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The Barcelona Declaration

Towards an Integrated Approach to Basic Ethical Principles

Abstract

From 1995 to 1998, the European Commission supported the "Basic Ethical Principles in European Bioethics and Biolaw" research project (1995–1998). The project was based on cooperation between 22 partners coming from most EU countries. Its aim was to identify the ethical principles relating to autonomy, dignity, integrity and vulnerability as four important ideas or values for a European bioethics and biolaw. An important resume of the BIOMED project was the partner's Policy Proposals to the European Commission, the Barcelona Declaration *of 1998 (reprinted as an appendix to this article), which is unique as a philosophical and political agreement between experts in bioethics and biolaw from many different countries.*

In this article, we want to compare the Barcelona Declaration *with some other recent international Documents on bioethics and biolaw. We will relate the* Barcelona Declaration *to the framework of different international documents and codes of conduct about bioethics and biolaw. In particular, we will look at the similarities and differences when compared with the Council of Europe's* Convention for the Protection on of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine*, adopted by the Committee of Ministers in 1996. Moreover, we will look at The UNESCO* Declaration on the Humane Genome *from 1997.*

Thus, the Barcelona Declaration *does not only represent European ethical principles for bioethics and biolaw, but the document should also be conceived as a conceptual clarification and articulation of major ethical principles, which are central to international concerns for a universal bioethics and biolaw.*

Key words

Barcelona Declaration, bioethics, biolaw, integrative approach, basic ethical principles

Basic ethical principles and the *Barcelona Declaration*

In the report to the European Commission *Basic Ethical Principles in European Bioethics and Biolaw. Autonomy, Dignity, Integrity and Vulnerability* (2000) we gave a definition of the basic ethical principles (Rendtorff & Kemp: 2000). They are four values to guide decision-making about bioethics and biotechnological development in relation to law and public policy in late modernity. After three years research and preparation of the report partners gathered in Barcelona, the final meeting, in order to decide about policy proposals for application of basic ethical principles. This was the basis for the policy proposals which are printed in the *Barcelona Declaration* that adopts the definition of basic ethical principles expounded in the report to the European Commission. In this context, we defined four ethical principles an explained them in the report as follows:

1. Autonomy should not only be interpreted in the liberal sense of "permission", instead five aspects of autonomy should be put forward: 1) the capacity of creation of ideas and goals for life, 2) the capacity of moral insight, "self-legislation" and privacy, 3) the capacity of rational decision and action without coercion, 4) the capacity of political involvement and personal responsibility, 5) the capacity of informed consent. However, autonomy remains merely an ideal, because of the structural limitations given to it by human weakness and dependence on biological, material and social conditions, lack of information for reasoning etc.
2. Dignity should not be reduced to autonomy. Although originally a virtue of outstanding persons and a virtue of self-control in healthy life – qualities, which can be lost, for instance by lack of responsibility or in extreme illness – it has been universalised as a quality of the person as such. It now refers to both the intrinsic value of the individual and the inter-subjective value of every human being in its encounter with the other. Dignity concerns both oneself and the otherothers: I must behave with dignity, and I must consider the dignity of the other; I must not give up civilised and responsible behaviour, and the other should not be commercialised andor enslaved.
3. Integrity accounts for the inviolability of the human being. Although originally a virtue of uncorrupted character, expressing uprightness, honesty and good intentions, it has, like dignity, been universalised as a quality of the person as such. Thus it refers to the coherence of life in time and space (in memory and corporeal life) that should not be touched and destroyed. It is coherence of life, which is remembered from experiences and therefore can be told in a narrative. Therefore respect for integrity is respect for privacy and personal environment and in particular for the patient's understanding of his or her own life and illness in body and soul. Integrity is the most important principle for the creation of trust between physician and patient, because it demands that the physician listens to the patient telling the story about his or her life and illness.
4. Vulnerability concerns integrity as a basic principle for respect for and protection of human and non-human life. It expresses the condition of all life as able to be hurt, wounded and killed. Vulnerability concerns animals and all self-organising life in the world, and for the human community it must be considered as a universal expression of the human condition. The idea of the protection of vulnerability can therefore create a bridge between moral strangers in a pluralistic society, and respect for vulnerability should be essential to policy making in the modern welfare state. Respect for vulnerability is not a demand for perfect and immortal life, but recognition of the finitude of life and in particular the earthly suffering presence of human beings.

The basic ethical principles are promoted in the framework of solidarity and responsibility. It is an expression of the movement of society in the civilising process towards the Kingdom of Ends. This framework indicates a movement toward global justice (equality). We stress that the four values have a universal foundation in a hermeneutical circle of "wide reflective equilibrium" and considerate judgement. The principles should be interpreted as expressions of the concrete phenomenological reality of the everyday human life-world.

Accordingly they have great importance as reflective ideas for concrete decision-making. This “weak universality” of the principles indicates their position as important values for European (and global) ethical and legal culture.

The *Barcelona Declaration* and the history of bioethics and biolaw

In this sense we argue in the report that the idea of treating human beings as ends-in-themselves (autonomy, dignity, integrity, vulnerability) is expressed in the biotechnology laws of different European countries, where the constitutional democratic state is the guarantee of the protection of the human person. This protection of the individual is already present in the *European Human Rights Declaration* that should be implemented as a framework for the national constitutions. Such a concept of respect for persons, freedom, democracy and the rule of law is inherent in declaration of human rights e.g. the *European Human Rights Convention* from 1950, and the following European declarations of protection of specific human rights.

Some of the first European initiatives for regulating biomedicine were the initiatives of the German Weimar Republic to develop guidelines for protection of human beings in medical treatment and biomedical research in 1931. Free and informed consent was proposed as the basis for participation in biomedical research. The Nazis grossly violated these rules, when they experimented violently with human beings in concentration camps. As a result of the Nuremberg processes, the Nuremberg Code (1948) became the starting point for *European and International Declaration of protection of human beings in biomedical research*. In this declaration, principles of informed consent and “do no harm” have become central to the establishment of international regulation of biomedical research. The World Medical Association in 1964 and 1975 made the *Helsinki Declarations* (Helsinki I and Helsinki II) that correspond to these principles. Helsinki II extends Helsinki I by inviting all countries to establish ethical committees for evaluation of biomedical research projects. The basic principles of these two declarations are that the interests of science and society in biomedical research must never prevail over the concern for the welfare of the individual.

In the *Barcelona Declaration*, we go far beyond the *Helsinki Declarations* because we do not restrict ethical protection to biomedical research but instead we propose ethical principles as a general foundation for protection of human beings when they are confronted with biomedical science and treatment. The *Barcelona Declaration* represents a development of human rights of the body, which can be determined as bio-rights in a broader horizon for human rights. The constitutional state and the democratic legal order should treat human beings as ends-in-themselves and the ideas of respect for autonomy, dignity, integrity and vulnerability are realisations of this political ideal of the formation and creation of law. In this way, the basic principles form the anthropological premises for the legal respect for the human person and the law should be the social and cultural realisation of this protection of the human person as the basis for an European constitutional culture.

The European Convention of bioethics and human rights

If we look closer at Council of Europe’ *Convention on Human Rights and Biomedicine*, we can argue that the protection of the humanity of the person and its right to self-development in this convention include the formulation of a sphere of privacy based on the principles of autonomy, dignity, integrity and vulnerability and linked to basic human rights such as the right to life, protection of degrading treatment during torture and the inviolability of the human body.

The use of the notion of "human being" instead of "person" in the convention as general definition of what is human, signifies the importance of the concept of human dignity and of the special position of the human body in the social community. A consequence of this is the non-commercialization of the human body and its elements; that is prohibition of sale of the human organs, of embryos and of humane genes. This also relates to the prohibition of germ-line therapy and human cloning and therefore it concerns future generations containing the protection of their genome as a part of the rights to genetic integrity and identity. And, as such, this is a new horizon for human rights in European and in international law.

The basic principles in the work of the Council of Europe on biomedical questions aims at the protection of human rights as protection of the physical and intellectual integrity in the progress of biology, medicine and bio-chemistry. This implies the rights of human beings to know their biological roots, self-determination on the human body, respect for its genetic constitution and identity as a human being. Such a general tendency in this development of biolaw can be interpreted as a concretization of the basic principles of autonomy, dignity, integrity and vulnerability, the rights and freedoms of the individual in relation to some of the most important biomedical fields.

The Council of Europe is indeed in the Convention aware of the rights of the sick and vulnerable persons. It affirms the spiritual value of the person, the primacy of the dignity of the human being in relation to scientific progress. This protects the rights of the vulnerable by respecting the integrity of privacy. Further is developed the idea of the special value of the human person that is realized in the protection of the human genome from certain forms of manipulation i.e., reproductive cloning and germ-line therapy and in the concept of the non-commercialization of the human body. This is, for example, realized in the distinction between invention and discovery in relation to the rights of patents to their genes. Further, the development in the Council of Europe integrates the protection of the bodily-incarnated human person in broader light of social responsibility and solidarity.

UNESCO's convention of protection of human genome

It is this conception of humanity that also is expressed in the UNESCO *Declaration of protection of the humane genome*. The concept of human dignity may be said to include the human body, because human beings are considered as a unity of body and soul, where the body has its own rights of protection of autonomy, dignity, integrity and vulnerability. To respect the human body is therefore to recognize its dignity as manifestation of a human person. This concept of the human being does not only refer to the individual but to the common destiny of humanity as a form of life.

The UNESCO Declaration says that every human being has the right to respect for its unique genetic structure. Humanity ought to take care of the plurality and difference of our human genes. Society ought to have solidarity with those human beings who have weak genes and it should not systematically favor people with a specific genetic constitution and therefore the Declaration characterizes the human genome in its diversity as the "Common Heritage of mankind". The human genome can be considered as an irreplaceable work of art that we are required to protect. This concern for human dignity in genetic research is an international obligation which goes beyond internal affairs of states and signifies that the interests of the individual always should prevail over the utilitarian use of the body in the interest of society.

When using biomedical technology we have the obligation to respect human rights of autonomy, self-determination and informed consent and indeed "the right not to know" if an individual does not want to know its own genetic structure. UNESCO's Declaration connects human dignity with the legal notions of human physical and psychological integrity as an important foundation for regulation of biomedical progress. This does not mean that no intervention in the human genome should be allowed, but when gene technology is used for medical treatment it should not be allowed to make interventions that have direct eugenic purposes of modifiying specific human characteristics. The concern for the humane genome as common heritage of mankind therefore includes the protection of valuable aspects of the genetic structure of future human individuals. At the same time, personal information about the genetic structure is considered as a part of the integrity and vulnerability of individuals. There is a close relation between protection of the right to privacy and this integrity that expresses the human body as a private sphere of self-determination.

Towards a universal biolaw

We can deduce from the *European Convention on bioethics and human rights* and from the UNESCO *Declaration on protection of the human genome* that the concepts of human autonomy, dignity, integrity and vulnerability require concrete significance in bioethics and biolaw because protection of individual human beings prevails over the interests of science and society. Recognition of the significance of technological progress for collective interests, respect for the human body, extension of law to be valid for life before birth and after death and in relation to future generations are important aspect of this protection of human privacy based on protection of the inviolability of the human body. Thus, concern for human dignity precedes self-determination and society has a duty to avoid that human individuals in despair or desperation are forced to violate their own bodies in selling their organs or offering themselves for dubitable genetic experiments. Therefore, development of universal biolaw contributes to realize the basic ethical principles of protection of autonomy, dignity, integrity and vulnerability as they have been spelt out clearly in the *Barcelona Declaration*. The concept of humanity implied in the international conventions and declarations can be considered as an expression of the humanism of the philosophy of the basic ethical principles that cares for humanity and wants the persistence of "real" human life on earth in the future.

References:

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Appendix:

THE BARCELONA DECLARATION POLICY PROPOSALS

to the European Commission
November 1998

by Partners in the BIOMED-II Project
Basic Ethical Principles in Bioethics and Biolaw

A. Preamble

This document is the result of a process of discussion undertaken in a three-year EU BIOMED research project by a group of 22 partners based in different countries within the enlarged European Economic Community and coordinated by the Centre for Ethics and Law in Copenhagen. The partners were drawn from several different disciplines and horizons but their common interest was in ethical questions raised by the progress in modern biomedicine and biotechnology.

This process consisted of four big meetings (Copenhagen, Sheffield, Utrecht, Barcelona) and ongoing debate between the partners. It resulted in a two-volume publication (Basic Ethical Principles in European Bioethics and Biolaw Vol. I-II) together with a series of Working Papers as a first step towards stimulating and supporting a wide democratic debate about the most controversial questions in bioethics and biolaw. The first volume is co-authored by Jacob Dahl Rendtorff and Peter Kemp, but it was extensively discussed by the partners who participated at the final meeting in Barcelona in November 1998. The second volume contains particular papers by the partners relating to the project.

This short discussion document with policy proposals is aimed at a number of audiences, at decision-makers in the European Union at all levels, at educators at every level, researchers and practitioners, but most importantly at citizens generally within Europe (not just within the European Union). Its aim is to stimulate and assist a broader controversial public debate on some of the most vital and conflictual questions of our times. These questions have to be discussed not only in relation to the local European environment but in a globally sensitive way. The questions are not simply about the welfare of humans but also about social equity, the welfare of animals and the sustainability of the global environment.

In this document, you will find some remarks about the context within which the partners believe that the issues should be debated, four principles that the partners think are helpful guiding ideas in carrying forward the contemporary debate, and an agenda revealing some of the leading questions and some proposed pathway responses.

Indeed, the partners offer this document as experts but also in the spirit of responsible citizenship. In particular, it would be unethical for the partners to impose their specific proposals suggested below. Thus, it is the partners' explicit intention, and the purpose of this document, to facilitate critical democratic debate and responsive and accountable decision-making.

B. Context

For the purposes of discussion of policy proposals, the partners worked with the idea that the value of "autonomy" (networked with integrity, dignity, and vulnerability) should be placed in the context of care for others – a context that already presupposes an ethic of solidarity, responsibility and justice (fairness). However, it is important that the idea of "autonomy in the context of care for others" itself should be placed in the broader context of biomedicine and biotechnology, economy, and culture in Europe in the late decades of the Twentieth Century.

First, the accelerated development of biomedicine and biotechnology – particularly in the area of genetics – has created (and is creating) many new possibilities but also it is posing many questions about the place of humans, animals, plants, and the environment (both natural and social). These are questions that the partners believe need to be debated as widely as possible and as a matter of urgency, but without the need being felt to arrive at hasty conclusions. However, there are considerable difficulties in articulating the terms in which such issues are to be framed and discussed, let alone resolved. The proposals below identify four key terms of reference for such a debate (namely the four principles of autonomy, dignity, integrity, and vulnerability) as well as outlining some policy suggestions indicated by these regulative basic concepts in a normative context.

Secondly, the proposals should be read as a contribution to a process of dialogue and debate about bioethical and biolegal policy in Europe. To a considerable extent, policy in Europe already reflects a culture of care for others – witness, for example, , which was finalised while this project was underway. There is also considerable support in Europe for the principle of non-discrimination and the long-term sustainability of the environment. However, there can be little doubt that Europeans share the sense, first, of a responsibility for, and a responsivity to, others (the sense that others really do matter), and secondly a responsibility for ecological viability. Nevertheless, we are still marking out the conceptual terrain on which we can meet to express our agreement but also our disagreement. The four principles of autonomy, dignity, integrity, and vulnerability, are, we think, important features of that terrain. It is not claimed, though, that these principles represent the whole of that terrain, nor indeed the only way of expressing an ethic of care for others and the quality of the global environment. The way they have been articulated is driven by the wish to achieve an open consensus. While the group agreed that the four guiding ideas are central to the analysis of bioethics and biolaw there was a considerable disagreement about a substantive interpretation of the guiding ideas and in particular the notion of dignity, while there were total agreement on the importance of articulating the notion of vulnerability. It should also be made clear that any application of the four guiding ideas will depend heavily on the particular interpretation of the principles.

Thirdly, the proposals offer a conceptual framework within which Europeans can debate issues of bioethics and biolaw. It should not be thought, however, that a common language implies an easy resolution of the matters to be discussed. Facilitating debate is one thing; resolving value differences is another matter altogether. Each of the four regulative principles presented in the next section should be regarded as guiding ideas for debate and decision-making. However, these principles are open to competing interpretations; the precise relationship between each of the principles will be informed by more general theoretical positions taken by disputants; and which life forms are to be included within the idea of the "other" (whether as a rights bearer or as one with interests to be protected and promoted) is contestable, as is the relationship between humans and the natural environment.

Fourthly, the framework is offered at one level for use within the European Union, as an economic community within the global market. Within this market, it must be understood, that biotechnology and biomedicine represent highly competitive global business. The market involves a process of exclusion which operates at a number of levels. At one level, citizens have difficulty in intervening in decision-making in this market. This document seeks to compensate for this democratic deficit. At another level, this post-national market operates to exclude the underprivileged throughout the world, North as well as South. Although this document has been drafted by Europeans for debate amongst Europeans, as we have emphasised, biotechnology is a global business. Whereas the significance of it being a global business is that the ethic of care for others knows no regional boundary, the significance of it being a global 'push' business is that ethics must address the commercial investment and imperatives driving modern biotechnology. That is to say, agreed positions within European bioethical debate will not be defensible if they neglect the interests of non-Europeans. Nor will they be effectively promoted if they fail to engage with commercial practice.

Finally, it is worth drawing out a crucial sense in which we (even the autonomous) are all vulnerable. The ethic of care for others is not simply a matter of protecting those who are incapable of acting autonomously (the most vulnerable forms of life). Rather, it is an ethic that builds on the premise that we are all capable of being wounded by the uncaring (and sometimes paternalistic) actions of others.

Despite recognition of complexities, in applying the four guiding ideas in context, the group was nonetheless able to tentatively agree on the following prescriptions, at least in principle:

C. Articulations

1. Autonomy should not only be interpreted in the liberal sense of "Permission" given for treatment and/or experimentation. Five qualities should be considered: 1) the capacity of creation of ideas and goals for life, 2) the capacity of moral insight, "self-legislation" and privacy, 3) the capacity of reflexion and action without coercion, 4) the capacity of personal responsibility and political involvement, 5) the capacity of informed consent. But autonomy cannot express the full meaning of respect for and protection of the human being. Autonomy remains merely an ideal, because of the structural limitations given to it by human finitude and dependence on biological, material and social conditions, lack of information for reasoning etc. We must recognise the human person as a situated living body. Autonomy in relation to small children, persons in coma and persons that are mentally ill should remain an open question.
2. Dignity is the property by virtue of which beings possess moral status. There are several contested conceptions of dignity in European culture. Dignity is, variously, identified with the capacity for autonomous action, the capacity for experiencing pain or pleasure, being human (in the biological sense) or being a living organism or even system. Acknowledging

various definitions our view is that it is nonetheless possible to argue successfully that human being have duties towards the nonhuman part of living nature.

3. Integrity. The idea of integrity expresses the untouchable core, the basic condition of dignified life, both physical and mental, that must not be subject to external intervention. Therefore respect for integrity is respect for privacy and in particular for the patient's understanding of his or her own life and illness. Integrity refers to the coherence of life of beings with dignity that should not be touched and destroyed. In relation to human beings it is coherence of life which is remembered from experiences and therefore can be told in a narrative. It is the lifestory of a person, the narrative unity or history of human society and culture. Some would also include the natural grown coherence in the life of animals and plants and finally the created wholeness of the world which makes the conditions for all life.
4. Vulnerability expresses two basic ideas. (a) It expresses the finitude and fragility of life which, in those capable of autonomy, grounds the possibility and necessity for all morality. (b) Vulnerability is the object of a moral principle requiring care for the vulnerable. The vulnerable are those whose autonomy or dignity or integrity are capable of being threatened. As such all beings who have dignity are protected by this principle. But the principle also specifically requires not merely non interference with the autonomy, dignity or integrity of beings, but also that they receive assistance to enable them to realise their potential. From this premiss it follows that there are positive rights to integrity and autonomy which grounds the ideas of solidarity, non-discrimination and community.

D. Applications

5. The four guiding ideas or principles do not abolish cultural variations in Europe as long as they comply with the principle of subsidiarity.
6. The application of guiding ideas should not be restricted to the human sphere; dignity, integrity and vulnerability might also be considered as a basis for legislation and legal practice in relation to animals, plants and the environment.
7. Each country should have a national health service based on the principle of social insurance.
8. A Patients' Charter, specifying patient rights and a role for patients in health care policy decisions, should be enshrined in the legislation of all European countries.
9. Patients have the right to consent and refuse treatment and experimentation.
10. Lay persons should sit on research ethics committees.
11. Children born as a result of gamete donation have a right to information about their genetic parents, but donors should have no responsibilities or duties to such children.
12. Embryos should be accorded a proportional moral status according to their degree of development.
13. There should be protection of animals and the biosphere in legislation.
14. Anonymity of organ donors should be further discussed.

15. Euthanasia and other end of life decisions should be the subject of extensive debate and public consultation.
16. The commercialisation of human tissue, including the human genome and organ donation should be the subject of extensive debate and public consultation.

The policy-proposals were signed by the following partners:

1. Francesc Abel, Institut Borja de Bioètica, Spain
2. Mylène Botbol-Baum, Université Catholique de Louvain, Belgium
3. Roger Brownsword, Faculty of Law, University of Sheffield, England
4. Jean-François Collange, Faculté de Théologie Protestante, Université des Sciences Humaines de Strasbourg, France
5. Geneviève Delaisi de Parseval, France
6. Torben Hviid Nielsen, Senter for teknologi og menneskelige værdier (TMV) (Centre for Technology and Culture), Norway
7. Teresa Iglesias, Dept. of Philosophy, University College Dublin, Ireland
8. Peter Kemp, Centre for Ethics and Law, Denmark
9. Joao Carlos Loureiro, Centro de Direito Biomédico, Universidade de Coimbra, Portugal
10. Catherine Manuel, Faculté de Médecine, Université Aix Marseille II, France
11. Madeleine Moulin, Centre de Sociologie de la Santé, Université Libre de Belgique, Belgium
12. Rui Nunes, Centro De Estudos De Bioética, Portugal
13. Francesco Rubino, Dep.of Civil & Economic Relationships, Salerno University, Italy
14. Jan Helge Solbakk, Senter for medisinsk etikk (Centre for Medical Ethics), Universitetet i Oslo, Norway
15. Georges Thill, PRÉLUDE réseau international, Facultés Universitaires Notre- Dame de la Paix, Namur, Belgium
16. Helge Torgersen, Institute of Technology Assessment, ITA, Austrian Academy of Sciences, Austria

These policy proposals were made at the last meeting of the BIOMED-II Project in Barcelona, November 1998. They are reprinted in the *Final Project Report* (two volumes) *on Basic Ethical Principles in European Bioethics and Biolaw*, Institut Borja de Bioètica, Barcelona & Centre for Ethics and Law, Copenhagen, 2000, which contains an extensive discussion of the four guiding ideas and their applications. Comments from Partners to Policy Proposals, see Volume II of the *Final Project Report*.

Peter Kemp, Jacob Dahl Rendtorff

Deklaracija iz Barcelone

Prema integriranom pristupu temeljnim etičkim principima

Sažetak

Europska komisija je od 1995. do 1998. podupirala istraživački projekt »Temeljni etički principi u europskoj bioetici i biopravu« (1995–1998). Projekt se temeljio na suradnji 22 partnera iz većine država Europske unije. Cilj projekta bio je identificirati etičke principe povezane s autonomijom, dostojanstvom, integritetom i ranjivošću kao četirima važnim idejama ili vrijednostima za europsku bioetiku i biopravo. Važan sažetak BIOMED projekta bio je Prijedlog Smjernica Europskoj komisiji – Deklaracija iz Barcelone *iz 1998. godine (priložena ovome tekstu) – koja je jedinstvena jer predstavlja filozofsku i političku suglasnost stručnjaka za bioetiku i biopravo iz mnogih država.*

U ovome tekstu želimo usporediti Deklaraciju iz Barcelone *sa nekim drugim novijim međunarodnim dokumentima o bioetici i biopravu. Povezat ćemo* Deklaraciju iz Barcelone *sa okvirom koji nude različiti međunarodni dokumenti i propisi o djelovanju u bioetici i biopravu. Posebno ćemo se usmjeriti na sličnosti i razlike sa* Konvencijom o zaštiti ljudskih prava i dostojanstva ljudskih bića u pogledu primjene biologije i medicine*, koju je prihvatilo Vijeće ministara 1996., te ćemo promotriti i UNESCOvu* Deklaraciju o ljudskom genomu *iz 1997.*

Dakle, Deklaracija iz Barcelone *ne predstavlja samo europske etičke principe u bioetici i biopravu, nego ujedno pojašnjava i artikulira osnovne etičke principe koji se nalaze u središtu međunarodnog interesa za univerzalnu bioetiku i biopravo.*

Ključne riječi

Deklaracija iz Barcelone, bioetika, biopravo, integrirani pristup, temeljni etički principi

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Die Barcelona-Deklaration

Für einen integrativen Zugang zu den ethischen Grundprinzipien

Zusammenfassung

„Ethische Grundprinzipien in der europäischen Bioethik und im Biorecht" ist der Titel eines Forschungsprojekts, das von 1995 bis 1998 von der EU-Kommission unterstützt wurde. Das Projekt gründete sich auf die Zusammenarbeit von 22 Partnerorganisationen aus der Mehrzahl der EU-Staaten. Es sollten ethische Grundprinzipien ermittelt werden, die sich ableiten aus Autonomie, Würde, Integrität und Verwundbarkeit als den vier Ausschlag gebenden Ideen bzw. Werten, die in der Bioethik und im Biorecht in Europa zum Tragen kommen sollen. Aus dem Resümee des EU-BIOMED-Projektes wurde ein Rahmenprogramm der EU-Kommission abgeleitet und 1998 in der Deklaration von Barcelona *festgehalten (die dem Text beiliegt). Bei dieser Deklaration handelt es sich um einen einzigartigen Text, der die philosophische und politische Übereinstimmung von Experten aus dem Bereich der Bioethik und des Biorechts aus vielen Staaten dokumentiert.*

Im vorliegenden Artikel soll die Barcelona-Deklaration *mit einigen internationalen Dokumenten zu Bioethik und Biorecht jüngeren Datums verglichen werden. Die Autoren stellen die Deklaration in Zusammenhang mit den Richtlinien, die in verschiedenen anderen internationalen Dokumenten und Rechtsvorschriften zum Vorgehen im Bereich der Bioethik und des Biorechts vorgegeben sind. Besondere Aufmerksamkeit gilt dem Vergleich mit der* Konvention zum Schutz der Menschenrechte und der Würde der Menschen im Hinblick auf die Bereiche Biologie und Medizin*, die 1996 vom EU-Ministerrat verabschiedet wurde. Sodann wurde die* UNESCO-Deklaration betreffend des menschlichen Genoms und der Menschenrechte *aus dem Jahre 1997 näher untersucht.*

Die Barcelona-Deklaration *präsentiert also nicht nur die in Europa angestrebten ethischen Grundsätze in Bioethik und Biorecht, sondern erläutert und artikuliert ethische Grundprinzipien, die sich weltweit im Mittelpunkt des Interesses für universale Bioethik und Biorecht befinden.*

Schlüsselwörter

Deklaration von Barcelona, Bioethik, Biorecht, integrativer Ansatz, ethische Grundprinzipien

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La Déclaration de Barcelone

D'après l'approche intégrée des principes éthiques de base

Résumé

La Comission européenne a soutenu, de 1995 à 1998, le programme de recherche intitulé « Les principes éthiques de base en bioéthique et en bio-droit européens ». Le projet était basé sur la collaboration de 22 partenaires issus de la plupart des pays de l'Union européenne. L'objectif du projet était d'identifier les principes éthiques d'autonomie, de dignité, d'intégrité et de vulnérabilité comme étant les quatre idées et valeurs majeures de la bioéthique et du biodroit européens. Les Propositions et les recommandations à la Commission européenne – la Déclaration de Barcelone *de 1998 (ci-jointe) – constitue un résumé important du projet BIOMED. Cette déclaration est unique dans son genre car elle représente l'unanimité philosophique et politique des experts en bioéthique et en biodroit de nombreux pays.*

Dans ce texte, nous souhaitons comparer la Déclaration de Barcelone *avec quelques nouveaux documents en bioéthique et en biodroit internationaux. Nous situerons la* Déclaration de Barcelone *dans le cadre proposé par les différents documents internationaux et les règlements relatifs à l'action dans le domaine de la bioéthique et du biodroit. Nous examinerons tout particulièrement les similitudes et les différences par rapport à la « Convention pour la protection des droits de l'homme et la dignité de l'être humain à l'égard des applications de la biologie et de la médecine », adoptée en 1996 par le Conseil des ministres. Enfin, nous étudierons la « Déclaration sur le génome humain » de l'Unesco de 1997.*

Donc, la Déclaration de Barcelone *ne représente pas seulement les principes éthiques européens en matière de bioéthique et de biodroit, mais éclaire et articule les principes éthiques de base se trouvant au cœur de l'intérêt international pour une bioéthique et un biodroit universels.*

Mots-clés

Déclaration de Barcelone, bioéthique, biodroit, approche intégrée, principes éthiques de base