

BIOETHICS

METHODS, THEORIES, DOMAINS

MARCUS DÜWELL



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Methods, theories, domains

Marcus Düwell



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Bioethics

This book is a philosophically-oriented introduction to bioethics. It offers the reader an overview of key debates in bioethics relevant to various areas, including organ retrieval, stem cell research, justice in health care and issues in environmental ethics, as well as issues surrounding food and agriculture. The book also seeks to go beyond simply describing the issues in order to provide the reader with the methodological and theoretical tools for a more comprehensive understanding of current bioethical debates. The aim of the book is to present bioethics as an interdisciplinary field, to explore its close relation to other disciplines (such as law, life sciences, theology and philosophy) and to discuss the conditions under which bioethics can serve as an academically legitimate discipline that is at the same time relevant to society.

As a systematic and methodologically rigorous overview, *Bioethics: Methods, Theories, Domains* will be of particular interest to academics and students in the disciplines of law, medicine, ethics and philosophy.

'This is a book that embraces neither a single ethical theory nor a pragmatic melange of just-so-principles. It is a thoughtful and engaging analysis of diverse theoretical foundations in Bioethics. It is also an enormous step towards conceptual and philosophical clarity in this fascinating area.' (Professor Christian Illies, Chair for Practical Philosophy at the Otto-Friedrich University Bamberg, Germany).

Marcus Düwell is Professor of Philosophical Ethics at Utrecht University, director of the Ethics Institute of Utrecht University and until 2012 director of the Netherlands Research School for Practical Philosophy. His research concentrates on questions concerning the foundation of morality and on applied ethics in its relation to ethical theory and political philosophy.

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Professor Sheila McLean is International Bar Association Professor of Law and Ethics in Medicine and Director of the Institute of Law and Ethics in Medicine at the University of Glasgow.

Preface

The aim of this book is to provide an introduction to a broad range of discussions in bioethics. However, its purpose is not merely to outline debates on cloning, gene therapy or environmental biotechnology. Rather, this book endeavours to put up for discussion the profile of the discipline of bioethics and its multifaceted methodological and theoretical preconditions. Bioethics takes place in interdisciplinary contexts with the participation of legal professionals, biologists, physicians, theologians and philosophers. Yet bioethical questions also arouse considerable interest among the general public, in the media and in politics. Nonetheless, bioethics is an academic enterprise which is organised in research institutes, for which professorships are established and in which students gain degrees. Like other academic disciplines, bioethics is accountable for its research standards, its academic self-conception and its place within the collectivity of academic disciplines. For that reason, this book will introduce and critically discuss positions that are important for a methodological understanding of the discipline. In the course of these discussions it should also become clear which approach to bioethical questions I deem appropriate.

I understand bioethics as a philosophical subdiscipline which is concerned with normative questions that confront us in the domains of medicine, biosciences and related fields (regarding the matter of the precise demarcation of domains see Chapter 1). The aim of bioethics is to formulate, scrutinise and justify criteria, in order to answer the question 'What actions are morally defensible?' in a philosophically solid manner. In order to attain this, a comprehensive engagement with the life sciences as scientific, technical, political and social phenomena is required. Therefore, interdisciplinary collaboration is indispensable for bioethics. Yet questions of bioethics form a challenge for ethics insofar as they confront moral traditions and perceived matters of course with their boundaries. Many of the practices that are currently the centre of attention were once not even considered morally relevant in the first place. Moreover, all recommendations and statements in bioethics are put forward in a situation characterised by a plurality of moral convictions and ethical theories. Bioethics discusses concrete moral questions, but in doing so it must consider the whole range of ethical theories. For that

reason, engagement with the moral-philosophical aspects of bioethics is of great significance.

Chapter 1 is aimed at a more detailed description of the situation of the life sciences and bioethics, as a reflection on these academic developments. Chapter 2 discusses the relation of bioethics to moral philosophy. Chapter 3 addresses cultural, social and humanities-based perspectives relevant to bioethics. Chapter 4, to conclude, attempts to provide an overview of the most important bioethical discussions. The exposition of these discussions obviously cannot be exhaustive. Rather, the most important objective is to evoke an awareness of the questions and problems that confront any attempt to reflect on the ethical aspects of the biosciences and their application. In light of the political, economical and societal meaning of the life sciences, I believe that this theme is central to our contemporary culture.

Since the relation of bioethics to moral philosophy is key to my understanding of bioethics, a discussion of some more general issues in philosophical ethics cannot be avoided. This presents the author with the unfortunate choice between either writing in such an advanced manner that only those who already have a solid basis in philosophical ethics can follow or, in addition to providing an introduction to bioethics, also giving a general introduction into ethics. Forgoing a critical portrayal of moral-philosophical discussions would, however, lead to a situation in which the author would introduce his moral-philosophical presuppositions underhandedly, to some extent, rather than – as philosophical honesty requires – confronting them with competing approaches and arguing for the cogency of his own position. The present volume aims to solve this problem by, on the one hand, choosing to bring up a few questions of metaethics and normative ethics but, on the other hand, presenting these debates principally with a view to their relevance for bioethics. I hope that the results will be of interest to specialists and laypersons alike.

When writing this kind of introduction, one cannot be neutral. Whoever would make a claim to neutrality for himself would be rightly suspected of trying to conceal his own standpoint. Therefore, I do not in the least wish to beat around the bush about the fact that my personal position is part of a Kantian tradition, and is informed by a strong emphasis on human dignity and individual rights. I do not, however, consider us merely morally obligated to respect the personal rights to freedom of the individual. Rather, it is the *empowerment* of the individual to an autonomous way of taking up his or her life that is, to me, the most important moral starting point (see Chapter 2).

Currently, bioethics poses a challenge to this position inasmuch as developments in the biosciences have made both the proper subjects of moral rights and the contents and scope of legitimate moral claims all the more difficult to determine. From a metaethical point of view, I am rather sympathetic to transcendental philosophy as a point of departure for ethics in general. Still, I have made an effort to deal fairly with competing standpoints. The point of this book, however, is not primarily to defend my personal bioethical standpoints,

but to clarify in what ways bioethical assertions, theories and positions are dependent on moral-philosophical premises. Reflection upon these premises is, I believe, the essential 'ethical' element of bioethics. In this way, bioethics can make a fundamental contribution to the transparency of the way moral judgments are formed in a situation of moral pluralism, and thus, moreover, be exceptionally conducive to understanding and constructive communication in public debate.

This book reflects, in multifarious ways, my bioethical work over the last 20-odd years. As an academic coordinator of the Interdepartmental Centre for Ethics in the Sciences and Humanities in Tübingen I have collaborated on a number of academic projects. Particularly exciting were the many doctoral projects of the research training group 'Ethics in the Sciences', the broad interdisciplinary team as well as the European research projects. I have learned much, in particular, from liaisons with Dietmar Mieth and Klaus Steigleder. For over 10 years now, my working context has been the Department of Philosophy at Utrecht University, where I am director of the Ethics Institute, and from where I directed for the last 7 years the Netherlands School for Research in Practical Philosophy. The move to a new country and the encounter with a different academic culture has certainly disclosed a number of new perspectives. The intensive contact with students of philosophy and the students on our international MA programme in Applied Ethics, and the collaboration with the doctoral students of the institute and the research school has been the most enriching challenge.

I thank Sigrid Graumann and Micha H. Werner for their numerous comments on the concept and individual sections of the manuscript. My gratitude also concerns the comments and corrections I gained from a discussion in the colloquium of the Ethics Institute at Utrecht University, in particular from Marcel Verweij and Jan Vorstenbosch. Robert Heeger's detailed enquiries have – as always – taught me a great deal. This book is the English version of an introduction into bioethics that was first published in German in 2008. I thank Metzler publishing house, especially Ute Hechtfisher, for the support when writing the German manuscript and for the permission to translate it into English. I thank Routledge, especially Katherine Carpenter and Stephen Gutierrez, for their support and patience in the publishing process, and Sheila McLean for the willingness to consider the manuscript for publication in the *Biomedical Law and Ethics Library*. I thank Candice Cornelis for various suggestions concerning the English text, Gerhard Bos and Andre Krom for literature suggestions. But first and foremost I have to thank Naomi van Steenberg. Naomi has translated the whole manuscript from German into English. She did a really wonderful job and I am very grateful for her scrupulous and reliable edition of the text. Sabine Antony, to conclude, has critically read the entire manuscript and has supported its development. For this I am grateful and for much more.

Utrecht, Spring 2012
 Marcus Düwell

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1 What is bioethics?

An introduction

1.1 An introduction to bioethics?

Since the end of the 1950s, physicians have been able to use heart-lung machines to keep people alive for whom previously there was no prospect of recovery. Shortly thereafter, it also became possible to remove their organs for transplantation purposes. For many physicians, however, this raised the question whether it could be morally right simply to take away organs from living, breathing people. Interesting is the way in which an answer to this moral conundrum was sought: a number of medical practitioners asked the pope to pass judgment. This is an instance of a very early bioethical discussion. Another example would be the debate on the conduct of doctors in concentration camps in the Third Reich, as held in the Nuremberg Doctors' Trial. Since then, developments in the life sciences have led to numerous discussions about cloning, embryo research, genetic diagnosis and selection, xenotransplantation and interference with the human brain – to highlight but a few themes. The contexts of these debates are no longer restricted to individual domains of medical practice, but have a far-ranging influence on the entirety of medicine and on everyday life. In addition, there is no universally accepted moral authority which could provide definitive answers. Bioethical discussions are partly held with considerable public participation and against a backdrop of extensive pluralism of moral convictions.

These are the circumstances and the very diverse contexts in which bioethics has established itself globally over the last 40 years. There are bioethics committees affiliated with parliaments, ministries, churches and scientific organisations. There are numerous research institutes engaged in bioethics, and enormous numbers of books, journals and other publications. In this respect, an introduction to bioethics is confronted with an unwieldy abundance of materials. It would seem positively implausible if a single author were to claim to possess an overview of all these different debates, positions and publications. Moreover, bioethical debate can change at such a speed that an introduction like that would see its expiry date pass in the blink of an eye.

For these reasons, the objective of the present introduction is not in the first place to provide an overview of the entirety of concrete discussions. Rather, the point is to provide an overview of the *range of methodological problems and theoretical viewpoints* that play a role in bioethics. It is important to keep in mind from the start that an introduction to bioethics is confronted with a variety of particular difficulties; in opposition, for instance, to an introduction to quantum physics, which presumably would not be an easy undertaking either. The difficulty of gaining an overview of bioethics is connected to the fact that bioethical debates take place *on the boundary of academic and public-political discourse*, that academic bioethics has an *interdisciplinary* character and that there is *no agreement on what exactly bioethics is in the first place*. In order to close in on the question of what 'bioethics' means, or should, or could mean, I shall first of all (in 1.1.1) take a look at some forms of institutionalisation and (in 1.1.2) elaborate on the interdisciplinarity of bioethics. Subsequently (in 1.2), I shall discuss the role of bioethics in the context of developments in the biosciences and, finally (in 1.3), I shall comment on a number of efforts to determine the meaning of the concept of 'bioethics'.

1.1.1 *Institutionalisation of bioethics*

Bioethics, as I have indicated above, came into existence in the context of public debates about issues in (bio)medical science. The *institutionalisation of bioethics* is mostly a consequence of the increasing need of parliaments, governments and churches to obtain advice on ethical questions in the light of developments in medical science and biotechnology. Numerous ethics committees have been formed to fulfil this need. The functions of these institutions vary. Some committees were established merely to advise on concrete, well-defined questions; others are permanent advisory boards concerned with a whole range of societally relevant questions in the domain of the biosciences or other new technologies (i.e. the European Group on Ethics in the Sciences and New Technologies, the advisory board of the European Commission). While varied in assignment, they are also varied in size and composition. As a rule, these committees are interdisciplinary (with physicians, jurists, philosophers and theologians) and they usually consist not only of academics, but of representatives of relevant parties in society as well (churches, disability rights advocates, etc).

Besides ethical advisory boards affiliated with political institutions, committees have also been formed to advise *researchers* and *hospitals*. These so-called '*ethics committees*' at *medical faculties* are geared towards verifying that the protection of medical test subjects with regard to risks and informed consent is guaranteed. The title 'ethics committee' for these bodies is somewhat misleading, since their intention is not to carry out ethical reflection on the research project at issue, but merely to certify that the relevant codes of conduct are observed. These committees are standardly composed of physicians, complemented by a (theological or philosophical) ethicist and a jurist.

In recent years *clinical ethics committees* and institutionalised forms of *ethics advisory boards in hospitals* have also been created, to which doctors, nurses and patients can turn in case of conflicts and difficult decisions in treatment and nursing. The task of these advisory services is geared towards individual cases, and is typically not very well defined. Mainly, the point is to create a space within the clinical praxis in which conflict situations can be dealt with transparently with regard to both argumentation and procedure. It may be that, as a rule, these committees are forums that are partially about conflict moderation and the protection of decision-makers. But in any case they are places that should make it possible for difficult practical situations to be dealt with in morally responsible ways.

With these three types of committees, the contexts in which bioethics emerged have already been laid out. From the start, the objective of bioethics was to advise and reflect on *complex decisions in politics, research and clinical practice*. In the domain of medicine, more and more situations arose in which the traditional ethical guidelines of the discipline were not helpful, for which moral intuitions were not prepared, and in which there were no (or insufficient) legal arrangements to guide a decision-making process. In these contexts, the expression 'bioethics' signalled first and foremost a need for reflection on the moral and legal standards regulating medical practice, as well as a need for guidance on the part of decision-makers. It is still undefined, however, in what ways this specific form of advice and reflection differs from other kinds of conflict moderation. And it is even less clear how the advisory task of these boards relates to what has been established as 'bioethics' in academic spheres.

In addition, this advisory task turns out to differ greatly between the forms of institutionalisation discussed. A *clinical ethics committee* is confronted with *particular cases*. As a rule, these particular cases are settled against a backdrop of legal regulations, established practices and widely shared moral convictions. However, the great need for ethical advice indicates that ever more practices are becoming problematic, and ever fewer moral convictions can be taken for granted as shared. Nonetheless, no comprehensive ethical theories are called upon when such conflict situations are being dealt with in medical practice. Rather, those involved tend to fall back on medical knowledge, somewhat familiar standards of medical and nursing practice and moral principles that are (rightly or wrongly) considered to be unproblematic. Incidentally, the customs of medical practice are based only in part on the question whether those acts could meet with general approval in the public sphere. The medical profession has simply been successful in asserting certain standards of medical practice within its strongly hierarchically organised and legally regulated domain. In any case, factual observance of a given standard and its moral acceptance are two different things. Whenever the call for ethical advice arises in the clinic it is never enough merely to assess the *particular case* in light of established practical standards and moral convictions. These *standards and convictions* themselves must also be considered. The call

for ethical advice is thus also an indicator for the necessity to think about established forms of practice.

Discussions of bioethical themes that are widely held in the *public sphere*, on the other hand, are characterised by the fact that in this sphere there are no collectively shared moral convictions; there is at best partial consensus. To an extent, that may be a consequence of the fact that many areas of research, for instance stem cell research, are rather inaccessible to day-to-day experience. Moreover, on many bioethical topics people's moral intuitions are extremely varied. In these cases, a much more systematic kind of ethical guidance is called for. Discussions in media and politics, as well as institutionalised ethics committees, therefore, fall back on academics who inform participants about scientific, legal, sociological and ethical aspects of new forms of practice and new technologies. These informatory tasks then fall to biologists, jurists, sociologists and ethicists. This means that *academic ethical discourse* plays a role in *public discussions* as well. Yet the relation between the academic discipline and public bioethical debates is remarkable in several respects. First of all, the academic discipline did not exist until the need for reflection on its subject arose in practice. Now that is not all that surprising. Ever since Aristotle, ethics in general has been understood as a philosophical reflection on practices, and has conceived its task as guidance towards a good *praxis*. But there are some further particularities of bioethics compared with other debates on the boundary of academic and public discussion. For one, it is striking that many debates – for instance those on cloning – are largely defined by academics but disseminated by public media. It has thus been possible to read articles containing elaborate philosophical argumentation in national newspapers. Occasionally, philosophers and theologians will speak out and express their standpoints on cloning in the press before engaging with the subject in academic journals. Sometimes, philosophers and theologians will even present themselves publicly as bioethicists, despite the fact that their academic publications are in very different areas. Those practices, of course, evoke the question of exactly what competencies a bioethicist may be expected to have.

The relation between bioethics as a *topic of public debate* and as an *academic discipline* is thus unclear in many respects. In a public debate, every citizen can vocalise his own moral intuitions. Is the bioethicist then something like an official who receives a salary for expressing her moral beliefs? If bioethics is a practice of advising politics, is it merely a rhetorically pretentious way of making one's own standpoint heard? Is the establishment of bioethics a product of some strategy to evade the plurality in the battle of opinions by grounding a pseudo-expertocracy? Is incapacitation of the public sphere impending?

This relation between academic bioethical debates and the public and political spheres makes it difficult to provide a systematic introduction to bioethics in the first place. Yet insofar as bioethics constitutes a reflection on the *praxis* of medicine and the development of the life sciences, *ethical consultation* of politicians, physicians, etc. is only possible if there is a background of *academic debates* as well. Bioethics as an academic activity is therefore

also presupposed in the established practices of various kinds of ethics committees, if their claim to provide guidance is in fact taken seriously.

For this reason, considering the academic profile and the expectations for bioethics is necessary in light of the public debate as well. But given the *interdisciplinarity* of bioethics it is not easy to identify a clear-cut profile of the field (Green 1990; Holmes 1990; Pellegrino 2002). As a branch of ethics, bioethics seems to have a special connection to philosophy (and theology), yet as an institutionalised subject it is often part of medicine or interdisciplinary centres. Opinions regarding the methodological and professional roles of the different disciplines in bioethics vary greatly. Below, I shall work out *one single proposal* for understanding the interdisciplinarity of bioethics by way of the example of 'enhancement'.

1.1.2 *Interdisciplinarity: judgments in bioethics are mixed judgments*

For a few years now there has been a discussion of the question to what extent it is morally defensible to use the possibilities of medical science not only to cure people from disease, but also to improve their physical or mental capabilities (Parens 1998; President's Council on Bioethics 2003). These 'improvements', which are known as 'enhancements', range from plastic surgery to memory-improving pharmaceuticals. The range of applications is broad and the boundaries with therapy are fuzzy. The same medication can be used to slow down the loss of memory in people suffering from dementia or to boost the mental capabilities of students shortly before an exam. Enhancement is morally controversial, since traditionally, the task of medicine has been formulated in terms of therapy, diagnosis and prevention of *disease*. Yet the question what exactly health and disease are in the first place is itself disputed in medical science (Murphy 2009). If one understands the medical task of healing to be the rectification of dysfunction in order to enable a functioning that is typical for the human species (Daniels 1985: 26ff), the applications mentioned above do not necessarily qualify. But why should this definition of disease be our guiding thread? And what right would we have to deny people medical possibilities that would improve their lives? So-called 'transhumanists' even claim that one should free oneself as much as possible from the arbitrary limits to which humankind is evolutionarily subject (see e.g. Bostrom 2005). I shall return to the subject of *enhancement* (see Chapter 4) shortly. At this point, I merely want to differentiate between some questions and topics in order to make the division of the roles of the various disciplines within bioethics a little more transparent.

1.1.2.1 *Scientific and technical possibilities*

First of all, no bioethical reflection will be able to say anything about enhancement without being informed about the possibilities that are currently