since the immorality of the practice under evaluation is supposed to be intrinsic (or conceptual) and therefore beyond empirical testing.

If immorality is taken to mean deviation from rules set by humans, the claim that genetic engineering is immoral does not have much bite. Rules set by humans can be altered by humans, and therefore laws and regulations prohibiting genetic experiments and therapies do not by themselves prove anything about the ultimate ethical wrongness of these activities. On the other hand, if the objection is based on spontaneous human sentiments, the difficulty is to bridge the gap between those sentiments and critical morality. Feelings certainly influence the opinions that people have on ethical issues, but it has never been conclusively shown that feelings should be uncritically allowed to enter reflective moral judgements. The fear and suspicion people may feel towards gene technology does not, therefore, count as a valid objection against it.

If, however, immorality is taken to mean transgressions of the divine or natural laws, the matter is at once far more complicated. Those who oppose genetic engineering may say, for instance, that to interfere with the human germ line would be ‘unnatural’ or ‘against God’s will’ or an instance of ‘playing God’. But what exactly do these expressions mean? Can they be translated into plain language which could be understood without prior commitment to theological or metaphysical systems?

Six ways of playing God

Ruth Chadwick has thoroughly analysed and assessed the argument of ‘playing God’.[3] According to her analysis, the objection that an action is wrong because it is an instance of playing God has two different meanings in two different kinds of setting. In the context of sensitive medical decision-making the point of the objection is that human beings are in no position to decide legitimately about each other's fates on the basis of quality-of-life judgements. In the context of new medical technologies, again, the crux of the argument is that actions describable as playing God can lead to disastrous and unpredictable consequences. These two aspects are both present in certain forms of genetic engineering, such as germ-line gene therapy, and it is therefore useful to take a closer look at Chadwick's account.

With regard to the decision aspect of the playing-God objection, Chadwick distinguishes three major lines of argument, two of which she finds untenable.[4] First, the wrongness of playing God can be based on the idea that it is God's prerogative to give life and to take it away. Active euthanasia, for instance, has been attacked by referring to this notion. But the problem here is that no reasonable morality condemns doctors and nurses who do their best to save and prolong lives, although this work can, according to the interpretation, be described as playing God. Second, the point of the objection may be that in certain matters the natural course of events should be preferred to human interference. An example of such matters is the reallocation of health through medical decisions. To kill one patient in order to save two others would be the best thing to do in crude utilitarian terms, but it would also be a hideous instance of playing God.[5] In situations like this, so the argument goes, doctors can act morally only by letting nature take its course. The obvious difficulty in this second interpretation is that whatever decisions doctors make, they cannot help playing God in the defined sense. Refusals to alter the 'natural' course of events affect the patients and their lives as much as any positive action.

Third, the formulation that Chadwick finds plausible and morally relevant is founded on the equality and limited knowledge of human beings. In matters concerning life and death we may justifiably feel that no one else is qualified to judge whether our lives are worth living. This conviction stems from two factors. On the one hand, it can be argued that every human life has equal value, and that no person or group has the right to make decisions concerning the lives of others on assumptions of inequality. It is not, for instance, justifiable to allocate scarce life-saving medical treatments on the basis of quality-of-life measurements.[6] On the other hand, even assuming that some human lives are more valuable than others, the judgements concerning them may require superhuman capacities. The traditional theological assumption is that while human beings are imperfect and their knowledge limited, God is omniscient. This implies that even if God, as an omniscient being, could pass valid judgements concerning human lives, the comparisons made by human beings would still be mere arrogant instances of playing God.[7]

As Chadwick herself notes, the playing-God objection may in this third form have some moral relevance as a reminder of the limits of our knowledge. It may also serve as a counsel or warning against employing irrelevant criteria, like life quality, in the inescapable human decisions concerning life and death. But the objection is not by itself sufficiently strong to refute any actual practices.

With regard to the technology aspect of the playing-God objection, Chadwick argues that divine omnipotence rather than divine omniscience provides the key to this side of the issue.[8] People who oppose activities like genetic engineering or artificial reproduction typically see these technologies as attempts to rival God's power by trying to create life or life-forms.[9] When it comes to artificial insemination and in vitro fertilisation, the counterargument can be made, as Chadwick in fact does, that reproductive technology only aims at rearranging materials, not at creating previously nonexistent entities. The same is not, however, quite true with regard to genetic engineering, which may, after all, create completely new life-forms. Admittedly, new life-forms have been created for centuries by animal and plant breeding. But these processes have been relatively slow, and humans have not been explicitly included in the programme. The opponents of genetic engineering may wish to argue that there are certain limits beyond which human beings cannot go without unlawfully playing God.

If this idea of fixed moral limits is taken seriously, the next step is to find out where the lines have been drawn and by whom. Chadwick considers three possibilities.[10] First, playing God can be understood literally, as a transgression of the invisible boundaries that separate immortal gods from mortal human beings. People who try to assume the role of gods are guilty of what the ancient Greeks used to call 'hubris', that is, of excessive pride. In the Greek mythology, overstepping the limits set by a divine will was generally punished in unusual and cruel ways. This literal interpretation of the playing-God objection is clear and intelligible, but its value as a moral guide is suspect. No critical morality can be based on the assumption that divine beings have set us limits which they continuously protect. Even if one believed in the existence of such divinities and in the sacredness of their will, it would be impossible to discover what the chosen deity would want us to do. In fact, one could well argue that the humans who pretend to be acquainted with the divine will are in fact putting themselves in the divine role, and thereby themselves playing God.

Second, the playing-God objection in the context of medical technologies may also be meant to state that the natural environment as a whole sets certain limits to our action. Humankind has during the last few decades acquired powers which could be used to destroy most of the biosphere. Many people seem to think that genetic engineering is one of these powers, and they fear that, for instance, the release of genetically altered organisms into the environment may have irreversible ecological consequences. Assuming that we are interested in the preservation of the biosphere, this objection against genetic engineering does indeed have some moral relevance. But the problem is that the appeal to consequences, which gives this argument its weight, also deprives it of its categorical disguise. It would, no doubt, be pragmatically unwise to destroy the only environment where we can live at present, but this does not amount to a categorical rejection of genetic engineering. The wrongness of the activity remains conditional upon the actual consequences.

Third, the limits of playing God can be set by human beings on the ground that certain actions, especially technology-related actions which have never been taken before, are liable to produce unforeseen, unpleasant and unpredictable consequences. Despite the appeal to consequences, this approach may be genuinely categorical, since no weight is given to the nature of the feared outcome or to the probability or improbability of its occurrence. According to Chadwick, the logic of the playing-God objection here is that the unknown consequences of going beyond (present) human limits cause fear, anxiety and uneasiness in many people.[11] Some of these people believe that we will be faced with unimaginable disaster if new technologies are implemented. Others may have the feeling, unjustified perhaps but nonetheless painful, that divine retribution will follow the alleged human arrogance. And still others may be worried about the preservation of the current worldview, which may suffer from the breakdown of its customary limits.

None of these negative feelings amounts, by itself, to an independent refutation of new technologies. But as Chadwick points out, the appeal to unforeseen consequences may be taken as a counsel advising us to be very careful in assessing certain delicate decisions. If the pros and cons of a given new technology are otherwise equal, the scales can be tipped by the unpleasantness inflicted on people by the mere thought of the innovation.

Are genetic engineers playing God?

Let me now summarise those parts of Chadwick's account which are relevant to my own question concerning genetic engineering and the alleged categorical wrongness of playing God. The development of gene technology is obviously subject to the remarks concerning unpredictable consequences. But, as we have seen, the only way in which this unpredictability can be brought to bear on the moral assessment of genetic engineering is through the fears and anxieties that people may have. This means that the technology aspect of the playing-God objection must be expressed in pragmatic and conditional terms after all. Gene-splicing, as an instance of 'playing God', is morally objectionable only if people's feelings are strong enough to outweigh the expected net utility of employing the technique. The playing-God complaint, understood in this way, is not a categorical claim, but an appeal to empirical facts which can be verified or falsified by observation and testing.

As regards the decision aspect of the matter, the playing-God objection can be interpreted as a warning against large scale eugenic programmes. What I have in mind are genetic programmes which would aim at altering the human phenotype, either nationally or globally, to accord with the aesthetic or ethical views of scientists, politicians or others who claim to possess expert knowledge concerning the 'ideal human nature'. The possession of such knowledge would indeed require divine omniscience, and the majority of people would probably like to state that in this particular context the playing-God objection is valid without reservations. It should be noted, however, that the argument does not refute genetic engineering as such, but rather its misapplication to political purposes. One does not condemn conventional medicine on the ground that medical skills can be employed in the execution of cruel and mutilating punishments. Similarly, one should not condemn biotechnology because it could be misused to create monstrous future dystopias.

Whether or not the argument against eugenic programming is categorical is a matter of some dispute. The theorist who prefers pragmatic interpretations can argue that the ultimate reason for rejecting the programmes is the decrease of happiness which is expected to result from them. The opponents of this view, in their turn, can reply that the expected outcome in terms of human pleasure or happiness is not decisive, since there are stronger, deontological reasons for banning designs to alter people. These deontological reasons cannot include appeals to 'playing God' or 'God's will', because those are the concepts we are trying to analyse here. But an alternative can be found in the claim that genetic engineering, especially when it takes the form of manufacturing human beings, is 'unnatural' or 'against nature'.

Is genetic engineering unnatural?

The mere statement that an action is unnatural does not, of course, prove that the action in question is immoral, let alone that it ought to be banned.[12] Phenomena and practices which are rare, new, alien, or in any other way deviate from the everyday experience are often labelled by common sense as unnatural. But there is surely nothing inherently immoral in actions which are infrequent or previously not seen or heard of. More sophisticated analyses for the concepts of natural and unnatural are not always helpful, either. Take, for instance, the interpretations criticised by Ruth Chadwick: actions are unnatural if they interfere with the natural course of events, or put life on Earth in jeopardy.[13] As for interfering with the course of nature, people have been doing exactly that for centuries, and most of the interventions have never been regarded as immoral. On the contrary, it could well be argued that once the significance of, say, hygiene, adequate nutrition and health care was discovered, it became a moral duty to employ these measures against the 'natural course of events', which would lead to diseases and starvation. And as for protecting life on Earth, the reasons for a preservationist policy seem to be conditional rather than categorical. Whether or not an activity can be considered unnatural depends on its consequences, not on its intrinsic qualities. No logical connection exists between actions which are unnatural in the defined two senses and actions which are 'categorically' immoral.

An attempt to formulate and employ the argument of unnaturalness against genetic engineering can be found in the report of the Enquete Commission to the German Bundestag.[14] The Commission tackled three questions which are fundamental to the issue, namely the definition of the natural as opposed to the unnatural, the reasons for preferring naturalness to unnaturalness, and the division of different kinds of biotechnology according to their natural and unnatural characteristics.

As for the question of definition, the development of individual human beings was regarded in the report as natural only if it is not determined by technical production or social recognition. Technological and social processes can, according to the Commission's view, produce only unnatural artifacts.

The value of promoting naturalness and avoiding artificial elements in practices which concern human development was linked in the report with the need to protect the humanity and dignity of human beings. Our humanity, so the Commission asserted, 'rests at its core on natural development', and our dignity 'is based essentially on the naturalness of our origins'.[15] If technological or social interventions are allowed, then the result is that people will be created by other people, and the Commission regarded this possibility with extreme suspicion. Human beings whose existence and personal qualities depend on the planning or caprice of other human beings are not free persons in the full meaning of the term, and their lives lack the individual worth of naturally developed human lives. It is the untampered chance of nature that secures our independence from other people, our personal freedom, and our individual worth as human beings.[16]

These considerations lead to the following normative views regarding different kinds of human genetic engineering. First, somatic cell therapies performed on foetuses, infants and adult human beings are, at the moment, justifiable as experimental treatments. Whether or not such treatments should be abandoned or condoned in the future remains to be judged by their practical success. But the humanity of individuals is not threatened by the use of genetic medicine when the individuals in question have already developed into the beings that they 'naturally' are. Second, the mapping of the human genome is legitimate as long as it is employed to diagnose the need for somatic cell therapies. The potential use of gene maps for other (eugenic) purposes is more controversial. Third, cloning and large-scale eugenic programmes must according to the report be banned as gross instances of manufacturing people. And fourth, if a strict interpretation is given to the Commission's ideas concerning naturalness, germ-line gene therapies must also be prohibited. All interventions in the germ lines of individuals diminish, according to the foregoing argument, their independence, uniqueness, and worth as human beings.[17]

The opinions among the Enquete Commission diverged, however, regarding the legitimacy of germ-line gene therapies. Only some members of the Commission upheld the strict interpretation of naturalness, while others advanced a more moderate view. The core of the latter, moderate interpretation is that the medical corrections of obvious defects are not unnatural, as they do 'not manufacture the human genome capriciously, but measure it against nature, that is, good health.'[18] Illness and suffering can be a part of a person's identity, but if they are prevented before the person even exists, there is no point in maintaining that her or his individuality is unlawfully changed or manipulated. The genetic treatment of early embryos is, so the moderate reading goes, directly comparable to any conventional treatment of foetuses and neonates who cannot give their consent to the procedures.[19]

The divergence of opinions within the Commission is, no doubt, an interesting detail for those who believe that the unnaturalness objection is tenable as such. There are, however, several good reasons for thinking that this is not the case.

First, the argument from unnaturalness seems to apply to many practices which have been traditionally considered quite acceptable. If genetic engineering is to be condemned due to its power to change individuals by technical means, then most medical interventions should be condemned as well. Surgical operations, for instance, often alter people by transforming them from fatally ill patients into perfectly healthy citizens. And changes of personal identity may be even more drastic in the case of radical psychiatric treatments.[20]

Second, the Commission's argument presupposes theoretical elements which are by no means universally accepted. The report's entirely biological view concerning personal identity is a case in point. According to the view, human beings are who they are and what they are almost exclusively owing to the arrangement of their genes. Culture, education and social environment cannot significantly change the individual's identity, only biotechnology can do that. Very few philosophers today believe that such a strict biological definition of personality and individuality could be credibly defended.[21] Another presupposition in the report which can be criticised is its underlying view of human freedom and independence. The argument requires that human beings can be free from each other's influence in the sense that people are not 'manufactured' by other people. This is obviously true if the manufacturing of people is understood literally: human beings cannot at the moment be mechanically created by each other except in science fiction. But when it comes to less obtrusive types of interaction, it is also true that people simply cannot survive and function without the often restrictive and moulding presence of other people. Human freedom without the individual's dependence on others is only an abstraction with no reality to it.

Third, the unnaturalness objection presented in the report rests on the assumption that genetic engineering would undermine the worth, humanity and dignity of the individuals produced by using the technique. This assumption is not only dubious but it may be positively insulting towards those human beings who will be born in the future genetically altered or cloned, perhaps against prevailing laws. The depth of the actual insult depends upon the interpretation that one gives to the Commission's view. One possibility is to state that, according to the report, genetically engineered individuals would in fact lack humanity, dignity and personal freedom because their chromosomes have been tampered with. This line of argument would obviously be unreasonably unfair towards the individuals in question. Another possibility would be to assume that the Commission did not discuss the objective worth of human life in the first place, but the individual's subjective sense of worth in her or his life. The argument would then be that genetic engineering is wrong because the knowledge of one's 'artificial' and 'unnatural' origin reduces one's sense of worth and dignity. And yet another possibility is to claim that other people's adverse attitudes will make genetically engineered individuals unhappy.

The statements concerning attitudes can, no doubt, materialise under predictable circumstances. But since people's attitudes towards themselves and towards others are subject to change, the argument in this form is conditional rather than categorical. If genetically altered human beings can be expected to have difficulties in coping with the question of their origins, these difficulties may constitute a weak prima facie case against germ-line gene therapy, cloning and eugenic programmes. But this does not imply that these practices could be categorically rejected.

Conclusions

It seems, then, that appeals to the unnaturalness of biotechnology do not amount to tenable categorical arguments against its use. Nor do these appeals lend any support to the playing-God objections discussed in the above. In fact, the only thing of any normative value to be deduced from the unnaturalness objection is the fear that people may come to see and treat genetically engineered individuals as inferior to other human beings. But the significance of this point is minimal, since, first, people do not need to know who is genetically altered, and, second, there is no reason to believe that people's attitudes towards each other would be dependent upon what they know about each other's genomes.

On a more general level, it seems that the allegedly categorical objections against gene manipulation do not in the end merit the attention that they have been given in the literature. Such objections are employed frequently and without discrimination, but closer scrutiny either dissolves them entirely or reveals that their sound core, if any, is conditional or pragmatic. This is true about the playing-God objection, which can be interpreted as a counsel or reminder against forgetting improbable consequences and people's feelings. The same is true about the unnaturalness objection, which can serve as a warning against making people whose human worth and dignity will be questioned either by themselves or by others. But no decisive arguments for or against genetic engineering can be found from these quarters. The ultimate justification or rejection of biotechnology must be based on pragmatic considerations.

Notes

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[1] The abbreviation DNA stands for 'deoxyribonucleic acid'. The first successful human somatic cell therapy was reported by Timothy J. Ley and his colleagues in December 1983 in the *New England Journal of Medicine*. As for germ-line gene therapy, successful experiments have been made since 1982 with (at least) fruit flies and mice, and it seems that there are no overpowering technical hindrances to medical success in humans. See, e.g., A.J. Varga, '"Playing God": The ethics of biotechnical intervention', *Thought* **60** (1985): 181-195; 'A report from Germany – An extract from *Prospects and Risks of Gene Technology: The Report of the Enquete Commission to the Bundestag of the Federal Republic of Germany*',

Bioethics 2 (1988): 256-263; S. Kingman, 'Buried treasure in human genes', *Bioethics News* 9 (1990), No. 2: 10-15.

[2] I forego here the question whether or not these objections are well-taken.

[3] R.F. Chadwick, 'Playing God', *Bioethics News* 9 (1990), No. 4: 38-46 (first appeared in *Cogito*, Autumn 1989).

[4] Chadwick 1990, 40-42.

[5] Cf. J. Harris, *Violence and Responsibility* (London: Routledge & Kegan Paul, 1980), 71.

[6] Chadwick 1990, 41. Cf. J. Glover, *Causing Death and Saving Lives* (Harmondsworth, Middlesex: Penguin Books, 1977), 102-103. Glover seems to present two arguments concerning equality, but he does not differentiate between them. The first argument refers to the decision-maker's equality with those whose lives the decisions influence. Frankly, I do not see the point of this remark. My fundamental equality with other people cannot, as far as I can see, change the fact that if I am put in a position where decisions between other people's lives must be made, I must make them. The second argument is more intelligible to me, and refers to the mutual equality of those whose lives my decisions concern. This is the argument that Chadwick mostly employs, and the one that I have presented in the main text. See also J. Glover, *What Sort of People Should There Be?* (Harmondsworth, Middlesex: Penguin Books, 1984), 45-47.

[7] Chadwick 1990, 42.

[8] Chadwick 1990, 43-45.

[9] For a theological refutation of this objection, see Varga 1985, 186-187.

[10] Chadwick 1990, 43-45.

[11] Chadwick 1990, 45.

[12] On the (ir)relevance of naturalness to morality see, e.g., J. Radcliffe Richards, *The Sceptical Feminist: A Philosophical Enquiry* (Harmondsworth, Middlesex: Pelican Books, 1982), 65 ff.; P. Singer and D. Wells, *The Re-*

production Revolution: New Ways of Making Babies (Oxford: Oxford University Press, 1984), 36 ff.; J. Harris, *The Value of Life: An Introduction to Medical Ethics* (London: Routledge & Kegan Paul, 1985), 186 ff.

[13] Chadwick 1990, 40, 44.

[14] 'A report from Germany' 1988, 257-258.

[15] 'A report from Germany' 1988, 257. The quoted passage in full goes as follows: 'The starting-point of every evaluation must be that the humanity of human beings rests at its core on natural development, not on technical production and not on a social act of recognition. The dignity of human beings is based essentially on their being born and on the naturalness of their origins, which all humans share with each other.'

[16] 'A report from Germany' 1988, 257. In full: 'The fact that human beings are not the project and the planned experiment of their parents, but are the product of the chance of nature, secures the independence of human beings from each other, their individual worth.' '["T]o make the formation of our genotype [...] dependent on the caprice of other people is incompatible with the essence of a free person."' The latter passage is quoted in the report from R. Loew, 'Gentechnologie: Vom Können zum Dürfen – Philosophische Überlegungen', *Die Neue Ordnung* **38** (1984): 176 ff.

[17] 'A report from Germany' 1988, 258.

[18] 'A report from Germany' 1988, 258.

[19] There are two intrinsic problems within the 'moderate' view, which are not essential to my main line of argument, but which are nevertheless worth mentioning. First, defining 'good health' is not an unambiguous matter, and one could well argue that human caprice always enters germ-line gene therapies through the particular definition employed. Second, the moderates of the Commission seem to assert that eugenic programming can be categorically prohibited due to unnaturalness even though germ-line gene therapies cannot. This is a highly controversial view which presup-

poses that a tenable distinction can be drawn between the two practices.

The alleged difference between gene therapies and genetic improvement programmes is that the former is aimed at eliminating hereditary diseases while the latter is intended to bring about or intensify some positive qualities in future individuals. This distinction is unclear, as it is obvious that illness may hinder the development of certain positive qualities and promote the development of others. A physically disabling disease, for instance, may prevent the individual from being strong and athletic (which are often regarded as 'good qualities'), but it may indirectly promote the individual's willingness to learn useful cognitive and artistic skills (which are also often considered good).

The main point to be noted here, however, is that the argument which supports gene therapy on individuals can also be used to defend demographic genetic changes which are not, strictly speaking, disease-related. The justification for bypassing the patient's consent is, according to the moderate view, the best interest of the patient her or himself. How could positive improvements in the patient's best interest be ruled out if the elimination of negative factors in the patient's best interest is accepted?

[20] Besides, as the Commission's moderates note, there are social arrangements, such as marriage rules, which have been interfering with the 'natural' human gene pool for millennia, thereby modifying the qualities of individuals. To condemn germ-line gene therapies categorically would require the condemnation of all these social practices as well. See 'A report from Germany' 1988, 259.

[21] For a critique, see, e.g., H.-M. Sass, 'A critique of the Enquete Commission's report', *Bioethics* **2** (1988): 264-275, 269.

5. What the Fox Would Have Said, Had He Been a Hedgehog

- On the methodology and normative approach of John Harris's *Wonderwoman and Superman*[*]

> LADY BRACKNELL: I would strongly advise you, Mr. Worthing, to try and acquire some relations as soon as possible, and to make a definite effort to produce at any rate one parent, of either sex, before the season is quite over.
> - Oscar Wilde, *The Importance of Being Earnest*.

Philosophical books on real-life moral issues can be assessed on many grounds, most importantly according to their contents and conclusions, style and clarity of presentation, their general significance, and the methodology and normative approach chosen by the author.

John Harris's *Wonderwoman and Superman*[1] is an important and comprehensive study of the moral and legal dimensions of human biotechnology, including assisted reproduction, organ transplants and the possibilities of genetic engineering. The arguments for and against suggested solutions have been presented forcefully and clearly, and the style throughout the book is spontaneous, witty and provocative. The conclusions, which are always convincing and most often exceedingly liberal, are well argued and ingeniously defended against many popular objections.

My aim in this comment is, however, to examine the methodology and normative approach employed by Professor Harris in *Wonder-*

woman and Superman. I shall argue that the ethical theory behind his reasoning, although not systematically presented, can be easily traced, and that the justifications he gives for this theory and for his normative conclusions are equally detectable. I shall, furthermore, argue that the few occasions where the conclusions drawn in the book are less than obviously acceptable arise either because Professor Harris inadvertently flirts with axiological views which are not necessarily compatible with his overall theory, or because he tries to extend the scope of his moral doctrine too far.

What the fox thinks he is doing

In a chapter dealing with research on embryos Professor Harris introduces a distinction, originally made by Isaiah Berlin, which is useful here. He divides people into two categories according to their ways of thinking and justifying their views. 'There are those,' he writes, 'who pursue many ideas and those who like to bring everything under one central vision or organizing principle. The latter are hedgehogs, the former are foxes.'[2]

In the introduction of *Wonderwoman and Superman* Professor Harris clearly counts himself among the foxes of applied philosophy, at least for the purposes of the present book. He writes:

> While this book is about the ethics of human biotechnology I have not here attempted to give any general introduction to moral philosophy, nor have I tried to outline in general terms my own basic approach to ethics. I have tried rather to let the arguments speak for themselves. There is always a danger when la-

> bels are attached to philosophical positions for people to assume that if they reject a particular school of philosophy in general, or adhere to a different philosophical tradition or approach, they can safely ignore or reject arguments from another school of philosophy. But most philosophical schools are united by their demand for rational argument and for the justification of moral conclusions. What matters is the quality of arguments, reasons, and justifications produced. Here I am interested simply in what can be said for and against using biotechnology in various ways.[3]

The suggestion is, then, that it would be futile and even dangerous to do what the hedgehog would do, that is, to inform the readers of the organizing principle or principles of the author's moral views, since the information could unnecessarily alienate the readership. Instead, Professor Harris wants to be the fox who pursues all the ideas that members of various philosophical schools have put forward, employing as his only criterion of rightness the quality of particular arguments and justifications.

What the fox would have been doing, had he been a hedgehog

The difficulty with assuming the strategy of the fox in the analysis of practical moral problems is, however, that the flow and exchange of arguments can usually be halted only if a consensus is reached, or when the justification process has advanced to fundamental principles which are not open to any further proof. When it comes to controversial issues like biotechnology, the chances of finding universal agreement are slim. Therefore, two questions arise here. The first is, does Professor Harris always arrive at different axioms at the end of his arguments, thereby reinstating his position as a philosophical fox? The second is, if he does not, what are the basic principles he employs to support his arguments?

The answer to the first question is clearly negative – the ultimate justification of policies and actions can in all the cases dealt with in the book be traced down to a limited number of moral axioms. This, of course, is not surprising to those who are acquainted with Professor Harris's previous work, especially *Violence and Responsibility* and *The Value of Life*.[4] Neither is it surprising that the basic ethical tenets employed in *Wonderwoman and Superman* are of the type that is usually dubbed in the literature as consequentialist or utilitarian. There are three normative principles which are essential to Professor Harris's view, and to the arguments he presents for and against particular uses of biotechnology.

The first is the principle of *consequentialism*, which can be stated as follows:

> (1) The moral status (rightness or wrongness) of acts and omissions depends on the probable beneficial and harmful consequences of these acts and omissions to individuals who are worthy of moral consideration.[5]

A few comments and specifications must be added to this brief formulation.

Professor Harris believes, as all utilitarian philosophers should, that acts and omissions are in themselves morally symmetrical, in other words, that it is equally right or wrong to bring about beneficial or harmful consequences by actively doing something and by passively allowing things to happen.[6] In order to be morally responsible for the consequences of their actions, however, agents must be aware of them. The rightness or wrongness of moral choices is determined by their expected, or probable, or foreseeable, outcome, not necessarily by the consequences that actually occur.[7]

As regards the semantics of normative statements, Professor Harris seems to follow the usage established by the utilitarians of the early twentieth century.[8] If an action is wrong, it is morally prohibited, that is, it ought not to be performed. If, on the other hand, an action is right, it can be either obligatory or merely permissible. In the former case it is our duty to undertake the action, in the latter case it is not our duty to perform it, nor to forgo it. The distinction between duties and other right actions is in Professor Harris's theory, as in most utilitarian doctrines, slightly vague.

Individuals who are worthy of moral consideration can according to Professor Harris's view be divided into two groups. Persons, that is, individuals who are capable of valuing their own lives, should be equally entitled to life, liberty, and the avoidance of needless suffering. Sentient beings who are not persons should not be subjected to unnecessary pain or anguish. Individuals who will in the foreseeable future develop into persons need not be respected as the potential persons they presently are, but they are worthy of moral consideration as the primary medium, or raw material, of the persons they will become.[9]

One dimension of the principle of consequentialism is that it rules out many other approaches to moral issues. Among the solutions that are more or less explicitly rejected in *Wonderwoman and Superman* are religious ethics,[10] deontological arguments[11] and a doctrine that

Professor Harris calls 'moral sentimentalism'.[12] The moral sentimentalist believes that actions and policies should be banned if they evoke feelings of outrage.

The second axiom of Professor Harris's theory, already touched upon in the passage concerning the moral standing of individuals, is the principle of *negative utilitarianism*, which can be expressed in the following form:

> (2) It is wrong deliberately to bring about or to allow avoidable harm or suffering.[13]

One specification is worth mentioning here. As a partial definition of the concept of avoidability, Professor Harris asserts that 'suffering is avoidable where an individual who is or will be disabled can be replaced with an individual who is not disabled'.[14] I shall return to this point in the critical part of my comment.

The third cornerstone of utilitarianism is the principle of *equality*, or *strict impartiality*, which states:

> (3) The lives and fundamental interests of each individual should be granted equal weight, equal consideration and equal respect in ethical decision-making.[15]

Like many self-confessed utilitarians, Professor Harris employs this axiom in order to tackle the questions of fairness and justice. The principle of strict impartiality is not, in fact, generally regarded as an efficient tool for the evaluation of competing models of distribution and retribution. But within the utilitarian framework it establishes firmly the norm of anti-favouritism. When the beneficial and harmful consequences of policies and actions are assessed, no weight should be given to the possibility that some of those affected by the choices can be emotionally, genetically, racially or ethnically related to the individuals who make the decisions.

In addition to these normative moral principles Professor Harris also seems to recognize a distinct metaethical view, which can perhaps be called *rational intuitionism*. At least the following points are included in this view:

> (4) All moral choices and principles should be justified by rational arguments.[16] These arguments, in their turn, must ultimately be based either on the normal usage of language,[17] the cool consideration of rational preferences,[18] or on thought experiments involving hypothetical, and often exceedingly fanciful, examples.[19]

The idea that ethical decisions ought to be justified by good arguments encapsulates, of course, the official ethos of the book, stated in the introduction. The specifications concerning language, rational preferences and imaginary examples can be found in the chapters dealing with the substantive issues of biotechnology.

Where the fox has stuck his nose into the spines

The moral theory underlying the arguments of *Wonderwoman and Superman* is, then, a version of modern utilitarianism, not unlike the doctrines employed, for instance, by R.M. Hare, Jonathan Glover and Peter Singer.[20] It will be remembered that the rationale Professor Harris gives for his decision not to define the view in his book is that many readers could be adversely affected by the information. This concern can, for all I know, be either justified or groundless. But there is another, entirely unrelated reason which makes me at least believe that the book could have been even better had its moral framework been explicitly stated at the outset. The reason is that certain normative points made by Professor Harris seem to be incompatible with the principles of negative utilitarianism and with some of the conclusions he reaches. This, I think, may not have happened if he had been forced to examine the results against the background of a definite set of moral axioms.

Three passages in *Wonderwoman and Superman* stand out as examples of incongruence. These are:

> (i) If children are wanted, it is better to have healthy children than to have disabled children where these are alternatives, and it is better to have children with disabilities than to have no children at all.[21]

> (ii) [It] seems to me clearly wrong for human beings to decide to destroy the world. [...] However, the wrong of all presently existing individuals, say, simply deciding not to reproduce, simply deciding that the present generation should be the last, is of a different order. It is different because it would not involve violating the will to live of any person, nor the destruction of the ecosystem. [But] it would I think be wrong for two distinct and important reasons. The first is that it would be to prefer a universe with less happiness and less satisfaction of desires than the alternative in which persons did continue to exist, and secondly

> because it might involve the permanent end of the only creatures anywhere who have both these capacities.[22]
>
> (iii) If your child is suffering from fatal kidney disease and mine has the only available kidney, would I be wrong to risk my child to save yours? I do not think that I would in fact do so, but that is because I am a parent and I have fierce protective feelings towards *my* child.[23]

Let me explain why these statements are at odds with the general ethos of the book, and what could be done to straighten the situation.

(i) In the first passage Professor Harris asserts that if individuals want children, 'it is better to have children with disabilities than to have no children at all',[24] in other words, that it is better to bring about suffering than to refrain from doing so.[25] He supports this apparently anti-utilitarian view by arguing that in certain situations suffering is unavoidable, and when it is, the principle of negative utilitarianism does not prohibit slightly harmful actions. According to his definition, suffering is unavoidable, for instance, when individuals who cannot have healthy children nonetheless want to produce their own offspring.[26]

But to define the concept of 'unavoidable' in this way is to contradict the principles of rational intuitionism. In his critique of Joel Feinberg's views on harming and wronging, Professor Harris argues, reasonably I think, that 'to be harmed is to be put in a condition that is harmful',[27] and that Feinberg's more artificial definition 'is strongly counter-intuitive'.[28] Similar remarks can be extended to Professor Harris's own account of avoidable suffering. To say that a result is unavoidable is surely to say that the result in question cannot be avoided, not that it can be avoided only by refraining from action.[29] If individuals can abstain from having children, as they in most cases can, the suffering they produce by bringing into existence a disabled child seems to be, following our linguistic intuitions, avoidable, and therefore also unacceptable.

(ii) In the second passage Professor Harris states that the voluntary self-extinction of humankind would be wrong, because 'it would be to prefer a universe with less happiness and less satisfaction of desires than the alternative in which persons did continue to exist'.[30] This view is clearly utilitarian in nature, but it represents the 'positive' rather than the 'negative' version of the doctrine. The principle employed here makes it our moral duty to maximize happiness and happy individuals, whereas the axiom used elsewhere in the book restricts our duties to the minimization of misery and pain.

The problem with the expanded model of moral obligations is that it is incompatible with some of the conlusions reached in *Wonderwoman and Superman*. Professor Harris makes it clear that abortion at the request of the pregnant woman should always be permitted. As he puts the matter: 'She wrongs no one because in ending the life of the fetus she deprives the fetus of nothing that it can value and she benefits no one since there is no one she brings into existence.'[31] But if happiness and happy lives ought to be maximized, it is difficult to see how aborting a healthy and potentially well-off fetus could ever be permissible. This would, after all, mean that the decision-maker prefers a universe with less happiness to a universe with more. It would be equally problematical to condone contraception or celibacy, if the alternative is to bring into existence healthy and happy human beings.

(iii) In the third passage Professor Harris informs us that he would not risk his child to save mine, because he has fierce protective feelings towards his own offspring. This decision violates the rule of equality, or strict impartiality. As William Godwin wrote in evaluating the choice between the lives of a known benefactor and the rescuer's own father or brother: 'What magic is there in the pronoun "my", that should justify us in overturning the decisions of impartial truth? My brother or my father may be a fool or a profligate, malicious, lying or dishonest. If they be, what consequence is it that they are mine?'[32] Godwin concluded that if more happiness can be brought into the world by rescuing the benefactor, it would be immoral to save the life of one's own father or brother.

The conclusion that Professor Harris draws in his own example can, I think, be justified more easily than Godwin's choice. But on the other hand, Godwin's result is consistent with the principle of equality, while Professor Harris's decision is not. What this implies, in my opinion, is that the requirement of strict impartiality ought to be rejected in situations where the basic interests, or basic needs, of individuals are in conflict.[33] The classical utilitarian rules of the minimization of suffering and the maximization of happiness cannot be reasonably employed if the security of one person ought to be sacrificed in order to promote the welfare of another. Any acceptable moral theory must recognize at least our entitlement to defend ourselves, and those we care for, against peril.

What the veterinarian can do

If I have interpreted the arguments and results of *Wonderwoman and Superman* correctly, two points are worth mentioning in conclusion.

First, it seems to me that unless Professor Harris wants to revise his ethical theory considerably, the ideas he puts forward concerning children with disabilities and the voluntary self-extinction of humankind ought to be reversed.[34] Second, it also seems to me that as Professor Harris is right in defending his own child against the claims of others, he should grant other parents the right to defend their children as well.[35]

My observations, and the inferences I have drawn from them, can be skewed on two accounts. On the one hand, it is perfectly possible that I have read the arguments of *Wonderwoman and Superman* through my own theoretical lenses, and distorted them beyond recognition in the process. On the other hand, even if the problems that I have unearthed are real, Professor Harris may well be able to come up with blindingly obvious solutions to them. But be that as it may, I cannot help having the feeling that *Wonderwoman and Superman*, albeit a fine achievement, could have been still a notch finer, had the moral principles employed in the book been defined explicitly at the outset.

Notes

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The paper was subsequently published in V. Launis, J. Pietarinen and J. Räikkä (eds), *Genes and Morality: New Essays*. Amsterdam and Atlanta: Rodopi, 1999, 11-19.

[1] J. Harris, *Wonderwoman and Superman: The Ethics of Human Biotechnology* (Oxford and New York: Oxford University Press, 1993; originally published 1992).

[2] Harris 1993, 31.

[3] Harris 1993, 5.

[4] See, e.g., his *Violence and Responsibility* (London: Routledge & Kegan Paul, 1980) and *The Value of Life* (London: Routledge & Kegan Paul, 1985).

[5] Not a direct quotation. On consequentialism, see esp. Harris 1993, 5-6, 46.

[6] On the moral symmetry between acts and omissions, see Harris 1993, 5-6, 177-8.

[7] Harris 1993, 179.

[8] See, e.g., G.E. Moore, *Ethics* (London, Oxford and New York: Oxford University Press, 1965; originally published 1912).

[9] On the moral worth of individuals, see Harris 1993, 68-72.

[10] Harris 1993, 35, 46.

[11] E.g., Harris 1993, 146.

[12] Harris 1993, 40-43.

[13] Not a direct quotation. On negative utilitarianism, see especially Harris 1993, 69, 90.

[14] Harris 1993, 72.

[15] Not a direct quotation. See Harris 1993, 193-4.

[16] Not a direct quotation. See Harris 1993, 5.

[17] Not a direct quotation. See Harris 1993, 67, 87-8.

[18] Not a direct quotation. See Harris 1993, 72-3, 88.

[19] Not a direct quotation. See Harris 1993, 52-3.

[20] See, e.g., R.M. Hare, *Moral Thinking: Its Levels, Methods and Point* (Oxford: Clarendon Press, 1981); J. Glover, *Causing Death and Saving Lives* (Harmondsworth, Middlesex: Penguin Books, 1977); P. Singer, *Practical Ethics* (Cambridge: Cambridge University Press, 1979).

[21] Harris 1993, 71-2.

[22] Harris 1993, 176-7.

[23] Harris 1993, 116.

[24] Harris 1993, 71-2.

[25] Professor Harris seems to assume that all disabled individuals suffer from their disabilities – see, e.g., Harris 1993, 69. This, as Dr. Mark Shackleton pointed out to me, is not necessarily true. Autobiographies by handicapped persons have shown how disability can be overcome and how suffering is not always inevitable. Suffering is a part of everybody's experience - the able and the disabled. Many utilitarian philosophers who talk unquestioningly about 'lives which are worth living but less so than normal lives' should certainly take this point into account. I shall not, however, try to work out the implications of this remark to Professor Harris's views here.

[26] Harris 1993, 70-2.

[27] Harris 1993, 88.

[28] Harris 1993, 88.

[29] *Webster's Ninth New Collegiate Dictionary* (Springfield, Massachusetts: Merriam-Webster Inc., 1983) defines 'unavoidable' as 'not avoidable: INEVITABLE', and 'inevitable' as 'incapable of being avoided or evaded".

[30] Harris 1993, 177.

[31] Harris 1993, 71.

[32] W. Godwin, *Enquiry Concerning Political Justice and its Influence on Modern Morals and Happiness*, ed. by I. Kramnick (Harmondsworth, Mid-

dlesex: Penguin Books, 1985; originally published 1793), 170.

[33] I have argued for this view in more detail in my *Liberal Utilitarianism and Applied Ethics* (London and New York: Routledge, 1994), ch. 3.

[34] Should he go for changes in the theoretical foundation of his views, I believe that a model I have called elsewhere 'liberal utilitarianism' could be helpful (Häyry 1994, 124-7). According to this doctrine, utility calculations cannot be applied to situations where the basic needs of individuals are in conflict. Assuming, for instance, that individuals can have a serious need to have their own children, the decision described in the first passage could perhaps be defended on non-utilitarian grounds. The conclusion of the second passage, in its turn, could be defended on empirical grounds. Although the fully voluntary self-extinction of humankind ought to be condoned, there will, one could argue, always be people who want the human race to continue to exist. As these individuals cannot legitimately be forced to cooperate, the extinction must presumably be condemned.

[35] As I have argued in the above, liberal utilitarianism would offer a perfect solution.

6. Genetic Engineering and the Risk of Harm*

The concept of *risk* is one of the most important elements in consequentialist analyses of genetic engineering and biotechnology. The term, or its linguistic equivalents, can be found in teleological and deontological arguments as well, but the role of the concrete risk of harm is less central within these models.[1]

The paragon of teleological risk-taking is Pascal's famous wager-argument regarding our belief in the existence of God.[2] If God exists, Pascal argued, and if we fail to believe in Him, we stand to lose everything, whereas by believing in His existence we stand to gain an afterlife of eternal happiness. If, on the other hand, there is no God, we can only lose a few earthly pleasures by acting as if there was. Since the happiness and misery we encounter if God exists are infinite, it is always, no matter how small the probability, in our own best interest to place our trust on His beneficient existence rather than on the meagre pleasures of godless hedonism.

The ethos of Pascal's wager can be easily applied to genetic engineering. We can either believe or disbelieve that all living beings have an essence, or nature, which must not, for fear of an unnamed but absolute horror, be tampered with. As our belief in this essence would only cost us a few technological advances we can live without, we should not risk drawing upon ourselves the ultimate punishment by 'playing God' or by otherwise acting 'unnaturally'.[3]

Deontological critics of biotechnology typically argue that the new gene-splicing techniques can involve acts which should never be performed, whatever the consequences. For a proponent of this view, the dangerous element in genetic engineering is not the probability of concrete physical or psychological harm which can ensue from its use, but the likelihood that it can lead people into performing acts which are categorically forbidden. These acts are in some theories linked with the essence of humanity, and in others with the concept of absolute rights or exceptionless duties.[4] The underlying idea, however, is similar in all deontological *and* teleological views, namely, that the acceptability or unacceptability of taking certain risks depends on the intrinsic qualities of the agent's actions rather than on their actual or expected consequences in terms of human well-being, animal welfare, or harm.[5] It seems to follow from this that it is always the safest policy to prohibit the implementation of new inventions if there are any doubts concerning their moral rightness.[6]

The four main elements of consequentialist decision-making

When genetic engineering is analysed and assessed in a consequentialist framework, four main elements should be taken into account. These elements can be labelled as the benefits, the dampening factors, the costs and the risks.

The *benefits* – that is, the good things that will probably flow from the development and use of biotechnology – include all the desirable contributions that genetic engineers can be expected to make to medicine, pharmacy, agriculture, the food industry, and the preservation of our natural environment.[7]

'Dampening factors' is a label which can be attached to those prevailing rules, practices and arrangements which tend to counteract the benefits of biotechnology either by lowering their quantity or quality,

or by promoting their unequal distribution. The attitudes and economic aims of industrialists can prevent corporations from creating products which would maximally promote the well-being of humankind, and useful innovations can benefit only or mainly affluent individuals and nations, leaving the lot of the less well-off unaltered.[8]

The financial *costs* of genetic engineering are huge, and unless the benefits are even huger, it can be argued that the money should be spent in more worthy programmes.

The main *risks* of biotechnology are connected with the containment of genetically altered organisms, with their release to the natural environment, and with the untoward social, economic and political consequences of the use of biotechnology.

The first three elements – the benefits, the dampening factors and the costs – can be assessed without employing the concept of 'risk', except in the economic sense. The probability of the good outcomes is not a risk, because, by definition, risk has to do with undesired results. The factors which decrease the probability of the good outcomes are, of course, unfortunate, but as long as they are not produced by biotechnology they cannot be counted among the risks of genetic engineering itself. And costs are not a danger or a risk, they are simply the price we have to pay for any attempt to improve the human condition.

Accordingly, if the benefits, even in an analysis which takes diligently into account the dampening factors, outweigh the costs, then genetic engineering is, in the light of these considerations, a praiseworthy enterprise. But what, then, about the dangers, the risks?

The risks involved in biotechnology

Risk can be defined as the possibility or probability of harm – that is, of a loss, an injury, an unwanted outcome or an undesired result. The main risks involved in genetic engineering are the following.

The *release* of genetically altered organisms in the environment can increase human suffering (when medical measures are concerned), decrease animal welfare (in experiments or through the use of recombinant DNA-techniques in breeding), and lead to ecological disasters. The *containment* of biotechnological material in laboratories and industrial plants involves two layers of risk. The first is the possibility of an accidental release in and by itself. Whether or not this will cause any further damage, the escape of an altered organism into the environment is normally seen as an undesired event. The second layer of risk becomes visible in the case of accidental release, and it is the increased probability with which this can produce harm. These are matters which have traditionally been dealt with by systematic risk assessment.

A risk that lies between the 'scientifically controllable' dangers of release and containment, and the more indirect political hazards of biotechnology, is the probability of the inadequate handling and irresponsible use of genetically altered material, prompted by the economic self-interest of research groups and industrial corporations. The difference between this type of risk and the more calculated hazard is the following. In the case of balanced decision-making we can reasonably suspect only the intellectual capacities of those who assess the possible outcomes. But in the cases of inadequate handling and irresponsible use we can also rationally fear that other types of human weakness and immorality are involved.

The purely social and political dangers of genetic engineering include the possibility of increased economic inequality accompanied by an increase in human suffering, and the possibility of large-scale eugenic programmes and totalitarian control over human lives. The risk in these cases is clearly moral rather than technical. If multinational corporations choose to supersede the national products of Third World countries by their own biotechnological substances, millions of workers will in a few years' time be unemployed. And if governments decide to develop racial programmes and surveillance systems based upon the achievements of genetic engineering, the undesired outcome is certain, not possible or probable. The danger is that the decision-makers act immorally, not that they have miscalculated the consequences of their actions.

In debates concerning the risks of biotechnology the social and political dangers are not discussed as often as the hazards of responsible and irresponsible containment and releases. A partial reason for this can be that economic inequality and totalitarian measures are not seen by all as unwanted, undesired, or evil. Another partial explanation could be that the probability of these outcomes is small, especially in the assessment of particular biotechnological innovations or products. It is difficult to see a connection between, say, a technological process designed to produce inexpensive pharmaceuticals on the one hand and the emergence of an unjust, totalitarian political order on the other.

Yet another explanation for the limited scope of the discussion is that many people tend to confuse the genuine political risks of biotechnology with the dampening factors which reduce its beneficial effects. It can be argued that the harm and injustice which may follow the introduction of genetic engineering in a given environment are always caused by social or psychological factors which have no intrinsic connection with the new techniques. If this were the case, then it would indeed be futile to debate the political dangers of biotechnology. But although there are, no doubt, attitudes and structures which can alone bring to the fore the evil aspects of scientific innovations, genetic engineering can also create new types of injustice, and strongly contribute to already existent misery. When this occurs, the possibility of undesired outcomes should be counted among the risks of biotechnology in the proper sense, and discussed as such.

The morality of risk-taking

If risk can be defined as the probability of expected harm, then how should we define the concept of 'acceptable risk', on which analyses of the morality of risk-taking often centre? Is a risk acceptable if the *probability* of harm is on a reasonable level, or should we require that the expected *harm* is also tolerable? The quick answer to this question is that the acceptability of a risk is the product of the acceptability of the expected harm and the acceptability of its probability. But acceptability to whom, and when, and on what criteria?

Industrial corporations have a tendency to treat risks as probable costs. This is not always commendable, because some of the harms inflicted by the production and marketing of goods cannot be easily compensated to those whom the harm befalls. When, for instance, the directors and engineers of an American automobile company noticed that they had produced a car which exploded in a rear crash if the speed was right and the left rear blinker was on, they went on to market the model on the ground that the overall economic loss incurred by the expected lawsuits would be lower than the price of repairing the cars. This decision cost many people their lives and caused others inordinate suffering, and even if the statistics had been correct, which they were not, the company's policy was clearly immoral. At the very least, the buyers should have been given the chance to decide for themselves whether or not they wanted to take the risk, perhaps by purchasing the car at a lower price. Death and suffering caused by attempts to make an economic profit are not commensurable with the work and capital invested in the enterprise.

The attitudes of individuals towards the acceptability of risk vary, of course, considerably. But from the conceptual point of view, it is important to notice that the decision to take a risk does not turn better or worse because of the events that follow the decision. This claim can be clarified by two examples.

In the first example, Smith takes a foolish risk by playing Russian roulette with the gun pointed at the head of his sleeping friend, Jones. When he pulls the trigger, the firing pin hits an empty chamber, no bullet is fired, and Jones remains unharmed. She does not even wake up. But although no tangible harm was, in the end, inflicted on Jones, Smith's decision was, nonetheless, foolish, because he imposed an unacceptable risk of death on her.[9]

In the second example, Jones knows that with a probability of one to ten billion she will blow up Smith's apartment by turning on her computer (there is something wrong with the wiring). As we all take much higher risks every day, let us assume that Jones's decision to turn on her computer today is rational and morally acceptable. Let us further assume that today, when Jones turns on the computer, Smith's apartment is blown up. Now, did Jones take a foolish risk today? Probably not. The decision to take the risk was, and still is, in retrospect, rationally and morally legitimate, despite the unfortunate fact that the improbable, unwanted outcome was materialized.[10]

How, then, should the acceptability of the risks of genetic engineering be defined? One good suggestion is that the assessment should in each case be left to those who can be harmed by the decision in question. Economic risks are acceptable, if they are condoned by the biotechnological corporations and governments who take them. The risks imposed on laboratory personnel by the containment of dangerous materials ought to be evaluated by the laboratory personnel themselves. All other risks involved in genetic engineering are more or less universal, and should therefore be assessed – and eventually accepted or rejected – as democratically as possible. How, exactly, this should be accomplished, must be worked out separately in each social and political context.

The examples featuring Smith and Jones annul an objection that can be levelled against democratic risk assessment by scientists, industrialists and autocratic political decision-makers. The representatives of these groups can assert, namely, that their expertise enables them to predict with greater accuracy the consequences of policies and actions. If the choices are left to democratic processes, the objection continues, many good outcomes which would have been perfectly safe fail to come into existence, while many undesired results are brought about by the prevailing lack of knowledge.

What this objection overlooks is that the acceptability of a risk for a given group is not determined exclusively by the facts of the matter, but also by the way the members of the group perceive the facts, and by the way they evaluate them. People cannot fully commit themselves to decisions which are based on epistemic and moral values that they do not share. Thus if anything goes wrong with the predictions of the experts, people feel entitled and are entitled to resent the consequences of the authoritarian choices. The risks taken by experts on behalf of others are therefore unacceptable. But if risk-taking is based upon the considered choices of those who themselves can be harmed by the consequences, the situation is different. Even if the undesired outcome is realized, the risk is acceptable, because it is embedded in their own system of ethical and epistemic values.

Notes

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[1] A short description of the meaning of the terms 'consequentialist', 'teleological' and 'deontological' is included in M. Häyry and H. Häyry, 'Genetic engineering', in: R. Chadwick (ed.), *Encyclopedia of Applied Ethics* (San Diego, California: Academic Press, 1998).

[2] B. Pascal, *Pensées*, § 233 (Paris: Le livre de poche, 1972, pp. 111 ff.).

[3] See, e.g., R. Chadwick, 'Playing God', *Bioethics News* 9 (1990), Nr 2: 10-15; M. Häyry, 'Categorical objections to genetic engineering', in: A.

Dyson and J. Harris (eds), *Ethics and Biotechnology* (London and New York: Routledge, 1994).

[4] R. Chadwick, 'A Kantian approach to biotechnology', in: R. Chadwick, M. Levitt, H. Häyry, M. Häyry and M. Whitelegg (eds), *Cultural and Social Objections to Biotechnology: Analysis of the Arguments, with Special Reference to the Views of Young People* (Preston: Centre for Professional Ethics, 1996).

[5] On such views, see J. Bennett, 'Whatever the consequences', in: James Rachels (ed.), *Moral Problems: A Collection of Philosophical Essays* (New York: Harper & Row, 1971).

[6] The deontological concept of risk seems to be represented, for instance, by Hans Jonas in his *Das Prinzip Verantwortung: Versus einer Ethik für die technologische Zivilisation*, seventh edition (Frankfurt am Main: Insel, 1987).

[7] H. Häyry, 'How to assess the consequences of genetic engineering?', in: A. Dyson and J. Harris (eds), *Ethics and Biotechnology* (London and New York: Routledge, 1994), pp. 144-146.

[8] H. Häyry 1994, 146-148.

[9] J. Thomson, 'Imposing risks', in her: *Rights, Restitution, and Risk*, ed. by W. Parent (Cambridge, Massachusetts, and London, England: Harvard University Press, 1986), pp. 181.

[10] Thomson 1986, pp. 177 ff.

7. Biotechnology and the Environment: From Moral Objections to Ethical Analyses*

In American television series involving lawyers, clashes between their moral beliefs and their ethical commitments frequently occur. The typical situation is that defence advocates know their clients to be guilty of some hideous crimes, but cannot, due to the ethical rules of their profession, reveal this to anybody, although they themselves feel that their clients ought to be punished for their deeds. The conflict arises, because the lawyers know that their ethical standards serve, as a rule, the best interest of the members of their societies, but also that their moral feelings reflect views which are widely shared in their communities. As the solutions to these conflicts are in the series often reached through breaches of confidentiality, or by other acts which violate the professional code, we, the viewers, are left with the impression that moral demands should in difficult situations always override ethical norms.

This impression is, however, deceptive, if 'moral demands' are defined as our unreflected reactions to thorny issues, and 'ethical norms' as rules or principles which are designed to make human life in ideologically fragmented societies tolerable to everybody. The reason why we accept the solutions given in the television courtroom dramas is that we regard the guidelines of the legal profession as subordinate to *better* accounts of social ethics, not necessarily that we see the immediate moral responses of individuals or groups as normatively binding.

If the – admittedly fragile – conceptual distinction between 'morals' and 'ethics' is applied to the questions of biotechnology and the environment, the claim can be made that the majority of popular and philosophical responses are, at the moment, founded on the same faulty logic as these television series. This is the methodological starting point and hypothesis of this paper. Because of the relative obscurity of the distinction between 'morals' and 'ethics', however, it is not employed systematically in the following – the terms are used more or less interchangeably.

Impacts or attitudes?

Many forms of modern biotechnology can have an impact on our natural environment. These impacts range from the possibly beneficial to the potentially harmful, and they can be felt either by human beings, other living beings as individuals, entire species, or by more abstract entities like ecosystems or the biodiversity of certain regions or of our planet as a whole. Due to these impacts, it would seem reasonable that at least critical philosophical responses to questions concerning biotechnology and the environment would be centred on, or guided by, the harms and benefits produced by genetic engineering, and by their moral acceptability or unacceptability. But philosophical responses in this field are primarily generated by emotional reactions and inapplicable ethical theories rather than by any facts regarding the consequences of our actions. This may not be particularly amazing in the frameworks of virtue-based and duty-based ethics, but the observation seems to be valid even in the context of traditional utilitarian moral thinking. The proposal put forward here is that we can render moral analyses sensitive to the impacts of genetic engineering on our natural environment only by employing a lighter conceptual machinery, which takes into account both the consequences of our actions, or what we can know about them, *and* the attitudes we have regarding their acceptability.

Three traditional approaches to normative ethics

There are three traditional approaches to normative ethics in the West, namely the teleological, deontological and consequentialist models. These views all provide different answers to two basic questions, namely, 'What is the human nature like?' and 'How should individuals behave in order to be moral?'

The proponents of the *teleological* model hold that all beings have a *telos*, or a goal towards which they are inclined to move or to develop. The telos can be secular, like in the ethics of Aristotle, who thought that the natural goal of human beings is a good life in a just society, and beyond that, an elevated state of intellectual contemplation.[1] The ultimate end can also be defined theologically, in which case the most likely candidates include an afterlife of everlasting joy, and some other states of being that transcend our earthly experiences.[2] Within the secular reading of the teleological model individuals should live their lives according to the rules of a just society, to be virtuous and to pursue the complicated pleasures of social life and intellectual perfection. The theological version can state, in addition, that we should adjust our life-styles to the received wisdom handed down to us by our parents and religious authorities.

The basic *deontological* view of human nature is that our actions are guided by two competing motives – desires and a sense of morality. This view is open to two main interpretations when it comes to defining how people should find the guidance they need for their lives. In the intellect-based version, *reason* commands us to obey the moral law, usually against our own desires. Immanuel Kant's theory is the paragon of this doctrine.[3] The emotion-based reading states that *feelings* tell us what to do in each particular situation.[4]

The way proponents of *consequentialist* thinking see the human nature, people want to obtain pleasure, happiness or well-being, and they want to avoid pain and suffering. Individuals are equally capable of egoism and altruism, that is, of promoting only their own self-interest *and* of taking others into consideration. According to the normative part of this doctrine, individuals should aim to be universally altruistic, either by trying to maximise the happiness of humankind ('positive utilitarianism') or by trying to minimise suffering ('negative utilitarianism').[5]

Virtues and duties

What, then, could be the most typical responses of the different ethical doctrines to our present issue?

To begin with the Aristotelian tradition, it is not easy to apply the teleological model in its original secular form to the questions of genetic engineering and the natural environment. The link between recombinant DNA-techniques and the human good, not to mention the good of the planet as a whole, is obscure, and it seems that an accurate view of the consequences of genetics would be required to support an adequate analysis of the connection. Otherwise all judgements will inevitably be based on the attitudes we already have toward biotechnology, and appeals to virtues and the rules of a good society remain unsupported by the theory.

Similar remarks can be extended to Kant's original views. The fundamental duty postulated by him is our obligation to treat humanity in ourselves and in other persons always also as ends, never as a mere means.[6] This obligation, which we owe to our fellow humans but not to the members of other species, is based on our nature as rational agents. The way we ought to treat animals, plants and other life-forms is determined by our duties towards ourselves and other persons, not by their (non-existent) worth as ends in themselves.

The difficulties of applying Kant's views to the manipulation of nonhuman beings by recombinant DNA-techniques include the fact that he did not clearly specify what our duties as regards animals, plants and other nonhuman organisms are. He believed that violence and cruelty towards animals set a bad example to our treatment of other people, and that not even inanimate objects should be wantonly destroyed because that would prevent others from making use of them. But how these remarks should be interpreted in the context of genetic engineering in a purely non-consequentialist analysis remains an unanswered question.

It seems that Aristotle and Kant are in and by themselves unhelpful as regards the issues of biotechnology and the environment, because the application of their ideas leads us either to ideological choices which have nothing to do with their models, or to the consequences of our actions which have no legitimate place in them. But traces of more theologically-inclined readings of the Aristotelian teaching and of Kantian ethics can be found in many popular objections to biotechnology, especially in the claims that what genetic engineers do is *unnatural*, or an instance of *playing God*.

Unnaturalness

The strand of thought in the Aristotelian tradition since Thomas Aquinas which is relevant to the first claim is the reliance on the notion of the *natural law*. The natural law, according to Thomistic thinkers, is based on our genuine being and good as persons, and it defines certain restrictions to our actions and our ways of life.[7] When this doctrine is given its secular reading, its main methodological message is that we ought to act upon the precepts of reason and oppose our inborn inclination to submit to our passions and desires. Kant's formulation to the same idea was that we should always act in ways which we can accept in the light of our practical reason as universal modes of human behaviour.[8]

Depending on the concept of 'reason' employed in the formula, it is presumably possible to argue within these views that genetic engineering is unnatural, because it is a violation against the unhampered order of things in this world, or a practice which we cannot universally condone. But this argument, if it is an argument somebody would seriously wish to put forward, is problematic on two accounts. First, its acceptance would imply that all present and future technological advances should be banned because they go against reason, or the natural order. Secondly, its theoretical tenability requires that we subscribe to the particular definition of reason which forbids us to alter the environment in any way. Both demands seem rather excessive.

Playing God

Another line of argument teleological and deontological moralists can employ is that the prohibition of genetic engineering stems from the fact that there are *limits* to what we can do as moral agents, and applied biologists are overstepping these limits, or 'playing God', by trying to create new forms of life against the dictates of the natural or moral law. This argument has been thoroughly examined by Ruth Chadwick.[9]

According to Chadwick's analysis, the crux of the argument in the context of new technologies is that actions describable as 'playing God' can lead to disastrous and unpredictable consequences. But where should the lines of these actions be drawn and by whom? Chadwick considers many possibilities, one of which is particularly relevant here. The playing-God objection in the context of new technologies can, namely, be meant to state that the natural environment as a whole sets certain limits to our actions. Humankind has during the last few decades acquired powers which could be used to destroy most of the biosphere. Many people seem to think that genetic engineering is one of these powers, and they fear that, for instance, the release of genetically altered organisms into the environment may have irreversible ecological consequences.

Assuming that we are interested in the preservation of the biosphere, this objection against genetic engineering does indeed have some moral relevance. But the problem is that the appeal to consequences, which gives this argument its weight, also deprives it of its categorical disguise. It would, no doubt, be pragmatically unwise to destroy the only environment where we can live at present, but this does not amount to a teleological or deontological rejection of genetic engineering. The wrongness of the activity remains conditional upon the consequences.

Disgust

An alternative, emotion-based deontological approach to ethics is provided by Patrick Devlin, who in his influential essay 'Morals and the criminal law' argued that activities should be reproached and banned by law if they provoke strong feelings of disgust even in individuals who are calm and appreciative of the demands of reason and common sense.[10] Devlin recognised the fact that feelings can vary from one location to another, and confined, accordingly, the prescriptive power of any given set of feelings to the community where it is prevalent. He also explained the moral force of disgust by maintaining that it indicates the boundaries within which the public morality must remain in order to keep the society viable.

Applied to our present case, the Devlinian argument would be that biotechnological activities which can have an impact on our natural environment ought to be banned, because they would evoke strong negative feelings in Western societies *and* damage their moral foundation. But the difficulty with the emotion-oriented model is that it is exceedingly relativistic. In most cases there is no consensus concerning feelings, and many questions remain unanswered. Whose feelings should be respected? Should genetic engineering be banned only if *everybody* feels that it is bad? Or is it sufficient that the *majority* feel that way? Or perhaps prohibitions ought to be employed if a significant *minority* nurtures these feelings? Or should we say that if *anybody* feels this way, biotechnology ought to be rejected? Furthermore, the question also remains as to how the damage to the moral foundation of societies can be verified. There seem to be no good responses to these queries either at the general level or in the context of biotechnology.

Consequences

As we noted at the outset of this paper, it is not all that surprising that the responses of teleological and deontological moralists rely either on ethical presuppositions which ignore the impacts of biotechnology on the environment, or on ill-defined considerations of the consequences of our actions. What is more amazing, however, is that the situation is similar as regards standard utilitarian models of moral thinking, which should be centred on the advantages and disadvantages of the practices we accept or reject. This is because there are two stories which can be told about these, and the choice between them has very little to do with the actual or expected consequences of our actions.[11]

The advantages of genetic engineering, as seen by its proponents, include many actual and potential contributions to medicine, pharmacy, agriculture, the food industry, and the preservation of our natural environment. The applications of genetic engineering to agriculture include the development of plants which contain their own pesticides. As for other food products, gene technologies can be applied to manufacture substances like vanilla, cocoa, coconut oil, palm oil and sugar substitutes. And biotechnology can even provide an answer to the problems of pollution, as genetically engineered bacteria can be employed to neutralise toxic chemicals and other kinds of industrial and urban waste.

The disadvantages of biotechnology, as seen by its opponents, are in many cases closely connected with the alleged benefits. One problem is that, despite the undoubtedly good intentions of the scientists, the actual applications of genetic engineering are often positively dangerous. Consider the case of plants which are inherently resistant to diseases, or which contain their own pesticides. Although there are no theoretical obstacles to the production of such highly desirable entities, corporations – who also sell chemical pesticides – might prefer to market another type of genetically manipulated plant, which is unprotected against pests but highly tolerant to toxic chemicals. The result of this policy would be an increase in the use of dangerous chemicals in agriculture, particularly in the Third World – which is to say that the outcome is exactly opposite to the one predicted by the proponents of biotechnology.

An oft-used criticism against agricultural biotechnology is that the introduction of altered organisms into the natural environment can lead to ecological catastrophes. Scientists working in the field of applied biology have themselves noticed this danger, and set for themselves ethical guidelines which are designed, among other things, to minimise this risk. But as the opponents of genetic engineering have repeatedly pointed out, not all research teams follow ethical guidelines if the alternative is considerable financial profit.

Thus, although the expected advantages and dreaded disadvantages of genetic engineering are fairly well publicised, it is difficult to assess objectively what the actual consequences of employing the techniques would be. The results of assessments depend more on the optimism and pessimism of those evaluating the situation than on the consequences themselves.

Risk

A possible way out of these dilemmas is, we suggest, to concentrate only on the negative consequences of genetic engineering, or *risks*, as people perceive them in the light of the facts available to us.

‘Risk’ can be defined as the possibility or probability of a loss, an injury, an unwanted outcome or an undesired result. Some of the potential harms involved in genetic engineering are the following. The *release* of genetically altered organisms in the environment can increase human suffering when medical measures are concerned, decrease animal welfare in experiments or through the use of recombinant DNA-techniques in breeding, and lead to ecological disasters. The *containment* of biotechnological material in laboratories and industrial plants involves two dangers: first is the possibility of an accidental release and second is the increased probability with which uncontrolled releases can produce undesired results. A risk that lies between these ‘scientifically controllable’ dangers and the more indirect political hazards of biotechnology is the probability of *inadequate* containment and *irresponsible* releases, which can be prompted by the economic self-interest of research groups and industrial corporations.

Given that ‘risk’ can be defined as the probability of harm, then how should we define the concept of ‘acceptable risk’, on which analyses of the morality of risk-taking often centre? Our own view is that the assessment should in each case be left to those who can be harmed by the decision in question. Economic risks are acceptable, if they are condoned by the biotechnological corporations and governments who take them. The risks imposed on laboratory personnel by the containment of dangerous materials ought to be evaluated by the laboratory personnel themselves. All other risks involved in genetic engineering are more or less universal, and should therefore be assessed – and eventually accepted or rejected – as democratically as possible.[12]

Scientists, industrialists and autocratic political decision-makers can argue against democratic risk assessment by claiming that their expertise enables them to predict with greater accuracy the consequences of different policies. What this objection overlooks, however, is that the acceptability of a risk for a given group is not determined exclusively by the facts of the matter, but also by the way the members of the group perceive the facts, and by the way they evaluate them. People cannot fully commit themselves to decisions which are based on epistemic and moral values that they do not share. If anything goes wrong with the predictions of the experts, people feel, and are, entitled to resent the consequences of the authoritarian choices. The risks taken by experts on behalf of others are therefore unacceptable. But if risk-taking is based upon the considered choices of those who can be harmed by the consequences themselves, the situation is different. Even if the undesired outcome is realised, the risk is acceptable, because it is embedded in their own system of ethical and epistemic values.

Rights

In conclusion, let us add a few words on *rights*. Rights can in ethical analyses be founded on any of the systems we have discussed in this paper – on the natural law, on the duties postulated by deontological ethics, and on the consequences of our actions. The concept of risk we have outlined supports a theory of rights which provides at least individual human beings with the entitlement not to be harmed by the environmental impacts of biotechnology. The analysis can, we believe, also be extended to the rights of animals and possibly ecosystems, who can be harmed by our actions as well as human beings. The further examination of these harms and rights would probably be the best way to proceed from emotional moral objections to truly ethical analyses in the context of biotechnology and the environment.

Notes

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[1] Aristotle, *Nicomachean Ethics*.

[2] There are germs of this line of thinking in the *Nicomachean Ethics*, book X, chapter 8, and the idea has been further developed in the works of Thomas Aquinas and his followers.

[3] I. Kant, *Grundlegung zur Metaphysik der Sitten* (1785). The subsequent references to this work are to J.W. Ellington's translation in I. Kant, *Ethical Philosophy*, second edition (Indianapolis and Cambridge: Hackett Publishing Company, 1994).

[4] The best defence of emotion-based deontological ethics is probably Patrick Devlin's 'Morals and the criminal law' (1959), which is reprinted in R.M. Dworkin (ed.), *The Philosophy of Law* (Oxford: Oxford University

Press, 1977): 66-82.

[5] On the many faces of utilitarian thinking, see, for instance, M. Häyry, *Liberal Utilitarianism and Applied Ethics* (London and New York: Routledge, 1994).

[6] Kant 1994, p. 36.

[7] For a detailed analysis of the natural law tradition, see, e.g., J. Finnis, *Natural Law and Natural Rights* (Oxford: Clarendon Press, 1980); J. Finnis, *Fundamentals of Ethics* (Oxford: Clarendon Press, 1984).

[8] Kant 1994, p. 30.

[9] R. Chadwick, 'Playing God', *Cogito* **3** (1989): 186-193; see also M. Häyry, 'Categorical objections to genetic engineering – A critique', in A. Dyson and J. Harris (eds), *Ethics and Biotechnology* (London and New York: Routledge, 1994): 202-215, pp. 205-209.

[10] Devlin 1977, p. 80.

[11] This point has been made and thoroughly defended by Heta Häyry in her 'How to assess the consequences of genetic engineering', in A. Dyson and J. Harris (eds), *Ethics and Biotechnology* (London and New York: Routledge, 1994): 144-156. The following paragraphs have been borrowed from M. Häyry and H. Häyry, 'Genetic engineering', in R. Chadwick (ed.), *Encyclopedia of Applied Ethics* Vol. 2 (San Diego, California: Academic Press, 1998): 407-417, pp. 408-409.

[12] A more detailed analysis of 'risk', and a more comprehensive account of our views regarding its acceptability, can be found in M. Häyry and T. Takala, 'Genetic engineering and the risk of harm', *Medicine, Health Care and Philosophy* **1** (1998): 61-64.

8. Commercial Genetic Testing and the Right to Know*

Ethicists and consumer groups have suggested that the direct access of individuals to commercial genetic tests should be restricted and regulated. In this paper it is examined how such restrictions could be defended. The intermediary conclusion is that the reasons given for many suggested regulations are good, but they all miss an important point, namely the question, 'What if individuals have a right to know about their genetic makeup?' This question calls forth comparisons with other practices which are not subject to constraints, although their aim and features are similar to the aim and features of genetic testing. Different conceptions of autonomy and different views regarding the responsibility of the scientific community offer partial explanations to disagreements concerning the proper limits of genetic testing. But in the end, we are left with the question, 'What is so special about *genetic* information?'

Ann, Bob, Carol, David and Emma

Consider the following examples.

> Ann is preparing to work abroad for five years. For reasons best known to herself, she believes that she may have contracted the Human Immunodeficiency Virus (HIV). Ann has no confidence in the health services of her destination, and she wants to be tested for her HIV status at home. The result of the test will probably influence her future decisions in many ways.

Bob is planning on taking on a new job as the sparring partner for Mike Tyson. For reasons best known to himself, he believes that he may have suffered some injuries to the head, which would render him vulnerable to permanent brain damage in his prospective job. He wants to be examined by a physician. The result of the examination will probably influence his future decisions in many ways.

Carol believes, for reasons best known to herself, that she is pregnant. She wants to verify the belief by using a pregnancy test kit. The result of the test will probably influence her future decisions in many ways.

David's wife, who happens to be the President of the United States, is preparing herself for an important international meeting concerning world peace. David, for reasons best known to himself, believes that the position of the stars and the planets is not right for such a meeting. He wants to find out if this is so by consulting an astrologer. David has considerable influence on the decisions of the President, and the astrologer's reading will probably have an impact on the lives of numerous people.

Emma suspects, for reasons best known to herself, that she is at increased inherited risk to develop breast cancer. She wants to find out if this is the case by consulting a commercial company which markets genetic tests for her possible condition. The result of the test will probably influence her future decisions in many ways.

These cases have many similarities, but there is at least one striking difference. While nobody seems to deny that Ann, Bob, Carol and David should be free to purchase the information they want, there are those who say that Emma's choice is subject to legitimate restrictions. Let us see what the reasons for this view could be.

The commercialisation of genetic tests – good and bad

Genetic testing has contributed to the improvement of diagnoses, prognoses and the treatment of genetically-based diseases, and provided individuals with an opportunity to find out about the risks that their inheritance poses on their health. The commercialisation of genetic testing can make the tests accessible to larger groups of people. Without economic incentives private enterprises cannot afford to develop tests and offer them to the public. Commercial genetic testing can increase human well-being, reduce suffering, and enhance individual freedom and autonomy. In addition, the production and marketing of genetic tests either through health care providers or directly to the consumers generate profits and create employment. These are good reasons for allowing the free production and distribution of genetic services to their ultimate consumers, that is, the members of the general public. Within liberal democratic societies there are also strong political grounds for market freedom.

Despite these potential benefits, however, some philosophers have argued that commercial genetic testing ought to be regulated, or even partly prohibited. For instance, Rogeer Hoedemaekers and Henk ten Have have recently argued that the commercialisation of genetic diagnostic services involves dangers and raises ethical questions which make it necessary to limit the availability of such services.[1] They employ concepts like ‘reasonable risk’ and ‘fair dealing’, and conclude that genetic tests, including predictive genetic tests like the breast cancer test, should be offered only through health professionals, and only after the information provided by the producers of the tests have been reviewed by an overseeing body which is independent from commercial interests.

As regards the free, unmediated predictive testing of apparently healthy persons, which is the focus of this paper, the suggested restrictions have been based on three major observations. The unrestricted marketing of predictive genetic tests can be, it has been suggested, *harmful*, *manipulative* and a source of *inequality*. Similar constraints can be proposed, for similar reasons, on genetic tests which are not directly marketable to the consumers. The focus here is on commercial testing, because this is the area where the pressure for regulation is at its most intensive.

Harm

What harm can commercial genetic testing inflict and on whom? Several groups have been identified by Hoedemaekers and ten Have as possible recipients of physical or mental harm or economic damage.

Those tested can feel uncertainty and anguish, for various reasons. The interpretation of the test results is often difficult – the tested individuals themselves do not know what to make of them; medical professionals are not always knowledgeable enough to help them adequately; and some tests yield results which are, in and by themselves, so ambiguous that no easy decisions can be based on them. And even if the reading of the result is clear – perhaps especially then – individuals can be anguished by the knowledge of an adverse genetic condition, and by the choices they are forced to make because of that knowledge.

The relatives of those tested can also be harmed by the information, if the condition in question is hereditary. Their privacy can be violated by the tested individuals or by health professionals, who see it as their right or duty to inform them – and thereby make them share the uncertainty and anguish. Even if they are not told, their right not to know about their own condition is violated by the fact that they see their relatives undergo treatments or life-style changes which can only be taken as indications of hereditary diseases.[2]

Moving to another area, the sphere of business, private insurance companies, and subsequently their other policyholders, can be economically harmed, if those tested positive for fatal diseases conceal this information when taking a policy.

Finally, on a very general level, anybody and everybody can be harmed by the free commercial marketing of genetic tests: there will be increased social pressures towards testing oneself for a variety of conditions, and towards changes in one's life-style.

Manipulation

Even if nobody is directly harmed, physically or mentally, by the commercialisation of genetic testing, there are wider social concerns. One of them is that the test offers made by private enterprises may be manipulative and play on the anxieties of the general public. This may hinder, or even prevent, rational and autonomous decision-making by individuals.

Inequality

Another wider social concern is that commercial genetic tests can be expensive, especially if they are accompanied by extensive counseling. This means that genetic tests will be more readily available to those who have the money to pay for them, and this can be seen as an instance of inequality and injustice.

It must be added, though, that the nature of the injustice here is unclear, with all the harm and anguish that can be caused by genetic testing. Or, to put it crudely, if the rich want to be tested, why not let them suffer the consequences of their privilege?

Countermeasures

What, then, can be done to reduce the harm caused by commercial genetic testing, and to remove the elements of manipulation and inequality from it? The following solutions have been suggested:[3]

1. *That the quality of genetic tests offered commercially be controlled by an independent, possibly governmental, body.*

This would reduce the unnecessary anxieties and uncertainties created by false test results.

2. *That the promotional material of the testing companies and laboratories be checked and revised by an independent supervising body.*

This would prevent the manipulation of the decisions of individuals by evoking fears and anxieties through the use of false, exaggerated or one-sided images.

3. *That the conveyance of the test results be accompanied by adequate counseling.*

This would reduce unnecessary fears and uncertainties, and check the harm inflicted on others by the knowledge.

4. *That some more complicated or controversial tests be available only through health professionals.*

This would be a way to prevent, for instance, prenatal testing where this is not aimed at promoting the health of the unborn child. The constraint could also reduce unnecessary anxieties, depending on the counseling skills of health providers.

5. *That some tests be restricted to the public health services.*

This would remove the injustice of unequal access to some rarely needed testing services which could only be obtained by those who can afford them.

6. *That some tests be banned altogether.*

This could be limited to the prenatal testing of the non-health-related features and qualities of future children – sex, expected beauty or intelligence, and so on. The desired outcome would presumably be the prevention of abortions.

All these regulations can, arguably, be defended by appeals to the prevention of harm, manipulation and inequality.

Public reasons, private choices

Let us return, at this point, to the example where Emma wants to be commercially tested for inherited susceptibility for breast cancer. What do all these regulations mean in her case?

Since the relevant genetic test can only predict that *it is or is not probable, given an array of other factors,* that Emma will develop breast cancer, almost all the regulations listed in the above can be applied here.[4] False – and poorly interpreted – test results are a definite risk in susceptibility testing for breast cancer, and it would clearly be reasonable, according to the cited criteria, that the quality of the tests be somehow publicly controlled. Emma's decision to seek the information can well stem from fear and anxiety, and if the unchecked promotional material of the testing laboratories has influenced her choice, this is not, in terms of considered decision making, a good thing. The information she is seeking is ambiguous and uncertain, and it can therefore be required that the conveyance of the test results should be accompanied by extensive counseling. It is by no means impossible that the result of the test can prompt Emma not to have children, or to terminate her pregnancy, if she is pregnant, so that the proposed conditions for the involvement of health professionals are met. The genetic tests for breast cancer susceptibility are relatively expensive – from hundreds to thousands of US dollars – and the injustice resulting from unequal access to them can perhaps be removed only by confining them to the public health services. And if the information can prompt Emma to choose an abortion – perhaps because the test result changes her life plans – the protection of unborn human life provides grounds for banning the test altogether.

But the problem here is that from Emma's own viewpoint she only wants to know something about *herself*. The reasons given for the regulations are public and wide-ranging, while Emma's wish to obtain the information is private and concerns primarily herself. And many of us believe that individuals have *a right to know* what happens in their bodies and in their environment, even if this is not always 'for the common good'. In most cases, moreover, this right is also recognised by the public authorities.

The right to know in nongenetic matters

Let us reconsider examples A to D, presented to throw light on Emma's predicament. Ann would like to be tested for her HIV status. Bob wants to get his head examined. Carol wishes to buy a pregnancy test kit. David wants an astrologer to tell him if the position of the celestial bodies is favourable to international peace negotiations.

In all these cases, many of the features which made genetic testing for breast cancer susceptibility subject to restrictions are present. In each example, a person wants to know something that will affect her or his future. The information received in most of them is uncertain and open to many interpretations. The information, once acquired, can lead to actions which affect the persons themselves and others – in some cases lethally. The actions induced by the information are not always undertaken in a fully autonomous manner. Some of the methods of acquiring information are expensive, so that the information and the potential benefits flowing from the knowledge are only available to those who can afford them.

Despite these similarities, nobody prevents Ann, Bob, Carol and David from seeking the information they want, provided that they know where to find it and have the financial means to achieve it. It is true, of course, that some of the methods of acquiring information are controlled in some ways. There are quality controls for HIV tests and pregnancy kits, and medical examinations can be properly performed only by qualified physicians. But nobody has suggested that Ann, Bob or Carol should be prevented from knowing what they want to know. And in David's case there are virtually no controls. So why single out Emma? What is it in *genetic* information that would justify the extra regulations?

Is genetic information special?

The idea that genetic information is somehow special has been recently criticised by Søren Holm,[5] Joseph S. Alper and Jon Beckwith,[6] and Veikko Launis.[7] They have identified four aspects which *could* distinguish genetic from nongenetic information but which do not, in closer examination, do this – at least not in any normatively binding sense. These aspects are *predictiveness*, *transmissibility*, *informativeness regarding other individuals* and *personal sensitivity*.[8]

It can be argued that genetic information is predictive, or more accurately predictive than other types of information. But the response to this is that Ann's HIV test result, Bob's head examination and Carol's pregnancy test also predict certain physical changes in them. Carol's case is slightly problematic in this respect, because the test result indicates, or diagnoses, rather than only predicts her condition.[9] She is pregnant or she is not. The same remark seems to apply to Ann, as her test reveals whether or not she is HIV positive – and in this sense indicates her condition. But the significant information in this case is clearly predictive, namely that without proper medication she is likely to develop the Acquired Immune Deficiency Syndrome, AIDS. And Bob's situation is even more straightforward. His examination can undeniably reveal future tendencies which, if combined with the right environmental factors, can lead – or fail to lead – to physical injuries. As for accuracy, there are two things to be said in our present context. Genetic tests for breast cancer susceptibility are *not* accurate. And if they were, many of the ethical problems referred to by Hoedemaekers and ten Have would be solved, because they arise from the *in*accuracy of the information.

It has also been pointed out that genetic tests often tell individuals about features or conditions which can be transmitted to their offspring. This remark is perfectly true in the case of breast cancer susceptibility detection, but it can also be extended, for instance, to HIV testing. And, as noted by Holm, social characteristics like class and level of education are also transmissible in the sense that more often than not children belong to the same social class as their parents, and acquire roughly similar levels of education.

What, then, about the fact that genetic tests can provide information about other people, especially about the family members of those tested? Well, it is a fact, but not a fact specific to genetic testing. Ann's HIV status can also tell something about her husband, to whom she has been sexually faithful all through their long marriage. And it can give information regarding the HIV status of Ann's baby, whom she has breast-fed until recently. Carol's pregnancy test, too, gives information concerning the fertility of her only sex partner in years, and so on.

The final attempt to draw the distinction is to assert that genetic information is particularly sensitive, or more profoundly personal than other types of knowledge, because it describes the deepest, immutable level of human biology.[10]

It is not necessary here to analyse in detail the sensitivity of various types of information, or the immutable depths of the human constitution.[11] This is because the distinction, if it exists, can, at least arguably, only strengthen Emma's claim to the information she wants. If the knowledge concerning her susceptibility to breast cancer is deeply and immutably a constitutive part of her person, then who could justifiably deny her access to it? Yes, there is the risk that other people can learn about her condition through, for instance, the indiscretion of the testing laboratory. And assuming that the information is sensitive, this can be a problem. But not necessarily. Should she develop breast cancer at some point in her life, others would be likely to find out in any case. And what if Emma wants to know, anyway? What if she says, 'I don't care how many other people will know about this – the only thing that matters to *me* is that *I* have access to this profoundly personal, sensitive and self-constitutive knowledge.'

Accurate knowledge as a right

'Access to what', however, is the next question the defenders of the restrictions are likely to ask. A possible justification for the suggested regulations is, namely, that consumers have a right to *accurate* information in genetic matters, and this right cannot be protected without proper constraints. But this is a tricky argument to use.

The 'right to know' normally implies that the information individuals want must not be withheld from them. This right is perfectly compatible with market freedom in cases like Ann, Carol and Emma's. If they want accurate knowledge, they can consult a physician or a genetic counsellor, or take whatever additional steps they see fit. But if they have decided to settle for less precise guidance, they should also be free to order a test kit by mail.

There are two ways to take the restrictive argument further than this. The first is to say that autonomous individuals have a right to accurate information even if they do not themselves want it. This approach turns the *right* to know into a *duty* to know. The second option is to claim that people's healthy desire to acquire information has been dulled by their general confidence in medicine, and that medical professionals therefore have a special duty to protect them in this matter.

Autonomy as a duty

According to the first line of argument, it would be immoral to demand unregulated predictive testing opportunities, because consumers have a duty to make fully autonomous decisions and this is not possible in the light of ambiguous information. People must know the ramifications of their actions in order to make the right choices.

The force of this argument depends on the notion of autonomy one holds.[12] In the ethics of theorists like Immanuel Kant, we do indeed have an obligation to be autonomous, and to act in accordance with the best information we can obtain.[13] But the Kantian model has been challenged by another school of thought, exemplified by John Stuart Mill, which maintains that we are allowed to make uninformed and even self-destructive choices as long as we do not significantly harm others by doing so.[14] The question is, which doctrine should we employ to tackle the problem of commercial genetic testing?

A brief argument for the Millian alternative can be based on the distinction between individual and social ethics. Kant's philosophy deals primarily with the morality of individuals as atomistic, self-sufficient agents, whereas Mill's view centres on the legitimacy of the social regulation of people's lives. Since commerce is essentially a social enterprise, it would seem reasonable to analyse it in terms of the Millian rather than the Kantian concept of autonomy. This is not to say that Kant's ideas should be dismissed altogether. If individuals make foolish decisions because they have intentionally acquired potentially misleading information, their decisions can be criticised in terms of 'Kantian' autonomy. But this criticism ought to be limited to 'remonstrating', 'reasoning', 'persuading' and 'entreating', to use Mill's original language.[15] Individuals must not be coerced or compelled to behave rationally in matters which concern mainly or only themselves. In the present context, this means that people can be *morally* criticised by others for purchasing genetic information which it is, nevertheless, their *legal right* to purchase.

On the other hand, the Kantian concept of autonomy can also be employed to *support* the freedom of commercial genetic testing. If individuals have a duty to make their own decisions, then they must not be legally forced into acting in accordance with the opinions of others, whatever their medical or scientific expertise may be. Rational, autonomous individuals can have a moral duty to seek the best possible information concerning their health status. But they must decide for themselves where and how to find this information, otherwise they would be acting 'heteronomously' – following somebody else's law.

The responsibility of the medical profession

According to the second line of argument, however, the social nature of commercial genetics implies that the medical profession has a special duty to protect people from incomplete information which can play on their health-related anxieties. This duty does not extend to the field of, say, horoscopes, because physicians and biologists are not responsible for the beliefs and ideologies which lie behind this practice. But it does extend, so the argument goes, to predictive genetic testing, since the expectations of the general public concerning the beneficial effects of genetic knowledge are, to a fair degree, created by scientists and medical professionals. The crux of the argument is that physicians and genetic counsellors must safeguard their clientele against false hopes and fears, for which they themselves are partly responsible.

It must be noted that this line of reasoning has not been clearly explicated in the discussion, although traces of it can be detected in both academic and public debates. The idea of professional responsibility helps to clarify, however, two norms which pertain to predictive genetic testing. If physicians and molecular biologists can be held responsible for building up the expectations of others with regard to the value of genetic information, then they can justifiably feel that they should warn others against the risks of unregulated commercial testing. This is a Kantian duty they are entitled to assume as long as they do not coerce or compel others to conform with their own views. But as feelings of responsibility, however deeply felt, do not justify any restrictions on other people's lives, medical professionals have no right to dictate policies which would curtail the freedom of choice of their clientele.

No grounds for extensive regulation?

What conclusions can be drawn from these observations? To what extent should Emma's decision be subject to public regulations?

If the current respect for people's right to *nongenetic* information is well-founded and well-proportioned, then the cases of Ann, Bob, Carol and David can offer some guidance. Perhaps the laboratories which offer genetic tests for breast cancer susceptibility should be controlled for the quality of their products like the laboratories which offer HIV tests and the companies which manufacture pregnancy test kits. And perhaps none of these should advertise their products in misleading ways.

But even these regulations are not extended to David's choice. Astrologers are allowed to market their services in whichever way they wish, and there are no quality controls in their work. This is puzzling in view of the fact that their predictions are even more ambiguous and more open to interpretations than genetic test results. Should it be inferred from this that even quality control and marketing regulation are excessive and illegitimate hindrances on acquiring information in modern Western societies?[16] Or should astrologers be required to submit their methods and predictions to an independent review board for inspection?

In the cases of Ann and Bob it seems reasonable to demand that the health profession should somehow be involved in the process of conveying the medical knowledge to the ones seeking it. Counseling helps them to understand the implications of the information, reduces unnecessary anxieties and prevents people from jumping to hasty conclusions. But in many countries pregnancy test kits can be purchased without any intervention from physicians, nurses or social workers. Even if Carol's life, and the lives of other people, can be profoundly influenced by the result of the test, she is not required to seek counseling or medical assistance. Why should Emma's predicament be interpreted differently?

The only conclusion here can be that not many regulations seem justifiable in the context of genetic testing. The foregoing discussion may, of course, have missed some obvious differences between the cases of Ann, Bob, Carol, David and Emma. But until somebody explains what these differences are, and why they make a moral or legal difference, there are no good grounds for the heavy regulations proposed for commercially acquiring genetic information.

Notes

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The paper was completed with Tuija Takala, to whom I extend my thanks for the permission to publish it here. Our thanks are also due to all those who have criticised our ideas in conferences and in correspondence for forcing us to see clearer many dimensions of the genetic information discussion. All the remaining mistakes are due to our own stubbornness, not their lack of effort.

[1] R. Hoedemaekers and H. ten Have, 'Commercialisation of genetic diagnostic services', *Medicine, Health Care and Philosophy* **1** (1998): 217-224. Despite the title, the article discusses predictive as well as purely diagnostic genetic tests.

[2] On the legitimate uses of this argument, see T. Takala, 'The right to genetic ignorance confirmed', *Bioethics* **13** (1999): 288-293.

[3] The following list contains mainly regulations proposed by Hoedemaekers and ten Have. But others have supported similar caution – see, e.g., *Genetic Screening and Testing: toward Community policy on insurance, commercialisation and promoting public awareness (ÆUROSCREEN 2) Final Report*, Preston: Centre for Professional Ethics, 1999.

[4] See, e.g., NIH-DOE Working Group on Ethical, Legal and Social Implications of Human Genome Research, *Genetic Information and Health Insurance: Report of the Task Force on Genetic Information and Insurance*, Bethesda, Maryland: US Department of Health and Human Services, 1993; National Advisory Council for Human Genome Research, 'Statement on use of DNA testing for presymptomatic identification of cancer risk', *Journal of the American Medical Association* **271** (1994): 785; National Breast Cancer Coalition, *Presymptomatic genetic testing for heritable breast cancer risk*, Washington DC, 1995; American Society of Clinical Oncology, 'Statement of the American Society of Clinical Oncology: Genetic testing for cancer susceptibility' *Journal of Clinical Oncology* **14** (1996): 1730-1736; G. Geller, J.R. Botkin, M.J. Green et al., 'Genetic testing for susceptibility to adult-onset cancer: The process and content of informed consent', *Journal of the American Medical Association* **277** (1997): 1467-1474.

[5] S. Holm, 'There is nothing special about genetic information', in: A.K. Thompson and R.F. Chadwick (eds), *Genetic Information: Acquisition, Access, and Control*, New York, Boston, Dordrecht, London and Moscow: Kluwer Academic/Plenum Publishers, 1999: 97-103.

[6] J.S. Alper and J. Beckwith, 'Distinguishing genetic from non-genetic medical tests: Some implications for antidiscrimination legislation', *Science and Engineering Ethics* **4** (1998): 141-150.

[7] V. Launis, 'The use of genetic test information in insurance: The argument from indistinguishability reconsidered', *Science and Engineering Ethics* **6** (2000), forthcoming.

[8] Holm discusses all four aspects, while Alper, Beckwith and Launis do not comment on transmissibility. In what follows, the ideas presented by Holm (1999, 98-100) are employed, if not otherwise indicated.

[9] Critics who have read earlier drafts of this paper have argued that since pregnancy tests are used when symptoms are visible, they are diagnostic

rather than predictive. But this is not necessarily a good argument. The 'symptoms' which motivate the purchase of the kit are often vague and ambiguous. Delayed menstruation, probably *the* reason for commercial home-made testing, is not a reliable sign of pregnancy, and neither are sickness, family history or personal conviction. The relevant point here is that these signs do not differ drastically from the hints that drive people into genetically testing themselves. The distinction between 'predictive' and 'diagnostic' tests is not clear-cut.

[10] 'Sensitivity' and 'descriptive of the deepest biological level' are expressions used by Holm, 'more profoundly personal' and 'immutable' are attributes discussed by Launis. The drift of their arguments is, however, the same.

[11] Both Holm and Launis do a good job of showing that these features are not normatively relevant in discussions regarding genetic information.

[12] On genetics and autonomy, see, e.g., R. Rhodes, 'Genetic links, family ties and social bonds: rights and responsibilities in the face of genetic knowledge', *Journal of Medicine and Philosophy* **23** (1998): 10-30; T. Takala and M. Häyry, 'Genetic ignorance, moral obligations and social duties', *Journal of Medicine and Philosophy* **25** (2000): 107-113.

[13] See, e.g., I. Kant, *Ethical Philosophy* (translated by James W. Ellington; Indianapolis and Cambridge: Hackett Publishing Company, second edition 1994).

[14] See, e.g., J.S. Mill, *On Liberty and the Subjection of Women* (Ware: Wordsworth Editions Ltd, 1996).

[15] Mill 1996, 13.

[16] Academics who have read or heard earlier drafts of this paper have argued that the analogy between genetic tests and personal horoscopes is flippant and inappropriate. For one thing, people do not, they have asserted, take the predictions made by astrologers as seriously as they take the

claims of molecular biologists. But the empirical fact is that, when asked, 12 to 30 percent of Westerners report that they believe in astrology. (A Gallup Poll conducted in 1990 indicated that one out of four Americans believe in the truth of astrology – C.C. French, M. Fowler, K. McCarthy and D. Peers, 'Belief in astrology: A test for the Barnum effect', *Skeptical Inquirer* **15** (1991): 166-172.) The percentages seem to be higher among teenagers, and presumably among other vulnerable groups as well. (This is reported in S. Feher, 'Who looks to the stars? Astrology and its constituency', *Journal for the Scientific Study of Religion* **31** (1992): 88-93.) People can also be prompted into dramatic action by horoscopes, as evidenced, most notably, by Nancy Reagan's attempts to influence her husband's policy decisions based on her astrologer's advice. It seems fair to conclude that many people do take astrology at least as seriously as they take scientific knowledge.

9. Genetic Ignorance, Moral Obligations and Social Duties*

In a contribution to *The Journal of Medicine and Philosophy* Professor Rosamond Rhodes argues that individuals sometimes have an obligation to know about their genetic disorders, because this is required by their status as autonomous persons. In this comment, her analysis, which is based on Kant's concept of autonomy and Aristotle's notion of friendship, is extended to consequentalist concerns. These are of paramount importance if, as Professor Rhodes herself implies, the Kantian and Aristotelian doctrines can be helpful only in the sphere of private morality, not in the public realm. Better tools for assessing the right to genetic ignorance as an issue of public policy can, it is contended here, be found in Mill's ideas concerning liberty and the prevention of harm. The conclusion, based on the Millian way of thinking, is that individuals probably do have the right to remain in ignorance in the cases Professor Rhodes presents as examples of a duty to know.

Introduction

In the ethical literature concerning genetic information it has become customary to maintain or at least to imply that under certain circumstances individuals have a duty to know about hereditary disorders in their constitution, and that they do not always have the right not to know that their genes are in some respect less than perfect. Few philosophers have, however, taken the time and mustered the energy to defend this position with any cogency. It was, therefore, a pleasant surprise to find that Rosamond Rhodes has taken on this task in her intriguing article 'Genetic links, family ties and social bonds: rights and responsibilities in the face of genetic knowledge,' which was recently published in the *Journal of Medicine and Philosophy*.[1]

Two concepts of autonomy

Professor Rhodes argues that individuals do not have a moral right not to know about their own genetic disorders, because without all the relevant information they cannot make autonomous choices, which, however, are the hallmark of morality. If decisions are made without adequate knowledge, our actions are guided by mere chance, and this is not sufficient to warrant their true freedom. She writes:

> Now, if autonomy is the ground for my right to determine my own course, it cannot also be the ground for not determining my own course. If autonomy justifies my right to knowledge, it cannot also justify my refusing to be informed. [...] From a Kantian perspective, autonomy is the essence of what morality requires of me. The core content of my duty is self-determination. To say this in another way, I need to appreciate that my ethical obligation is to rule myself, that is, to be a just ruler over my own actions. As sovereign over myself I am obligated to make thoughtful and informed decisions without being swayed by irrational emotions, including my fear of knowing significant genetic facts about myself.[2]

From this Professor Rhodes concludes that individuals are ethically required to be informed about their genetic disorders whenever it can be judged that reasonable persons would want to know about them.

There are, however, serious limitations to the argument presented. While Professor Rhodes's sense of moral duty is admirable, and her presentation of the Kantian view coherent and persuasive, there is an alternative reading of the concept of autonomy which yields completely different normative conclusions as regards the right to remain in ignorance. The following passage is composed by superimposing Professor Rhodes's text by Millian additions, which retain the intuitive acceptability of the message, but change the emphasis considerably:

> Now, if autonomy is the ground for my right to determine my own course *if and when I so wish*, it *can* also be the ground for not determining my own course *if and when I so wish*. If autonomy justifies my right to knowledge *when I want to know*, it *can* also justify my refusing to be informed *when I do not want to know*. [...] From a *Millian* perspective, autonomy is the essence of what morality requires *others to respect in their dealings with* me. The core content of *the duty of others towards me* is *respect for my* self-determination. To say this in another way, *they* need to appreciate that *their* ethical obligation is to *let me* rule myself *if and when and to the degree that I so wish*, that is, to *let me* be a just ruler over my own actions. As sovereign over myself I am *entitled* to make *my own* decisions without being *coerced by the opinions of others*.[3]

The conclusion to be drawn from this revised passage is that individuals are, after all, entitled to ignorance in genetic matters, if this is what they themselves want.

Kant, Aristotle, and the moral obligation to know

In all fairness to Professor Rhodes's position, it must be noted that her focus in the article is not how others should respond to our preference to remain in ignorance. As a matter of fact, she explicitly denies this application of her argument in a footnote by stating that 'prescribing social policy and policy for the professions is beyond the scope of [the] paper.'[4] Let us take a look, therefore, at her own examples of situations where individuals can have a duty to know about their genetic condition, and see how she has defended her position in these cases.

Professor Rhodes's examples are the cases of Tom, Dick, Harry and Harriette.[5] Tom has to decide whether to participate in a population study which would provide scientists with a more accurate picture of the genetics of Huntington's disease. Dick has been asked to take part in a linkage study to find out what his cousin Martha's chances are for having a child who does not suffer from the Marfan syndrome. Harry, who has a strong family history of Huntington's disease, faces the choice of genetic testing, because he is planning on marrying Sally and starting a family with her, although he may die young and pass on the disease to their children. And Harriette and her husband have decided not to find out if they are recessive carriers of the Tay-Sachs gene, and to have a child despite the fact that the child's life can be short and full of agony.

Professor Rhodes's argument to prove that Tom, Dick, Harry and Harriette have at least a *prima facie* moral duty to know about their genetic condition seems to proceed in two stages. First, the Kantian account of autonomy shows that there cannot be a general right to remain in ignorance concerning facts which reasonable individuals would, or should, want to know about themselves in order to make morally tenable decisions. Secondly, reasonable individuals would, or should, want to know about facts which can affect the lives of their fellow human beings, especially the lives of their friends and family members.

The second step of the argument is defended by an appeal to Aristotle's remarks concerning the obligations of friendship and family ties.[6] By citing convenient passages of the *Nicomachean Ethics*, Professor Rhodes manages to show that Aristotle indeed asserted that we owe something to everybody, and more to our relatives and friends than to our fellow citizens and strangers. From this she goes on to conclude that Tom has a responsibility to his fellow human beings to participate in the population study,[7] Dick is obligated by his family ties to Martha to provide a blood sample for the linkage study,[8] Harry has an obligation to pursue genetic knowledge due to his social relationship with Sally and his undertaking as a future father,[9] and Harriette and her husband have 'at least a *prima facie* reason for [thinking] that they are ethically obligated to learn crucial genetic facts about themselves.'[10] These are all, according to Professor Rhodes's account, duties which reasonable people would recognise because of their special relationships with other people.

From moral obligations to social duties?

How, then, can these moral duties assigned to individuals be prevented from generating social policies and rules of professional conduct, which Professor Rhodes wants to exclude from the scope of her article, and how firm is the basis of these obligations in ethical theories? Unfortunately for the arguments of the article, the answer constitutes a dilemma. If the postulated duties are founded on the Aristotelian remarks concerning friendship and family ties, then they need not, and cannot, be reasonably enforced by legal regulations or professional codes. It would presumably be alien to Aristotle's thinking to insist that physicians or public health authorities should direct or coerce us into doing good to our family members or friends. But, apart from the references to Aristotle's assertions in the *Nicomachean Ethics*, Professor Rhodes does not offer any arguments for holding this ethical view. If, on the other hand, the duty to know is based on the Kantian concept of autonomy as presented in the article, and this concept is accepted, then the obligations of at least Harry and Harriette can be firmly founded. They must know about their genetic constitution in order to make fully informed decisions.[11] But if this line is taken, it is difficult to see how social and professional control could be kept apart from the requirement to know. The duty to act autonomously is, after all, the cornerstone of Kantian ethics, and banning its enforcement would, at least according to Professor Rhodes's analysis, undermine the functioning of the human society.[12]

There are two significant conclusions that do *not* follow from these remarks. The first is that the critique does *not* disprove the Aristotelian, or any other, notion regarding the relevance of special relationships and knowledge about ourselves in ethics. There may be good grounds for thinking that Aristotle's ideas concerning the primacy of family members and friends are correct. And perhaps Kant's demands can be restricted to the sphere of individual morality by employing the concept of imperfect duties, or by showing that, in his system, social regulations and professional guidelines can legitimately condone morally reprehensible policies. But none of these defences has been articulated in the article.

The second conclusion that does *not* follow from the foregoing remarks is the rejection of all duties in the cases of Tom, Dick, Harry and Harriette. The Millian notion of autonomy reconstructed at the outset of this note, for instance, can be combined with a consequentialist morality which bans the infliction of unnecessary and avoidable harm on innocent third parties, and which assigns many duties to our four protagonists and their relatives and associates. Case by case, the most important of these duties are the following.

Obligations based on consequences

Since Tom is indirectly harming other people by not participating in the population study, he should reverse his decision in order to be fully moral. However, as the accumulation of scientific data does not in any way require that he himself be informed, he is allowed to remain in ignorance. Dick, on the other hand, harms nobody and has therefore no duty to expose himself to the harm that he foresees in acquiring the information. Subsequently, the question of violating his right not to know does not even arise. In this case, the duties can be assigned, instead, to Martha, who should either pursue the knowledge in other ways,[13] or simply contain her urge to reproduce altogether.

The case of Harry generates, in the consequentialist framework, an array of obligations, including a conditional duty for himself to find out about the constitution of his genes. Sally, in her turn, has a prudential obligation to reconsider her attachment to a man who is willing to impose risks on their potential offspring. Furthermore, Harry himself has an obligation to provide for the needs of the possible children in case of his early demise, and, failing that, he has either a duty to refrain from having offspring, or to have himself tested.

Finally, Harriette and her husband have the strictest duty not to bring into existence a child whose life would probably be short and full of suffering. But even they have the moral right to remain in ignorance, provided that they decide not to reproduce, after all.

Within the consequentialist view, however, all the duties introduced in the last few passages are *moral* duties to individuals, not *social* obligations which could be enforced by law or social policy. The decisions facing lawmakers and public health authorities are different from the ones facing individuals. Harm can also be inflicted on citizens and families by legal restrictions, and therefore consequentialist analyses do not always require us to transform moral norms into legal regulations. Medical professionals can, however, persuade people into doing the morally right thing, as long as the ultimate decision-making powers remain with the individuals, especially in matters which concern only themselves. Incidentally, this means that physicians do not, in theory, have any strict moral duties not to give directive advice to their patients or clients, as long as the advice given is intended to prompt individuals into right action. But it seems, alas, that non-directiveness is a good practical guideline, as even philosophers disagree on the rightness and wrongness of many actions – as evidenced by a comparison between the views put forward here and those of Professor Rhodes.

Conclusions

In conclusion, Professor Rhodes has not been able to prove that the only, or the best, way to tackle the issue of genetic knowledge would be through the Kantian concept of autonomy and the Aristotelian notion of friendship. Her attempt to provide this proof is laudable, and merits, without doubt, further study. But until proven wrong, one can continue to rely on other ways of thinking, and believe that individuals do have a *prima facie* right to remain in ignorance concerning their genetic constitution.

Notes

This paper was originally published, in a slightly different form, with Tuija Takala, in the *Journal of Medicine and Philosophy* **25** (2000): 107-113. My thanks are due to her for the permission to reprint the paper here.

[1] R. Rhodes, 'Genetic links, family ties and social bonds: rights and responsibilities in the face of genetic knowledge,' *Journal of Medicine and Philosophy*, **23** (1998): 10–30.

[2] Rhodes 1998, 18.

[3] Rhodes 1998, 18; italics indicate the added text.

[4] Rhodes 1998, 27, n. 2.

[5] Rhodes 1998, 12–14.

[6] Rhodes 1988, 22–23. There are also, in an earlier part of the article (18–19), some references to the Kantian duty of keeping one's promises, which

may have some relevance in the cases of Harry and Harriette, but since not all the examples involve promises, and since Harry and Harriette's duties can be defined in alternative ways (as we will do towards the end of this paper), this line of argument is not studied in more detail here.

[7] Rhodes 1998, 23.

[8] Rhodes 1998, 23.

[9] Rhodes 1998, 24.

[10] Rhodes 1998, 20. Strangely, however, the duties Professor Rhodes assigns to Harriette and her husband are weaker than those assigned to the others. As a matter of fact, the only clear obligations to Harriette can be found in the quoted passage which belongs to an earlier part of the article.

[11] The cases of Tom and Dick remain more fuzzy, as the knowledge would influence the actions of others more than their own.

[12] This is, at least, a natural way of reading her comments (17) regarding Kant and truth-telling, in which she cites Kant saying that telling lies would do 'wrong to men in general.'

[13] In the description of the case, Professor Rhodes refers, in passing, to another, more expensive, way of acquiring the information needed (13).

10. How to Apply Ethical Principles to the Biotechnological Production of Food - The Case of Bovine Growth Hormone[*]

Ben Mepham has proposed that a 'matrix' be used in the analysis of ethical problems in food production and elsewhere. In particular cases, this matrix would ideally cross the most important moral principles involved, and the individuals and groups affected by the decisions. In the following, Mepham's model is assessed in the case of genetically engineered bovine growth hormone. My argument is that a more straightforwardly 'consequentialist' analysis can draw attention to the problems of using the hormone better than Mepham's original proposal. It is possible, however, that some nuances will be lost in the process. I do not, therefore, argue for the overall superiority of my suggestion – it is merely a slightly different, and perhaps sometimes a more promising, way to analyse the ethical dimensions of food production and marketing.

Introduction

Bovine growth hormone, also known as bovine somatotrophin, or BST, has been used since the 1930s to increase the milk yields of cows, and the hormone, which was identified as the cause of the improvement in the 1950s, is now being produced by recombinant DNA-techniques. Cows are injected with the genetically engineered hormone (rBST) once every fourteen or twenty-eight days, and their milk production is increased, on the average, by fifteen to twenty-five per cent.[1] The companies who manufacture the recombinant hormone are expected to benefit enormously by marketing the product, given that they are allowed to do so freely, and the dairy farmers who subject their cows to the treatment can also expect a moderate raise in their incomes.

An analysis of the use of rBST: Mepham's Matrix

The use of rBST has, however, been opposed for several reasons, most of which can be classified as ethical rather than economical or political. These reasons have been well presented by Ben Mepham in his recent book *Food Ethics*,[2] where he employs a modified version of the principlist approach to bioethics, introduced by Tom Beauchamp and James Childress in their *Principles of Biomedical Ethics*.[3] Mepham presents a matrix for ethical analyses by applying the principles of well-being, autonomy and justice to four groups of beings or entities who can be seen as morally significant in assessments of biotechnological food production, namely the treated organisms, producers, consumers and the biota, or the animal and plant life of a region. The results of his analysis concerning rBST have been summarized in Table 1.

The main problems that Mepham sees in the use of rBST are its influence on the well-being of the dairy cows, the unfair treatment of the producers who do not want to adopt the rBST method of dairy farming, and the ill-effects of rBST milk on the general public. The treated cows are at increased risk of a number of side effects, many of which have painful symptoms, including

> increased cystic ovaries and disorders of the uterus; higher incidence of retained placenta; increased risk of clinical and subclinical mastitis; increased digestive disorders such as indigestion, bloat and diarrhoea; increased numbers of enlarged hocks and lesions of the knee; disorders of the foot: and injection site lesions which may remain permanent.[4]

	Well-being	Autonomy	Justice
Treated organisms	The use of rBST increases the incidence of diseases in cows and causes them discomfort.	Diseases and zero-grazing infringe the freedom of the cows treated with rBST.	The intrinsic nature, or telos, of the cows treated with rBST is not respected.
Producers	The manufacturers and users of rBST can expect considerable profits. Other dairy farmers will lose.	The autonomy of the farmers who would not like to use rBST is undermined.	The farmers who are not prepared to profit from bovine discomfort are unfairly penalized.
Consumers	rBST milk and decreased milk consumption can create health hazards and cause unease.	Unless rBST milk is labelled, the freedom of choice of consumers is restricted.	The affordability of milk is not enhanced, as implicitly promised by the innovation.
Biota	The use of rBST can reduce global pollution, but it can also intensify it both locally and globally.		

Table 1.

In addition, the behavioural freedom of the animals is infringed by lameness caused by diseases, and their freedom of movement is almost totally blocked by the requirements of energy-dense feeding. Yet another concern for Mepham is that the natural functioning of the treated cows, or life according to their natural *telos*, is rendered impossible by the administration of rBST.

As regards the producers of milk, Mepham points out that while those dairy farmers who adopt the method will probably gain economically, the losses of those who are not prepared to use rBST will be considerably greater. It follows from this that the non-adopters will be economically coerced into changing their farming methods, and that they will also be unjustly punished for their decision not to subject animals to needless suffering and their fellow human beings to unnecessary anxieties and health hazards.

The physical dangers imposed on the consumers by rBST milk are partly due to compositional changes in the product. As Mepham notes:

> The galatopoietic effect of BST is associated with an increase in the concentration in milk of insulin-like growth factor 1 (IGF1), a substance which is biologically active in humans. Concerns have been expressed that at the concentrations IGF1 attains in BST milk, and because it is protected from digestion by the milk protein, casein, it might have inappropriate effects on the cells of consumer's intestinal tract.[5]

Another set of health-related risks brought to the fore by Mepham are the public health implications of reduced milk consumption. It has been estimated that the use of milk products would decrease by 11% in the European Community by the introduction of rBST, because many people would favour a total boycott of food associated with the substance. Yet milk is an essential source of calcium, proteins and vitamins, and further reductions in its use could trigger, for instance, an epidemic of osteoporosis in postmenopausal women especially in the United Kingdom.

Mepham also points out that the ill-effects of rBST extend beyond physical harm. Opinion polls indicate that the majority of people are seriously concerned about the use of genetic engineering in milk production, which means that permitting the practice may cause wide-spread distress in those who do not want to abandon milk-associated nutrients altogether. Besides, if rBST-treated products are not labelled, which is the case in the United States where the use of the hormone is allowed, the freedom of choice of consumers is seriously curtailed.

Appeals to environmental damage cannot, as Mepham observes, be employed either for or against the use of bovine growth hormone. Increased milk production per cow means fewer cows, and this equals less methane gas which is a greenhouse gas – a cause of global warming. On the other hand, however, the use of rBST requires intensified farming, which in its turn pollutes local environments and is highly dependent of fossil fuels, artificial fertilizers, machinery and transportation.

Despite the risks of rBST use, Mepham does not want to draw any normative conclusions based on the ethical matrix he has presented. He does note that the political decision-makers who decide about the fate of rBST use in Europe in the near future should pay attention to the ethical considerations revealed by the model. (rBST has been temporarily banned in Europe, but this ban, or moratorium, can be revoked.) But Mepham stresses the descriptive nature of his matrix, and offers it 'as a framework for encouraging wider public participation in policy-making' rather than as a prescriptive tool.[6]

An alternative analysis: the consequences of using rBST

The open-endedness of Mepham's conclusions can be attributed to many factors, among them a healthy suspicion regarding the normative scope, or motivational power, of conceptual analyses. Another factor is, however, the way in which Mepham classifies the arguments for and against the use of rBST in dairy farming. His matrix in the analysis of the rBST case contains only three ethical principles, as opposed to the four moral norms introduced by Beauchamp and Childress in their pioneering work. He has grouped together their principles of beneficence and non-maleficence under the heading of 'well-being', which is fine if the aim is merely to describe the pros and cons of human choices, but which can, I believe, confuse the issue if more prescriptive results are sought for. If the harm inflicted on rBST cows and the consumers of their milk is lumped together with economic gains in a crude calculation of utilities and disutilities, it is easier to conclude that decisions either for or against the use of the hormone are impossible to reach on the basis of ethical analyses, and that democratic procedures are the only acceptable method for weighing the different values enhanced and undermined by the practice. But the situation is, arguably, altered if the harms and benefits are evaluated separately, as originally proposed by Beauchamp and Childress, especially if the avoidance of harm is seen as the most important consideration.[7]

The ethical implications of the use of bovine growth hormone in dairy farming have been presented in Table 2 in a form which takes into account the division between harms and benefits.

My normative starting point for assessing the considerations summarized in Table 2 is that avoidable harm ought not to be caused, unless considerably greater harms can thereby be prevented or alleviated. Loss of autonomy which can be equalled with physical or psychological damage can, according to my reading, also be regarded as harm, although it is presented in a separate column. More symbolic violations of autonomy and justice are ethically significant only insofar as practices cannot be judged by appeals to the harm inflicted by them, directly or indirectly. The main results of the revised ethical matrix are the following.

	Harms	Benefits	Autonomy	Justice
Treated organisms	The treated cows suffer from many ailments and from the extra-tight containment.			
Producers	The ethically-oriented dairy farmers are economically harmed.	Ethically indifferent producers and users of rBST are benefited.	The ethically-oriented dairy farmers are economically coerced.	Justice does not prevail.
Consumers	The users and refusers of treated milk products are subjected to health hazards.		If rBST milk is not labelled, the freedom of choice of consumers is curtailed.	
Biota	Intensified farming causes local pollution and may add to global pollution.	The decreased number of cows reduces methane gas releases and global warming.		

Table 2.

As long as dairy cows can be expected to suffer from the use of rBST, and consumers are subjected to health hazards by unlabelled rBST milk products, the use of the bovine growth hormone is harmful, and should therefore be banned. This means that the policy prevailing in the United States is unethical, and should be altered forthwith. It also means that the moratorium in the European Community regarding the use of rBST should be continued. The situation in Europe can be slightly better, if the producers of treated milk are required to label their merchandise, as recommended by the European Commission Group of Advisers in 1993,[8] but the increased suffering of the cows would still provide a strong reason against the practice.

On the other hand, however, the revised matrix also shows that *if* rBST could be administered to cows without causing painful side effects, *and if* treated milk would be labelled, there would probably *not* be sufficient grounds for prohibiting the use of the hormone. Both consumers and producers could choose to be involved with the recombinant hormone or to avoid it, and the economic losses and health problems possibly related with the use of the treated substances could be avoided by those who want to avoid them. The economic restrictions on their freedom of choice would still exist, but since safer products are often more expensive than others, this does not justify legal prohibitions.

A possible counterargument to my analysis is that by ignoring issues of justice and autonomy I have reduced Mepham's original model to a mere utilitarian calculus, thereby compromising its status as a matrix which should facilitate ethical decision-making regardless of one's moral views.[9] In a sense, this is perfectly true. I have tried to show how a person of a consequentialist persuasion would like to interpret Mepham's ideas, and this inevitably leads to the mitigation of factors like 'respect for the *telos* of cows'. From my point of view, if cows suffer, that is bad. If they do not suffer from the violation of their 'intrinsic nature', then I cannot see what the problem is.

But it must be kept in mind that, according to the evidence available to us now, dairy animals do suffer from the administration of rBST, and I believe that this fact becomes more visible, if the harms and benefits of the chosen policies are presented separately. And regardless of people's particular moral views, I hope that the suffering of the cows is at least a factor among others when decisions concerning the use of rBST are made. For those of us who think that the consequences of our actions on the subjective well-being of sentient beings is paramount, this factor strongly suggests that the use of bovine growth hormone to increase the milk yields of cows should not be condoned.

Notes

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[1] The facts of the rBST case have been presented, for instance, in S. Nottingham, *Eat Your Genes: How genetically modified food is entering our diet* (London and New York: Zed Books Ltd, 1998).

[2] He has used the same framework for GM maize in B. Mepham, 'A framework for the ethical analysis of novel foods: The ethical matrix', *Journal of Agricul-*

tural and Environmental Ethics **12** (2000): 165-176.

[3] T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics*, 4th edn (New York and Oxford: Oxford University Press, 1994).

[4] Mepham borrows this list from the 1993 package insert of Posilac, one of the rBST products on the market (manufactured by the Monsanto Company) – B. Mepham, 'Ethical analysis of food biotechnologies: an evaluative framework', in B. Mepham (ed.), *Food Ethics* (London and New York: Routledge, 1996), 101-119, 108-109.

[5] Mepham (1996, 110) refers here to T.B. Mepham, P.N. Schofield, W. Zumkeller and A.M. Cotterill, 'Safety of milk from cows treated with bovine somatotrophin', *Lancet* **344** (1995): 1445-1446; and C.J. Xian, C.A. Shoubridge and L.C. Read, 'Degradation of insulin-like growth factor-1 in the adult rat gastrointestinal tract is limited by a specific antiserum of the dietary protein casein', *Journal of Endodocrinology* **146** (1995): 215-225.

[6] The cited passage is from Mepham 1996, 117. He makes the same point in slightly different terms on page 112, and in Mepham 2000.

[7] I have sketched an alternative reading of the four principles, based on the idea of the supremacy of avoiding harm, in M. Häyry, 'Ethics committees, principles and consequences', *Journal of Medical Ethics* **24** (1998): 81-85.

[8] European Commission Group of Advisers on the Ethical Aspects of Biotechnology, *The Ethical Implications of the Use of Performance-enhancers in Agriculture and Fisheries* (Rapporteurs M. Warnock and M. Sinisalo), 1993.

[9] I owe this point to Dr Mepham.

Appendix

My Way to Bioethics

A Story of Otherness and Chance Encounters*

I was first introduced to the combination of philosophy and medicine in December 1983. Heta Gylling, my wife at the time, and I had attended mind-boggling lectures on 'Being', 'Time' and 'Differance' at the University of Helsinki during the Fall term, and wanted desperately to get our hands on something more concrete. She read Peter Singer's *Practical Ethics* [1] and I wrote a seminar paper on Judith Jarvis Thomson's 'A defence of abortion' [2] – which was suggested to me by our supervisor, Timo Airaksinen.

Thomson's essay was difficult to understand, but Singer's provocative and clearly stated views on abortion, euthanasia and other life-and-death matters were an instant hit. Our Master's dissertations in practical philosophy dealt with abortion and euthanasia, and set us both on a definite course toward bioethics.

For the following decade or so Heta and I worked closely together, which means that many events recorded here belong to her history as well as mine. But I have tried to focus on those aspects of the events which made them a part of *my* personal, and still ongoing, quest to find my way to bioethics – or out of it, as the case may be.

The primal encounters

When I look back to the years between the completion of my dissertation on abortion in October 1984 and the present time, April 2000, I am forced to realise that my research topics have been more or less dictated by chance meetings with philosophers, bioethicists, and other people in general. I can make out six episodes which have significantly shaped my quest.

The first episode involves an encounter with journalists and the general public in Finland. In 1986 Heta and I published our Master's dissertations as a book [3], which caught some media attention for a while. In addition to transforming us into unbearable know-it-alls, the transitory fame led at least me to believe that people are truly interested in rational arguments, and that philosophers can make a real difference by analysing policies and attitudes which underlie medical decisions. For two or three years I worked on the problems of abortion, euthanasia, AIDS and reproductive medicine under the illusion that everything I write will be read and celebrated by wide international as well as national audiences. It took the blunt rejection of a particularly hubristic paper on AIDS, and the monumental commercial flopping of an edited book on new reproductive technologies [4] for me to grasp that popularity and philosophical integrity are two different things.

The second episode started with an encounter with Sakari Karjalainen – then a young medical doctor who worked as a research fellow at the Finnish Cancer Registry. His own research interest was epidemiological, and collaboration with him produced during 1988-89 a series of rather decent studies on AIDS, smoking policy, vaccinations, and justice in health care allocation [5-10]. This was a clear shift towards the ethics of social medicine from the more individualistic realms of abortion and euthanasia. Among other things, it provided the sidelight necessary for the completion of some previously drafted articles on the beginning and the end of life [11-15].

During a creative interlude from bioethical research – I think I was completing a dissertation on neo-idealistic aesthetics for a degree in theoretical philosophy – four more people came into the picture, and changed it significantly over time. These were Ruth Chadwick, John Harris, Søren Holm and Peter Singer, first met in philosophical and bioethical conferences in England and in Scotland. The meeting with Peter Singer was particularly educational. He was at the time under heavy attack in Germany, where his lectures had been violently interrupted and people with whom he collaborated had been academically persecuted [16]. Quite apart from the fact that Peter is one of the kindest persons I have ever met, the unfairness and irrationality of the movement against him was so obvious that I have still not, although a decade has passed, been able to wholly restore my faith in the German mentality in bioethical matters.

Drifting towards theory

The third episode involves a short but consequential encounter with Matti Hakama, whom I met through Sakari. He encouraged me to explore the ins and outs of quality-of-life measurements in medicine and health care [17], and directed my interest to the methodological dimensions of bioethical work. At the same time, in early 1990, Timo Airaksinen began prompting me to finish my doctoral thesis, which I did by lumping together ten articles under one cover and writing an introduction where I defined the method I felt was best suited to the philosophical study of issues in medical and health care ethics [18]. As one of my internal examiners, Heikki Kannisto, noted, there was the slight embarrassment that the chapters of the thesis did not in any way follow the method set out in the introduction. That did not prevent Timo and my external examiner, John Harris, from accepting the work. Their comments, over dinner right after the public defence of the thesis, determined, however, the shape of the fourth episode of my journey.

Timo and John argued that the method I proposed for bioethical work was utterly relativistic. I was rather taken aback by their remarks, because I believed that my model set a firm foundation for ethical judgements, based on the consequences of human actions, interpreted through logic and, in difficult cases, through moral emotions shared in the communities where the judgements are made. True, I rejected the possibility of an absolute, universal, all-encompassing theory which would tell every human being in every situation at all times and all over the world what they must or must not do. But I thought this rejection was self-evident in medical ethics. One only has to think about matters like abortion and euthanasia – nobody has come up with solutions which would be even remotely acceptable to all others.

Anyway, being the impressionable fool that I am, I tried for the following three years to escape from medical ethics, and attempted to create a theory which would show everybody how applied ethics should be done and on what theoretical basis. The literary result was a book on utilitarianism which John promptly published in 1994 in a series he edited [19], and a bunch of articles which expand on its themes [20-25]. Normatively, however, this project left me exactly where I had been. It made it no clearer to me how anybody can believe that there is one ethical model which universally solves all moral problems.

During my adventures in the never-never-land of universal moral theory Peter Singer reappeared in another context. At some point Heta and I had become involved in animal welfare issues, and in Fall 1992 Peter visited Helsinki and gave a series of academic and public lectures. I mention this because one meeting with Peter changed my diet in a way which has become also philosophically important to me. On one October evening Peter, Heta, Timo and I had dinner in an Indian restaurant where Peter had a vegetarian meal while the rest of us had portions of chicken, pork and beef. The author of *Animal Liberation* [26] did not comment in any way our choices, but his mere presence stirred something up in Heta and me. When we went home that night, we threw, after a brief negotiation, away all food products which contained pork. The reason was, vaguely, that pigs are the cleverest animals people usually eat, and should be left alone. But whatever the reasons, I for one have not knowingly eaten pork since that day. And every time I come upon somebody who holds immutable moral convictions which I find alien I think about the times when I have had to explain to hostesses and hosts who have made an effort to serve a delicious dinner that something in their cooking does not agree with my self-chosen dietary principles. In other words, I can now understand categorical arguments in bioethical discussions, even if I do not accept them myself.

Projects – the cages with golden bars

In 1993 I was dragged back to bioethics – which I had, I must admit, hardly left – by John Harris whose international project on AIDS and justice drew together academics from many European countries. This fifth episode of my academic journey was regulated by meetings of the group and by the topics we were supposed to cover. At the outset John expressed his concern that some of us might have already 'written ourselves out' of the AIDS issue by previous research and publications. This turned out to be a self-fulfilling prophecy at least in my case.

I started by preparing a paper on the role of philosophers in bioethical research programmes [27]. My main point was that while others can be assigned duties to collect data and provide facts, philosophers should be left in peace to prepare their snide conceptual remarks on the work done by others. Understandably, these views did not gain much popularity in a group which consisted mainly of medical professionals, lawyers and people involved in psychology and social work. I also wrote on people's reactions to their own impending illness and death [28], and argued, among other things, that devoted Christians and Jews should not be overtly resentful when they are confronted with a fatal disease. Simple logic dictates that faith in the ultimate wisdom of God's decisions should check their bitterness. This modest theological insight was not greeted with enthusiasm in the conventionally religious audience.

Finally, as a reaction to what had been said in earlier meetings, I presented a paper entitled 'Is it intolerable that children are born infected with HIV?' [29]. Members of the group had asserted that it is intolerable, or at least strongly undesirable, that newborns are congenitally infected. But they had also stated that pregnant women who are HIV positive should be counselled into having their babies. Others had noted that people have an internationally recognised human right to reproductive freedom. But they had also said that needless suffering should be avoided. Amidst all this, my argument was that if it is a bad thing that babies suffer, then people who intend to bring into this world a baby who would probably suffer can be met with moral pressure not to conceive. In practical terms, this means that people should be allowed to say to each other: 'Don't have a child if there's a good chance that it will suffer horribly and die young! If you do, I'll think that you are immoral.' Somehow this made me a monster in the eyes of most members of the group.

While I was hitting this all-time low in my academic popularity and self-esteem, one person in the project group, Søren Holm, helped me, perhaps unwittingly, to redirect my activities once again towards ethical theory. Our discussions on the philosophical aspects of the group's work and, above all, Søren's tolerance and wide learnedness, convinced me that knowledge of the tradition preceding us is essential to the understanding of our contemporary concerns. Besides, no argument sounds quite so suspicious if you can put it into the mouth of a respected philosopher of the past. I resolved to clarify to myself the history of Western moral and political philosophy.

The sixth episode of my quest had been prefaced already in 1991 by John Harris, who had, following the defence of my doctoral thesis, invited Heta and me to Manchester to take part in a conference on the ethics of genetic engineering. The publication of the proceedings in 1994 [30], with Heta's paper and mine [31], apparently convinced Ruth Chadwick that we might know something about the ethics of genetics. In any case, during the next four years my bioethical research topics were defined to a large extent by the needs of Ruth's two European projects, one on the attitudes of young people to biotechnology, and the other on the moral and legal aspects of genetic screening and testing [32-33]. This time, the structure given by the projects was all right by me, partly because the issue was relatively new, and partly because I had seized a temporary teaching job which allowed me to explore the depths of moral theory in the best way I know – by infesting my views on unsuspecting young minds. I prepared a series of studies on the ethics of biotechnology [34-38], taught introductory courses of philosophy, and landed in 1997 funding for a project, and a research position for myself, at the Academy of Finland. Combining my two interests, I entitled the project for my research fellowship 'European moral philosophy and the possibility of consensus, especially regarding legislation on gene technology'.

In a way, my present philosophical and bioethical existence is a continuum to the genetics and moral theory episode. During the last two years, I have been appointed to yet another temporary teaching position in philosophy, completed book manuscripts on the history of moral and political philosophy [39-40], and continued turning out papers on the ethics of genetics [41-46]. The most tangible change in my life is personal, but it has also influenced my academic activities. I now work with Tuija Takala, my wife since 1999, and a community of people with whom it is increasingly pleasurable to explore the intricacies of human morality. These people include Sakari Karjalainen and others in Helsinki, some old friends in Turku, Simo Vehmas in Jyväskylä, and Rosamond Rhodes in New York. Appropriately for my story, the last paper I wrote before starting these memoirs was on Rosamond and Simo's conflicting views on abortion – on my very first topic in bioethics sixteen years ago [47-49].

Logic and emotions

The abortion issue continues to be, for me, one the best laboratories to clarify the relationship between ethical theory and moral practice. When I first started to write on abortion, my implicit aim was to find a justification for the 'moderate' policies which prevailed in Finland. In other words, I felt, like most people seem to do, that abortions are in some cases wrong and in other cases acceptable. But the more I studied the philosophical arguments, the clearer it became to me that only the extreme positions have any real coherence, or cogency. The official Catholic view in all its restrictive absurdity is a beautiful construction, and the entirely permissive view is impervious to theoretical criticism, if its basic tenets are assumed. Moderate views, on the other hand, were at least in the mid-eighties clumsy edifices dictated more by practice than by theory, which did not stand up to the tests of logical consistency or conceptual coherence. The intermediary conclusion I drew from this was that on purely philosophical grounds the choice must be made between the restrictive and permissive views. This means, among other things, that I had to change my mind about the legitimacy of the prevailing abortion policy.

The next question, however, is, 'How should the choice between two internally consistent but mutually contradictory policies be made?' And my response to this was to resort to shared moral emotions and intuitions. Policies which generate, in real or imaginary situations, prohibitions and permissions, which are seen as repulsive or unfair within a certain community, can be rejected, in that community, as counterintuitive. When it comes to abortion in the affluent West, for instance, the fully restrictive view can be ruled out by appeals to rape, incest, and contraceptive failures. Like Thomson argued in her essay [2], the majority of people in the United States and Europe would consider it unfair if abortions were prohibited in some of these cases. And this provides some indirect support to the fully permissive view as the only logically *and* emotionally acceptable solution.

There are two ways of using emotions as the basis of moral judgements. The first is to state, like Patrick Devlin stated in his lecture 'The enforcement of morals' [50], that practices like homosexuality, abortion and cruelty to animals should be banned because they arouse feelings of intolerance, indignation and disgust in ordinary people. This strategy is both theoretically and practically problematic [46], which is why I have never employed it. The second way, my way, is to use emotions only in order to falsify ethical views which pretend to be universal [18,19,27]. If someone asserts that abortions should *always* be forbidden, the assertion can be repudiated by finding or creating one case where the prohibition would clearly be unreasonable, unfair, or otherwise emotionally unacceptable.

The same model can, of course, be applied to attack the entirely permissive view on abortion. When somebody says, like I do, that abortions should *never* be forbidden, those who disagree are free to seek cases in which the license to abort would be unreasonable. The proponents of restrictions normally seem to think that third-trimester terminations of pregnancies which are going well both for the 'mother' and the 'child' are a case in point [47,48]. I think I agree with them morally, but disagree legally.

By the last remark I mean that ideally the law should not interfere with actions which do not physically or mentally harm others. And since there is no 'other' in the abortion case, *the law* should not dictate what the woman should or should not do. If people want to argue about *the morality* of late terminations without coercing women into having children, they can, of course, do so. In these arguments they are allowed to use elements which would be illegitimate in legal analyses – appeals to virtues, ethical duties, reasonable expectations, shared moral beliefs and the like. But these moral considerations must not be smuggled back to discussions concerning the law.

Otherness

My career in bioethics, such as it is, has been marked throughout by a sense of 'otherness', or dissidence. I am a philosopher first, and find it difficult to be a part of a multidisciplinary community which pretends to have positive answers to practical questions in medicine and health care provision. I do not believe that philosophers can, or should, become hospital bioethicists, legislators, politicians or administrators. I believe, instead, that philosophers are at their best in the role of 'barking dogs' – as critics of intellectually lame attempts to justify, after the fact, practices and policies which may be economically or politically necessary but which are not based on reason, or even on shared moral intuitions. This is not a popular message in an age which wants to domesticate philosophers into explaining why the already chosen policies must be accepted.

My otherness also extends to the realm of ethical theory. I do not believe, like some of my colleagues do [47,48], that Aristotle or Kant could provide us with the right answers to all bioethical questions. Nor do I believe, although I have sometimes sounded like I did [44,52], that consequentialist thinking would fare much better. I have my doubts concerning the mixed approaches which are exemplified by the American 'principlism' of Tom Beauchamp and James Childress [53]. And I do not think that philosophical answers to practical questions could be found in psychoanalysis, sociology, history, or literature, like some European ethicists seem to think.

I suppose I could still become a proper bioethicist – a teacher of medical ethics, an administrator, a legislator or a politician. Given the choice, however, I would rather not. Other people are better trained, and more disposed, to occupy those positions. I like my role as a philosopher who knows something about the ethics of medicine but is not required to know it all, or worse, to pretend to know it all.

Cast (in order of appearance)

Heta Gylling continues to teach philosophy at the University of Helsinki, and to participate in international bioethical activities.

Timo Airaksinen still holds the position of Professor of Practical Philosophy at the University of Helsinki. His research interests do not include bioethics.

Sakari Karjalainen completed his doctorate in epidemiology in 1991. He works currently as the Secretary General of the Research Council for Health at the Academy of Finland, and participates actively in bioethical discussions in many European committees and working groups.

Ruth Chadwick is Professor of Moral Philosophy and Head of the Centre for Professional Ethics at the University of Central Lancashire. She established during the 1990s her position at the very top of international bioethics.

John Harris is Professor of Bioethics at the University of Manchester and heads the Centre for Social Ethics and Policy there. His international reputation, which was initially gained already in the 1970s and the 1980s, has only grown stronger.

Søren Holm moved recently from his native Copenhagen to Manchester, where he awaits his imminent Professorship in bioethics and the philosophy of medicine. In addition to his present Readership in Manchester, he is a part-time Professor of Medical Ethics in Oslo.

Peter Singer just left his native Australia to become a Professor of Philosophy at Princeton. His arrival was greeted with loud objections by the spokespersons of organisations for handicapped people, who probably have a very vague idea regarding the content of his work.

Matti Hakama is Professor of Epidemiology at the Tampere University School of Public Health, and participates in bioethical decision-making as a member of the Research Council for Health at the Academy of Finland.

Heikki Kannisto continues, after a brief episode in practical philosophy, to teach theoretical philosophy at the University of Helsinki and other Finnish universities.

Tuija Takala is currently finalising her doctoral thesis on the ethics of modern biotechnologies at the University of Turku.

Old friends in Turku include Professor Juhani Pietarinen, Doctor Juha Räikkä and Mr Veikko Launis.

Simo Vehmas works as a Research Associate at the Jyväskylä University Department of Special Education. He is preparing a doctoral thesis on the moral (ir)relevance of intellectual disabilities.

Rosamond Rhodes, although slightly exploited by her current employers at Mount Sinai Hospital, New York, where she is Professor of Philosophy and Director of the Bioethics Programme, is rapidly becoming one of the best Kantian bioethicists in the world.

About the Author

Matti Häyry (b. 1956) began studying philosophy at the ripe age of twenty-five after spending six and a half years in military service. The questions of philosophical medical ethics have been on his agenda since 1984. He earned his doctorate in practical philosophy at the University of Helsinki in 1991, and has since then been working mainly in Helsinki at the Department of Practical Philosophy. In 1985-95 he was a Research Fellow, in 1995-96 an Acting Professor of Practical Philosophy, and in 1996-2000 a Senior Research Fellow of the Academy of Finland. His main publications in the field have been included in the list of references. He has been the participant of concerted action groups within the Commission of the European Communities research programmes BIOMED 1, BIOMED 2 and BIOTECH. He is a permanent expert to the National Research and Development Center for Welfare and Health, and a member of the sub-committee on medical research ethics of the National Advisory Board on Health Care Ethics. In 1999 he was appointed to a Professorship in Philosophy at the University of Kuopio.

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Index

Playing God

Essays on bioethics

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Doctors, nurses and scientists have often been accused of 'playing God' in life-and-death decisions, reproductive medicine and genetics. The tenor of this book is that the same accusation can be extended to ethicists and public decision-makers who refuse to examine the issues analytically before they pass their judgements.

Matti Häyry is Professor of Philosophy at the University of Kuopio and Head of Centre for Professional Ethics and Professor of Moral Philosophy at the University of Central Lancashire in England. He has taught philosophy and bioethics in Finnish Universities since 1985, and coordinated many projects on the ethics of genetic engineering and new biotechnologies. His previous books include *Critical Studies in Philosophical Medical Ethics* (1990) and *Liberal Utilitarianism and Applied Ethics* (1994).

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