JAHR
UDK: 179:61 | ISSN: 1847-6376

JAHR
Volume/godište 1, Number/broj 1, pp/str. 1-220

Publisher/Nakladnik:
Department of Social Sciences and Medical Humanities (University of Rijeka School of Medicine, Croatia)
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Annual JAHR is published annualy in edition of 200 copies./Godišnjak JAHR izazi jednom godišnje u nakladi od 200 primjeraka.

The price of a copy is 3 €./Cijena pojedinog primjerka je 20 kuna.

Account number/Žiro račun: 236000-1101410222; reference number/poziv na broj 4200.

UDK: 179:61

ISSN: 1847-6376

JAHR

ANNUAL
of the **Department of Social Sciences and Medical Humanities**
University of Rijeka School of Medicine

GODIŠNJAK
Katedre za društvene i humanističke znanosti u medicini
Medicinskog fakulteta Sveučilišta u Rijeci

Volume/godište 1 | Number/broj 1 |
pp./str. 1 – 220 | May/svibanj 2010 |

Rijeka/Croatia

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Foreword/Uvodna riječ

Assisting the birth of a new journal must be similar to assisting the birth of a child: a mixture of proud and enthusiasm, of hope and expectation, of fear and anxiety. The birth of the first JAHR, however, is everything but unexpected. Department of Social Sciences and Medical Humanities of University of Rijeka School of Medicine has cherished the interest for bioethics and humanities in general for years, organizing 11 annual conferences (Rijeka Days of Bioethics), the 9th World Congress of Bioethics (Rijeka-Opatija, September 2008), and publishing tens of monographs, proceedings, and papers (among other, the translations of Potter, Sass, Sakamoto, Tai, Campbell, Shinagawa, Pessini, and other into Croatian). The educational activity encompasses about 50 courses (mandatory or elective), delivered to students of various programs at University of Rijeka School of Medicine. Until summer 2008, the Department had been headed for three decades by Professor Ivan Šegota to whom my personal gratitude has to be expressed once again for his enlightening efforts that do not cease even now.

JAHR is supposed to offer one more option for international exchange of ideas, to all those who are not ready to resign to numerous ethical and logical challanges of the modern world. The name of the Annual was chosen to honor Fritz Jahr (1895.-1953.), the Protestant theologist who introduced the concept of bioethics (*Bio-Ethik*) in 1927, thus anticipating the growing collision between human material progress and human (declared) spiritual goals. (That the German word *Jahr* (year) so wittily corresponds to the notion of »annual,« represents a mere, but symbolic concidence.)

We expect the JAHR be published once a year, but special and/or extraordinary issues might become reality, especially if we succeed in provoking more scholars to submit papers. A part of the JAHR will always be devoted to the papers presented at the previous-year Rijeka Days of Bioethics round table. Those contributions, as well as all others, will be peer reviewed by recognized experts in the field. We also would like to introduce some permanent rubriques, like »The Fathers' angle« (devoted to the work of the founders of bioethics, like Jahr, Potter, etc.), »Partner institutions« (the presentation of institutions involved in bioethical research), »News from the Department and Activity report,« letters to the Editor, book reviews, Bioethical calender, etc. Of course, we are open for your suggestions as well.

We have limited the selection of languages to those our public and the Editorial Board can deal with more easily. We also hope to fulfill our ambitions regarding the JAHR's international indexing and databasing as soon as possible.

I would like to thank all those who, despite of their numerous obligations, accepted to become members of the Scientific Council and Editorial Board, respectively. We cordially invite the bioethical community to share its ideas and research results with us. You are doing important and promising work: do not prevent it from its indispensable impact upon the world in peril.

Amir Muzur
Editor-in-Chief

A cultural and moral vision for the 21St century

Science and technology are value-neutral. They are one sector only of a larger human culture, overcoming the cruelties and inhumanities of raw nature and uncivilized and inhumane people. Thus, humanities studying the impact of science and technology on cultures and societies are an essential and indispensable part of human culture. Ever since Kain killed his brother Abel, we humans have used sticks, knives, ammunitions, laws and regulations, knowledge, sciences and technologies, drugs and medical interventions for good or for bad purposes, - for cultivating raw and cruel nature to become a better home for humankind and human culture or for being cruel and exploitive to humans, co-creatures, and environments. Thus, science and technology need to be guided by moral values and cultural visions. Medicine and medical research are one of the proudest fields of serving fellow humans who are in pain and despair and who need information and education, therapy, nursing and other forms of help. Therefore, the moral and cultural guidance and control of modern medicine and modern sciences, including the social sciences, is a necessary and indispensible vision for the third millennium. The Department of Social Sciences and Medical Humanities at Rijeka Medical University has to be congratulated to take a European and global leadership in communication and cooperation into a more cultivated and morally responsible future of research, review, teaching, and training.

In connecting the title of the new Annual to the visionary Fritz Jahr and his concept of bio-ethics, the Department focuses on a similar pioneering enterprise as Jahr did nearly a century ago. It is the vision, that Bioethics in the broadest sense is a necessary and indispensible counterpart and a guiding tool for all fields of modern Biosciences. The stronger the powers of science, technology and medicine, the more we need moral review and moral guidance and a framing into cultural and human goals of protecting and supporting life and lives, of protecting social and cultural communication and cooperation, of protecting and enriching the globe and her habitats and environments. Bioscience and Bioethics belong together the same way the head of the Centaur Chiron and his massive body belong to each other; jumping off would mean suicide: without moral control the powers of the body are dangerous and aimless, without the powers of the body, the head is powerless.

The »sanctity of life« is the foundation of Jahr's 1927 Bioethical Imperative, while Kant in 1788 named the »sanctity of the moral law« as the foundation of the Categorical Imperative: ‘The moral law is sacred (inviolable). The person is not sacred, but humankind in his person must be recognized as sacred. Everything in the entire creation, if one wants and has power over it, can be used as a means only; only the human person and with it every intelligent being *is an end in himself.* He is the subject of the moral law, which is sacred, based on the autonomy of his will’ [A156]. We need a new Categorical Imperative, not a formal as Immanuel Kant requested, but a content-rich material Categorical Imperative, - in the words of Fritz Jahr »The rule for our actions may be the Bioethical Imperative: *Respect every living being in principle as a goal in itself and treat it, if possible, as such!*«

The original term Bioethics coined by Fritz Jahr in 1927, is wider than the concepts, developed by Potter and Hellegers in the 1970’s in the United States, and even wider than the narrow contemporary focus on bioethics as a synonym for medical and clinical ethics, research ethics, or even public health ethics. Bioethics encompasses the entire world of life, even social entities such as teams, families, neighborhoods, institutions, corporations, hospital wards and hospitals, - all having internal metabolisms and interactions with their respective partners and environments. Is it correct and professional to use such a wide term as bioethics as a synonym for very precise fields of professional activity such as clinical ethics or ethics of medical research? Spinoza in his *Ethics* once said »omne esse verum quod valde clare et distincte percipio« and Wittgenstein would add »whereof one cannot speak, one must be silent«. Unclear terminology leads to unclear investigations, goals, and actions, not only in science but in the humanities and in morals as well. If ethics and every-day attitudes can learn anything from science, then that precision in definition is a priority and a precondition for clear conceptual and practical work, for communication and for cooperation. Should we really call hospital-based offices for clinical ethics »bioethics centers« or rather more precisely »clinical ethics centers«? Unclear terminology leads to unclear reasoning and acting; it is an expression of unclear thinking itself. There are different terms available for different subjects, fields, and issues: bioethics, medical ethics, hospice ethics, health policy ethics, hospital ethics, biomedical ethics, medical research ethics, physician’s ethics, nursing ethics, health care ethics, public health ethics, gene ethics, consultation ethics, environmental ethics, animal ethics – just to name a few. We must be much more precise in our terminology and in our reasoning! We call apples apples and oranges oranges and not vice versa; of course, apples and oranges belong to the vegetable family of eatable fruits. Being more precise in terminology, will free up the term bioethics to the original broad vision, – another global heritage of the European roots of Bioethics and of Fritz Jahr.

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JAHR

PROCEEDINGS

OF THE 10th BIOETHICS
ROUND TABLE OF RIJEKA:
UNESCO AND BIOETHICS
(Rijeka, Croatia, May 15, 2009)

ZBORNIK RADOVA

10. RIJEČKOG BIOETIČKOG
OKRUGLOG STOLA:
UNESCO I BIOETIKA
(Rijeka, 15. svibnja 2009.)

ANNUAL
of the **Department of Social**
Sciences and Medical Humanities
University of Rijeka School of Medicine

GODIŠNJAK
Katedre za društvene
i humanističke znanosti u medicini
Medicinskog fakulteta Sveučilišta u Rijeci

Introduction/Predgovor

Proceedings of 10th Bioethics Round Table of Rijeka: UNESCO and Bioethics (Rijeka, Croatia, May 15, 2009) represent the collection of papers (sometimes only summaries of the papers) presented at that international meeting, organized as a part of 11th Days of Bioethics in May 2009 in Rijeka. The tradition of publishing proceedings of the Rijeka Bioethics Round Tables had existed for a long time (the former series of proceedings being known since 2005. under the title of *Clinical Bioethic*, edited by Ivan Šegota). The five published volumes of proceedings comprise *Bioethics and the Question of Refusing Blood Transfusion* (2001, eds. Ivan Šegota, Nada Gosić, and Zvonko Bošković), *Bioethics and Palliative Medicine* (2005, ed. Ivan Šegota), *Bioethical Aspects of Communicating with Deaf Patients* (2006, ed. Anamarija Gjuran-Coha), *Bioethics and Genetics: Between Possibilities and Responsibilities* (2008, ed. Iva Rinčić Lerga), and *Bioethics and Medical Law* (2009, ed. Iva Sorta Bilajac).

From this year on, however, the proceedings are meant to become a »permanent rubrique« of a new journal we are about to launch, the *JAHR – Annual of Department of Social Sciences and Medical Humanities at University of Rijeka School of Medicine*. In the first-JAHR proceedings section, seven full papers are published: five of them only in English and the rest both in Croatian original and in English translation, according to the linguistic policy of JAHR. Two more summaries of the papers are published as well. Unlike practice of the former proceedings, all full papers published in JAHR passed a double-blind peer-review process, resulting in not only quality check but also in the categorization of articles. For all that thorny procedure we express our deepest gratitude to our reviewers, who have indebted both the authors and the editors of JAHR. For the linguistic correctness of all the papers originally submitted in English, the responsibility stays with the authors themselves.

Due to the specific topic of the present-year proceedings section (UNESCO and Bioethics) and the frequent refering of almost all the papers to the analyzed declarations, we originally planned to publish also the integrative text of the collection of the basic documents (*Universal Declaration on the Human Genome and Human Rights*, 1997; *International Declaration on Human Genetic Data*, 2003; *Universal Declaration on Bioethics and Human Rights,* 2005*)* but, all those texts being available on the Internet, we abandoned the idea of re-publishing them (Croatian versions of the declarations can be found at http://web.ceu.hu/celab/unesco_hr2.pdf, while the English versions can be found at http://portal.unesco.org/en/ev.phpURL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html; http://portal.unesco.org/en/ev.phpURL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html; and http://portal.unesco.org/en/ev.phpURL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html, respectively).

It is tough to try both to be innovative and to preserve a rich tradition. The only way for JAHR to reach success, nevertheless, is to follow the example of its eponym: to search for and propagate timeless values.

Iva Rinčić
Editor of the 2010 issue of JAHR

Proceedings of the 10th Bioethical Round Table: UNESCO and bioethics – a collection of basic documents (Rijeka, 15th of May 2009)/

Zbornik radova 10. riječkog okruglog stola: UNESCO I BIOETIKA – zbirka temeljnih dokumenata (Rijeka, 15. svibnja 2009)

Round table program/Program okruglog stola

Schedule of presentations held at the 10th Rijeka Bioethics Round Table (BOSR10)/Raspored izlaganja održanih na 10. bioetičkom okruglom stol u Rijeci (BOSR10)

UNESCO and bioethics: a collection of fundamental documents (under the auspices of Croatian Commission for UNESCO)/UNESCO i bioetika: zbirka temeljnih dokumenata (pod pokroviteljstvom Hrvatskog povjerenstva za UNESCO)

15. 5. 2009.

Amir Muzur, Ivan Šegota:
Foreword and opening of Round Table BOSR10: UNESCO and bioethics – a collection of fundamental documents/Uvodna riječ i otvorenje okruglog stola BOSR10: UNESCO i bioetika – zbirka osnovnih dokumenata

Universal Declaration on the Human Genome and Human Rights (1997)/
Opća deklaracija o ljudskom genomu i ljudskim pravima (1997.)

International Declaration on Human Genetic Data (2003)/
Međunarodna deklaracija o ljudskim genetskim podatcima (2003.)

Universal Declaration on Bioethics and Human Rights (2005)/
Opća deklaracija o bioetici i ljudskim pravima (2005.)

Plenary session/Plenarna izlaganja

9,20 Petra Bárd
The force of law: genetic data protection in Central and Easter Europe

I section/I sekcija

10,20 Dean Donev
The development of bioethical consciousness in Macedonia: the absence of legislative dismissals and its consequences/Razvoj bioetičke misli u Makedoniji: odsutnost legislativnih razrješenja i njene posljedice

10,40 Nada Gosić
Contribution of The Universal Declaration on the Bioethics and Human Rights to the culture of dialogue in medicine/Doprinos Opće deklaracije o bioetici i ljudskim pravima kulturi dijaloga u medicini

11,00 Željko Kaluđerović
Bioethical analysis of the United Nations Declaration on Human Cloning/ Bioetička analiza UN deklaracije o kloniranju ljudi

11,20 Jasminka Katić Bubaš, Ervin Jančić
Achieving purpose of The Universal Decalaration on Bioethics and Human Rights in work of hospital ethics committees/Ostvarivanje namjere Opće deklaracije o bioetici i ljudskim pravima u radu bolničkih etičkih povjerenstava

II section/II sekcija

12,40 Amir Muzur, Iva Rinčić
Individual vs. society: on some (eternally) questionable formulations of Article 3 the UNESCO's Universal Declaration on Bioethics and Human Rights/ Pojedinac vs. društvo: o nekim (vječno) upitnim formulacijama članka 3. Opće deklaracije i bioetici i ljudskim pravima UNESCO-a

13,00 Gordana Pelčić
UNESCO, bioethics and child/ UNESCO, bioetika i dijete

13,20 Marija Todorovska
Interpretation and implementation of UNESCO's Universal declaration on Bioethics and Human Rights

13,40 Final disscusion/Završna rasprava
(chairpersons/predsjedavajući: Nada Gosić, Amir Muzur)

Conclusion/Završna riječ

Closing of the Days of Bioethics/Zatvaranje Dana bioetike

14,00 Refreshment/Domjenak

JAHR | Vol. 1 | No. 1 | 2010

UDK: 179:61
Review Article/ Pregledni članak
Received/Primljeno 22/03/2010

Enikő Demény[*]

Universal values, contextualization and bioethics: knowledge production in the age of genetics

»There can be no culturally and psychologically perceptive ethics without taking into account the diversity of moral lives, but there can be no ethics at all without universals ... The hard part is to devise a theory that can readily join universality and the moral complexity of everyday life« (Callahan 2000, p. 38, 41).

ABSTRACT

The impact of biotechnology on all living things is an interdisciplinary inquiry into some of humanity's most fundamental questions: Who are we? How do we live together? How do we relate to the biosphere, to the rest of the living world? Are the answers given to these questions shaped by various contexts: social, cultural, economic, so on? Are there universal answers to these questions? Choosing this interdisciplinary field of knowledge production as object of inquiry offers an opportunity to investigate how traditional theories and disciplines are challenged to evolve in new directions as a response to techno-scientific developments of our times. It also allows us to study patterns of knowledge production, to examine hierarchies of knowledge and expertise, as well as the possibilities of interdisciplinary/transdisciplinary practices in a multicultural context.

I will argue that a framework that incorporates universal principles shall constitute one dimension of an adequate ethical theory in the context of new genetics providing that its principles are formulated in non-exclusionary terms that reflect the relational context of individual lives. As Judith Butler has formulated »the problem is not with the universality, as such, but with an operation of universality that fails to be responsive to cultural particularity and fails to undergo a reformulation of itself in response to social and cultural conditions it includes within the scope of its applicability. When a universal precept cannot, for social reasons be appropriated or when …it must be refused, the universal precept itself becomes a site of contest, a theme and an object of democratic debate« (Butler, 2006, p. 6). What both femi-

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nist and critical bioethicists emphasize in connection with universalistic claims in bioethics is the necessity of reflectivity upon such norms and concepts. Habermas also concludes that sociological reservations offer salutary corrections to normativism, but these critiques do not condemn normative theories to failure by social complexity. According to Habermas, purely normative considerations retain their relevance as long as we accept that complex societies shape themselves in a reflexive manner through law and politics (Habermas, 2008, p. 276) The selective readings of norms that have the grammatical form of universal statements but at the semantic level are vulnerable to particularistic interpretations of their basic concepts, such as persons, human being, call for an empirical explanation (Habermas, 2008, p. 285). Taken all these into account, and noting that the issues that are at stake in the ethical debates on the applications of various biotechnologies and genetics can deeply affect the ways we perceive us as humans, our relationships with others, and with the environment it would be more than desirable that in these debates a plurality of approaches to be represented, as this is stipulated in the three UNESCO Declarations on Bioethics.

Key words: bioethics, feminist bioethics, critical bioethics, knowledge production, contextaulisation

Introduction

The developments in life sciences and in the »new and emerging« technologies have raised issues that have called into question those beliefs which are constitutive of our perspectives of ontological reality. As philosophers of technology highlight, new technologies are going to produce not only new ontologies, but new roles and new responsibilities too (Boenink 2010; Vos and Willems 2000). The impact of the techno-scientific developments on all living things represents therefore a field for interdisciplinary inquiry into some of humanity's most fundamental questions: Who we are? How do we live together? How do we relate to the biosphere, to the rest of the living world? How do we define what is 'natural'? What it means to be a human person?[1] Relating to and deciding about certain applications in this context it is not merely a question of negotiating the risks and benefits of a particular application, but often entails probing our conceptions of life, personhood, death, the meaning of illness and suffering, and of human nature. The emerging medical technologies for example continuously shift our notions of health and disease, and these shifts lead to new conceptions of health. Such changes than inevitably result in new ethical challenges in the field of healthcare (Stempsey 2006, p. 241). As birth, illness, and death increasingly come under technological control, struggles arise over who should control the body and define its limits and capacities. Biotechnologies turn the traditional »facts of life« into matters of expert judgment and public debate (Brodwin 2001). As Fisher points out, the spread of new technologies will require

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[1] See more about this in Habermas 2003; Fukuyama 2002; Brodwin 2001; Rifkin 1998.

new forms of commentary and new forms of public consultation around the legitimacy of techno-scientific research and innovations (Fischer, 2001, pp. 374).

The answers one gives to some basic ontological and conceptual questions influences the ways in which he or she thinks and produce knowledge about new technologies. A number of questions shall than be posed: Can the various values, views and opinions related to these technologies and their applications be negotiated? Are there universal answers or solutions to these issues? Or the answers given to the various problems raised by the techno-scientific developments are shaped by various contexts: social, cultural, economic, political and scientific? The difficulties we face when trying to relate to and especially to take responsible decisions about the future of techno-scientific developments in the present context are indeed significant. Bioethics has facing these difficulties too. In the current context it can not always relay on its traditional theories and methods to answer such questions, since these are also challenged to evolve in new directions as a response to techno-scientific developments of our times. It is thus not surprising that in the recent years there can be observed a renewed concern regarding methodological issues in bioethics which also suggests that it is time to reevaluate the role of bioethical theory in a pluralistic society. Bioethics is struggling to find or to develop new frameworks and methodologies that are suited to the techno-scientific culture and scientific context we are living in.

One of the biggest challenges in the current context is to agree on global, universal norms and frameworks, while respecting the plurality of values and opinions too (Pellegrino 2000, p. 658; Turner 2003). It is not surprising thus that the ongoing debate in bioethics about the relation between universalism and particularism, between normative and descriptive, empirical approaches became highly relevant in this context. While more and more voices join those views that support a dialog between these two approaches rather than continuing the dualistic 'either-or' approach, there is still much to be done on the matters of how exactly such integration can be achieved. Our knowledge about how to integrate empirical findings into the formulation of normative bioethical principles without losing the normative approach is very limited yet. Empirical ethics literature suggests the need for further elaboration of the methodological process of reaching normative conclusions through empirical ethics (Molewijk et al. 2004).

Taking into account that the context of knowledge production in which all the above mentioned issues are embedded has gone itself through significant changes too I will start my paper with a brief characterization of this context, highlighting the role of bioethics in it. Than I will focus my attention on some theoretical and methodological issues related to the possibilities of theory building in bioethics in this current context, focusing on those attempts that try to transgress the gap between normative and empirical approaches. Choosing this interdisciplinary field of knowledge production as object of inquiry offers an opportunity to investigate not only specific patterns of knowledge production but also the possibilities of interdisciplinary practices in a multicultural context. The lenses that guide my analysis are feminist epistemology and critical bioethics. I will argue that a framework that incorporates universal principles shall constitute one dimension of an adequate ethical theory in the context of life sciences and new technologies providing that the principles it relays on are formulated in non-exclusionary terms that reflect the relational context of individual lives. Such a framework than can provide useful background for developing and employing methodologies that are suited for interdisciplinary inquiry on various bioethical issues and problems. In this paper I will discuss contextualization as one of the possible methods that could be efficient (off course combined with other methods) in interdisciplinary attempts aimed to understand the relationship between universal and particular, global and local when dealing with issues raised by new techno-scientific developments.

Bioethics and the context of knowledge production

Many analysts have noted that fundamental changes are taking place in the ways in which scientific, social and cultural knowledge is produced.[2] We are witnessing a new mode of knowledge production, which operates within a context of application, and in which problems are increasingly set in an interdisciplinary or transdisciplinary framework, rather than within a disciplinary one (Gibbons et al. 1994, p. vii). In addition to this the interactions between science and technology, on the one hand, and societal issues on the other hand, have intensified, and the issues at stake are increasingly becoming public ones.

Biotechnology, together with nanotechnology, information technology and cognitive sciences, often named as »converging technologies«, constitute a virulent field of knowledge production. In this field the knowledge generated by various »sciences« is applied, and the resulting »technologies« have various impacts on the individuals, families, society, environment, and so on. But this is not supposed to be a unidirectional impact. According to current »knowledge politics«, »society« shall

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[2] See for example: Gibbons et al. 1994; Thompson-Klein 2001; Nowotny et al. 2001, 2003. Gibbons' main idea was that the old paradigm of scientific discovery (Mode 1) – characterized by the hegemony of theoretical or, at any rate, experimental science; by an internally-driven taxonomy of disciplines, and by the autonomy of scientists and their host institutions, the universities – has been superseded by a new paradigm of knowledge production (Mode 2), which is socially distributed, application-oriented, trans-disciplinary, and subject to multiple accountabilities (Gibbons et al. 1994).

influence, through »deliberative processes« what type of knowledge and what kinds of technologies should be developed.[3] Shaping knowledge thus became a central element for »building society« and an unrestricted production, diffusion and use of new knowledge and technology is regarded as no longer feasible. Knowledge shall be regulated and restricted, and side-, long-term and accumulative effects have to be taken into account, possible risks have to be identified, and observance of ethical norms monitored (Schmidt 2007, p. 313).

According to Kastenhofer due to the development of a techno-scientific culture the former hierarchical relationship between 'hard' and 'soft' sciences might be transformed into a hierarchy between techno-sciences and sciences for accompanying or policy support research (Kastenhofer 2007, p. 267-268). While natural and technical sciences provide knowledge for the development of new technologies, other disciplines, such as bioethics, economics or social sciences are supposed to produce knowledge *about* these technologies: about their ethical and economic impact for example, or about their »societal robustness.« What is interesting for us here in relation to bioethics is the fact that bioethics is not only a discipline *about* (bio)technology, but due to its engagement with regulatory and policy related issues it has the power to make possible (or impossible) certain applications of (bio)technology by legitimizing them (or not). This is why and how bioethics is connected with power. Not only has ethics the power to define new subject positions, but, as Strathern notes, it seems to have the capacity to structure social expectations in such ways as to create new principles of organization (Strathern 2000, p. 281).

As we can see, bioethics, a discipline developed about 40-50 years ago to solve the ethical issues in medical research and clinical practice, by now transcended the strict borders of medicine and health care and became an important field of knowledge production *about* a range of life sciences and technologies: genetics, biotechnology, nanotechnology, nano-biotechnology, synthetic biology, to name only a few of them. In the last two decades, the realization of the impact of biotechnology on all of us has propelled bioethics into the public square where law, policy and adjudication of conflicts take place. With its engagement with »policy« and »legal or regulatory« issues, bioethics had an amazing development, not only as it regards its influence on decision making processes but from the point of view of its institutionalization too. Bioethics, beside technology assessment, risk assessment and intellectual property law, gained special relevance as an instrument for framing

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[3] »Knowledge politics« is a new field of political activity that has emerged during the last 40 years. It normatively defines and asses the specific type of knowledge that is deemed to be the most important and most desirable for the society (Stehr 2005).

issues, ordering new knowledge, and (re)allocating power in issues related to biotechnology (Jasanoff 2005, p. 28).

These developments provided bioethics not only with power and recognition, but they posed to it new challenges too. Its traditional theories and methods are not always applicable in a context in which more and more problems require global answers. At the policy level some degree of consensus has to be reached among various values, worldviews and opinions to can formulate guidelines or to develop universal frameworks for action. Taken into account that the issues raised by the life sciences and the new and emerging technologies related to them often touch upon some the most important segments of human existence such as birth, death, family, health, illness or disease it is not surprising that finding consensus is not an easy task. On the one hand the fact that these issues are common experiences of each human being could raise the hope that to reach a consensus about some problems related to them would not be so problematic. On the other hand however we have the detailed ethnographic and cross cultural studies that show us how differently we interpret and relate to the same basic human experiences as members of different cultures. A number of questions shall be answered than: Can basic assumptions about the human condition and worldviews be negotiated? Can a community made up of diverse individuals and groups find ways to transcend differences in order to reach a consensus on some issues, can all of us agree on some universal norms?

Bioethics and policy

In the policy field there have been attempts to define and set up a universally shared framework to address the issues related to new technologies and bioethics.[4] The Universal Declaration on Bioethics and Human Rights (UDBHR) propose the concept of human dignity as the overarching principle of bioethics and the human rights framework as a way to anchor bioethics in the field of international law. Along with human dignity and human rights, non-discrimination, autonomy and individual responsibility, informed consent, respect for human vulnerability and personal integrity, equality and justice, solidarity and cooperation, and social responsibility to the common good and the biosphere, Article 12 of the Declaration clearly upholds 'respect for cultural diversity and pluralism' as a major bioethical principle. In order to achieve its aims the Declaration propose »to foster multidisci-

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[4] The UNESCO Universal Declaration of Bioethics and Human Rights (2005), The UNESCO International Declaration on Human Genetic Data (2003), The UNESO Universal Declaration on Human Rights and Human Genome, Council of Europe: Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (Convention on Human Rights and Biomedicine) (1997)

plinary and pluralistic dialogue about bioethical issues between all stakeholders and within society as a whole« (UDBHR Article 2/e), and to promote »opportunities for informed pluralistic public debate, seeking the expression of all relevant opinions« (UDBHR Article 18/3).

My aim in this paper is not to evaluate or interpret the Declaration.[5] I will use the Declaration as an example for pointing to the difficulties of reaching global consensus on some sensitive bioethical issues. Although the UNESCO instrument is recognized by many as a valuable tool in policy field and »as an extension of international human rights law into the field of biomedicine« (Andorno 2009), a number of reservations have been formulated on its address: the principles in the Declaration are stated in absolute and inconsistent terms (Selgelid 2005, p. 267-273), the relationship between 'universal' or 'fundamental' principles and the plurality of complementary values in the UDDBHR is problematic, the Declaration quotes many and diverse values, but does not provide a ranking method, and this can lead to serious disagreements (Häyry & Takala 2005, p. 232), the Declaration does not pay attention to the existing structural inequities, it only asserts the 'fundamental equality of all human beings in dignity and rights' but it does not explicitly recognize disparities of power and wealth that deny equal dignity and rights to many (Rawlinson and Donchin 2005). While recognizing that the purpose of the UNESCO document is to draw attention to fundamentally important bioethical values, rather than to resolve deep philosophical questions about conflicts between them, the difficulties inherent in the attempt to create a framework that incorporates some universally shared principles and in the same time is sensitive enough to the wide range of contexts in which these principles are going to be applied in real life are obvious.[6]

The advantage of thinking theoretically about bioethical issues related to new technologies is that we are not forced by those constrains policy makers are, namely to reach a consensus on various complex issues in order to be able to take decisions on them. Theoretical thinking is free of such constrains and thus can freely engage in open and often never ending debates. Such debates, although not directly useful for the policy context, can be however helpful in other ways. They can offer insights for finding ways to transgress the duality of normative and empirical approaches and to develop solutions that might be suitable to incorporate both of these approaches in

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[5] This has been done by scholars who have a deep knowledge about the issues that were involved in adopting the UDBHR, since they were involved in different ways in the process of drafting the Declaration. See for example Andorno 2009; Sándor 2007.

[6] For a more detailed discussion of the UNESCO Declaration on Bioethics and Human Rights see: Developing World Bioethics 5(3): 197-273; Macer 2009, Kaelin 2009.

the understanding and interpretation of complex bioethical issues. In the followings I will try to contribute with my analysis and suggestions to this endeavor.

Normative and empirical approaches in bioethics

It has to be noted and acknowledged that there are many ways of doing bioethics, and bioethics is a dynamic, changing, multi-sited field (de Vries, Turner et al. 2007, p. 3). However, according to Jasanoff the »Western«, mainstream, mainly principialism informed bioethical discourse has the most authority, voice and visibility in biotechnology related discussions (Jasanoff 2005, p. 202) and it is also the one that has been increasingly criticized from a number of perspectives: feminist, indigenous people, social science, so on. What is common in these critiques is the reference to »mainstream« bioethics' abstract universalism and its indifference to the socio-cultural context. According to social science critique, principialism gives a dominant role to the idealized, rational thought, and tends to exclude social and cultural factors, relegating them to the status of irrelevancies, and acts as if concepts like autonomy, patient, justice, equity, non-directive, so on, would have the same meaning in each context (Fox and Swazey 2005). Even if one accepts the importance of principles in bioethics there are still crucial questions that remain unanswered, for example how one should weigh competing ethical claims in real life situations. Several attempts have been made to find solution to this question, however, the development of different models or approaches in ethical decision-making – the interpretation and application of competing principles in »the real world« - remains seriously under-studied. As we could see this theoretical problem has been one of the critiques formulated with regard to the Universal Declaration of Human Rights and Biomedicine too.

There are authors who suggest that instead of abstract principles it would be better to focus on values in bioethical theory building. More and more scholars started to share the idea that in a pluralist, post-modern scenario, theory loses ground to narrative. In order for the variety of religious and cultural voices to be heard in the field of bioethics, many scholars have called for an »empirical turn« in bioethics (Borry et al. 2005, Lopez 2004).[7] As a response to such initiatives the defenders of »principle« based bioethics predict the danger of (moral or cultural) relativism, which would occur with taking into account the socio-cultural context, the »particulars« and regard empirical

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[7] The place of social science in bioethics varies by cultural and social context. In the Netherlands and Belgium the creation of »empirical bioethics« has given social science an established voice in the bioethical conversation (Borry et al. 2005). In North America and the UK, social science methods are widely used in bioethics, but social scientists remain, to a certain extent, strangers to the field (Hedgecoe 2004). In Central and Eastern Europe social science and bioethics are just starting the dialog, in this context philosophical, legal and theological approaches, as well as medical ethics have a more important presence in the field.

social science as purely descriptive (de Vries, Turner et al. 2007, pp. 2). It is argued that the very descriptive nature of the ethnographic social science which gives it its usefulness in addressing the dilemma of religious and cultural pluralisms simultaneously highlights its inadequacies for engaging in the normative ethical inquiry which is characteristic of the 'ethics' in 'bio-ethics' (Callahan 1999, Solomon 2005).[8]

Many scholars agree on that the 'empirical turn' on itself is unable to solve the problems in bioethics. Callahan points out that »(o)ne is the need for ethically relevant knowledge from social scientists. Another is the parallel need for types of ethical theory that have a way of efficaciously using social science knowledge. Still another is a way of climbing that most intimidating mountain known as the is-ought fallacy: the belief that a moral »ought« can be deduced from a factual »is«.« (Callahan 1999, p. 286) Therefore the question is still open: is there a way for not only switching from an approach (principialism, universalism) to other (empiricism, particularism) but to start a real dialog between them and achieve some degree of integration?

Challenging the dualistic approaches

In the above mentioned debate on principialism and its critiques the main line of divide was actually between the abstract normativity of mainstream/traditional bioethics and the contextual, embedded, situated, descriptive or narrative approaches proposed as alternatives to the mainstream approach. There are many ways to relate to this dualism. Traditionally it was held that the integration of the philosophical/normative approach and the empirical one is both epistemologically and methodologically an impossible attempt. There are however some scholars who point out the problems that are inherent in separating facts and values and they propose to transgress the gap between a descriptive, empirical argument and ethical analysis (Hugaas 2009). Such proposal has been formulated already in the late 50' by Edel and Edel in their book on ethics and anthropology. The authors called for a »working partnership« between anthropology and ethics »which avoids any jostling for primacy, or quarrels over vested rights in either methods or problems« (Edel and Edel, 1959, p.6).[9] According to the authors moral philosophers »have dealt with morality as an isolated and self-contained domain, cut off from relations to psychological and cultural processes,« their »vocabulary has been explored as though the field were separate and meaningful in total isolation, as though its processes of justification were utterly unique and unrelated to processes in knowledge generally, and

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[8] For an up to date discussion about empirical research in bioethics see in *The Americam Journal of Bioethics*, 2009, 9(6-7): 59-103 Kon's target article (Kon 2009) and the responses to it.

[9] I made an attempt to respond to their call in an article about bioethics and anthropology (Demény 2008, p. 272)

a conceptual chasm has been created between fact and value to preserve the distinct character of moral judgment. And what has resulted is …a deadlock or impasse in ethical theory« (Edel & Edel *2000, p. vi-vii).* Nelson is also questioning the orthodox model of how »is« relates to »ought,« according to which empiricists supply the facts; moral philosophers, theologians, and humanists provide the values; and philosophers clarify relevant concepts and ensure valid argumentation. He criticized this view as too linear because »it keeps 'is' and 'ought' on their respective sides of the fence,« and he calls instead for »inventing the common wisdom about the relations between the normative and the descriptive« (Nelson 2000, p. 7-11).

The proponents of a critical bioethics are interested in engaging in such approach. Critical bioethicists, beside the classical ethical theories are informed by critical social science too, which claims that it is necessary to understand the lived experience of real people in context. In addition critical theories share the ideas and the methodologies of some interpretative theories, examine social conditions in order to uncover hidden structures, and admit that knowledge is power. Informed by these ideas critical bioethics asks how social science research can meaningfully contribute to philosophical bioethics? According to the adepts of critical bioethics a practice that simply documents the ethical practices of a specific environment could be rather conservative, supporting rather than challenging systems and practices. To avoid this, critical bioethics must be more than purely descriptive, it should be reflexive, it should review theories if they are challenged by practice and last but not least it should be rooted in empirical research (Hedgecoe, 2004).

Transgressing the gap between a descriptive, empirical argument and a normative, philosophical one is not only a methodological, but also an epistemological challenge, which, if it is successfully solves, creates a space for interdisciplinary practice, a practice that seems to be extremely needed and valuable exactly in the current context of knowledge production created by the proliferation of new converging technologies. Research in the act of knowing helps us to produce a deeper understanding of issues at stake, to realize that there are more than one way to see things, that each problem have at least two sides, and there can be credibility on both sides. It also helps in not coming too quickly to a conclusion; to be willing to hold off on passing judgment; to be a little bit more willing to play with possibilities and not having to come to closure on something too fast (Nikitina 2002).

We have to examine thus first of all whether bioethics has an explicit epistemology, a theory of how bioethical knowledge is produced. One widely held, although not universal approach is that generating bioethical insight does not require agreement at the level of fundamental theory. This approach has been advanced by Beauchamp and Childress, who reject the notion that one must choose a single theory from among the existing theories. They claim that there is much more social consensus about principles and rules drawn from the common morality (Beauchamp and Childress 2001, p. 4-5). If this approach would indeed mean the openness to a variety of moral positions and arguments, we could say that it is indeed inclusive and pluralistic**.** However, feminist critiques draw into our attention that in practice mainstream, principialism informed bioethics often tend to be a conversation among experts, bioethicists, physicians, scientists, and governmental authorities. Wolf points out that although there is a great concern in the mainstream bioethics' discourse with patients' and research subjects' rights, these people tend to be the objects of concern and not participants on their own right in the ethical conversation (Wolf 1996, p. 25). Jasanoff also points out that arguments for a meaningful deliberative politics in relation to biotechnology did not emerged from official bioethics in any of the three countries she has analyzed (Janasoff 2005, p. 202).

Feminist scholars find this practice problematic and point out that the conception of the generic subject implicit in the principle-based approaches actually privileges the perspective of an elite group of experts and scientists.[10] Therefore feminists propose to re-examine the principles of bioethics; to create new strategies and methodologies that interject the standpoints of socially marginalized people, and instead of applying abstract principles they call for a more critical approach that would question why and how certain dilemmas get cast and than managed as ethical problems (Wolf 1996; Tong et al. 2004; Butler 2005). To achieve these aims, they can rely on feminist epistemologies, which place emphasis on the relationship between power, gender and the means of generating authoritative knowledge, and aim for a more democratic process of knowledge production. A bioethics informed by such epistemology requires a restructuring of practice of bioethics to be more inclusive. Such epistemology emphasizes the importance of acknowledging the standpoint from which knowledge is generated and acknowledges the relational nature of knowledge production. If this epistemological claim would be taken seriously it would seriously challenge the physician, scientist or bioethicist centered »expert« discourse of mainstream bioethics, and it would give more floor for others perspectives too, such as lay people's accounts or social sciences' ones.

This epistemology can be useful in the field of policy making too, in a context in which deliberative processes are highly valued in ethical and political decision making. Such deliberative approaches have been advanced in knowledge production re-

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[10] Some further feminist critiques of the principle based approach in bioethics refer to the abstract character of bioethical theory, the emphasis on abstract universal norms and the framework of allegedly universal moral principles; the use of generalized abstract categories that overlooks key components of morality including the contexts that frame health care and the relational bonds that inform patient decision-making. For more feminist views on bioethics see for example Tong et. al. 2004.

lated to new and emerging technologies as a suitable method of knowledge production about the new technologies in the present context. Taking into account the novelty of these technologies it is preferable by science policy makers to include in the debate as many perspectives as possible. The UNESCO declaration also encourages dialog and the incorporation of a variety of perspectives in the bioethical debates. An epistemology that put an emphasis on the situated and relational character of knowledge can be thus very adequate in this context.

Feminists challenge traditional bioethics to reveal its own perspective(s), to acknowledge and embrace the plurality of human (male and female) voices, to accept and work with the essential nature of human connection and embodiment. Bioethics is and should be strongly committed to autonomy and patient decision-making, but, as many empirical studies show, cherished principles may not be equally salient to the very people whose rights and well-being bioethicists seek to protect. It is more realistic to admit perhaps that the human condition is a condition of dependency, and this contradicts the ideologies of rational autonomous agency of modernity. As Tong formulated, »denial of perspective does not achieve neutrality, denial of plurality does not bring unity, and denial of connection and embodiment does not achieve self-sufficiency for the rational, autonomous self.« (Tong in Wolf 1996, p. 89) If we take all these into account we can conclude in saying that feminists require ethical analysis to be contextual, inclusive and flexible (Boetzkes 2001).

Making bioethics discourse more inclusive is certainly necessary and feminist epistemology is useful in this context. But can a feminist epistemology transgress the gap between particular and universal, between a descriptive, empirical argument and a philosophical one in (bio)ethics? Feminist traditionally have been critical toward the so called »universal« norms and pointed out that many of them have been formulated exclusively from a male point of view, while women's experiences have been left aside. However, many feminist also admitted that the problem was not with the universality, as such, but with the way its »content« has been defined. It can be seen as a great achievement of feminist thinking that defining »universality« only from one privileged perspective has started slowly to change.

In the field of ethics too, a growing contingent of feminists think that a framework that incorporates universal principles should constitute one dimension of an adequate ethical theory providing that its principles are formulated in non-exclusionary terms that reflect the relational context of individual lives. As Judith Butler has formulated »the problem is not with the universality, as such, but with an operation of universality that fails to be responsive to cultural particularity and fails to undergo a reformulation of itself in response to social and cultural conditions it includes within the scope of its applicability. When a universal precept cannot, for social reasons be appropriated or when …it must be refused, the universal precept itself becomes a site of contest, a theme and an object of democratic debate« (Butler 2006, p. 6). Habermas also concludes that sociological reservations offer salutary corrections to normativism, but these critiques do not condemn normative theories to failure by social complexity. According to Habermas, purely normative considerations keep their relevance as long as we accept that complex societies shape themselves in a reflexive manner through law and politics (Habermas 2008, p. 276) The selective readings of norms that have the grammatical form of universal statements but at the semantic level are vulnerable to particularistic interpretations of their basic concepts, such as persons, human being, call for an empirical explanation (Habermas 2008, p. 285). What both feminist and critical theories emphasize in connection with universalistic claims is reflectivity upon such norms and concepts. Taken all these into account, and bearing in mind that a feminist ethical analysis shall be contextual, inclusive and flexible, I am joining Daniel Callahan's view according to which »there should not ordinarily be any decisive victory for particularism or universalism. They should over the long run fight to a draw, existing in tension with each other, with context and circumstance determining their relative weight« (Callahan 2000, p. 37-38).

Contextualization: a useful method for interdisciplinary inquiries

Transgressing the gap between a descriptive, empirical argument and a normative, philosophical one is not only an epistemological, but a methodological challenge too, (Parker 2007) which, if it is successful, creates new methods for interdisciplinary practice, a practice that seems to be extremely needed and valuable in the current context of knowledge production created by the proliferation of new converging technologies. Indeed, interdisciplinarity and transdisciplinarity appear to be one of the most prized/acknowledged characteristics of current knowledge politics, both are highly valued and are seen as signals for post-academic knowledge. To can asses whether a practice is interdisciplinary or not there is necessary either a definition of interdisciplinarity, or a set of criteria that should characterise interdisciplinary practice. Even if we take only a brief account of possible definitions and criteria of interdisciplinarity we can see that »interdisciplinarity« is a relational and socially constructed concept, whose actual content depends on agreed criteria, on how disciplines and multidisciplinarity are defined, so on. As studies carried out on concrete examples of knowledge production practices demonstrate, interdisciplinarity in practice can take various forms, with various results, and often processes of knowledge production labelled as interdisciplinary turn out to be more a kind of multidisciplinarity in practice.[11] Interdisciplinary practice thus is contextual too.

It seems that as easy is to prize interdisciplinarity, as difficult is to define its contours, and it is definitely less easy to practice it in an »authentic« way, and the field of bioethics it is not an exception of this problem either. Many scholars highlighted that even if the problems raised by the new life sciences and technologies are truly interdisciplinary in their nature, and the body of theoretical knowledge under the name of bioethics has indeed an interdisciplinary character, the methods used to produce new knowledge in the area are mainly rooted in monodisciplinary traditions (Bowden 1995; Kjølberg and Wikson 2007; Azevêdo 2007, Rafols 2007). According to Azevêdo »the contentment with the application of the existing methods will dismiss the need for creative ideas on new interdisciplinary methods in bioethics and this may become the greatest epistemological challenge to bioethics in the present century« (Azevêdo 2007, p. 34).

The context of this paper does not allow me to address in details such an important methodological challenge. Therefore my intention here is only to draw attention to the method of contextualization, as one of the potentially valuable tools for interdisciplinary approaches of bioethical issues that are informed by an integrative epistemology that does not strictly separates normative and empirical approaches.[12]

Contextualization in a broad sense is the act or process of putting information into context; and of making sense of information from the situation or location in which the information was found. In the context of bioethics this would mean that scholars interested in the ethics of a particular technology should develop a deeper understanding from within the problematic situation instead of using only ethical tools developed from outside the situation in case. They should focus their attention not only on standard issues of bioethics (such as informed consent, moral status of the embryo, autonomy, so on), but they should also take into account the context in which that particular technology is applied.[13]An example for such practice from the context of new biotechnologies is given by Rayna Rapp who shows through a detailed ethnographic account how one of the least important issues for women con-

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[11] See for example Demény et al. 2007

[12] There are other such proposals in the literature, for example »integrated empirical ethics« (IEE) research is advanced by Moljewik et al. IEE »refers to studies in which ethicists and descriptive scientists cooperate together continuously and intensively. Both disciplines try to integrate moral theory and empirical data in order to reach a normative conclusion with respect to a specific social practice. IEE is not wholly prescriptive or wholly descriptive since IEE assumes an interdepence between facts and values and between the empirical and the normative« (Moljewik 2004). See more about this method in: van der Scheer and Widdershoven 2004.

[13] We can think of various contexts: social, cultural, economic, legal, but epistemological or metaphysical contexts too. For socio-cultural contextualization see for example Gordon et al. 2007.

templating prenatal testing is the moral statues of the embryo, a main issue in mainstream bioethics. In this light, those bioethicists who wish to engage with ethical decisions as they are lived in the real world should turn their attention towards the rights and duties that are involved in relationships with other people in that certain context rather than focusing only on abstract moral issues (Rapp 1999). Another example for the critique of the decontextualised approach in relation to new biotechnologies is the work of De Melo-Martin, who argues that a decontextualised approach to ethical issues is not just unhelpful for the decision making process of real, situated human beings, but dangerous (De Melo-Martin 2006). If we neglect the context in which people make moral decisions we run the risk to reinforce further injustices against already disadvantaged groups. Miller and Find, in a study on placebo-controlled trials of pharmacological treatments and deep-brain stimulation for psychiatric and neurological disorders bring to our attention how moral principles and standards can conflict when applied to contextually complex situations. They claim that careful balancing of morally relevant considerations and an understanding of moral norms should guide ethical judgment instead of categorical or absolute rules (Miller and Fins 2004).

If we take into account that bioethics discourse about biotechnology has the power to define new subject positions, it would be more than desirable to understand how medical technologies intervene in the processes and possibilities, not only of self enhancement, but also of self-formation. The issue of subject formation, of »the modes by which, in our culture, human beings are made subjects« (Foucault 1982) could be therefore another topic where contextualization could help an interdisciplinary approach. The contexts in this case would be the timeless metaphysical questions of human existence: issues of selfhood, worldview, moral belief, and social responsibility can serve as the connecting glue. To be constituted as a person does not only mean that one is provided with physical and psychological capabilities by nature, capabilities that eventually can be enhanced with medical technologies. To be constituted as a person means more than this, it is also about developing an identity within the meaning patterns of the life world. If these patterns are changed in fundamental ways it will have not only ethical, but also existential, ontological consequences for us. This would not mean necessarily changes in the human genome. It might also happen that new knowledge established by way of medical science alters for example our self-understanding, the ways we perceive ourselves as human beings (Hoeyer 2002). By taking a look for example to the case of genetic engineering, we can see that this has impact not only through its ability to affect the structure of living tissue. It has also impact as a field of knowledge that, as it becomes increasingly normalized, influences the way we conceptualize human existence and social interaction. It is important, therefore to take into account the socio-political way in which we learn who we are as human beings and the discourses that surround this process (Fitzsimons 2005, p.2).

These are only some issues that the contextualizing strategy can effectively address. All the examples presented above highlight the utility of contextualization as an interdisciplinary method. It can help to »fine-tune« the universal framework proposed to bioethical issues by making it more sensitive to various contexts and offer solutions that are more helpful in real life decision situations and are endorsed and accepted by a larger audience, public. It also demonstrates how both normative and empirical arguments have to be considered in order to make sense of how certain technological applications are »working« in real life and what type of moral, ethical and ontological concerns they raise. According to the new science policy on technological and scientific development such knowledge shall be used not only to understand the ethical, social and economic implications of some new technologies but preferably the process of development of new applications shall take it into account. Only in this way it can be claimed that a given technology will be »socially robust«.

Conclusion

Taken into account that the issues that are at stake in the ethical debates on the applications of various biotechnologies and genetics can deeply affect the ways we perceive us as humans, our relationships with others, and with the environment it would be more than desirable that in these debates a plurality of approaches and voices to be represented. In this paper I tried to contribute with some ideas to how dualistic approaches in bioethics can be changed with more inclusive and integrative approaches both at the level of epistemology and methodology. Relying on ideas of feminist epistemology and critical bioethics I supported the view that a framework that incorporates universal principles shall constitute one dimension of an adequate ethical theory in the context of life sciences and new technologies providing that the principles it relays on are formulated in non-exclusionary terms that reflect the relational context of individual lives. I argued that such a framework could provide useful background for developing and employing methodologies that are suited for interdisciplinary inquiry on various bioethical issues and problems, suggesting contextualization as one of the possible methods that could be efficient in interdisciplinary attempts aimed to understand the relationship between universal and particular, global and local when dealing with issues raised by new techno-scientific developments.

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JAHR | Vol. 1 | No. 1 | 2010

UDK: <179:577.214>342.7
Review Article/Pregledni članak
Received/Primljeno 06/07/2009

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Bioethical analysis of the United Nations Declaration on Human Cloning

ABSTRACT

The author analyzes in his work the process of negotiating and beginning of the United Nations Declaration on Human Cloning as well as the paragraphs of the very Declaration. The negotiation was originally conceived as a clear bioethical debate that should have led to a general agreement to ban human cloning. However, more often it had been discussed about human rights, cultural, civil and religious differences between people and about priorities in case of eventual conflicts between different value systems. In the end, a non-binding Declaration on Human Cloning had been adopted, full of numerous conpromises and ambiguous formulations, that relativized the original intention of proposer states. In author's opinion it would have been better if bioethical discussion and eventual regulations on cloning mentioned in the following text had been left over to certain professional bodies, and only after the public had been fully informed about it should relevant supranational organizations have taken that into consideration.

Key words: UN Declaration, human cloning, reproductively, therapeutically, bioethics

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The Declaration on Human Cloning (No. 59/280)[1] was adopted on the 82 OUN plenar session held on 8 March 2005. This declaration represents the crown of efforts taken since 2001 by France and Germany to adopt a convention against reproductive human cloning. Instead of unanimous consent from the international community, negotiations followed that lasted 4 years and showed the diversity of the world in which we live. The negotiations were originally conceived in a completely different way, as a clear bioethical debate that should have led to general agreement to ban human cloning.[2] However, more often it had been discussed about human rights, cultural, civil and religious differences between people, their interactions and priorities in case of eventual conflicts between different value systems. Neither the Declaration nor the negotiations gave any answers to these difficult questions, but they did allow superficial insight into problems. They showed that international legislation does not possess the knowledge to deal with problems when there is no professional argumentation but political and other differences in the middle of discussion.

The adopted declaration represents the negotiation result, and it includes, both in bioethical and in scientific sense, ambiguous formulations that can be interpreted different ways. If one reads the declaration carefully, it has an unexpected result, since it does not ban cloning[3] explicitly, not even reproductive cloning. However, the significance of years of negotiations can be hardly limited to the very Declaration. Of equal, or maybe even of more importance, is to make the public, wider scientific community and state governments aware of different bioethical questions as well as to urge the authorities and scientific associations for establishment of a suitable legislation and giving references for the explorations of stem cells.

Taken into account the fact that, at the given moment, only a small number of scientists and institutions dispose of required technical education, Germany and France held that reproductive cloning[4] of people can affect the whole mankind,

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[1] Out of 191 state members, 84 states voted in favour of the UN Declaration and 34 states voted against it. There were all together 37 abstentions, whereas representatives of 26 states were absent on the occasion of voting.

[2] The word »cloning« comes from Greek masculine noun κλών, translated as »stem« or »twig«. It stood for »offspring« in New Testament. To find out more on cloning dilemmas see text: A. Švajger, »Kloniranje: pojmovi, zablude, obmana i strah«, see: http://www.vms.hr/school/klon01.htm.

[3] One of the definitons of cloning and research of stem cells says: »Cloning of an organism commonly involves a technique called somatic cell nuclear transfer, where the nucleus of an egg cell (containing its genetic material) is removed and replaced with the nucleus of a somatic cell taken from the body of an adult. If the reconstructed egg cell is then stimulated successfully to divide, it may develop to the pre-implantation blastocyst stage. In reproductive cloning, the cloned blastocyst is then implanted in the uterus of a female and allowed to continue its development until birth. However, in cloning for research or therapeutic purposes, instead of being implanted in the uterus the cloned blastocyst is converted into a tissue culture to make a stem cell line for research or clinical applications.« (InterAcademyPanel on International Issues, Statement on Human Cloning (Trieste, Italy, Sept. 22, 2003).

[4] There is a general, if not absolute agreement, in the international community on the view that reproductive cloning, for the purpose of creating new human beings, is a deeply unethical act. Arguments against reproductive

which is why they demanded wide action. They demanded global instruments that would produce relevant normative acts and so their wish was to entrust the task to the UN General Assembly instead of to some of the specialized agencies such as the World Health Organization (WHO) or UNESCO. It was expected that, due to the stance of the European Union and UNESCO Declaration, the negotiations would be of short duration and that the stances would be quickly and easily formulated into a clear and binding convention.

Council of Europe Additional Protocol to the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, on the Prohibition of Cloning Human Beings CETS No.: 168 adopted in January 1998 declares: 1. »Each intervention to create a human being identical to some other human being, either alive or dead, is forbidden.« 2. »In this article the term human being that is »genetically identical« to some other human being stands for the human being that shares the same set of genes with another human being«.[5] Article 11 of the Universal Declaration on the Human Genome and Human Rights (adopted on 11 September 1997 under the wing of UNESCO) declares explicitly: »Actions that are opposed to human dignity, as is reproductive cloning of human beings, are not allowed. States and authorized international organizations call for cooperation in unveiling such actions and taking measures on state and international level in order to enable the respect of principles established in this Declaration.«[6] Due to all of this, it was expected that the whole procedure would pass ceremoniously, since it, amongst other things, enables the UN General Assembly to open a new chapter on political and legal regulations of some new field.

It seemed that the initiative was welcomed because it showed the agreement of the international community on one at first sight non-disputable situation. Moreover, the French-German initiative was immediately upheld by forty-nine states. Only Vatican had reservations about it. »The Holy Chair« considered that the ban on reproductive cloning represents only a part of problem mentioned beforehand, and

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cloning are of technical and medical nature such as weakening and undermining of the original idea of producing offspring and the concept of family, unclear relationship between the cloned baby and its »creator«, confusable personal identity and possible disturbance of psychologic development of the cloned baby, eugenic questions, promoting creation of babies and their »enhancement«, belief that reproductive cloning contradicts human dignity. Key argument that goes in favour of reproductive cloning is the increase of favourable reproduction possibilites. By helping infertile people with cloning one promotes their welfare, preserves their personal autonomy and satisfies their natural desire for producing offspring (C. Strong, »Cloning and adoption: a reply to Levy and Lotz«; bioethics, 22(2), 130-136, 2008).

[5] Additional Protocol of the Council of Europe taken from the following web address: http://conventions.coe.int/Treaty/Commun/ListeTraites.asp?CM=8&CL=ENG.

[6] Taken from: *Unesco i bioetika*, zbirka osnovnih dokumenata, Center for Ethics and Law in Biomedicine 2008, p. 6

rejects, in moral and ethical repects, all aspects of human cloning, including the so-called therapeutic cloning.[7]

Taken into account the novelty in consideration of the aforementioned problems and unfamiliarity with medical and technical terminology, negotiations of 2002 started by informing scientists and philosophers on basic mechanisms of cloning process, as well as on the ethical implications of the aforementioned process.[8] At first, the problem was aimed only at those states involved in genetic research or those who had capabilities to do it. Some of them thought that the French-German initiative was acceptable, since it tended to ban human cloning, on which they all agreed, leaving research of stem cells and »therapeutic cloning«[9] by side. Other states didn't think that there's a difference between the two types of cloning, taken into account that both include the manipulation of a human embryo. The discussion on cloning had quickly turned into the discussion on when does human life begin and on dilemmas regarding abortion, the topic on which there is no agreement in international community.[10]

Human cloning is connected with different religious, cultural, civil, moral and ethical questions; as well as with human rights, freedom of thinking and scientific formation. In general, delegations agreed that the production of cloned babies should be banned. Still, there were disagreements regarding answers to such questions as »what is »a human being« and, already mentioned, »when does human life begin«. There were religious implications of conflicts between different states in regards to defining the beginning of human life. Vatican, for example, holds that a human embryo not implanted into the uterus is a human being and if one destroys it, one prevents the development of new human life. Therapeutic cloning, seen from this perspective, requires millions of human embryos, that will be produced in order to be destroyed in the process of scientific research. For states sharing this opinion, a

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[7] UN Doc. A/C.6/56/SR.27, supra note 5, paras. 2-26. The delegation of Vatican pinpointed that generation of children produced non-sexually, i.e. without insemination, would feel no union between their persona and a gamete; instead of imposing the person of donor to the new human being, one refuses to recognize child's human dignity.

[8] Habermas (J. Habermas) tends to claim that ethics is the best approach to deal with the problem of cloning. As long as cloning remains the consequence of human actions, it also remains a subject to human responsibility, therefore to ethics as well. J. Habermas, *Postmetafizičko mišljenje*, Beogradski krug, Beograd 2002

[9] Some scientists call therapuetic cloning »cloning for research purposes«, or »research cloning«. The intention is to avoid the use of the term »therapeutic«, which, in their view, can have positive connotations, but since they are not proven at this moment, it is suggested to use a more neutral syntagm. Be that as it may, it is expected that therapeutic cloning will help in the treatment of many serious and chronic diseases, of which most oftenly mentioned are Parkinson's disease, Alzheimer's disease or diabetes. The biggest ethical question regarding therapeutic cloning ic concerned with debates on moral status of the embryo.

[10] The international community could not agree not even on whether these themes should be subject to debate on international level.

partial ban on human cloning or partial approval of the same, break fundamental religious principles, according to which life begins with a human embryo.

States whose religious beliefs suggest that the moment of conception is, by itself, not of crucial importance for their belief system, or states who took no stands on certain questions, were not willing to accept the positions of other denominations. During the negotiations, Iran, who spoke on behalf of the Organization of the Islamic Conference members (OIC), supported the ban on human cloning only for reproduction purposes, adding that OIC members did not form their joint position on the research of stem cells and that they are not ready to vote for a ban of such reseearch at the given moment. The state members of the Organization of the Islamic Conference based their stands on potential profit from research of stem cells.

States sharing a dominatly secular view of things opposed therapeutic cloning from a religious perspective by suggesting arguments against the use of anesthetics and *in vitro* insemination (IVF). Many of them thought it was inappropriate to impose one religious value system in such a diverse and sensitive world, not only in regards to religious norms but others as well. The challenge was to achieve an agreement in the human cloning debate, that would respect cultural, civil, ethical and religious diversity, thereby not obstructing human freedom. In order to bridge a gap, the use of terminology was suggested, similar to the one from the Additional Protocol to the Ban on Human Cloning from 1998, in which the »human being« is defined by national legislation.[11]

The concept of human rights was also a subject of debate, as the additional argument for defending one's own positions. Both opposing sides agreed that creating human beings with the help of cloning would hurt and weaken human individuality and dignity.[12] In later debates, the representatives of Vatican claimed therapeutic cloning was, from an ethical perspective, even worse than reproductive cloning, since it uses a newly created »human being« as a mere laboratory material. »Such instrumentalistic use of a human being seriously hurts human dignity and human species.«[13] So, the production of embryos that are going to be destroyed after the

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[11] This suggestion was unacceptable to those states suporting universal ban on all forms of cloning.

[12] The very concept of human dignity is not defined specifically. Representatives of the universal ban on all forms of cloning related this term to non-sexual production of human beings. The representative of Vatican tried to define dignity as an intrinsic value, common and equal for all human beings, no matter their social, intellectual or human condition. Human dignity was also often brought in connection with Kant's second formulation of categorical imperative (»Act in such a way that you treat humanity whether in your own person or in the person of any other, always at the same time as an end and never merely as a means to an end.« I. Kant, Zasnivanje metafizike morala, Dereta, Beograd 2004, p. 74), i.e. with the fact that creation of children by means of cloning could lead to treatment of offspring as an object, i.e. as a material thing as is a house or car (H. Putnam, »Cloning People«, in: J.Burley, ed., The genetic revolution and human rights, Oxford University Press, Oxford 1997, p. 1-13).

[13] UN Doc. A/C.6/59/INF/1, para. 8 (2004).

research ends, according to this view, directly abolishes human rights of the embryons.

States supporting all bans on cloning thought that the techniques of reproductive and therapeutic cloning are the same. Therefore, the approval of therapeutic cloning would enhance the very technology of cloning**.** If the human embryo would be available and useful one could not fully control the use of it. If the technique of cloning would be raised to the perfect level one could not withstand requests for »ordered« babies, in spite of the present legal restraints. Supporters of all bans on cloning claim that, if a healthy cloned baby is born, people could not withstand the »production« of new babies. Therefore, partial ban on cloning would be uneffective and preventing the development of such technology would provide a better chance for a total ban to stop the occurrence of human cloning.

States that were only pro-ban on reproductive cloning, rejected, explicitly or implicitly, the perception of an embryo as a human being, as well as the application of human rights and levels of protection to the very embryo. Their arguments were based on view, according to which *in vitro* insemination, certain forms of birth control and abortion, also destroy embryons. Therefore, according to this interpretation, there is no justification for not banning therapeutic cloning, although the aforementioned procedures are at the same time allowed.

Beneficial to therapeutic cloning was the mentioning of the rights on freedom of thought and freedom of scientific research. Article 12b of the Universal Declaration on the Human Genome and Human Rights was quoted as relevant: »Freedom of research which is necessary for the progress of knowledge, is part of freedom of thought. The applications of research, including applications in biology, genetics and medicine, concerning the human genome, shall seek to offer relief from suffering and improve the health of individuals and humankind as a whole.«[14] It was emphasized that cloning techniques had, to a large degree, been used with DNA genes and cells, in the vaccine production, diagnostics and pharmaceutics, thereby not provoking special ethical dilemmas and controversies.

In an effort to secure the agreement from a larger number of states, France and Germany complemented their first suggestion to ban reproductive human cloning, with the idea to include regulations for research of stem cells. Their suggestion was immediately supported by Belgium, China, India, Japan, Russia, Singapore, South Ko-

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[14] Taken from: *Unesco i bioetika*, zbirka osnovnih dokumenata, Center for Ethics and Law in Biomedicine 2008, p. 6. Parts of the Universal Declaration on Human Rights (art. 18 and 19) and International Agreement on economic, social and cultural rights (Art. 15(3), were also quoted as arguments that go in favour to research connected with therapeutic cloning.

rea and Great Britain; these being either the states already involved in the research of stem cells or the states that intended to move their research in that direction. Contra-suggestion on convention that would ban all forms of cloning, was given by Costa Rica and supported by Vatican, Italy, Portugal, Spain and the United States of America. These states also made certain concessions in order to make their suggestion more acceptable to a larger number of states. For this purpose, the transfer of nucleus or other cloning techniques for obtaining DNA molecules, organs, plants, animals tissues and cells, with the exception of human embryos, were excluded from the suggestion for a general ban. The gap between the blocks of these states was large and the issue they dealt with was not the reconciliation of opposite positions, but lobbying among other undecided states in favour of their own viewpoint. In a specific stalemate position, Iran's suggestion was accepted on behalf of the Organization of the Islamic Conference, in order to postpone the negotiations of opposing sides for two years, more precisely for 2005.[15]

Publicity provoked by the aforementioned controversy raised the interest of the public for these issues. Non-governmental organizations, which supported inviolable right to life. were, of course, supportive of a general ban on cloning. Scientific organizations and many scientists, alternatively, were concerned that such radicalization of stances would lead to either limitations or a complete ban on research of stem cells. »The InterAcademy Panel on International Issues (IAP)«, an association composed of sixty national academies of science from different parts of the world, published a notice on 22 September 2003, opposing the ban on therapeutic cloning and supporting the ban on reproductive human cloning.

The key group of states from the Organization of the Islamic Conference finally decided to accept only the declaration on which they would achieve a consensus. This accelerated the negotiations of opposing sides in order to create the text of the resolution that would be acceptable to all. After many turning-points, a compromised version suggested by Habermas was accepted, along with Belgium's amendment to the first preambular paragraph.[16] The long negotiations and eventual compromise certainly enabled both sides to proclaim »freedom«, and to interpret paragraphs according to their own standpoint. To make it clear how much the positions had changed during four years of the negotiation process, it is suffice to say that initial proposers adjourned after the final voting. France voted against the Declaration and Germany in favour of the Declaration! Great Britain and the USA, two close allies on many fronts, also found themselves on opposing sides. The British could not

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[15] The suggestion was accepted by a vote of only 80 in favour to 79 against, with 15 abstentions.

[16] UN Doc. A/C.6/59/SR.28, para. 42 (2005).

support a political declaration which could be interpreted as a ban on all forms of human cloning. They added that one should reach a consensus on cloning within each state, taking into account the benefits these new actions could bring to millions of people. The British finally thought that the adopted Declaration was non-binding and that it does not reflect the fact that the international community had, with help of Declaration, confirmed its despise towards human cloning, and that it obliged itself to protect the sacredness of human life and respect towards human dignity. The Americans understood the Declaration as a call for the United Nations members to prescribe laws that would, without delay, ban all forms of human cloning. The USA have also emphasized that the effect of the Sixth Committee represents an important step towards life culture, in a way it would insure that scientific achievements serve to human dignity.

The representatives of following states voted, among others, in favour of the Declaration: Australia, Austria, Bosnia-Herzegovina, Chile, Croatia, Malta, Mexico, Slovenia, Switzerland, Macedonia…Some states voted against the Declaration: Brazil, Canada, China, Denmark, India, Japan, Holland, Norway, Singapore, Spain… Following states abstained: Argentina, Egypt, Indonesia, Iran, Israel, Rumania, Serbia and Monte Negro, South Africa, Turkey, Ukraine… Following states did not attend voting: Armenia, Ghana, Greece, Libia, Nigeria, Peru, Russia, Turkmenistan, Venezuela, Vietnam…

The United Nations Declaration on Human Cloning[17] is short and meaningful and it consists of eight preambular and six operative paragraphs. The language of the Declaration is common and each of its paragraphs has gradual transitions, careful qualifications and key terms implications. This shows that one tried to reach balance between dissenting and hardly compatible definitions of human life, presented by opposing sides. As a result of that the Declaration conveys the consensus neither on human cloning nor on the beginning of human life, and it does not define none of the aforementioned concepts. As stated in the introduction, the Declaration neither defines human cloning nor does it directly or unconditionally ban human cloning, including reproductive cloning.

One reference to reproductive cloning can be found in the second preambular paragraph, that states: »Recalling the Universal Declaration on the Human Genome and Human Rights adopted by the General Conference of the United Nations on 11 November 1997, and in particular article 11 thereof, which states that practices that are contrary to human dignity, such as the reproductive cloning of human beings,

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[17] The Declaration was, as a less non-binding document, adopted instead of the originally predicted convention. The full name is »The United Nations Declaration on Human Cloning«; for its English version see: http://www.unescobkk.org/fileadmin/user_upload/shs/BEfiles/chapterE.eng/E8.2E.pdf.

shall not be permitted.« Other paragraphs in the preambular part discuss the application of »life sciences«. This syntagm »life science« was a subject to objections coming from state delegations pleading for the Declaration on Human Cloning to be summarized and paraphrased into the Declaration on Human Cloning for reproduction purposes. In their view, the negotiation process was never directed at the debate on life sciences in general, adding it is not clear neither what does the mentioned concept include nor what does it stand for.[18] In the preambular part of the Declaration life sciences are only mentioned in relation to the concern about »human dignity«, »fundamental freedoms of individuals« as well as »relief from suffering«, »health improvement both of individuals and of mankind in general« and »benefits for all«. Therefore, no matter what life sciences actually signify, they should be understood in the context of terms with which they were brought in connection with, especially with the term »human dignity«. This is especially visible in the last eighth preambular paragraph which states that the General Assembly »is convinced of the urgency of preventing the potential dangers of human cloning to »human dignity«. Words from this paragraph that can be interpreted different ways are »potential dangers« and »human dignity«.[19] Meticulously stated formulations are also visible in the emphasis of the word *potential* that stands before *danger*, suggesting that the dangers human cloning can cause to human dignity can also be interpreted as *potential*, i.e. only as *possible*.

Two extremely important paragraphs of the second operative part of the Declaration, paragraphs »a« and »b«, were heating the discussions between the opposing sides till the very end of the negotiation process. Paragraph (a) declares: »Member states are called upon to adopt all measures necessary to protect adequately human life (put in italics by Ž.K) in the application of life sciences.« This paragraph was supported by delegations who voted in favour of the general ban on cloning and it was strongly opposed by states supporting the ban on cloning only for reproduction purposes. Why this is so when cloning of people is not even mentioned in it? It refers to protection of human life in life sciences. The reason for opposing this paragraph lies within the fact that the phrase »protection of human life«[20] can be widely interpreted, including the interpretation of the abortion ban. The paragraph was also criticized because it mixes scientific definition of »human life« and determina-

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[18] One footnote (No. 42) from Professor Šegota in his text «Nova definica bioetike» I. Šegota, »Nova definicija bioetike«, In: A. Čović, *Izazovi bioetike*, Pergamena, Hrv. fil. druš., Zagreb 2000, p. 22. closely defines »life sciences«. According to article 27 of the Law of Higher Education of the Republic of Serbia there are natural and mathematic, social and humanistic, medical, technical and technological sciences and fields of art. In the definition of the field area there are no life sciences mentioned. The text of the Law on Higher Education was taken from the web addess: http://www.ius.bg.ac.yu/informacije/Zakon%20o%20visokom%20obrazovanju.pdf.

[19] In the source text there are words »potential dangers« and »human dignity«.

[20] In the original: »to protect…human life«.

tion of »human being«, which should be a subject to legal regulations. During negotiations the adverb »adequately« was used to modify the verb »to protect«, thereby emphasizing that the phrase »adequate protection of human life« differs from eventual »full protection of human life«. State delegations supporting only ban on reproductive cloning, could not accept paragraph (a), not even with this subtle annex. In their view, therapeutic cloning includes and comprehends the human embryo, which, seen through scientific prism, can be defined as a »form of human life«, but not as a »human being«. These states simply could not agree with the formulation requiring the protection of all »forms of human life«.[21]

Paragraph (b) is the only operative paragraph which bans human cloning, although it includes important alleviation of the original formulation. It declares: »Member states are called upon to prohibit all forms of human cloning *inasmuch as* (italics Ž.K.) they are incompatible with human dignity and the protection of human life.« This paragraph was also a subject to debate from states supporting only the ban on reproductive cloning. Although the phrase »all forms of human cloning« can be widely interpreted and it includes reproductive human cloning as well, it was alleviated and modified by the word »inasmusch as«. This expression was chosen in English because it could convey several meanings, which are »as«, »because« or »since« or in some other context »if« or »on condition that«, therefore allowing everybody to choose the interpretation that best suits them. Namely, the version of translation, in which one grasps »inasmuch as« as »since« (»Member states are called are called upon to prohibit all forms of human cloning *since* they are incompatible with human dignity and the protection of human life.«), is a call for a total ban on human cloning. Alternative translation, in which one interprets »inasmuch as« as »if« (»Member states are called upon to prohibit all forms of human cloning *if* they are incompatible with human dignity and the protection of human life.«), leaves the possibility open that there are forms of human cloning that can be »compatible« with the human dignity and protection of human life.[22]

Along with many restrictions and modifications paragraph (b) was unacceptable to many delegations, especially to the ones supporting only the ban on reproductive cloning. Their remarks were aimed at the fact that paragraph (b) does not explicitly ban human reproductive cloning and that it repeats phrases as »protection of human life«, which were already adequately explained in paragraph (a). For delegations supporting total ban on human cloning, paragraph (a) refers to the use of life sci-

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[21] Belgium, the leader of the countries opposing this paragraph, demanded its deletion , i.e. annulment, but its suggestion was rejected in the Sixth committee (with 57 to 48, 42 abstentions).

[22] The phrase »protection of human life« can also be understood in the aforementioned context modified by the adverb »adequately«.

ence but does not explicitly mention human cloning and issues mentioned in paragraph (b). Belgium was the leader of states opposing paragraph (b) and suggested the modified version of this paragraph: »Member states are called upon to ban reproductive cloning of human beings. They are also called upon to ban all other forms of human cloning inasmuch as they are incompatible with human dignity.« This suggestion recognizes different forms of cloning based on the intention (reproductive or therapeutic), and bans reproductive cloning and other forms of cloning (therapuetic), inasmuch as they are not respecting human dignity. The suggestion was unacceptaple to states supporting total ban on cloning probably due to its ambiguity and the fact that it does not mention human life. Therefore, it was rejected in the Sixth Committee.[23]

The following paragraph (c), calls upon member states to adopt the measures necessary to prohibit the application of genetic engineering technique that may be contrary to human dignity.

Paragraph (d) repeats, to a certain degree, parts of the seventh paragraph from the preambular part, calling upon member states to take measures to prevent the exploitation of women in the application of life sciences.

Paragraph (e) calls upon member states to adopt and implement without delay national legislation to bring into effect paragraphs from (a) to (d).

The last paragraph (f), suggested by the group of African states, does not actually refer to human cloning at all. It calls upon all member states, in their financing of medical research, including of life sciences, to take into account the pressing global issues such as HIV/AIDS, tuberculosis and malaria, which affect in particular the developing countries. The original suggestion was to redirect state funds provided for the research of stem cells (including adult stem cells) at these urgent global health issues. Final text, however, was cleaned and generalized and does not call upon anybody to change their national legislation in the mentioned direction. This paragraph reveals diversity of state priorities with relatively poor health care compared to middle-income and high-income developed countries. Human cloning does not represent neither close nor real medical or scientific problem for most of African, and not only African developing states, since they have to deal with more important health issues.[24]

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[23] The suggestion was accepted by a vote of 55 in favour to 52 against, with 42 abstentions.

[24] One can confirm this thesis by taking insight into the official statistic data of the OUN. According to them, leading causes of children's death in developing countries are following diseases: pneumonia, diarrhea, malaria and measles (these being diseases that can be prevented by elementary improvement of primary health care). Each year over million people in the world die of malaria, 90% of these deaths occurring in Sub-Saharan Africa. In 2006 over 240 000 children, mostly younger than five, died of measles. In the same year 1.7 million people died of tu-

The negotiations in the United Nations about the Declaration on Human Cloning, showed that bioethical dilemmas and scientific discourse were relatively easily replaced with statements that are not formulated in regards to the interests of profession and human needs. They were heavily coloured by political, economic, cultural and religious characteristics of individual state groups or individual states. The effort to make the standard universal in order to deal with one, in scientific sense, sophisticated problem, led to significant differences and disagreements on scientific and technological development and priorities between 191 UN member states. Therefore, there was no non-binding declaration that could be adopted without numerous compromises and ambiguities, which significantly relativized the original intention of proposer states. Finally, maybe it would have been better if the bioethical debate on the cloning issue and eventual regulations had been left over to experts and suitable professional bodies,[25] and only after the public had been fully informed about it, should relevant supranational institutions have dealt with the problem.

Translation/prijevod: Katja Dobrić, BA.

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berculosis. In 2007 around 2 million people died of AIDS. Finally, each year around ten million children younger that five die of curable diseases. The official UN data taken from: *The Millennium Development Goals Report 2008*, see: http://www.un.org/millenniumgoals/pdf/The%20Millennium%20Development%20Goals%20Report%202008.pdf.

[25] The general director of UNESCO Koïchiro Matsuura also considers that scientists and bioethicians should play a leading role in discussions on cloning and main ethical questions stated in relation to cloning, which are of interest for the whole mankind. He adds that other subjects, such as public opinion, should play a significant role in the wide etrhical debate on such an important question. *Human Cloning Ethical Issues*, UNESCO, Paris 2005, Preface, p. 5

JAHR | Vol. 1 | No. 1 | 2010

UDK: <174:61>342.7
Review Article/Pregledni članak
Received/Primljeno 14/12/2009

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Interpretation and implementation of UNESCO's Universal Declaration on Bioethics and Human Rights

ABSTRACT

The beginning of the 21 century imposes the need of synchronising the practical and the academic approach in the interpretation of bioethical problems and the implications of their solving. Some of the goals of the Declaration are the education of health-care professionals, the creation the infrastructure necessary for biomedical research and the education of the scientists involved in it, and the foundation of ethical committees. The Declaration provides with a legal and political guidelines, whereas for a full justification and development of the its general idea, a philosophical (epistemological and axiological) background as a sustaining meta-theory is much needed. The pluriperspectivity and the multidisciplinarity of the integrative bioethics construct a perfect methodological framework for a theoretical justification and a in-depth explication of the most important and the subtlest recommendations of the Declaration.

Key words: Declaration, meta-theory, pluriperspectivity, multidisciplinarity

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Introduction

The complex task of identifying, classifying and working on bioethical issues is one of the most elaborate examples of the double nature of human understanding of life. For reason and morality not only obviously meat in the realm of bioethics and the problems of humanity and the man-world relation, but they also combine in an explicit and creative manner, giving both succinct and extensive overview of problems and possible solution, as well as consistent anticipation of possible implications and side-effects of the process of resolving those problems. The modern world faces a number of challenges that have either been inherited from the past, having increased by not having been located and settled, or series of new ones of stunning proportions. When it comes to government - and nation – oriented guidelines for the various fields of the human rights theory and its practical realm, international documents such as the *UNESCO's Universal Declaration on Bioethics and Human Rights* are irreplaceable for a comprehensive study of the on-site ongoing and emerging situations, especially when a joint project of understanding and action of a concise yet broad-ranged set of guidelines and a full-fledged yet expanding multidisciplinary and pluriperspective theory is being established. Therefore, the interpretation and the implementation of the Declaration in the context of Integrative bioethics and as such, in terms of a versatile approach to problems and solutions is perhaps the most favourable way of analysing it meta-theoretically and the most advantageous way of providing and sustaining further guidelines for nations and individuals. For the Declaration has many merits, but they are not undisputed, and the integrative bioethics provides more than a fertile background for interpretation of the proposed manners of organisation and their eventual implications, as well as a theoretical framework for the unavoidable clashes of legal, cultural, scientific and religious positions. While the Declaration has a very extensive coverage of topics, the theory of the integrative bioethics can help attenuate the possible inequities bound to arise because of the differences in the legal, political and economical situations of the countries in the interpretation of the tasks proposed by the Declaration's articles and to channelize the spate of coverage and tackling of issues of human rights and bioethics.

Modern-world Challenges

It could be noted that a sort of 'general opinion' prevails about the present situation of the world – previously known as a generally unpleasant constellation of things and facts, it is believed to be getting from bad to worse, becoming a conglomerate of hatred and greed. This can be observed through the facts of intensifying inequalities and foul distribution of resources and chances, as well as the lack of significant improvements despite the ongoing efforts. The world is not supposed to be pleasant per se, of course. But as far as the average person with existential fears torn between the individual ephemeral condition and the generic immortality is concerned, it cannot be seen otherwise than as an utterly insecure place for completion of missions and fulfillment of dreams, however different and even incommensurable they might be. It is a place left scarred from the past, in the feeble present where the traditional values keep fading, where virtues are forgotten, where the other becomes a burden and not something to which the proper freedom should be dedicated to. New dangers are lurking while the old ones' consequences don't significantly subside, and maybe, after the Holocaust, and the nuclear bombs, and terrorist threats, and governments ready to sacrifice their citizens just for the sake of keeping some status quo, and peace keepers that violate the trust that's been given to them, and the irrationality and the dehumanisation of armed conflicts and wars and all the most gruesome violations of the human dignity, maybe after all that pointless suffering and incomprehensible waste, one is quite right in thinking that it is a pretty horrible world. And of course, we, the participants of the potential generic 'presence-on-Earth', we could agree and leave it to that. And yet, good deeds are so common, we're witnesses of goodness and grace, of high artistic, scientific, cultural and noble achievements. We create life, we evolve and grow and change in so many aspects. And that's where responsibility comes, and the blessings of having taken the role of a superior, an observer, and a doer. And a theoretician. And a critic. Or, just a critic, if all else fails. However, the distinction between »One«, »The People«, »the Human Race«, »Mankind«, presents a problem when used in different contexts, and not only hermeneutically speaking, but because of the political and social implications that it might bring up. One is forcefully reminded of the poem of Carl Sandburg, *I am the People, the Mob*, ending with: »When I, the People, learn to remember, when I / the People, use the lessons of yesterday and no longer / forget who robbed me last year, who played me for / a fool--then there will be no speaker in all the world / say the name: »The People,« with any fleck of a / sneer in his voice or any far-off smile of derision. / The mob--the crowd--the mass--will arrive then.« »The People« can work as a concept, but not identified with »Mankind«. And the simple »We« isn't simple at all, considering it must be well explained who and how constitutes the 'we'.

We have our small destinies of compromises, failed aspirations, and questionably satisfying settlements. Or our amazingly great destinies of courage and groundbreaking and new horizons. It is a big question whether the great project of modernism was in fact so great (although admittedly we wouldn't of reached this point of development without it. Or would have we?). Questions arise like: What gives anyone the authority to teach others how to think or act or even feel; what justifies anyone to label, to judge, to clarify; to ravish, change, dispirit concepts and values? What justifies the big and the »good« (but a strong and good is still not the same man, as Sczymborska observes) to despise and better the small ones, on the other hand, what makes the small or insignificant ones to overestimate, or underestimate themselves? The answer is in responsibility, in the goal of making a difference and the resolution of the modality of conducting in the process.

Responsibility cannot be considered as isolated and self-sufficient. Activism comes in large numbers and change can be analyzed through the big numbers theory. The joint efforts of everyone involved in a proceeding make it, hopefully, a successful one. Plurality, multi-disciplinarity, pluri-perspectivity, multiple choices and wide-spreading consequences, information, rules and patterns, and the spirit of the new, and the passion for more and better make both the core and the moving forces of the progress as we know it today. Therefore, there is no room for misinterpretations, wrong leads and dead ends in the pursuit for the necessary »better«. However, we're perfectly aware of badly calculated actions, things done exclusively for profit, violations gone from bad to worse, deterioration of important heritage, and the epistemological, axiological and practical vacuum that follows such cases, while instant efforts to remedy, to do damage control and start over should come instantly after.

Understanding and Action

The beginning of the 21 century imposes the need of synchronising the practical and the academic approach in the interpretation of bioethical problems and the implications of their solving. The *Declaration on Bioethics and Human Rights* presents an excellent example of understanding of the capacity of self-reflection, perceiving injustice, avoiding dangers, seeking cooperation, and most importantly, assuming responsibility. It also gives an excellent view on the need to understand the new particular situations arising from the rapid development of science and technology, and the need to respect life in general, and, more specifically, life taken into consideration through the concepts of persons and dignity, freedom and rights. The *Declaration* focuses on the necessity of explicitly formulated universal principles, as a foundation and guidelines for the timely and just resolution of problems and doubt arising from the bio-technological, bio-medical, legal and political occurrences.

The *Declaration* gives outstanding synthesis of legal and ethical recommendations, whereas for a full justification and development of the its general idea, a philosophical (epistemological and axiological) background as a sustaining meta-theory is much needed. The pluriperspectivity and the multidisciplinarity of the integrative bioethics construct a perfect methodological framework for a theoretical justification and a in-depth explication of the most important and the subtlest recommendations of the *Declaration*. Because, as enlightening as it is, it does face some problems. For example, while it »addresses ethical issues related to medicine, life sciences and associated technologies as applied to human beings« it does not mention the risks and benefits to humans involved in engineering, and in both social and physical sciences research, according to some criticisms[1] it also seems silent on biosafety: as there are many concerns, from the containment of pathogenic organisms, to protection against radiation hazards, to proper handling of hazardous chemicals, which are especially relevant for developing nations. Governments regulating to protect researchers, research participants and the general public from such hazards would benefit from guidance on the relevant bioethical issues. The development of bioinformatics should also benefit from a guidance of that kind. A considerable international effort has gone into the regulation of biotechnology, based on the special needs created by biotechnological research to deal with uncertainty, but the *Declaration* is unspecific when it comes to the ethical basis of regulation of biotechnology.

It does not slide over the problems of inequity of the global distribution of biological benefits and the risks from science and technology, but isn't too elaborate about them, although, it does, admittedly, help in noticing the need to formulate and solve those problems. As most scientific research is financed by developed countries and controlled by their researchers, and a significant part of the clinical trials are often done in developing nations that face the risks associated with such research, but can seldom afford to use the benefits derived from it. The problem remains the incapability of the developed and developing nations to balance the trial and gain, and often global research does not adequately address the needs of developing nations. While the interpretation of these problems on a bioethical level can be most beneficial, the implementation of some of the prescribed guidelines on these matters presents a bigger problem. The manner and reach of the implementation of these issues must be well planned in a national legal context and, more importantly, in a general far-reaching national strategy which often completely lacks in the developing nations. International effort usually applies well in the non-governmental sector but rarely goes beyond it, or if it does, the national public policies and public don't seem to pick up on the practical importance and necessity of action. The media should

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[1] Often discussed at the numerous conferences of the Models United Nation throughout the world. Models United Nations usually give an excellent example of youthful action and ideas as well as a pointer to where the actual United Nations should turn their focus. Also Letters From Readers - John Daly, »UNESCO bioethics—human rights declaration inadequate«, Rockville, Maryland, United States, 27 September 2005. 10 Dec 2009. <http://www.scidev.net/en/editor-letters/unesco-bioethicshuman-rights-declaration-inadequa.html>.

also intensify their educational influence and help increase the public understanding of the problems of medical and scientific research and the issue of poor distribution of the means and the benefits of the obtained results the *Declaration* warns about. But for such a joint effort in bettering the public awareness a good collaboration of several levels of authority must be established, which is hard in struggling developing countries.

Bioethics, despite its concern with issues that have profound implications for human life and welfare, has not often been thought of in a human rights context. By the same token, human rights theory has rarely been concerned with bioethical issues. This disconnection has recently been heavily criticised by many health activists, and we are beginning to see some convergence between the two[2], and the *Declaration* certainly helps in this. There might be identified a discrepancy between the bioethicists who see notions of what makes us human as topics for analysis and discussion, and the human rights specialists who take them for granted, having got into great difficulty trying to sort out, for example, whether abortion promotes human rights or is a direct attack on them, or whether the genetic engineering, nanotechnology and cybernetics would alter people so severely as to make them lose their rights[3]. The general critic opinion is also about the *Declaration*'s failure to represent significant progress in reaffirming human rights principles in the context of 21st-century concerns about biotechnology, the restructuring of health services or the natural environment, focusing on medical care and biomedical research, having made points that are merely simplifications of some of the principles set out in the *Declaration of Helsinki*, which provides ethical guidelines for medical research, or (re)formulating already existent principles of social justice and solidarity relevant to bioethics, and of benefit-sharing in biomedical research and development[4]. Also, critics feel, it will probably be an evidence, if cited in litigation or policymaking, that standards weaker than those in some existing international guidelines (such as the Helsinki Declaration) are legally and internationally acceptable; and it poses, contrary to most aspirational and goal oriented human rights-statements, barely a corpus of decent minimum standards[5]. The minimum standards are an absolute necessity, no matter how 'superficial' some theoreticians might find them, as the basic ground cannot be overly burdened. If anything, the *Declaration* might seem to be

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[2] P. Farmer, (2005), »New malaise: Medical ethics and social rights in the global era,« in P. Farmer, *Pathologies of Power: Health, Human Rights, and the New War on the Poor*, Berkeley, CA: University of California Press, 196-212.

[3] N. Bostrom, (2005), In defence of posthuman dignity, in *Bioethics,*19:202-214.

[4] Richard Ashcroft, Nothing to declare: UNESCO on ethics, human rights. 02 Dec 2009. <http://www.scidev.net/en/opinions/nothing-to-declare-unesco-on-ethics-human-rights.html>.

[5] Idem. Also, young delegates at the World Model United Nations in Puebla, Mexico, 2008 have debated whether the Declaration isn't just a sort of Helsinki-Supplement.

involving too much, to be too comprehensive: it tries to encompass as much as possible of the relevant topics, making it difficult to cope for integrative bioethics, what with all the different levels and the various aspects bioethics needs to tackle. In the context of human rights, while their theoretical universality is not questionable (as, of course, drafted in the *Universal Declaration of Human Rights*), this *Declaration* faces the same practical problems of control of the extent of practical involvement and probability as the former. Namely, it operates with the concept of human rights associated with and even bind by the concepts of fundamental freedoms and human dignity, both very vague and not yet fully and widely defined. Methodologically, such a connection is more than coherent, but fails in practice perhaps because all three general concepts are too broad and seem to either lack a genux proximum or a have too big of a differentia specifica, which causes serious problems in the implementation of the material of the *Declaration*'s articles.

The *Declaration* gets more praised than criticized, however. It does give a precious contribution to global policies by directing the scopes, and limiting the regulating spree; by highlighting the importance of access to scientific and technological information, particularly in developing countries; by insisting on the promotion of the sharing and free flow of scientific information; emphasizing the importance of people being able to access their local genetic resources and traditional knowledge systems; and stressing, for instance, the importance of obtaining prior informed consent from participants in scientific research. Many scholars and activists (as well as, of course, its advocates) feel that the *Declaration* is a sheer, much needed response to the stressing issues of the century, finding it »especially important in these times when many marginalized peoples all over the world have no support and think the world is simply exploiting them for medical science«[6], that it encourages governments to set up ethics committees to assess scientific developments, and stresses the need to help keep the public informed and encourage public discussion of bioethics issues, and that, although guidelines on ethical and human rights issues exist, this is the first time the two subjects have been combined in a single document aimed at governments[7] (as the *Helsinki Declaration* on research ethics is adopted only by the World Medical Association, a professional organization). Even the advocates stress the need to be careful when it comes to developing countries: for example, Udo Schüklenk, editor of *Developing World Bioethics*, thinks that a big concern is that if developing countries endorse the declaration in its current form they could put their citizens at risk, unless they are prepared for its subtle

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[6] The opinion of Carolyn Stephens, a lecturer in ethics, human rights and public health at the London School of Hygiene and Tropical Health, 02 Dec 2009. SciDev.Net <http://www.scidev.net/en/news/unesco-guidance-on-ethics-and-human-rights-slammed.html>.

[7] Henk ten Have, the director of UNESCO's division of ethics of science and technology, 02 Dec 2009. SciDev.Net <http://www.scidev.net/en/news/unesco-guidance-on-ethics-and-human-rights-slammed.html>.

meaning, because, »unlike developed countries, they are less likely to be equipped to undertake a comprehensive analysis of the practical implications of a given UN document«[8], in which case, the consequences could be disastrous for developing countries' capacity to respond to public health emergencies or their attempts to build up functional biomedical research infrastructures.

The journal's articles (*Developing World Bioethics* 5 (special issue), (2005)) vary in the strength of their criticism: John Williams, the World Medical Association's director of ethics, calls the declaration a »major disappointment« and questions the merit of UNESCO involving itself in an area about which it has no expertise, and which falls under the mandate of another UN body, the World Health Organization; Matti Häyry and Tuija Takala at the UK-based University of Manchester say the *Declaration* unnecessarily limits the scope of bioethics to life sciences and their practical applications, while bioethics also includes political and ideological choices, which in turn are based on preferences, religious beliefs, cultural convictions, and philosophical views. The journal's editorial by Schüklenk and co-editor Willem Landman states that values the *Declaration* claims are universal are »nothing of the sort« and that some of the document's principles are in direct conflict with others. Several authors point out that terms such as 'human dignity' are undefined and lack clarity, as a result (according to Williams) of, in part, UNESCO's haste in drafting the *Declaration*, but theoreticians disagree on this, as 'person', 'human being' and 'human dignity' are very blurry concepts that definitely need further work on, by philosophers, sociologists, scientists, politicologists etc. Atsushi Asai and Sachi Oe of Japan's Kumamoto University believe the *Declaration* should »be regarded as an up-to-date and well-organized compendium of bioethical knowledge«. Ruth Macklin at the Albert Einstein College of Medicine, United States, agrees that the document's strengths outweigh its weaknesses. Answering to the criticisms, UN officials state that they are the unfortunate product of misunderstanding of the way UN agencies work, and (Henk ten Have), that, rather than promoting 'academic' bioethics as this journal editors do, UNESCO aims to use its guidance, »to educate healthcare professionals and young scientists in ethics, to establish ethics committees, and create an infrastructure for bioethics«.

Pluriperspectivity in Integrative Bioethics

That is why the integrative bioethics should work as a bridge, not to the future this time, or not only to the future, but between the theoretical realm of thought and

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[8] Priya Shetty, UNESCO guidance on ethics and human rights slammed, 6 September 2005, *Idem.*

the practical realm of on-site problems, offering, as Ante Čović puts it, more an *orientation* than established invariable final objective truths about life. International documents are crucial to the implementation of some of its imperatives, but the theoretical background, its evolving and spreading, must continuously help diminish (if not, of course, eradicate) the constantly arising practical problems. The integrative bioethics supplies orientation for answers to some of the key questions of humanity as a whole now, and as a starting point for the future (again, »the future generations«, a point the *Declaration* addresses), in which sense, Čović holds that all the disciplines and perspectives integrated into the bioethical field have an »orientative value«, and that all of them can make »contributions to the interactive development of the orientation«, being a »pluriperspectival field, in which footholds and measures for orientation in the questions concerning life or the conditions and circumstances of the life-preservation are being created through interaction of diverse perspectives.«[9], mentioning a very important point (especially when in comes to delicate countries-peoples-conflicts-related questions), the goal of integrative bioethics of nurturing and articulating the growing bioethical sensibility,[10] stating that the integration of different (and all) topics and issues concerning *bios*, and the integration of different (and all) approaches to these topics and issues is the underlying presupposition of integrative bioethics, which, concentrated as an axiological constantly improving background to the *Declaration* and its implementation, can work wonders.

It can be noticed how the problems that the *Declaration* tackles, are completely compatible to some forms or stages of the methodological growth of bioethics: such as the origin of it, the focus on medical ethics at one point (Callahan, Beauchamp and Childress, Singer, and Kuhse[11]). The *Declaration* dominantly focuses on biomedical related problems, and the widening of their definition, status and direction; the »Bioethics« lexicon-type entry written by Otfried Höffe in his *Lexicon of Ethics* defines it as: »(…) understood to be an interdisciplinarily founded science of survival, whose main aim is to build bridges between the humanities and the natural sciences. Directed against a merely instrumental approach to nature, bioethics discusses the economic, social, political and cultural presuppositions of people's rela-

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[9] Ante Čović & Thomas Sören Hoffman (eds.), *Bioethik und kulturelle Pluralität. Die südosteuropäische Perspektive*, Academia Verlag, Sankt Augustin, 2005, 150-151.

[10] Ante Čović, »Wissen und Moralität«, *Synthesis philosophica* 26 (2/1998), p. 565.

[11] Daniel Callahan, »The Development of Biomedical Ethics in the United States«, in: D. Callahan & G. R. Dunstan (eds.), *Biomedical Ethics: An Anglo-American Dialogue*, New York Academy of Sciences, New York, 1988, 2.; Tom L. Beauchamp & James F. Childress, Principles of Biomedical Ethics, Oxford University Press, New York, 1994; Helga Kuhse & Peter Singer, »Introduction«, in: H. Kuhse & P. Singer (eds.), *Bioethics. An Anthology*, pp. 1-7; Helga Kuhse & Peter Singer, »What Is Bioethics? A Historical Introduction«, in: H. Kuhse & P. Singer (eds.), *A Companion to Bioethics*, 3-11.

tionship to nature. Extended to the field of *biomedical ethics*, it deals with moral questions of birth, life and death, particularly in the light of the more recent developments and possibilities introduced by biomedical research and therapy. It researches, amongst other things, the moral dimensions of abortion, sterilisation and birth control, (genetic) manipulation, euthanasia, experiments on humans (…), as well as animal protection.«[12] The »Bioethics« entry, written by Daniel Callahan for the second edition of the *Encyclopedia of Bioethics*, interprets the birth of bioethics as the result of the synergy of the extraordinary technological progress in the field of biomedicine and the gradual awakening to the environmental hazards posed by the human appetite for economic progress and the domination of nature[13], becoming »a child of remarkable advances in the biomedical, environmental, and social sciences«, concerning »our common duties to each other and to nature«.[14]

Integrative bioethics gets explained through multi-, inter- and trans-disciplinarity, and pluriperspectivism, giving a wide, stable ground for interpretation of all the crucial and subtle points and issues of the *Declaration*. The concepts of multidisciplinarity, interdisciplinarity and transdisciplinarity refer, respectively, to: the gathering of all human sciences and professions relevant to bioethical issues; the necessary promotion of dialogue collaboration; and the incorporation of their differences in a unique, bioethical view focused on questions that are impossible to discuss, and possibly, solve, through single fields of knowledge, without the interrelation of multiple perspectives.

The preservation and encouragement of the diversity the *Declaration* points out, gets fully accounted for in the integrative bioethics, a pluriperspective field of study, incorporating and mediating the dialogue of scientific and non-scientific or beyond-scientific contributions, being perfectly aware (as it is auto-reflective) of the sometimes colliding modes of interpretation, the different traditions and modes of reflection and action, and the different, precious traditions of thought, culture, religion, law and politics.

The fact that bioethics works with ambitious concepts, aiming way beyond its own present limitations is essential to the overcoming of verbal and practical problems that the implementation of the *Declaration* might trigger, and the overcoming of the epistemological and axiological problems its complex structure and framework face. And, finally, when it comes to the helping background (both protective and critic),

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[12] Otfried Höffe, »Bioethik«, in: O. Höffe (ed.), *Lexikon der Ethik*, Beck, München, 1997, 28.

[13] Daniel Callahan, »Bioethics«, in: Warren T. Reich (ed.), *Encyclopedia of Bioethics*, Vol. I, Macmillan, New York, 21995, 248.

[14] Idem., 247-248.

that the integrative bioethics provides to the *Declaration*, it becomes irrelevant the much abused fact that the talk of integrative bioethics is only logical due to the non-existent consensus on either its definition or footholds, as the methodological aspect gets rightly emphasized.

Conclusion

Facing the challenges of the rapidly evolving world torn by conflicts and inequalities; getting into account the disparity of the nature of the identified problems and the nature of their possible solutions; considering the need for a comprehensive set of guidelines for nations and governments as well as for smaller scientific communities and the non-governmental sector, it is necessary to acknowledge the merit of the guidelines provided by the *Declaration*. The theoretical background of integrative bioethics, concerning both the main core and the subtle details of the *Declaration*'s implications is much needed for a more successful apprehending of the pressing existential issues of mankind, including its safety, dignity and future.

JAHR | Vol. 1 | No. 1 | 2010

UDK:<174:61>342.7-053.2
Professional Article/Stručni članak
Received/Primljeno 08/02/2010

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UNESCO, bioetika i dijete

SAŽETAK

Pod okriljem UNESCO-a su donese tri glavne međunarodne deklaracije iz područja bioetike s ciljem zaštite »prirodnog dostojanstva, jednakih i neotuđivih prava svih članova ljudske obitelji«. Djeca su posebno osjetljiva kategorija »ljudske obitelji« čija su se prava pokušala zaštiti donijetim deklaracijama, bilo na direktan ili indirektan način, počevši od Opće deklaracije o ljudskim pravima. Prošlo je dvadeset godina nakon donošenja »Konvencija ujedinjenih naroda o pravima djece« (20. studeni, 1989.). U ovom ćemo se radu osvrnuti na temeljna prava djeteta prema UNESCO-vim dokumentima.

Ključne riječi: bioetika, dijete, pravo, UNESCO

Prema Konvenciji o pravima djeteta, »...dijete je svaka osoba mlađa od 18 godina, osim ako zakonom koji se primjenjuje na dijete granica punoljetnosti ne odredi ranije«(1).

Pod okriljem UNESCO-a su donese tri glavne međunarodne deklaracije iz područja bioetike s ciljem zaštite »prirodnog dostojanstva, jednakih i neotuđivih prava svih članova ljudske obitelji«(2). Djeca su posebno osjetljiva kategorija »ljudske obitelji« čija se su se prava pokušala zaštiti donijetim deklaracijama, bilo na direktan ili indirektan način. U Hrvatskoj je 2008. godine izdan prijevod deklaracija iz područja bioetike donjetim od strane Organizacije ujedinjenih naroda za obrazovanje, znanost i kulturu (UNESCO): Opća deklaracija o ljudskom genomu i ljudskim

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pravima, Međunarodna deklaracija o ljudskim genetskim podacima te Opća deklaracija o bioetici i ljudskim pravima(2). Cilj ovog rada je proučiti u kojoj su mjeri zaštićena prava djeteta u tim dokumentima i u kojoj su mjeri načela zastupana u tim dokumentima implantirana u našoj praksi.

Opća deklaracija o ljudskom genomu i ljudskim pravima donijeta je 11. studenog 1997. godine. Ljudski genom je definiran kao temelj najdubljeg jedinstva svih članova ljudske obitelji, priznanje njihova prirodnog dostojanstva i raznolikosti(2). Prije samog istraživanja, liječenja ili dijagnoze koji utječu na genom pojedinca, potrebno je procijeniti potencijlne štete i koristi. U svakom slučaju najprije se mora dobiti slobodan i upućen pristanak zainteresiranih osoba. Ukoliko osoba nije u mogućnosti dati svoju suglasnost, ista se mora osigurati na način propisan zakonom i u najboljem interesu te osobe. Osobe koje nisu u stanju dati punopravnu suglasnost s obzirom na istraživanje njena genoma, ono će se poduzeti samo onda ako ta osoba ima izravnu zdravstvenu korist od istraživanja, uz uvjet odobrenja i zaštitu u skladu sa zakonom. U slučaju da je ta osoba izložena najmanjem riziku i najmanjem naporu, dobrobit istraživanja je usmjerena ka osobama iste dobne skupine ili istih genetskih uvjeta(2).

U Općoj deklaraciji o ljudskom genomu i ljudskim pravima izravno se ne spominje zaštita prava djece. Važnost slobodne suglasnosti se navodi općenito bez detaljnijih uputa za one osobe koje nisu u mogućnosti dati svoju suglasnost. Deklaracija nam ne daje upute na koji način se djeca mogu uključiti u davanje suglasnosti za pojedine medicinske postupke već se poziva na važeće zakonske propise za sve osobe koje nisu u mogućnosti dati pravovaljanu suglasnost(2). U skladu s važećim zakonima u Hrvatskoj djeca ne mogu dati pravovaljanu suglasnost, to umjesto njih čine roditelj ili staratelj ili zakonski skrbnik(3).

Međunarodna deklaracija o ljudskim genetskim podacima donijeta je 16. listopada 2003. godine s ciljem jamčenja poštivanja ljudskog dostojanstva i zaštite ljudskih prava i temeljnih sloboda u prikupljanju, obradi, korištenju i pohranjivanju ljudskih genetskih podataka, ljudskih proteomskih podataka i bioloških uzoraka. Članak 2., između ostalih donosi definiciju genetskog probira kao »šire sustavno genetsko testiranje na nekoj populaciji ili jednom njenom dijelu određenom za otkrivanje genetskih osobina ljudi koji su bez simptoma bolesti«(2). I u slučaju postupaka vezanih uz ljudske genetske podatke, prikupljanje proteomskih i bioloških uzoraka potrebno je pribaviti prethodni slobodan i na informacijama utemeljen pristanak. Ukoliko osoba nije u mogućnosti dati svoj punopravan pristanak, sukladno domaćem zakonu isti će dati pravni zastupnik koji mora poštovati najbolje interese te osobe. Treba istaknuti kao pozitivan primjer i veliki korak isticanje poštovanja mišljenja maloljetne osobe u članku 8. Međunarodne deklaracije o ljudskim genetskim podacima. Značajno je da ova deklaracija o djetetu govori izravno, ističući važnost dobivanja i uzimanja u obzir njegovog mišljenja, sukladno godinama i zrelosti(2).

Genetski probir će biti etički prihvatljiv samo kada ima bitne posljedice za zdravlje osobe, poštujući njen najbolji interes.

Novorođenački skrining je postupak u okviru preventivne medicine kojemu je svrha sustavno otkrivanje bolesne novorođenčadi kod koje će pravodobna dijagnoza i liječenje dovesti do značajnog smanjenja smrtnosti, morbiditeta i invalidnosti(4). Skrining na fenilketonuriju i konatalnu hipotireozu su općenito svugdje prihvaćeni, pa tako i u našoj zemlji. Fenilketonurija je autosomno recesivni poremećaj hidroksilacije fenilalanina u tirozin koji neliječen dovodi do nagomilavanja fenilalanina i njegovih metabolita u tjelesnim tekućinama s posljedičnom teškom mentalnom retardacijom, epilepsijom i drugim neurološkim poremećajima. Skrining na konatalnu hipotireozu uveden je u nas 1985. godine mjerenjem TSH RIA metodom. Osim probira na fenilketonuriju i konatalnu hipotireozu u Hrvatskoj se još čini i probir sluha u rodilištima(4). Iz navedenih primjera vidi se da je novorođenački probir na fenilketonuriju hipotireozu ima za cilj dobrobit novorođenčadi što je u skladu s načelima Međunarodne deklaracije o ljudskim genetskim podatcima(2).

Opća deklaracija o bioetici i ljudskim pravima donijeta je 19. listopada 2005. godine. Ova deklaracija se osvrće na etička pitanja koja se odnose na medicinu, biološko-antropološke znanosti i prateću tehnologiju(2). Deklaracija ističe važnost poštivanja ljudskog dostojanstva, ljudskih prava i temeljnih sloboda. U skladu s time interesi i dobrobit pojedinca imaju prioritet nad interesom znanosti ili društva, kao i važnost poštivanja autonomije pojedinca u donošenju odluka, preuzimanja odgovornosti za te odluke i uvažavanje autonomnosti drugih, bez osvrta na autonomiju maloljetnih osoba. U daljnjem tekstu ove deklaracije se navodi važnost postupanja u skladu zaštite prva i interesa osoba koje nisu samostalno sposobne donjeti odluku. Deklaracija objašnjava smisao i daje važnost pristanka vezano uz preventivne, dijagnostičke i terapetuske zahvate. Na isti način se ističe važnost pristanka pri uključivanju u znanstveno istraživanje, kojem treba prethoditi dostatna informacija. Osobe koje nisu sposobne dati pristanak u slučaju provođenja istraživanja i primjene medicinske prakse, pristanak se mora dobiti u skladu sa zakonom. U ovoj deklaraciji se ističe važnost uključivanja te osobe u što većoj mjeri u donošenje odluke o pristanku kao i odluke o povlačenju pristanka. Ovaj dio je vrlo bitan u zdravstvenoj zaštiti djece, kao i u uključivanju djece u istraživanje, stoga što podrazumijeva aktivno sudjelovanje djece u odlučivanju o njihovu zdravlju(2).

Potrebno je poštovati privatnosti i povjerljivosti podataka koji su dobiveni od pacijenata. S obzirom na maloljetne pacijenate, Deklaracija u daljnjem tekstu ne objašnjava na koji način i u kojoj je mjeri moguće čuvati privatnost i povjerljivost podataka dobivenih od djece pri primjeni medicinske prakse.

Konvencija o pravima djeteta usvojena je na Glavnoj skupštini Ujedinjenih naroda 20. studenog 1989. godine(1). Sadrži obaveze odraslih u odnosu prema djetetu, obaveze različitih društvenih čimbenika s obzirom na zaštitu djeteta. Konvencija o pravima djeteta je prvi dokument u kojem se djetetu pristupa kao subjektu s pravima. Ona je pravni akt koji ima snagu zakona, uključuje pravo nadziranja primjene u državama koje su je prihvatile i ratificirale. Hrvatska je ratificirala 8. listopada 1991. godine. Ona osigurava građanska, politička, ekonomska, socijalna i kulturna prava djece. Bezuvjetno zahtijeva od vlada poduzimanje aktivnosti vezanih uz zaštitu prava djeteta. Holistički zagovara gledište da su sva prava temeljna, nedjeljiva i međusobno ovisna i jednako važna. Dana su četiri načela na kojima se temelje sva prava sadržana u Konvenciji:

1. Načelo nediskriminacije prema kojem djeca ne smiju trpjeti diskriminaciju.
2. Pravo na život i razvoj u svim vidovima života.
3. Dobrobit djeteta je najvažnija pri donošenju odluka ili izvršenju postupaka koji utječu na dijete.
4. Djeca su aktivni sudionici u sudjelovanju rješavanja svih pitanja koja utječu na njihov život i moraju imati slobodu izražavanja svog mišljenja.

Prema Konvenciji ne postoji hijerarhija dječjih prava, već su to obaveze koje države moraju ispunjavati spram djeteta. Svi moraju biti aktivni i angažirati se u pridonošenju ostvarivanja prava djeteta(1).

Hrvatska je danom osamostaljenja 8. listopada 1991. godine postala stranka Konvencije o pravima djeteta. Tim činom naša je zemlja preuzela obavezu izmjene i prilagodbe postojećih zakona i akata u skladu s Konvencijom. Države su obavezne upoznati djecu i odrasle s načelima i odredbama o pravima djeteta. Ta prava bezuvjetno moraju znati i poštovati oni koji žive i rade s djecom, koji su u svakodnevnom kontaktu s djecom i koji utječu na stvaranje sredine u kojoj dijete odrasta i razvija se kao osoba. Djeca moraju biti upoznata sa svojim pravima kako bi postali svijesni tih prava i mogućnosti u slučaju ugrožavanja istih. Svi navedeni čimbenici u Konvenciji imaju za cilj optimalan razvoj djeteta, naučiti dijete kako da štiti vlastita i tuđa prava(1).

Kada se raspravlja o pravima maloljetnih osoba u zdravstvenoj zaštiti mnogi autori svoja stavove temelje na članku 12. i 13. Konvencije o pravima djece koji su citirani u daljnjem tekstu.

Čl.12. »djetetu koje je u stanju oblikovati vlastito mišljenje, osigurat će se pravo na slobodno izražavanje svih svojih stavova o svim stvarima koje se na njega odnose, te ih uvažavati u skladu s dobi i zrelošću djeteta«. Dijete mora biti izravno ili putem posrednika saslušano u svakm sudbenom ili upravnom postupku koji se na njega odnosi«(1). Čl.13. »Dijete ima pravo na slobodno izražavanje, slobodno traženje, primanje i širenje obavijesti i ideja svake vrste«(1).

Na isti način i radna grupa Konfederacije europskih pedijatara (*Ethics Working Group of the Confederation of European Specialists in Paediatrics-CESP*) je 2003. godine u časopisu *Pediatrics* dala svoju izjavu o informiranon pristanka djeteta(5). Svoje stavove temlje na gore navedenom članku 12. Konvencije o pravima djeteta. Iako se u samom tekstu nigdje ne navodi da se prava na vlastito mišljenje i izražavanje svojih stavova odnose na područje zdravstvene skrbi djeteta, autori drže da se taj članak može primijeniti i na područje zdravlja djeteta. Definiraju djetetov pristanak kao njegovo slaganje s medicinskim postupkom u slučaju kada ono nije zakonom dozvoljeno ili nema dovoljnu zrelost spoznajnih funkcija dati kompetentnu informiranu suglasnost. Sva djeca bez obzira jesu li kompetentna ili ne imaju pravo na informaciju o svom zdravlju dobivenu na način da ju mogu razumjeti, te na osnovu te informacije dati svoj pristanak ili neslaganje u svim aspektima medicinske skrbi (preventivne, dijagnostičke i terapijske mjere, kao i istraživanja). Smisao i jednog i drugog je u partnerstvu, u pružanju informacija na osnovu kojih pacijent slobodno izabire onaj put koji mu najviše odgovara. Djeca mogu odbiti zahvat ili liječenje koje nije neophodno da im se spasi život. U slučajevima kada postupak spašava život ili sprečava nastajanje ozbiljne štete, liječnici imaju dužnost postupati u najboljem interesu djeteta. Autori ističu kako su djeca vlasnici prava, unatoč tome što ih ponekad ne mogu izraziti(5).

Svi mi koji se u svom radu susrećemo sa djecom dužni smo promovirati njihova prava, dati pravo glasa djetetu i djelovati kao djetetov istinski odvjetnik. Pružiti informaciju djetetu na njemu razumljiv način. Liječnici trebaju pažljivo slušati mišljenje i želje djece, procijeniti kompetenciju djeteta, zaštititi djetetovo dostojanstvo i privatnost, te nastojati dobiti djetetov pristanak koji je nužan u preventivnim, dijagnostičkim i terapijskim postupcima, kao i u istraživanjima(5). Izvještaj UNESCO-vog Međunarodnog komiteta za bioetiku o pristanku pacijenta ističe važnost postupanja u skladu s Konvencijom o pravima djeteta, napominjući kako se mora biti svijestan da se s rastom i razvojem djeteta razvija i njegova sposobnost odlučivanja. No još uvijek ostaje pitanje kada se to točno događa(6).

Prema Konvenciji (članak 24.) dijete ima pravo na uživanje najviše moguće razine zdravlja, pružanje obavijesti, obrazovanja i potpore u korištenju temeljnih spoznaja o svom zdravlju(1).

Opća deklaracija o bioetici i ljudskim pravima ističe kako svakoj osobi pripadaju sva prava i slobode u njima sadržane, kao i da djetinjstvu pripada posebna skrb. Bitno je naglasiti da članak 22. gore navedene deklaracije ističe zadaću države koja bi trebala poduzeti sve odgovarajuće mjere kako bi se provela njena načela. Ujedno se ističe da države trebaju nastojati njegovati obrazovanje i educiranje u bioetici na svim razinama, kao i poticati informaciju i programe za diseminaciju znanja o bioetici. Na tom tragu i ovo izlaganje podsjeća na dokumente koji se tiču prava djece u primanju zdravstvene zaštite, na važnost uključivanja djece kao aktivnih subjekata u davanju ili povlačenju pristanka, što ističu gore navedene deklaracije, Konvencija o pravima djeteta. Potrebno je napomenuti da su države, time i Hrvatska, pozvane na primjenu tih načela u svakodnevnom životu. Posebno treba napomenuti potrebu usklađivanja zakona vezanih na prava djece u zdravstvenoj zaštiti i u istraživanima. Primjerice Zakon o zaštiti prava pacijenata nije usklađen s Konvencijom o pravima djeteta. Ovaj zakon je propustio naglasiti mogućnost i potrebu aktivne uloge maloljetnog pacijenta u odlučivanju o zdravlju(3).

Liječnici moraju aktivno uključiti dijete u donošenje odluka o djetetovu zdravlju. To podrazumijeva mijenjanje naših stavova vezanih uz moralni status djeteta kao i zahtjeve na samo društvo koje mora te promjene pratiti promjenama u zakonskoj regulativi, i ono najvažnije, u samoj praksi.

Možemo zaključiti potrebu bezuvjetnog poznavanja Konvencije o pravima djeteta i UNESCO-ve deklaracija iz područja bioetike onih koji rade s djecom. Učiniti da dijete u zdravstvu postane aktivan SUBJEKT sa svim svojim pravima. Dijete ima pravo na slobodno izražavanje, slobodno traženje, primanje i širenje obavijesti. Država sukladno ovoj konvenciji i imenovanim deklaracijama u tekstu mora njegovati obrazovanje i obučavanje u bioetici na svim razinama, poticati informacije i programe te uskladiti legislativu.

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JAHR | Vol. 1 | No. 1 | 2010

UDK:<174:61>342.7-053.2
Professional Article/Stručni članak
Received/Primljeno 08/02/2010

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UNESCO, bioethics and child

ABSTRACT

UNESCO has adopted three principal international bioethics declarations with the purpose to protect »the inherent dignity of the equal and inalienable rights of all members of the human family«. Children are a particularly sensitive category of the »human family« whose rights were attempted to be protected through declarations, directly or indirectly, starting with the Universal Declarations on Human Rights. It has been twenty years since adopting the »Convention on the Rights of the Child« by the UN (20 November 1989). This paper shall look into the basic rights of the child in accordance with UNESCO's documents.

Key words: bioethics, child, law, UNESCO

According to the Convention on the rights of the Child, »... a child means every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier«(1).

UNESCO has adopted three principal international bioethics declarations with the purpose to protect »the inherent dignity of the equal and inalienable rights of all members of the human family«(2). Children are a particularly sensitive category of the »human family« whose rights were attempted to be protected through declarations, directly or indirectly. In Croatia the translation of the bioethics declarations adopted by UNESCO was published in 2008: Universal Declaration on the Human Genome and Human Rights, International Declaration on Human Genetic Data and Universal Declaration on Bioethics and Human Rights(2). The aim of this paper is to research the extent to which children's rights are protected by these docu-

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ments as well as the extent to which principles based on these documents are implanted in our practice.

Universal Declaration on the Human Genome and Human Rights was adopted on 11 November 1997. Human genome is defined as a fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity(2). Prior to research, treatment or diagnosis affecting an individual's genome, assessment of the potential risks and benefits is necessary. In all cases, the prior, free and informed consent of the person concerned shall be obtained. If the latter is not in a position to consent, consent shall be obtained in the manner prescribed by law, guided by the person's best interest. If a person does not have the capacity to consent, research affecting his or her genome may only be carried out for his or her direct health benefit, subject to the authorization and the protective conditions prescribed by law. Should the person be exposed to any risk or burden, the research is intended to contribute to the health benefit of other persons in the same age category or with the same genetic condition(2).

Universal Declaration on Human Genome and Human Rights does not directly mention protection of children's rights. The importance of free consent is stated generally and without detailed instructions for persons who do not have the capacity to consent. The Declaration does not provide instructions concerning manners in which children can participate in consenting for individual medical procedures, but it refers to legal regulations in force for all persons without the capacity to give valid consent(2). According to the Croatian law, a child may not give valid consent; instead, a parent or a legal guardian consents on behalf of a child(3).

International Declaration on Human Genetic Data was adopted on 16 October 2003 with the aim to ensure the respect of human dignity and protection of human rights and fundamental freedoms in the collection, processing, use and storage of human genetic data, human proteomic data and of the biological samples. Article 2, among other, provides a definition of genetic screening as »large-scale systematic genetic testing offered to a population or subsection thereof intended to detect genetic characteristics in asymptomatic people«(2). Prior to carrying out procedures involved in collecting human genetic data, proteomic data and biological samples, it is necessary to obtain free and informed consent. When a person is incapable of giving valid consent, in accordance with domestic laws, authorization should be obtained from the legal representative, who should have regard to the best interest of the person concerned. Emphasis of taking into consideration the opinion of a minor in Article 8 of the International Declaration on Human Genetic Data should be pointed out as a positive example and a great step. It is significant that this Declaration speaks of a child directly, emphasizing the importance of obtaining and taking into consideration his or her opinion in proportion to age and degree of maturity(2).

Genetic screening shall be ethically acceptable only when having significant consequences on health of a person, taking into consideration his or her best interest.

Newborn screening is the procedure within the field of protective medicine with the aim to detect diseases in newborns where timely diagnosis and treatment shall lead to a significant reduction in mortality, morbidity and invalidity(4). Screening for phenylketonuria and congenital hypothyroidism is widely accepted, including in our country. Phenylketonuria is an autosomal recessive disorder of phenylalanine hydroxylase in tyrosine and if it is not treated it leads to accumulation of phenylalanine and its metabolites in bodily fluids and result in heavy mental retardation, epilepsy and other neurological disorders. In our country screening for congenital hypothyroidism was introduced in 1985 through TSH RIA measuring method. Apart from screening for phenylketonuria and congenital hypothyroidism, Croatian maternity wards also a screen for congenital deafness(4). Given examples show that newborn screening for Phenylketonuria and hypothyroidism is carried out for the benefit of the newborns, which is in accordance with the principles of the International Declaration on Human Genetic Data(2).

Universal Declaration on Bioethics and Human Rights was adopted on 19 October 2005. This Declaration looks into the ethical issues concerning medicine, bioanthropological sciences and accompanying technology(2). The declaration emphasizes the importance of respect for human dignity, human rights and fundamental freedoms. In accordance with this, the interests and welfare of the individual should have priority over the sole interest of science or society, as well as the importance of respect for the autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, without mentioning the autonomy of minors. Further text of this Declaration states the importance of protecting rights and interests of persons who do not have the capacity to consent. The Declaration explains the meaning and expresses the importance of consent concerning preventive, diagnostic and therapeutic medical interventions. It emphasizes in the same manner the importance of consent concerning engagement in scientific research, which should take place after receiving adequate information. Authorization for research and medical practice concerning persons who do not have the capacity to consent should be obtained in accordance with law. This Declaration points out the importance of involving the person concerned to the greatest extent possible in the decision-making process of consent, as well as that of withdrawing consent. This section is particularly important in health care of children, as well as in involving children in research, because it implies active participation of children in decision-making related to their health(2).

It is necessary to respect the privacy and confidentiality of data obtained from patients. The Declaration does not explain how and to which extent it is possible to ensure privacy and confidentiality obtained from children during medical practice.

Convention on the Rights of the Child was adopted by a UN General Assembly on 20 November 1989 (1). It contains the responsibilities of adults towards a child, the responsibilities of different social factors concerning child's protection. Convention on the Rights of the Child is the first document that considers a child as a subject with his or her rights. It is a legally binding instrument and it includes the right of monitoring its implementation in countries that have adopted and ratified it. Croatia ratified the Convention on 8 October 1991. It ensures civil, political, economic, social and cultural children's rights. It requires governments to unconditionally pursue activities concerning protection of children's rights. It has a holistic viewpoint that all rights are fundamental, inseparable and inter-dependant and equally important. There are four principles on which all rights contained in a Convention are based:

1. The principle of non-discrimination according to which children should be protected from discrimination.
2. The right to life and development in all areas of life.
3. Welfare of the child is the most important factor affecting decision-making or medical procedures concerning child.
4. Children are active participants in resolving all issues affecting their life and must have freedom to express their opinion.

According to the Convention there is no hierarchy of children's rights, they are responsibilities towards children which must be met by states parties to the Convention. Everyone involved must be active and engaged when it comes to contributing of implementing rights of the child(1).

On the day of its independence, 8 October 1991, Croatia became a state party to the Convention on the Rights of the Child. By becoming a state party, our country has obliged to modify and adopt its laws and articles in accordance with the Convention. State parties have the obligation to acquaint both children and adults with the principles and provisions related to the rights of the child. These rights must be known and unconditionally respected by persons living and working with children, persons in daily contact with children, as well as persons creating the environment in which the child grows and develops. Children must be acquainted with their rights in order to be aware of both rights and possible solutions should their rights be threatened. The purpose of all factors stated in the Convention is child's optimal development and teaching the child how to protect his or her own rights, as well as the rights of others(1).

When discussing health care rights of minors, many authors base their arguments on Articles 12 and 13 of the Convention on the Rights of the Child, which are cited hereafter.

Article 12 - »States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child«. The child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body«(1). Article 13 - »The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kind«(1).

In the same manner, the *Ethics Working Group of the Confederation of European Specialists in Paediatrics-CESP)* issued their statement on the informed consent of a child in *Pediatrics* journal in 2003(5). They base their viewpoints on the abovementioned Article 12 of the Convention on the Rights of the Child. Although the text of the document does not state that the right to child's own views and the right to express those views freely refer to health care, the authors believe that the Article is applicable to health care as well. They define child's consent as his or her agreement to the medical procedure when it is not allowed by law or his or her cognitive functions are not adequately developed to give an informed consent. Every child, whether competent or not, has the right to information concerning his or her health explained in an adequate manner and based on such information the child can express consent or disagreement with all aspects of medical care (preventive, diagnostic, therapeutic and research). The purpose of both is partnership, providing information as basis for patient's choice of the course of action that fits him or her most appropriately. Children may refuse a medical intervention or a treatment which is not essential for saving their life. When a procedure is essential to save a life or prevent serious damage, physicians have the obligation to act in the best interest of a child. The authors emphasize that children own rights despite the fact that sometimes they are not able to express them(5).

All of us who work with children have the obligation to promote their rights, give the child the right to express him or herself and act as his or her true representative. We must provide the child with the information in a manner which he or she is able to understand. Physicians should listen carefully to child's opinion, estimate child's competence, protect his or her dignity and privacy and attempt to obtain child's consent necessary in preventive, diagnostic and therapeutic procedures, as well as in research(5). The report of UNESCO's International Bioethics Committee on patient's consent emphasizes the importance of acting in accordance with the Convention on the Rights of the Child, pointing out that one must be aware that the competence to make a decision develops with child's growth and development. But the question of when exactly that occurs still remains(6).

According to the Convention (Article 24) the child has the right to the enjoyment of the highest attainable standard of health, to be provided information, education and support concerning basic knowledge regarding his or her health(1).

The Universal Declaration on Bioethics and Human Rights emphasizes that every person is entitled to all rights and freedoms stated in it and that children are entitled to special care. It is important to state that Article 22 of the above-mentioned Declaration emphasizes the role of the state, who should institute appropriate measures to follow Declaration's principles. It also mentions that states should encourage information dissemination of scientific information on bioethics. In accordance with that, this paper reminds of documents concerning child's rights in receiving health care, the importance of active involvement of children in giving or refusing consent, as emphasized in the above-mentioned declarations and the Convention on the Rights of the Child. It is important to mention that countries, including Croatia, are invited to apply those principles in everyday life. The necessity to harmonize legal regulations concerning health care and research involving children should be particularly emphasized. For instance, the Act on Patients' Rights is not harmonized with the Convention on the Rights of the Child. This act has neglected to include the possibility and necessity of minors to play an active role in decision-making regarding their health(3).

Physicians should actively involve a child in decision-making process regarding his or her health. It implies change in our views regarding the moral status of a child, as well as requirements of society who must keep up with these changes by modifying legal regulations and, most importantly, changes must be implemented in practice.

We may conclude that it absolutely necessary for persons who work with children to have a perfect knowledge of the content of the Convention on the Rights of the Child and UNESCO's bioethics declarations. The child must become an active SUBJECT in health system, with all his or her rights. The child has the right to free expression, seeking, receiving and dissemination of information. The state has the obligation in accordance with this Convention and declarations to foster education and training in bioethics on all levels, encourage information and programs and harmonize legal regulations.

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4. Paediatr Croat 2004; 48 (Supl 1): 197-203.
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Translation/prijevod: Snježana Volarić

JAHR | Vol. 1 | No. 1 | 2010

UDK: 614.253
UDK: 174:61
Essay/Esej
Received/Primljeno16/12/2009

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Informirani pristanak u UNESCO-vim bioetičkim dokumentima

SAŽETAK

Analizirajući UNESCO-ve bioetičke dokumente, s posebnim osvrtom na Opću deklaraciju o bioetici i ljudskim pravima, te bioetički *Core Curriculum*, cilj je ovog rada ukazati na mjesto i ulogu doktrine informiranog pristanka (engl. *informed consent*), kako u njegovoj praktičnoj primjeni unutar sustava biomedicine i zdravstva danas, tako i kroz potrebu i važnost njegove međunarodne bioetičko-pravne regulacije.
Pronalazeći uporište u aktivnostima UNESCO katedre za bioetiku, koja je kao prevladavajući temat svojih edukacijskih aktivnosti uzela upravo informirani pristanak, prepoznaje se prisustvo višedimenzionalnog okvira za pristup razrješavanju pitanja opterećenih moralnim vrijednostima, prisutnih unutar sustava zdravstvene skrbi.

Ključne riječi: bioetika, informirani pristanak, UNESCO.

Definicija informiranog pristanka

Bioetička doktrina informiranog pristanka (engl. *informed consent*) postala je temom ozbiljnih znanstvenih rasprava tek početkom '70-ih godina prošlog stoljeća. Ruth Faden, američka znanstvenica s Kennedy instituta, koja je '80-ih doktorirala upravo na toj temi, definira ga kao »izjavu pacijenta ili ispitanika nekog znanstvenog istraživanja, koja liječnika, ili medicinskog istraživača opunomoćuje da provede određene mjere, terapiju, ili da uključi ispitanika u istraživački protokol.« (1). Radi se, dakle, o opunomoćenom djelovanju liječnika prema pacijentu ili prema ispitaniku.

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»Kamen temeljac« informiranog pristanka predstavlja Nürenberški sudski proces nacističkim liječnicima i Nürenberški kodeks koji je proizašao iz tog procesa 1947. g. (2). U njegovoj prvoj točci govori se o dobrovoljnom pristanku kao apsolutno bitnom (*The voluntary consent of the human subject is absolutely essential.*) (3).

Elementi informiranog pristanka

Informirani pristanak na neku medicinsku intervenciju je valjan ako i samo ako je tom pristanku prethodila informiranost osobe o proceduri, ako je osoba dobivenu informaciju pravilno shvatila, i na osnovi toga dobrovoljno dala pristanak (2).

Tom L. Beauchamp i James F. Childress se u analizi sadržaja informiranog pristanka služe sa sedam analitičkih elemenata, odnosno kategorija:

Preduvjeti:

1. sposobnost (razumijevanja i odlučivanja)
2. dragovoljnost u odlučivanju

Elementi informiranja:

3. saopćavanje sadržaja medicinske informacije (*disclosure*)
4. preporuka (npr. plana liječenja)
5. provjera razumijevanja rečenog

Elementi pristanka:

6. odluka u vezi plana (odobrenje/odbijanje)
7. autorizacija (npr. potpisom) (4).

Koncept informiranog pristanka, dakle, oslanja se na dvije temeljne premise: da pacijent ima pravo na količinu informacija potrebnu kako bi mogao donijeti informiranu odluku o preporučenom medicinskom tretmanu, te da ima pravo prihvatiti ili odbiti prijedlog, odnosno preporuku liječnika. Kako ističe Ksenija Turković: »pravo na odbijanje predloženog medicinskog zahvata samo je druga strana prava na davanje pristanka i s njim čini cjelinu« (5).

Funkcije informiranog pristanka u kliničkoj praksi

Prema dvojici istaknutih pravnika i bioetičara, Jayu Katzu i Alexanderu Capronu, informirani pristanak obnaša sljedeće funkcije:

1. promiče individualnu autonomiju pacijenta i ispitanika,
2. potiče racionalno donošenje odluka,
3. osujećuje uplitanje javnosti,
4. upućuje liječnike i istraživače na etičku samokontrolu,
5. smanjuje opasnost od građanske i krivične odgovornosti liječnika, istraživača i njihovih ustanova (6).

Ivan Šegota ističe kako bi ovdje trebalo dodati i 6. funkciju – komunikacijsku, jer informirani pristanak zapravo počiva na komunikaciji, moglo bi se čak reći da je komuniciranje njegov središnji problem. S komunikološkog stajališta, za utvrđivanje valjanosti informiranog pristanka najznačajnije je obratiti pažnju na sljedeće:

1. koliko je informacija dobro dana,
2. koliko ju pacijent razumije,
3. koliko je pristanak uistinu dobrovoljan,
4. kako se dobiva od nekompetentnih osoba, ili osoba sa smanjenom kompetentnošću, te osoba izloženih prikrivenim pritiscima (zatvorenici, vojnici, studenti...),
5. koliko se uopće troši vremena na komuniciranje s pacijentima, odnosno ispitanicima (6).

Bioetičko-pravni okviri informiranog pristanka

U domaćoj i međunarodnoj bioetičko-pravnoj regulaciji informiranog pristanka potrebno je izdvojiti:

- Zakon o zaštiti prava pacijenata (ZZPP, NN 169/04, čl. 6-18),
- Zakon o zaštiti osoba s duševnim smetnjama (ZZODS, NN 111/97, 27/98, 128/99, 79/02, čl. 3. st. 12., čl. 8. i 9.),
- Obiteljski zakon (čl. 89/5),
- Helsinšku deklaraciju, 1975. (čl. 9-12),
- Konvenciju o pravima djeteta UN-a, 1989. (čl. 12/4),
- Konvenciju o zaštiti ljudskih prava i dostojanstva ljudskog bića u pogledu primjene biologije i medicine: konvenciju o ljudskim pravima i biomedicini, 1997. (čl. 5/1, 6).[1]

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[1] Spomenuti dokumenti ovdje neće biti analizirani. Autorica preporuča konzultiranje Zbornika radova »Bioetika i medicinsko pravo« (7).

Prikaz informiranog pristanka u UNESCO-vim bioetičkim dokumentima

Analizirajući UNESCO-ve bioetičke dokumente, učinit će se poseban osvrt na Opću deklaraciju o bioetici i ljudskim pravima, bioetički *Core Curriculum*, te Izvješće UNESCO-vog Međunarodnog bioetičkog komiteta (IBC) o informiranom pristanku.

Opća deklaracija o bioetici i ljudskim pravima

U Deklaraciji koju je 33. Generalna konferencija UNESCO-a donijela 19. listopada 2005. problematika informiranog pristanka obrađuje se kroz članke 6. i 7. koji će ovdje biti u cijelosti prikazani (8):

Članak 6. – Pristanak

1. Bilo koja preventivna, dijagnostička i terapeutska medicinska intervencija može se provesti samo uz prethodni i slobodni pristanak dotične osobe koji podrazumijeva dobivanje dostatnih informacija. Kada je prikladno, dotična osoba treba izraziti svoj pristanak, a može ga i povući u bilo koje vrijeme i iz bilo kojeg razloga bez nepovoljnih posljedica i šteta.
2. Znanstveno istraživanje može se provesti samo uz prethodni i slobodni, izrečeni pristanak dotične osobe koji se temelji na dobivenim dostatnim informacijama. Informacije trebaju biti odgovarajuće, pružene u sveobuhvatnom obliku i trebaju uključivati modalitete za povlačenje pristanka. Pristanak može dotična osoba povući u bilo koje vrijeme i iz bilo kojeg razloga bez bilo kakvih negativnih posljedica ili štete. Izuzeci iz ovog principa mogu biti učinjeni samo u skladu s etičkim i zakonskim standardima koje su usvojile države, sukladno načelima i odredbama utvrđenim ovom deklaracijom, posebno u čl. 27. te Međunarodnim zakonom o ljudskim pravima.
3. U odgovarajućim slučajevima za istraživanja koja se provode na skupini osoba ili zajednici, potrebna je i dodatna suglasnost pravnog zastupnika te skupine ili zajednice. Kolektivni sporazum ili pristanak voditelja zajednice ili drugog tijela ni u kojem slučaju ne može zamijeniti individualni pristanak pojedine osobe dobiven temeljem dostatnih i relevantnih informacija.

Članak 7. – Osobe koje nisu sposobne dati svoj pristanak

U skladu s domaćim zakonodavstvom, posebna zaštita daje se osobama koje nisu sposobne dati svoj pristanak:

a) ovlaštenje za provođenje istraživanja i primjenu medicinske prakse mora se dobiti u skladu s najboljim interesom dotične osobe i sukladno s domaćim zakonodavstvom. Pa ipak, dotična osoba treba biti u najvećoj mogućoj mjeri uključena u proces donošenja odluke o pristanku, kao i odluke o povlačenju pristanka;

b) istraživanje se može provesti samo radi neposredne koristi za zdravlje te dotične osobe, što podliježe ovlaštenju i uvjetima zaštite koji su propisani zakonom, te ako ne postoji druga alternativa istraživanju a čija bi se učinkovitost mogla usporediti kod tog sudionika s nekim drugim istraživanjem na koje bi on mogao pristati. Istraživanja koja nemaju eventualnu izravnu korist za zdravlje ispitanika mogu se poduzeti kao iznimka, uz maksimalna ograničenja i minimalne opasnosti i opterećenja kojima se izlaže ta osoba, a ako se očekuje da ta istraživanja doprinesu koristima za zdravlje drugih ljudi iz iste kategorije, moraju udovoljavati uvjetima propisanim zakonom i biti usklađena sa zaštitom ljudskih prava individualnih osoba. Odbijanje takvih osoba da sudjeluju u istraživanju mora se poštovati.

Bioetički *Core Curriculum*

UNESCO-v Sektor za društvene i humanističke znanosti, Jedinica za etiku u znanosti i tehnologiji, donio je 2008. g. bioetički *Core Curriculum* koji se sastoji iz dva dijela: *Syllabus* i *Study Materials*. Njegova glavna svrha je edukacija i to poglavito studenata medicine. Iz sadržaja posebno valja izdvojiti poglavlja 6. i 7. *Syllabusa* (9):[2]

Poglavlje 6: Pristanak

Međupovezivanje: ljudsko dostojanstvo

ljudska prava

autonomija

odgovornost pojedinca

Svrha informiranog pristanka

Međuodnos informirani pristanak – autonomija

Objašnjenje i primjena informiranog pristanka

Izuzeće: hitna stanja

maloljetnici

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[2] Poglavlja se temelje na člancima 6. i 7. Opće deklaracije o bioetici i ljudskim pravima.

mentalni bolesnici

Jehovini svjedoci

eutanazija

HIV pozitivni pacijenti

Poglavlje 7: Osobe nesposobne dati pristanak

Kriteriji za procjenu sposobnosti davanja pristanka

Kategorije osoba nesposobnih dati pristanak: novorođenčad

djeca

neurološki stariji pacijenti

pacijenti s teškoćama u učenju

mentalni bolesnici

pacijenti bez svijesti

(*Advance Directives, Living Will*)

Pravni okviri informiranog pristanka i
sposobnosti davanja pristanka: međunarodni

nacionalni

Procedure: protokoli unutar zdravstvenog sustava

posebne procedure (surogat, princip najboljeg interesa)

Istraživanja na ljudskim subjektima

Izviješće UNESCO-vog Međunarodnog bioetičkog komiteta (IBC) o informiranom pristanku

Izvješće je publicirano 2008. g. i posvećeno je člancima 6. i 7. Opće deklaracije o bioetici i ljudskim pravima. Međunarodni bioetički komitet (IBC) je odmah po donošenju Deklaracije krenuo u njenu sustavnu analizu, te je u svibnju 2007. prezentirao ovo izvješće na Generalnoj konferenciji UNESCO-a. Izdvojeno iz sadržaja Izvješća potrebno je naglasiti sljedeće (10):

Sadržaj informacije

Uvjeti dobivanja pristanka

Način izražavanja pristanka

Izuzeće/opoziv/ustezanje od pristanka

Okviri primjene: klinička praksa:
        primarna zdravstvena zaštita
        invazivna medicina
    biomedicinska i klinička istraživanja
    epidemiološka istraživanja
    javno zdravstvo
    hitna stanja
    donacija organa, tkiva i stanica

Kategorije osoba s posebnom zaštitom

Ekonomski, edukacijski, socijalni i kulturološki kontekst

Međunarodni i nacionalni pravni okviri (uloga zemalja članica)

Prikaz aktivnosti UNESCO katedre za bioetiku Sveučilišta u Haifi

Početkom ‘90-ih počele su se osnivati UNESCO katedre za bioetiku. Do danas ih je osnovano ukupno osam (11):

- UNESCO katedra za bioetiku, 1994, Sveučilišta u Buenos Airesu (Argentina)
- UNESCO Chair in Bioethics, 1998, Egerton University (Kenja)
- UNESCO katedra za bioetiku: »Biojurídica y Bioética«, 1999, University Femina del Sagrado Corazón, Lima (Peru) s La Sociedad Española de Biojurídica y Bioética, Madrid (Španjolska)
- UNESCO Chair in Bioethics, 2001, University of Haifa, (Izrael)
- UNESCO katedra za bioetiku, 2005, Sveučilište u Braziliji (Brazil)
- UNESCO Chair in Bioethics, 2005, Ethics and Public Policy Center, Washington D.C. (SAD)
- UNESCO katedra za bioetiku i kliničku medicinu, 2007, Instituto Nacional de Enfermedades Respiratorias, México D.F. (Meksiko)
- UNESCO katedra za bioetiku, 2007, Sveučilišta u Barceloni (Španjolska)

Posebno valja istaknuti Katedru Sveučilišta u Haifi. Njeno interesno polje rada je medicinska etika. Osnovana je 2001. godine od strane Međunarodnog centra za zdravstvo, pravo i etiku (*The International Center for Health, Law and Ethics*) Pravnog fakulteta Sveučilišta u Haifi i Izraelske nacionalne UNESCO-ve komisije s ciljem koordinacije i stimulacije međunarodne mreže institucija za edukaciju iz medicinske etike (*Network of Institutes for Medical Ethics Training - NIMED*) povezujući institucije visokog školstva, kako u razvijenim zemljama, tako i u zemljama u razvoju. Posebno je usmjerena na kreiranje *up-to-date syllabusa* za edukaciju iz medicinske etike, koji bi zadovoljio potrebe i zahtjeve medicinskih fakulteta širom svijeta (12).

Upravo zahvaljujući Katedri iz Haife, 24. travnja 2009. osnovana je ***Jedinica UNESCO katedre za bioetiku i pravo Sveučilišta u Zagrebu.*** Njena prva aktivnost bila je prevođenje knjige »Informed Consent« (13), urednika prof. Amnona Carmija, predstojnika UNESCO katedre Sveučilišta u Haifi. Hrvatski prijevod, čije su urednice Ksenija Turković i Sunčana Roksandić Vidlička, obogaćen je i prijevodima Konvencije o zaštiti ljudskih prava i dostojanstva ljudskog bića u pogledu primjene biologije i medicine: konvencije o ljudskim pravima i biomedicini, s dodatnim protokolima Vijeća Europe, te Opće deklaracije o bioetici i ljudskim pravima (14).

Umjesto zaključka

Važnost koju *Jedinica UNESCO katedre za bioetiku i pravo Sveučilišta u Zagrebu* pridaje doktrini informiranog pristanka očituje se i u riječima prof. Amnona Carmija: »Temeljna prava čovjeka zasnivaju se na priznanju čovjekova statusa kao ljudskog bića, nepovredivosti njegova života i činjenici da je rođen slobodan, i da će uvijek biti slobodan. Uvažavanje vrijednosti i želja pojedinca je dužnost koja postaje čak i jačom ukoliko pojedinac postane ranjiv. Budući da su autonomija i odgovornost svake osobe, uključujući i one kojima je potrebna zdravstvena skrb, prihvaćene kao važne vrijednosti, donošenje ili sudjelovanje u donošenju odluka koje se tiču vlastitog tijela ili zdravlja mora biti opće priznato kao pravo.

Etički problemi koji proizlaze iz zahtjeva za pacijentovim informiranim pristankom toliko su raznovrsni da se čini prikladnim i ispravnim prvi od niza priručnika iz etike posvetiti ovoj temi i studente medicine, mnogo prije nego što i sami preuzmu osobnu odgovornost za obavljanje liječničke dužnosti, upoznati sa slučajevima koji nakon početne dijagnoze pacijentove bolesti zahtijevaju kako etičke, tako i medicinske ili kirurške odluke.« (14).

Jer, kako ističe Ivan Šegota: »*Informed consent* je jedna od najznačajnijih tekovina bioetike... ugaoni bioetički kamen koji dijeli staru od nove medicinske etike...« (6).

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Iva Sorta-Bilajac*

Informed consent in UNESCO's bioethics documents

ABSTRACT

The aim of this paper is to demonstrate, through the analysis of UNESCO's bioethics documents, with special reference to the Universal Declaration on Bioethics and Human Rights and the Bioethics *Core Curriculum*, the spot and role of doctrine of informed consent through its practical application within the systems of biomedicine and health today, as well as through the necessity and importance of international and legal regulations of bioethics.
By finding a foothold in the activities of the UNESCO Chair in Bioethics, whose prevailing topic of educational activities is the topic of informed consent, the presence of multidimensional framework of approaches to resolve issues burdened by moral values present within the health care system is recognized.

Key words: bioethics, informed consent, UNESCO.

Definition of informed consent

Bioethical doctrine of informed consent was not the topic of serious scientific discussions until early 1970s. Ruth Faden, an American scientist from the Kennedy Institute who did her PhD thesis in 1980s on that very topic, defines it as »patient's or research subject's statement that gives a physician or researcher the authorization to carry out specific measures, therapy or to include a subject in a research protocol«. (1). Therefore, it is an authorized activity performed on a patient or a subject by a physician.

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The »corner-stone« of informed consent is the Nuremberg Doctors' Trial and the Nuremberg Code which was constituted in 1947 as a result of the Doctors' Trial (2). Its first point states that the voluntary consent of the human subject is absolutely essential (3).

Elements of informed consent in UNESCO's bioethics documents

Informed consent to a medical intervention is valid only if the person involved in the procedure had previously been informed about the procedure, if the person had understood the given information correctly and has given voluntary consent on this basis (2).

Tom L. Beauchamp and James F. Childress use seven analytical elements, or categories, in their analysis of informed consent:

Threshold elements:

1. competence (to understand and decide)
2. voluntariness in decision-making

Information elements:

3. disclosure of the content of medical information
4. recommendation (e.g. of a treatment plan)
5. testing of understanding of what had been said

Consent elements:

6. decision (acceptance or refusal)
7. authorization (e.g. by signature) (4).

The concept of informed consent is, therefore, based on two basic premises: that the patient has the right to be provided with the amount of information necessary to make an informed decision on the recommended medical treatment and that he or she has the right to accept or refuse the doctor's recommendation. As Ksenija Turković states: »the right to refuse the recommended medical procedure is only the other side of the consent and together they constitute a unit« (5).

Functions of informed consent in clinical practice

According to two prominent jurists and bioethicists, Jay Katz and Alexander Capron, informed consent has following functions:

1. to promote individual autonomy of patients and subjects,
2. to encourage rational decision-making,
3. to prevent the involvement of the public,
4. to encourage ethical self-scrutiny in physicians and investigators,
5. to reduce the danger of civil and criminal liability of physicians, investigators and their institutions (6).

Ivan Šegota proposes that the 6th function should be added here – the communicational function because informed consent is based on communication, it might even be stated that communication is its central issue. From the communicational point of view, in order to establish the validity of the informed consent, it is most important to pay attention to the following:

1. how well is the information communicated,
2. how well is it understood by the patient,
3. how voluntary the consent truly is
4. the manner in which the consent is obtained from persons without the capacity to consent, persons with the reduced capacity and persons exposed to covert pressures (prisoners, soldiers, students...),
5. how much time is spent on communicating with patients or subjects (6).

Bioethics and legal framework of informed consent

Among domestic and international bioethics and legal regulations of informed consent, the following should be mentioned:

- Patients' Rights Act (ZZPP, The Official Gazette 169/04, Articles 6-18),
- Protection of Persons with Mental Disorders Act (ZZODS, Official Gazette 111/97, 27/98, 128/99, 79/02, Article 3, Paragraph 12, Articles 8 and 9),
- Family Act (Article 89/5),
- Declaration of Helsinki 1975 (Articles 9-12),
- UN Declaration on the Rights of the Child 1989 (Article 12/4),
- Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine 1997 (Articles 5/1, 6).[1]

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[1] Mentioned documents shall not be analyzed in this paper. The author suggests consulting the »Bioethics and Medical Law« Proceedings (7).

Overview of Informed Consent in Unesco's Documents on Bioethics

In analyzing UNESCO's documents on bioethics, there will be a special overview of informed consent in the Universal Declaration on Bioethics and Human Rights, in bioethics *Core Curriculum* and in the Report of the International Bioethics Committee of UNESCO (IBC).

Universal Declaration on Bioethics and Human Rights

In the Declaration adopted by the 33rd General Conference of UNESCO on 19 October 2005 the issue of the informed consent is addressed in articles 6 and 7, which are brought here in full (8):

Article 6 – Consent

1. Any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information. The consent should, where appropriate, be expressed and may be withdrawn by the person concerned at any time and for any reason without disadvantage or prejudice.
2. Scientific research should only be carried out with the prior, free, expressed and informed consent of the person concerned. The information should be adequate, provided in a comprehensible form and should include modalities for withdrawal of consent. Consent may be withdrawn by the person concerned at any time and for any reason without any disadvantage or prejudice. Exceptions to this principle should be made only in accordance with ethical and legal standards adopted by States, consistent with the principles and provisions set out in this Declaration, in particular in Article 27, and international human rights law.
3. In appropriate cases of research carried out on a group of persons or a community, additional agreement of the legal representatives of the group or community concerned may be sought. In no case should a collective community agreement or the consent of a community leader or other authority substitute for an individual's informed consent.

Article 7 – Persons without the capacity to consent

In accordance with domestic law, special protection is to be given to persons who do not have the capacity to consent:

a) authorization for research and medical practice should be obtained in accordance with the best interest of the person concerned and in accordance with domestic law. However, the person concerned should be involved to the greatest extent possible in the decision-making process of consent, as well as that of withdrawing consent;

b) research should only be carried out for his or her direct health benefit, subject to the authorization and the protective conditions prescribed by law, and if there is no research alternative of comparable effectiveness with research participants able to consent. Research which does not have potential direct health benefit should only be undertaken by way of exception, with the utmost restraint, exposing the person only to a minimal risk and minimal burden and, if the research is expected to contribute to the health benefit of other persons in the same category, subject to the conditions prescribed by law and compatible with the protection of the individual's human rights. Refusal of such persons to take part in research should be respected.

Bioethics *Core Curriculum*

UNESCO's Sector for Social and Human Sciences, Division of Ethics of Science and Technology drew up in 2008 the Bioethics *Core Curriculum* which consists of two parts: *Syllabus* and *Study Materials*. Its main purpose is the education, particularly of medical students. Units 6 and 7 of the *Syllabus* should be singled out from the content (9):[2]

Unit 6: Consent

Interconnection: human dignity

human rights

autonomy

individual responsibility

The purpose of informed consent

Interrelation between consent and autonomy

Explanation and implementation of consent

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[2] Chapters are based on Articles 6 and 7 of the Universal Declaration of Bioetics and Human Rights.

Exceptions: emergency situations
minors
mentally ill patients
Jehovah's Witnesses
euthanasia
HIV patients

Unit 7: Persons without the capacity to consent

Criteria for capacity to consent

Categories of persons without
the capacity to consent: neonates
children
confused elderly patients
patients with learning difficulties
mentally ill patients
unconscious patients
(*Advance Directives, Living Will*)

Legal provisions concerning
consent and capacity to consent: international
domestic

Procedures: protocols within a health system
special procedures (surrogate, best interest criterion)

Research on human subjects

Report on informed consent by the International Bioethics Committee of UNESCO (IBC)

The Report was published in 2008 and devoted to Articles 6 and 7 of the Universal Declaration on Bioethics and Human Rights. The International Bioethics Committee (IBC) began its systematic analysis immediately after its publication and in May 2007 it presented this report at the UNESCO General Conference. Taken out from the content of the Report, the following should be emphasized (10):

Content of the information

Conditions of obtaining consent

Manner of expressing consent

Withdrawal of consent

Circumstances of application: clinical practice:
        primary medical care
        invasive medical interventions
    biomedical and clinical research
    epidemiological research
    public health
    emergency situations
    organ, tissue and cell donation

Categories of persons requiring special protection

Economic, educational, social and cultural context

International and domestic legal frameworks (role of member countries)

Activity overview of UNESCO Chair in Bioethics at the University of Haifa

The establishment of UNESCO's Bioethics Departments began in early 1990s. So far, eight have been established (11):

- UNESCO Chair in Bioethics, 1994, University of Buenos Aires (Argentina)
- UNESCO Chair in Bioethics, 1998, Egerton University (Kenya)
- UNESCO Chair in Bioethics: »Biojurídica y Bioética«, 1999, University Femenina del Sagrado Corazón, Lima (Peru) s La Sociedad Española de Biojurídica y Bioética, Madrid (Spain)
- UNESCO Chair in Bioethics, 2001, University of Haifa, (Israel)
- UNESCO Chair in Bioethics, 2005, University of Brasilia (Brazil)
- UNESCO Chair in Bioethics, 2005, Ethics and Public Policy Center, Washington D.C. (USA)

- UNESCO Chair in Bioethics and Clinical Medicine, 2007, Instituto Nacional de Enfermedades Respiratorias, México D.F. (Mexico)
- UNESCO Chair in Bioethics, 2007, University of Barcelona (Spain)

The Chair in Bioethics at the University of Haifa should be particularly mentioned. Its field of interest is medical ethics. It was established in 2001 by The International Center for Health, Law and Ethics of Haifa University Law School and the Israel National Commission for UNESCO with the objective to coordinate and stimulate an international Network of Institutes for Medical Ethics Training (NIMED), associating higher education in both the developed and developing countries. It is particularly focused on developing an up-to-date syllabus for medical ethics education which will satisfy the needs and requirements of medical schools throughout the world (12).

Thanks to the Chair in Haifa, on 24 April 2009 the ***UNESCO Unit for Bioethics and Law at the Faculty of Law, University of Zagreb*** was founded. Its first activity was the translation of the book »Informed Consent« (13), edited by Prof. Amnon Carmi, the Chair holder of the UNESCO Chair in Bioethics at the University of Haifa. The Croatian translation, whose editors are Ksenija Turković and Sunčana Roksandić Vidlička, is enriched with translations of the Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, with the additional protocols of the Council of Europe and the Universal Declaration on Bioethics and Human Rights (14).

Instead of conclusion

The importance attached to the doctrine of informed consent by the UNESCO Unit for Bioethics and Law at the Faculty of Law, University of Zagreb is evident, among other, in Prof. Amnon Camri's words: »The fundamental human rights are based on the acknowledgement of person's status as a human being, the integrity of human life, and the fact that people are born free and shall remain free. The appreciation of individual's values and desires is the responsibility which becomes even greater if an individual becomes vulnerable. Since the autonomy and responsibility of each person, including those who need health care, are accepted as important values, making decisions or participating in making decisions concerning one's own body and health must become universally acknowledged as a right.

Ethical problems arising from a requirement for patient's informed consent are so diverse that it seems appropriate to devote the first from the line of ethics hand-books to this topic and to acquaint medical students, long before they themselves assume personal responsibility for performing medical duty, with cases that require making, upon the initial diagnosis, ethical, medical and surgical decisions.« (14).

Because, as Ivan Šegota points out: »Informed consent is one of the most important achievements in bioethics... the bioethics corner-stone that divides the new medical ethics from the old one...« (6).

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Translation/prijevod: Snježana Volarić

JAHR | Vol. 1 | No. 1 | 2010

UDK:575.113:34(4)
Essay/Esej
Received/Primljeno 26/12/2009

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The force of law: genetic data protection in Central and Eastern Europe

ABSTRACT

During the past decade the collection and processing of human biological samples and that of related data gained an increasingly important role in both medical research and the forensic field. The European Union legislator tried to keep up with this phenomenon, and attempted to reconcile freedom of research in the classical biobank context and the principle of availability in the criminal context with European Union-wide data protection safeguards. In the lack of a sufficiently homogeneous legal framework European jurisdictions greatly differ in regulating the protection of genetic data. Two main country groups can be identified: Member States can be grouped along the question whether they have or do not have specific biobank laws. In countries that do have such laws, comparison is easier, and they are following international standards. Whenever such specific laws are lacking, not only the identification of the respective legal rules, but also their comparison is difficult, since the interpretation of these vague and more general laws is left to the stakeholders, law enforcement agencies, and finally to the judiciary. Since in this latter group of countries however relevant judicial cases are very rare, the interpretation of the codes and other comprehensive laws happens on an ad hoc basis, and remains invisible. The differing legal and ethical issues concerning patients' data in the classical context, and suspects', convicts', victims' and other persons' data protection in a forensic context will be addressed in light of the 2003 International Declaration on Human Genetic Data. Actual examples from Central European jurisdictions will highlight the related theoretical and practical problems both in terms of bioethical research and forensic sciences on the one hand and data protection and privacy on the other.

Key words: Biobanks, genebanks, data protection, forensic genetics, Central and Eastern Europe

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The author is grateful for having had the opportunity to work together with Professor Judit Sándor, the Director of CELAB in the GeneBanC project, a Specific Targeted Research Project (STREP) funded by the European Commission in the Sixth Framework Programme. (Project number: FP6-036-751) The present paper is the outcome of the research conducted in the framework of GeneBanC. For further information please visit www.genebanc.eu.

1. Introduction

In the present paper I will discuss the existing regulatory framework of biobanks across the European Union focusing on the collection and analysis of legislation and regulation regarding the establishment, management and functioning of classical, population and forensic biobanks across Europe focusing on Central Eastern European Member States.

It is worth considering the international instruments applicable and binding even in lack of national regulation of the matter, as there is a great diversity as to biobank laws and related legislation across Europe. Moreover many countries do not have any biobank laws, and in a number of Central Eastern European states one has to rely on laws of diverse nature that serve as background pieces of legislation applicable to biobanks. These laws may include acts, statues or other pieces of legislation on health care, data protection, privacy, patients' rights, medical research, or even comprehensive codes, such as the Civil Code or the Criminal Code. Since in the majority of the Member States there is no specific law with a matching title, it is often a problem for biologists, doctors or even ethicists to identify the proper documents. Even if the laws are identified, the relevant parts have to be found and the often too general provisions need to be applied to the specific case of biobanks.

Before going into the merits and discussing the international and domestic pieces of legislation applicable to biobanks, there is a preliminary issue to be clarified: how we define, what we exactly understand under the term biobank. The issue of biobanks and the legal and ethical considerations surrounding them are rather novel, therefore it should not come as a surprise that there is no widely recognized international definition. As a natural consequence domestic jurisdictions greatly differ in the definition and regulation of biobanks. In the lack of a common denominator, all divisions seem to be arbitrary and therefore should be treated carefully and in a flexible manner.

One may differentiate population biobanks receiving supplies in an organized manner, containing biological materials and personal data and established to supply biological materials or data derived therefrom for multiple future research projects from research biobanks developed by and restricted to authorized clinical investigations at academic medical centers. These databases contain genetics and other biomedical information about connecting individual patients derived from their clinically collected tissues, with the electronic data sometimes being transmitted to a central database. Although sometimes discussed jointly with classical biobanking, forensic databases greatly differ in nature from the above classical and population biobanks. In the broad sense forensic databases are DNA databanks held by authorized laboratories of police and official forensic institutions for criminal and other legal procedures, such as the identification of victims, missing persons, perpetrators, the establishment or rejection of paternity, etc. There is a qualitative difference in the legal sense between the classical and population biobanks on the one hand, and forensic biobanks on the other.[1] The former group invokes questions such as whether the collection or storage of data are free, or whether donors are remunerated, whether consent is needed and what amounts to informed consent, or the way withdrawal happens. These questions do not make sense in the context of forensic databanks, where the question much rather is whether coercion can be used for data collection, and whether tissues, cells and connected data are destroyed once the purpose of the collection (identification of perpetrator, identification of victims, etc.) are fulfilled.

In the following the division between population and classical biobanks on the one hand, and forensic databanks on the other will be maintained, as they raise entirely distinct legal issues. In Part 2 the former group of biobanks will be addressed starting with international legal sources and then going into the Central European specificities,, while in Part 3 the specific and distinct legal issues concerning forensic databanks will be discussed. In relation to both types of genetic databanks recommendations follow the legal analysis.

2. Classical biobanks

International legal sources

When mapping relevant international legal sources it is worth starting with the UNESCO documents. UNESCO has adopted three declarations concerning bioethics, the Universal Declaration of Human Genome and Human Rights (1997), the International Declaration on Human Genetic Data (2003) and the Universal Declaration on Bioethics and Human Rights (2005).

The »Convention on Human Rights and Biomedicine« opened for signature in April 1997 is known as the Oviedo Convention. It came into force in December 1999 and was ratified by 34 Member States in February 2009. This is the first and only binding instrument that explicitly links human rights and bioethics. On several occasions the **European Court of Human Rights** has based legal decisions on

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[1] In most of the jurisdictions samples are only stored from unresolved crimes or crime scenes, and suspects' or convicts' samples are destroyed once the profile has been derived therefrom. Therefore forensic biobanks typically contain less samples than genetic profiles, if any, and accordingly a legitimate debate evolved as to whether they may be called genebanks or not. Keeping this debate in mind, and acknowledging its relevance I would like to stress that in the present paper the phrase »forensic biobank« refers to both databanks including samples and profiles, and also repositories only including one or the other.

the Oviedo Convention, including cases where the states had not ratified, or even signed the Convention.

Four Additional Protocols have been adopted on the following topics: the Prohibition of Cloning Human Beings (1998), the Transplantation of Organs and Tissues of Human Origin (2002), Biomedical Research (2005) and Genetic Testing for Health Purposes (2008).

Perhaps the most specific among all the texts adopted within the Council of Europe is the Recommendation (2006) 4 of the Committee of Ministers to Member States on research on biological materials of human origin. In its Preamble the Recommendation states that »population biobanks developed on the basis of donations of biological materials made in a spirit of solidarity should not be monopolized by small groups of researchers.« The Recommendation provides basic rules for obtaining biological materials, access to and oversight of biobanks. Article 4 promotes the establishment of codes of good practice to ensure compliance with this Recommendation.

As a background legislation the comprehensive Convention for the Protection of Human Rights and Fundamental Freedoms shall also be mentioned.

In addition to legal sources numerous professional bodies adopted in the field of biobanks.[2]

Among the primary sources of European Union law, the Charter of Fundamental Rights of the European Union of 2000 is to be mentioned. The Charter can be regarded as the Bill of Rights of the European Union, but opposed to most national constitutions listing fundamental rights, it is a novel document, therefore it is rather progressive. Article 1 on human dignity, and more specifically Article 3 on the right to the integrity of the person are of great relevance.

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[2] The European Science Foundation extensively dealt with and formulated recommendations for »Population Surveys and Biobanking« in its May 2008 Science Policy Briefing.
In 2004, a group of experts including those working in the fields of human genetics, sociologists, university researchers, the industry, patient organisations and the European Parliament published a report commissioned by the European Commission with 25 recommendations on ethical, legal and social aspects of genetic testing. Among these, six focused on biobanks and issues related to research.
In 2001, the European Society of Human Genetics (ESHG) published a background document discussing technical, social and ethical issues and a set of recommendations concerning data storage and DNA banking for biomedical research.
The OECD Working Party on Biotechnology was developing Council Guidelines on human biobanks and genetic research databases through an expert group of member countries. A background document with the title »Creation and Governance of Human Genetic Research Databases« came out already in October 2006.
An early document of the Human Genome Organization is also noteworthy. The HUGO Ethics Committee published a Statement on DNA Sampling: Control and Access already back in February 1998.

As to the sources of secondary legislation, the following documents are relevant: Regulation 45/2001 on the protection of individuals with regard to the processing of personal data by the Community institutions and bodies and on the free movement of such data, Directive 2006/86/EC implementing Directive 2004/23/EC as regards traceability requirements, notification of serious adverse reactions and events and certain technical requirements for the coding, processing, preservation, storage and distribution of human tissues and cells, Directive 2006/17/EC implementing Directive 2004/23/EC as regards certain technical requirements for the donation, procurement and testing of human tissues and cells, Directive 2005/62/EC implementing Directive 2002/98/EC as regards Community standards and specifications relating to a quality system for blood establishments, Directive 2005/61/EC implementing Directive 2002/98/EC as regards traceability requirements and notification of serious adverse reactions and events, Directive 2004/33/EC of 22 March 2004 implementing Directive 2002/98/EC as regards certain technical requirements for blood and blood components, Directive 2004/23/EC on setting standards of quality and safety for the donation, procurement, testing, processing, storage and distribution of human tissues and cells, Directive 2002/98/EC setting standards of quality and safety for the collection, testing, processing, storage and distribution of human blood and blood components and amending Directive 2001/83/EC, Directive 2001/20/EC on the approximation of the laws, regulations and administrative provisions of the Member States relating to the implementation of good clinical practice in the conduct of clinical trials on medicinal products for human use, Directive 98/44/EC on the legal protection of biotechnological inventions, and finally Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data.

The European Group on Ethics in Science and New Technologies (EGE) is also highly authoritative in questions related to biobanking. Almost all of its opinion are to be taken into account, just to name a few Opinion n°19 on the ethical aspects of umbilical cord blood banking, Opinion n°15 on ethical aspects of human stem cell research and use, and Opinion n°11 on the ethical aspects of human tissue banking are of great relevance. The Article 29 Data Protection Working Party adopted a Working Document on Genetic Data on 17 March 2004.

Mapping biobanks in CEE

Biobanks are nationally regulated, through a combination of general and specific laws and oversight bodies. The laws differ greatly from one another, their scopes greatly vary and extend from small scale sample collections to large population based databases. The confusion between data and sample frequently result in the duality of legal norms; while the collection, storage of biological samples are governed by laws on biomedicine, the data derived from the samples are subject of the data protection law. Even legal experts in the field seem to be ambiguous about the applicability of other legal norms such as law on biomedical research, organ and tissue transplantation, law on genetics, legal norms on patients' rights and on data protection. Most institutions have no written policies or agreements regarding this activity, and even if there was a willingness on the side of hospitals, clinics and research institutes to adjust their practice to some general norms, researchers or drafters of these internal guidelines are in an extremely difficult position due to the large number of international, national, and professional guidelines that contain different, sometimes even contradicting recommendations relevant for biobanks.

Probably the most crucial legal issues to be clarified are data protection and anonymization. Many important contemporary biobanks use a form of reversible anonymisation, or – with another terminology – pseudonymisation, because this is a way to assure protection while keeping a link to be able to update information and to re-contact participants whenever information valuable to the donors is discovered. This is the only way to ensure feedback which is a fundamental reason for many donors to participate in genetic research. The next logical step is to determine what kinds of pseudonymisation techniques are adequate: double coding, single coding or some other method. Even if one named a certain technique, a lack of consensus on the definition prevents researchers from agreeing on standardisation. Professor Bernice Elger proved the varied nature of the many terms. In the tower of Babel of terms – as she called it – one can find references to samples that are anonymous, anonymised, anonymously coded, coded, unidentified, de-linked, permanently de-linked, not traceable, unlinked, identifiably linked, pseudonomised, encoded, encrypted, directly identified, confidential, identifiable, not traceable, or in the UNESCO terminology: linked to an identifiable person. Different legal families adhere to distinct legal traditions, and prefer one or another term over others for legal historical reasons. Sometimes even the same term is used with a different meaning, like the words »anonymised« and »coded« which are filled with different content in Continental and common law jurisdictions.[3]

Putting these terminological discrepancies apart, the main controversy is evolved around the question how to assure adequate anonymisation – be it linked or unlinked. This issue can be subdivided into different narrower questions, like in which form should samples/DNA be stored, used, who shall decide which degree of ano-

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[3] Bernice Elger's presentation at the Tiss.EU Workshop organized by CELAB between 6-8 April, 2009 in Budapest at the Central European University.

nymisation is adequate, how many characteristics must be stripped to obtain truly irreversible or reversible anonymisation, and what are the standards for technical questions of security.

Apart from data protection and anonymisation, the issue of informed consent is a fundamental problem to be addressed in an ideal biobank-related legislation. Both the Nuremberg Code and the Declaration of Helsinki incorporate the principle of informed consent as a pillar in the practice of bioethics. Informed consent allows individuals to exercise their fundamental right to decide whether, and how, their body, body parts and associated data can be used in research. The principle of informed consent is applicable for any research on human beings or on human material and as it follows even in the lack of specific legal norm it should be applicable in the field of biobanks as well. As biobank projects are costly and often envisage the multiple use of the samples biobank operators are inventive as to the consent models. One consent type proposed by the Human Genome Organisation in 1998, namely presumed consent, is clearly favoured less often than the others. Estonia applies the so-called open consent model, which does not specify the research in which samples and data are used and applies a general consent form. This model may be corrected with the conditional consent model (in which a person may exclude in advance certain types of research use).

One of the most debated issues concerning the legal framework of biobanks are the property rights. These are often not mentioned at all in biobank law even if ownership of samples constitutes a key question in biobanks with serious implications on commercialization. While the Convention on Human Rights and Biomedicine of the Council of states that the human body and its parts shall not give rise to financial gain, this provision seems not to cover the data derived from the physical samples, although in practice data may be of even higher commercial asset than the samples themselves. At least two issues must be addressed regarding property. The first is the individuals' rights concerning their own biological material. The second is the nature of collaboration between academic researchers and private companies in the development of biobank research. Here, the question of ownership of the collections and intellectual property rights need to be addressed.

Professor Judit Sándor identified the good legal practices of classical and population biobank laws in the following.[4]

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[4] GeneBanC internal documents (manuscript on file with the author).

1. The process should start with the clear definition of the goal whether the law should cover population based public and private biobanks or certain disease specific ones.
2. The law should include clear arrangement for data processing. Problematic points include the following: anonym data is different from coded data, coded-double coded, genetic sample, specimen, data, linking-cross-linking, transfer.
3. Certain hospitals, universities, research institutes (or their departments) have a sample collection and have stored cells and tissues, but the legislative or a supervisory authority does not have any knowledge about it. It is therefore crucial to make these biobanks transparent with a corresponding obligatory registration system.
4. Researchers in the biobanks are often unaware of the existing background legislation, such as acts, statutes or lower pieces of legislation related to data protection, rules on research. Often the establishment of the biobank has not been preceded by a legal ethical screening and evaluation of the future operation of the institution. Mainly those researchers have an idea about the desirable way of collection, storage and process of data who participate in international, mainly European Union-wide consortia.
5. Identification of rights and interests of research participants, researchers and biotech industry is needed: dignity-privacy-liberty; right to be informed, right to decide (consent); freedom of choice right to withdraw sample/data; short term goals; long term goals (freedom of research); biobanks are often seen as investment in the future it poses legal challenges: validity of the consent, access to old collections, follow up procedure is still necessary
6. It would be crucial to develop mechanisms for biobank monitoring.
7. The law on new technologies often require further adjustment, corrections, therefore adequate follow up mechanisms are desired.

3. Forensic databanks

International legal sources

From among the three main UNESCO Declarations mentioned above, the second one, the International Declaration on Human Genetic Data of 2003 might be of relevance. The main focus of the document however is not on the forensic use of genetic information, but primarily on genetic research, the sequencing of the human genome, and its medical research and biomedical applications.

Beside the Convention for the Protection of Human Rights and Fundamental Freedoms and the related case-law of the European court of Human Rights,[5] Council of Europe member states are also bound by the Convention of 1981 for the protection of individuals with regard to automatic processing of personal data. Still in the framework of the Council of Europe, Recommendation No. R(87)15 regulating the use of personal data in the police sector is even more specific when it comes to the forensic use of data. Principle 2 lays down the purposes for which data may be gathered: permissible forensic purposes are the prevention of a danger, which must be real, or the suppression of a specific criminal offence. The Recommendation allows for exceptions if provided for by national law. The length of storage according to Principle 7 should be linked to necessity, i.e. data should be deleted if no longer necessary for the original purposes for which they were acquired and stored. In this regard special attention is to be given to the following: »the need to retain data in the light of the conclusion of an inquiry into a particular case; a final judicial decision, in particular an acquittal; rehabilitation; spent convictions; amnesties; the age of the data subject, particular categories of data.«

Recommendation No. R(92)1 is dealing specifically with the use of analysis of deoxyribonucleic acid (DNA) within the framework of the criminal justice system. Point 3 states that samples and profiles may only be used for the purpose of the investigation and prosecution of criminal offences. Any contrary or additional use would be in violation of the law, except if samples or profiles are needed for research and statistical purposes, and if it is made sure that the identity of the individual cannot be ascertained, i.e. if names or other identifying references are removed prior to the data's use in the extra-forensic context. Point 4 stresses the rule already existing under the Convention that the circumstances of sample taking and analysis are to be laid down in domestic law, in some cases specific authorisation from a judicial authority being needed. Point 8 limits the storage of samples and data: according to the provision they shall not be kept after a final decision is rendered, except if necessary for purposes that are directly linked to the original purposes for which they were collected. A mechanism shall be set up to ensure that samples and profiles are deleted when no longer necessary. A general exception from this rule is where the individual has been convicted of serious offences against the life, integrity or security of persons, in which cases strict storage periods have to be determined by domestic law. Rehabilitation is an important aspect of criminal policy. Should data of perpetrators remain in a forensic database for disproportionately long periods of time,

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[5] *Leander v. Sweden* of 26 March 1987, Application no. 9248/81, *Al-Nashif v. Bulgaria* of 20 June 2002, Application no. 50963/99, *Lupsa v. Romania* of 8 June 2006, Application no. 10337/04, *Puig Panella c. Espagne* de 25 avril 2006, Requête no 1483/02

especially if entities other than law enforcement agencies have access to these databanks, the objective of rehabilitation cannot be fulfilled. Both the Committee of Minsters Recommendation No. R (84) 10 on the criminal record and rehabilitation of convicted persons[6] and Recommendation No. R (96) 8 on crime policy in Europe in a time of change are putting emphasis on the aim of rehabilitation.

Although reference has already been to the case-law related to the European Convention on Human Rights, one particular decision, S. and Marper v. the United Kingdom[7] is worth of mention in greater detail. In this case the European Court of Human Rights held in a unanimous decision that the United Kingdom was in violation of Article 8 of the European Convention on Human Rights, when the UK authorities continued to retain the Applicants' fingerprints, DNA samples and profiles after criminal proceedings against them had ended with an acquittal or had been discontinued. The ECtHR adhered to its own case law when underlining that the mere storing of data relating to one's private life amounts to an interference within the meaning of Article 8, irrespectively of the further use of the stored data.[8] According to the Court in the present case all types of stored information, i.e. fingerprints, DNA profiles and cellular samples, constituted personal data within the meaning of the Data Protection Convention. The Court acknowledged the difference between the ways DNA and fingerprint storage may interfere with an individual's privacy due to the fact that sensitive information, such as one's ethnic origin, health status may be derived from genetic data. This difference however did not prevent the ECtHR from concluding that all types of data in the given case did constitute an interference with private life.

The next issue to be determined was whether such an interference was justified, i.e. whether it was in accordance with the law, whether it pursued a legitimate aim, and was necessary in a democratic society. In the Court's view the UK law can be seen as a clear legal basis for the interference, however the conditions under which storage and use are permitted, are less clear. The Court however did not stop the examina-

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[6] Also incorporated into Recital (10) of Council Decision 2005/876/JHA of 21 November 2005 on the exchange of information extracted from the criminal record: »Under Council of Europe Recommendation No R (84) 10 on the criminal record and rehabilitation of convicted persons, the main aim of establishment of the criminal record is to inform the authorities responsible for the criminal justice system of the background of a person subject to legal proceedings with a view to adapting the decision to be taken to the individual situation. Since all other use of the criminal record that might compromise the chances of social rehabilitation of the convicted person must be as limited as possible, the use of information transmitted under this Decision for use otherwise than in the course of criminal proceedings can be limited in accordance with the national legislation of the requested State and the requesting State.«

[7] *S. and Marper v. the United Kingdom* of 4 December 2008, Application numbers 30562/04 and 30566/04.

[8] *Leander v. Sweden* of 26 March 1987, Application number 9248/81, *Amman v. Switzerland* of 16 February 2000, Application number 27798/95

tion at this point, but noted that all the issues concerning the »prescribed by law« requirement of the interference are closely linked to the question whether the interference in question was necessary in a democratic society. The Court agreed with the UK Government that the limitation of private life, i.e. the retention of fingerprints and DNA pursued the legitimate purposes of crime detection, identification of future offenders, and as a result crime prevention. The case failed at the last prong of the test: the limitation was not considered to be necessary in a democratic society. The Court reiterated its case law on this test: for an interference to be necessary in a democratic society for a legitimate aim, it must answer a pressing social need, must be proportionate in relation to the aim to be pursued, and the reasons for the limitation must be relevant and sufficient. The Court stated that there is no sufficient link between crime scene sample matches and the retention of samples of unconvicted persons. The Court thus found the lack of an independent review mechanism for the justification of retention, and the »blanket and indiscriminate nature of the power of retention,« which is irrespective of the nature and gravity of the offence, unacceptable. The Court also remembered Article 40 Section (1) (viii) of the UN Convention on the Rights of the Child of 1989 on the heightened need of privacy protection in the criminal-justice sphere, and held that the retention of unconvicted persons' data may be especially harmful if the then suspect is a minor, like S. in the present case who was 11 at the time his samples were taken. When entering into the special dangers of applying the challenged rules to children, the Court also underlined a finding of the Nuffield Council, which proved the over-representation of young persons and ethnic minorities in the biobank.

The case is interesting so much the more as several Member States seem to be in violation of Article 8 as interpreted by the ruling of the Court. Details will follow in Part 7.

As it has already been proven the European Union proved to be a promoter of the exchange of law enforcement information. A novel, fifth freedom seems to be added to the free movements of goods, capital, services, and persons forming the basis of the internal market of the European Union. Already Directive 95/46/EC of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data (Data Protection Directive) mentioned in its title the addition to the four freedoms. Since the adoption of the Data Protection Directive the free movement of data gained increased importance among others in the third pillar. Examples are Council Framework Decision 2006/960/JHA on simplifying the exchange of information and information and intelligence between law enforcement authorities of the Member States of the European Union, or more specifically in the area of exchange of DNA information the Prüm Framework Decision 2008/615/JHA on the stepping up of cross-border cooperation, particularly in combating terrorism and cross-border crime and the implementing Council Decision 2008/616/JHA.

According to the former, Member States ensure that any type of information or data which is held by law enforcement authorities or by public authorities or by private entities and which is available to law enforcement authorities without the taking of coercive measures are exchanged among Member States' law enforcement authorities for the purpose of conducting criminal investigations or criminal intelligence operations. The latter two instruments also contain provisions that make the exchange of information less burdensome on the conditions and procedure for the automated transfer of DNA profiles, dactyloscopic data and national vehicle registration data.

The question than is what measures would balance the free flow of sensitive information from a human rights perspective.

In the framework of the European Union, the Data Protection Directive might seem relevant. The Directive reiterates Article 8 ECHR, the Data Protection Convention and remembers that data protection is also among the general principles of Community law. The Data Protection Directive however is a first pillar instrument and therefore its scope does not extend to criminal cases or criminal cooperation. In both Recital (13) and Article 3 (2) on the scope of the Directive it is clearly stated that Titles V and VI TEU on public safety, defence, state security, national criminal law all fall outside the scope of the Directive.

The question then arises whether the recently adopted Council Framework Decision 2008/977/JHA of 27 November 2008 on the protection of personal data processed in the framework of police and judicial cooperation in criminal matters (Framework Decision on Data Protection) applies to forensic biobanks.

Unfortunately the scope of the Framework Decision itself is rather limited. Both according to Recital (7) and Article 1 (2) there has to be a European element for the Framework Decision to apply.

The Framework Decision entered into force in January 2009, on the 20th day following its publication in the Official Journal of the European Union, and Member States have to take the necessary measures to comply with the provisions of the law until 27 November 2010.

Mapping forensic databanks in CEE and beyond

The purposes of a forensic databank may vary from prosecution and the identification of perpetrators to the identification of victims, the identification of victims in mass disasters (e.g. air crash or natural catastrophe victims),[9] or conducting familial searching or paternity tests.[10] The development of forensic genetics, especially the fact that genetic material can now be derived from small amount of samples, also enables the reopening of old so-called »cold cases«. Not only do these databases contribute to the finding of perpetrators, but may also clear convicts.[11]

Digitalized DNA profiles enable the tracing of suspects, the identification of victims, and sometimes also missing persons. The digitalized profiles are a sufficient means to achieve these aims, however beside the profiles samples are also stored for a number of purposes, such as retesting, quality control, submission to updated technology, etc.

Samples include skin cells, hair, blood, saliva, buccal swab, semen, etc. They are typically frozen at low temperatures (for example in case of blood banks -80 °C), other sampling techniques allow storage at room temperature.[12]

Data include the DNA profiles on the one hand, and on the other a number of personal data, depending on the jurisdiction. These latter may include name, maiden name, mother's maiden name, place and date of birth, address, sex, in some countries physical appearance, ethnic origin, the person and/or the laboratory who/where the sample has been taken, the type and method of testing, etc.

Current research enables forensic experts to derive profiles from very small samples. Once a match is found this does not automatically serve as conclusive evidence of guilt, first because a match does not prove but only that someone was present at a crime scene, and second due to the fact that forensic experts can only tell the prob-

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[9] Andrea Piccinini, Ferruccio Betti, M. Capra, Cristina Cattaneo, The identification of the victims of the Linate air crash by DNA analysis, in *Progress in Forensic Genetics* 10, Amsterdam: Elsevier, 2004, 39-41; T. Bille, R. Wingrove, M. Holland, C. Holland, C. Cave, J. Schumm and The Staff of The Bode Technology Group, Novel method of DNA extraction from bones assisted DNA identification of World Trade Center victims, in *Progress in Forensic Genetics* 10, Amsterdam: Elsevier, 2004, 553; Martin Steinlechner, Walther Parson, Walter Rabl, Petra Grubwieser and Richard Scheithauer, Tsunami-disaster: DNA typing of Sri Lanka victim samples and related AM matching procedures, in *Progress in Forensic Genetics 11 - Proceedings of the 21st International ISFG Congress held in Ponta Delgada, The Azores, Portugal between 13 and 16 September 2005*, Amsterdam: Elsevier, 2006, 741-743.

[10] In the present analysis the focus is on forensic databanks established for crime prevention and prosecution purposes, therefore identification of mass catastrophe victims or the establishment of paternity falls outside the scope of the paper.

[11] In the US Innocent project 238 convicted persons have proved to be innocent on the basis of the technique of forensic genetics. http://innocentproject.org/

[12] Robert F. Weir and Robert S. Olick, The stored tissue issue, Oxford: Oxford University Press, 2004, 79.

ability that a certain DNA profile belongs to a given individual. Third, there is the possibility of human error, as always.

In theory it would be sufficient to store the profiles derived from DNA electronically, and not keeping the samples. National data protection rules however do not seem to regulate this: even the data protection rules seem to apply to the profiles, and not to the samples.[13] In the lack of a common regulation, Member States' regulations greatly differ on this matter as well. Belgium, Germany, Lithuania, Sweden destroy the samples once the DNA profiles have been created, while in Hungary or Malta the period for which samples are stored depends on the crime committed by the convict, whereas in some Member States like in the UK samples are stored indefinitely. As to the DNA profiles, many more Member States allow indefinite retention, which seems to be disproportionate in light of the above Marper decision of the European Court of Human Rights.

A forensic DNA typically contains crime scene samples, samples and profiles of convicts and suspects, sometimes also of victims, volunteers, or missing persons. Crime scene samples are the least problematic ones from the point of view of bodily integrity, as the retention of such samples does not necessitate invasion into the body, however minor. As to suspects and convicts the case is rather different. As opposed to classical medical or population biobanks, persons suspected of having committed certain crimes are typically not free to opt not to have their samples taken. Sample taking is intrusion into spatial privacy or bodily integrity, however minor (like in case of buccal swab, or saliva) and in the majority of the Member States even coercion may be used to acquire samples.

In medical research, i.e. in case of classical biobanking this problem is solved by informed consent, i.e. persons whose samples enter a database agree to sample taking and data retention and processing with the possibility of withdrawal any time, without any reason. As a compensation for the lack of consent and the fact that force may be used against people who are supposed to be presumed innocent, in some Member States a court order or the permission of high ranked policepersons needs to be acquired.

In most of the jurisdictions there is a list of crimes or types of crimes the perpetrators of which are obliged to give samples. Other states argue that those committing serious crimes had already committed minor ones, therefore it is advisable to expand the list of offences. Germany took a more balanced approach and perpetrators committing minor offences are only obliged to give samples if they are recidivists.

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[13] Nathan Van Camp and Kris Dierickx, »National Forensic DNA Databases – Socio-Ethical Challenges and Current Practices in the EU,« *European Ethical-Legal Papers* No 9, Leuven, 2007, 25.

A further distinction shall be made between those suspected and those sentenced. Persons suspected against whom charges have been dropped or whose criminal liability has not been established in a judicial process under due process shall be presumed to be innocent. Retaining their data therefore is highly problematic, stigmatizing them, and if we consider that disproportionately more charges are taken and dropped in case of certain minority groups,[14] their discrimination will be reinforced by their overrepresentation in the forensic database.

At the same time some problems may arise also in relation to sample taking from convicts. If we accept that the sole aim of a forensic databank is the identification of persons who had committed crimes, the question arises why to take the sample from convicts already found and proven to be guilty. The only objective – beside the very technical consideration of checking the system and its upgrades – must then be to catch these individuals more efficiently if they commit further crimes. In this case however it needs to be proven that convicts are likely to engage in criminal activity after the perpetration of the first committed crimes as well. When relying on statistical findings it is worth differentiating between first offenders and recidivists, as their recidivism rates may be different. Even if a correlation can be found between first and second or multiple offending, after a certain period the likelihood that someone engages in further crimes, diminishes. Since criminal activity is typical for a certain age range, it might seem disproportionate keep data and/or samples of people who have once been convicted for decades. This is especially true for minor crimes.

A forensic database may also have the severe side effect of hitting disproportionately hard on persons belonging to a certain underrepresented ethnic origin or to a given social class – characteristics that may be searched for and indicated in the UK's NDNAD. Searching for close matches to information derived from a crime scene sample may result in the finding of relatives of perpetrators. Such familial searching however is highly problematic, as biologically related persons to perpetrators – in some jurisdiction including minors – become automatically suspect, eventually stigmatised. It is to be noted that the age of culpability is different in the EU's Member States, and in the UK for example the age of criminal liability, i.e. the age limit for entering someone's data into the NDNAD is 10 years.

Children and other vulnerable groups are typically granted higher protection in case of medical genetic research and data sampling or storage; in some cases retention of

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[14] E.g. in the male population of the United States of America 92 % of African Americans prove to be innocent as compared to the 62 % in case of Caucasian American citizens; in the European context almost two third of samples stored in the NDNAD belong to black men as opposed to 8 % of the samples taken from white men. Mairi Levitt, Forensic databases: benefits and ethical social costs, 83 *British Medical Bulletin* 1, 235-248 (2007), 242

data is entirely impermissible. As the Romanian Constitutional Court held in a recent decision,[15] the fact that samples are taken from persons between 14-18 years of age, i.e. from persons culpable, but still minors with the meaning of the Children's Rights Convention is not per se unconstitutional. However, at the international level, the United Nations Guidelines for the Prevention of Juvenile Delinquency warn against labelling and stigmatising a young person as »deviant,« »delinquent« or »predelinquent.«[16] Nevertheless in the NDNAD alone there were in 2006 40.000 people under 18 years of age who have never committed a crime.[17] There is no reason to disregard the need for greater safeguards in the criminal context, which raises eventually equally or more serious concerns as to human rights, since highly sensitive and possibly stigmatising data that may also distort the relation between the state and the individual, and that may result in self-fulfilling prophecies, are involved.

Based on the finding of our research, the following good practices may be formulated in the regulation of forensic databases.

1. The objectives of the forensic biobanks shall be clearly regulated. The branch of law to regulate the issue of forensic databases shall be clarified. Different purposes shall be regulated by laws belonging to different branches of law, and these rules shall be clearly separated.
2. Samples and profiles shall be clearly distinguished. Different rules shall apply to the storage of samples and profiles. They shall satisfy the requirements as laid down in binding international instruments and in the soft laws. Most importantly storage shall satisfy the test developed by the European court of Human Rights.
3. Sample taking shall be safeguarded by human rights guarantees. We do acknowledge that the requirement of consent is impracticable in the criminal context, but as a compensation preferably a judicial decision hall be needed for sample taking.
4. The purpose of the law – especially in the criminal context – shall be clearly defined. Should the main purpose be identification of perpetrators, the legislative has to give reasons as to why to take the samples from convicts after they have already been convicted – a practice in many jurisdictions.

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[15] Decision No. 485/2009 on the constitutionality of Article 5 Section (3) of the Law No. 76/2008 on the Organizing and Functioning of the National Judicial Genetic Data System

[16] FN 25 in Mairi Levitt, Forensic databases: benefits and ethical social costs, 83 *British Medical Bulletin* 1, 235-248 (2007)

[17] The DNA database and you, http://rinf.com/alt-news/surveillance-big-brother/the-dna-database-and-you/4820/

5. The list of crimes for which samples are to be taken shall be laid down by law. Preferably only perpetrators or suspects of the more severe crimes shall be subjected to sample taking, or recidivists. Whenever irrelevant, like in economic crimes, sample taking shall not be required.
6. Samples and profiles shall be stored for definite periods. We do acknowledge that the deletion of samples is impracticable, since it is essential to have samples available for retesting in case the tests or their methods are being disputed in a case, further quality control necessitates their storage, and finally, as technology develops, samples may be submitted to retesting again and again, and it may be impractical to recreate the database each time a new technological method has been invented. Nevertheless since they contain information irrelevant for identification purposes they shall preferably deleted once the profiles are derived therefrom or when a final decision has been rendered in the given case.
7. There shall be deadlines for the deletion of the profiles as well. These shall depend on the gravity of the crime. Samples and profiles of persons not found guilty shall be immediately destroyed and deleted respectively.
8. The scope of persons having access to samples and profiles shall be laid down by law.
9. Data transfer shall happen through secured means.
10. Sample taking, storage and erasure shall be monitored.
11. Forensic databased must never be interconnected with other databases, and especially not with population or classical biobanks.
12. Special regard shall be given to the right of children and other vulnerable groups.
13. A right to judicial remedy against sample and profile storage shall be guaranteed.
14. Unification of data protection standards across Europe would be the *sine qua non* of criminal cooperation. Without sufficient and uniform human rights mechanism the transfer of profiles remains highly problematic.

JAHR | Vol. 1 | No. 1 | 2010

UDK:179:61
UDK:179:61>:37
Essay/Esej
Received/Primljeno 01/09/2009

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The development of bioethical consciousness in Macedonia: the absence of legislative dismissals and its consequences

ABSTRACT

Unlike many neighbouring countries on the Balcany, in Macedonia one doesn't talk about bioethics as a developing discipline, which is a normal fact or part of scientific activities and research, or even less does one talk about bioethics as something that is a systematic part of education, including ethical education.

In the above mentioned context there are two approaches to the consideration of UNESCO documents on this subject:

- something that should become one of the objectives of any change within the educational system;
- something that the state, which tends to be systematic part of the globalisation process, and in this sense also of ethical globalization, above all, should approach in the way that it defines its own legislation, which is at the given moment everything else but bioethically oriented.

So the basic precept of the suggested text is the survey of the bioethical consciousness developed in the context of law absence, as well as indication to the possible consequences of such circumstances for the further state development.

Key words: bioethics, UNESCO, ethical education, globalization, legislation

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When one talks about the development of bioethical consciousness in Macedonia, it is necessary to emphasize that one can talk about it only as about something that is emerging and that it owes its emergence, above all, to the development of bioethical consciousness and activities of certain ethicists and philosophers from 1920 on.

Therefore, in order to conjure up the foregoing text, here, at the very beginning, I have to mention some people, books, activities and events that have, on the whole, contributed to our ability to talk more realistically about the emergence of bioethics both in today's sense and the use of this term from 2000 on. Still, there is a long way to its differentiation as a special science, at least among institutions for higher education in Macedonia.

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Historically, we owe the true foundation of bioethical consciousness and the development of ethics towards bioethics, at least concerning Macedonia, to a man who was neither a philosopher nor an ethicist. He did, through his actions in regards to Lake Ohrid and introduction of a completely new approach to examining the life environment (as is this lake), introduce the rule that nothing can be examined without taking into account the dependence of all the parts within the same whole and their influence on one another.

The man in question is the late academician Ph.D. Siniša Stanković, who had with his work and its results not only contributed to the development of bioethical consciousness in Macedonia but had also given a contribution to the world , although, as stated in the above paragraph, he was neither a philosopher nor was he famous for writing ethical instructions! Namely he was a biologist.

The mentioning of a biologist may seem off topic in the context of bioethics, at least in Macedonia. It can be justified by the fact that such examination and approach to the matter has, after almost fifty years since Stanković began his exploration in 1922, led to the introduction of books in high schools[1] dealing with ecologically accepted systems, habitats and environments.

However, he deserves merit for more than just this. Taken into account the time period in which he started his scientific work and the intellectual athmosphere in Macedonia, as well as the fact that Ph.D. Dušan Nedeljković founded the Philosophy Department as a branch of the University of Belgrad, Stanković' research and announcement of scientific results also indirectly created an athmosphere and influenced the lectures of Dušan Nedeljković.

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[1] Siniša Stanković, *Okvir života.* Kultura, Skopje and Naučna knjiga, Belgrad, 1954. (re-edited in 1977 in Naučna knjiga, Belgrad), as well as Siniša Stanković, *Ekologija čoveka*, Naučna knjiga, Belgrad, 1974.

More precisely, if one scans his »Skopska predavanja«,[2] it is completely clear that the choice of materials, topics, and philosophers' interpretations, independent of concrete lecture, more or less, authenticates the fact about the general correlation of everything and everybody with everything and everybody, i.e. about mutual stipulation and dependence.

This led to a later easier students' acceptance of Vuk Pavlović' efforts in introducing ethics and emphasizing the need for bioethical thinking, although the word cannot be derived explicitly from his works such as »Philosophies and the worlds«[3], »Call«[4] and »Ruins«[5]. More concretely, when we talk about Vuk Pavlović, one has to emphasize in this context, that although there's no resolute declaration about the need for bioethics, there remains a fact that the above mentioned works with their content, idea and objective, are a call for bioethicity. This is not only because their basic theme is »man« and »life«, but also because the way man and life are dealt with, imply the fact that one cannot be ethical if one does not accept that the foundation of every ethic is bio-existence.

His work and doctrine, as well as the education he gave to students, enabled the events in the middle of the fifth decade of the last century that made the foundation of todays bioethics. In 1959, he founded the Aesthetic Laboratory, the result of which was the book »Creativity and museum aesthetics«[6]. It was significant because, for the first time in Macedonia, it opened a debate on man's position in museum as well as on the relationship between the two, whereby the museum represents a space of man's ethical thinking and aesthetic work.

Without naming further chronological examples throughout history, one has to emphasize the fact that the endeavours mentioned led to the production of texts, books, and concrete research, activities and projects in the field of bioethics. The following examples are not chronological, but have been chosen according to the importance and influence on further development of bioethics in Macedonia. In this context one should mention the books »Ethics for children«[7] by professor Tem-

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[2] Dušan Nedeljković, *Istorija na filosofijata*. Makedonska kniga, Skopje, 1984.

[3] Pavao Vuk-Pavlović, *Philosophies and the Worlds.* Annual collection on Faculty of Philosophy in Skopje, number 14, Skopje, 1962, cf. Pavao Vuk-Pavlović, *On meaning of philosophy.* Institute for philosophy in University in Zagreb, Philosophical studies 1, Zagreb, 1969.

[4] Pavao Vuk-Pavlović, *Call.* Skopje, MCMLXIV.

[5] Pavao Vuk-Pavlović, *Ruins: Sonnets from Skopje.* Skopje, MCMLXIV.

[6] Pavao Vuk Pavlović, *Tvoreštvoto i muzejskata estetika.* Metaforum, Skopje, 1993.

[7] Kiril Temkov, *Etika za decata: Raskazi i pouki za ona što je dobro za decata.* Nova Makedonija - Kolibri, 2002-2005, SAMIZDAT, Pečat Društvo FLU, 2007.

kov, »Ethics of responsibility«[8] by professor Denko Skalovski, »Medical ethics«[9] by Nada Pop Jordanov, »Stomatological ethics«[10] by Branislav Daštevski, »Human genetics«[11] by doctor Vladimir Trajkovski and »Life environment«[12] by Jelena Dimitrijević. A few other projects on this topic are also worth mentioning: Ljubica Topuzovski's project on ethical and bioethical education of children from the second, third and fourth class of elementary school, OXO[13] project on the ecological education of children and teachers and cooperation and participation of the University »Sveti Kiril and Metod« from Skopje in the East European Bioethical Forum.

Of special importance are initiatives of citizens in the Ethics Centre from Skopje from 2004 till 2008, as well as endeavours of the newly opened Centre for Integrative Bioethics from Kumanovo to introduce bioethics (for the first time on a higher-educational level) at the Faculty for Health Management that is to be opened.

Despite the above mentioned facts, it is obvious, that in terms of presence of bioethics in the everyday life and legislation of Macedonia, there are neither proposals and obligations from the UNESCO Declaration and documents on bioethics nor is its role included into processes and eventual consequences of globalization.

The cause for this is an immature system, especially in the educational arena, and valid integration into the world educational movements motivated by the UNESCO Declaration and documents.

The other cause is the reluctance of government from the very beginning of Macedonia's independence to use laws realistically, objectively and suitably in the economic and social situation, i.e. that it passes laws not merely to satisfy the forms that Europe prescribes but that they deal with concrete conditions and their preventions.

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Taking into account the remarks and criticism of laws on bioethics, one should also consider the level of economic development and real economic indicators in Macedonia.

It would be too bold to claim that somebody had paid for the laws to remain understated; it is more realistic that the content of these legal decrees suggest the lack of

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[8] Denko Skalovski, *Etika na odgovornosta*. BIGOSS, Skopje, 2005.

[9] Nada Pop Jordanova, *Medicinska etika.* Kultura, Skopje, 2003.

[10] Branislav Daštevski, *Etika vo stomatologija.* Magnat, Skopje, 1998.

[11] Vladimir Trajkovski, *Humana genetika.* Filozofski fakultet, Skopje, 2005.

[12] Jelena Dimitrijević, *Životna sredina.* Signum, Skopje, 1998.

[13] for further detail see http://www.oxo.org.mk

consciousness and bioethical irresponsibility of a law maker. These structures are more aimed at the economic interests of the government than at passing concise laws and legal frameworks that would directly or indirectly create preconditions for supporting bioethical thought and responsibility both of the producer and of the capital and production means' owner.

The above described situation of the absence of bioethical consciousness in law maker is in great part the consequence of inferiority, i.e. regression of the educational process and the content of curricula.[14] The end result of these processes is a facade-like legislation that is not founded on a bioethical relationship towards an individual nor on preserving the whole human and other species.

Before we continue it is to be emphasized that the Republic of Macedonia is the OUN Declaration signatory country that is at the same time inaugural act of the UNESCO and all other declarations and documents, many of which are not declaratives but obligatory, of the above named legislative bodies. If one studies relevant documents and reads some of the main laws on bioethics, one can best define the situation with the expression »contradictio in adjecto«.

Macedonia is obliged to conform its own legislation to international obligations and standards. The laws passed have to be, more or less, in concordance with other more developed legislations. Such condition can be deceiving since legal decrees are inherently problematic: firstly because their sharpness is negligible and secondly because these decrees are in most cases contrary to the other laws related to these problems.

There are two reasons for this situation. I've metioned the first one, which is the inadequate education of law makers who act according to the COPY-PASTE principle, i.e. they adopt decisions from other legislations whereby they do not study the rest of the laws and legislation from which they adopt these decisions. The second reason are economic conditions in Macedonia. There are very few industrially significant objects, which use a 15-20 years outdated technology and are not designed bioethically, the consequence being large number of work medicine cases, i.e. there are more and more patients who suffer from illnesses caused by maladjustment of working conditions to human needs and to protection from consequences of working in such environment

This example clearly shows the absurdity of situation in the legislative framework in which these problems are dealt with. The laws had been passed on the one hand because of the pressure to »be liked by Europe« and on the other hand to claim in public that the state cares for these problems and solves them lawfully, taking into

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[14] http://www.bro.gov.mk/

account the content and obligations the Republic of Macedonia has as the OUN member state and that is, as such, obliged to carry out and hold on to documents and declarations of all its organisations.

Not going deeper into socio-political or political contemplations, one has to say that it is unfortunate but true that this kind of relationship towards the obligations from the UNESCO declarations and documents led to the situation that these laws serve more to enable negative bioethical consequences than to prevent them.

Apart from all the above mentioned reasons which lead to such laws, to make things even more concerning, there is a disintegration of the educational system and its function. If one looks carefully at the educational programs and sees what has been eliminated in the past 10 years[15], a question is raised if somebody would want to create the educational system similar to the so-called »developed western educational systems« or, more realistically, consciously or unconsciously, by reducing the amount of information, also reduces the quality of thinking of the future participants in economic and biological reproduction processes.

More concretely, these programs suggest that there are more and more people who, when passing, voting for or writing laws for prevention of bioethical consequences, act as I mentioned. To be more precise, the goverment in Macedonia is composed of relatively young people who finished their education in the so-called transitioanl period during which the above mentioned affairs in education were set into motion.

Corruption of the educational system, lack of concept and vision harmonized with the needs for further sustainable development lead to inadequate education and training of law makers who, by creating legal decrees, cannot reflect on their consequences and cannot but subordinate them to everyday political and democratic needs. They should create laws the essence of which should express bioethical consciousness not only of the state in which they are passed but also serve as evidence on consciousness and responsibility towards the state's biomass and biopotential, that should not be jeopardized on a global level and should be prevented locally.

All that has been stated so far unfortunately has one more consequence for the whole situation in Macedonia. Apart from culture, education and civil consciousness the economy also succumbs to the systematic desorientation in education, dubious passing of laws or, to be more precise, problematic reasons of the laws passed, economic environment, as well as the level of political culture by which one assumes authority. It is completely clear that methods of production, marketing and product advertising do not create an economic consensus on sustainable development of

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[15] http://www.bro.gov.mk/podracje/koncepciski/osnovno.html

Macedonia, especially if one takes into account the level of bioethical consciousness, responsibility and tendency as one of the most important factors for the economy to slowly but safely stop adapting to the modern sollutions of other economies, that impose their concepts based on previous development.

Even more dangerously, apart from plausible growth of gross national product, the standard is lowered not only by the world economy but also by the quality of products on the market. Secondly, the very absence of bioethical responsibility, consciousness and respect towards the UNESCO declarations and documents and refusal to adapt all segments of social life to them cause health deterioriation as well as physiological and biological degeneration of population, the consequence being problems among children aged 12 – 18 who later on develop chronic diseases.

The question is *whether one can even talk about the development of bioethical consciousness if the economy does not stop jeopardizing not only biomass and bioresources but also the ones it is intended for – the citizens!?*

One has to emphasize one more thing in relation with Macedonia's econonomy. Though not directly stated, the content of the UNESCO declaration requires from signatory states to plan, develop and conceptualize their economy in a way that part of the realized income, or if you want profit, has to be invested in new fields. This can be achieved only if the realized difference and part reinvested in already existing capacities in order to adapt their technology to changes, enable the reduction of life costs, which is certainly one of the preconditions to create means for investment in the development of bioethical consciousness and responsibility based on the above mentioned documents and declarations.

The following example explains the situation more concretely. If the state would invest in the quality of production conditions it would save money for treatments of illnesses developed at work places. This means that one has to invest in the conditions and not in the palliatives poor working conditions can cause. Such investments and economic preconditions, herewith creation of means for higher education of population and the ones educating the population, actually fulfill regulations stated in the UNESCO declarations and documents.

Unfortunately we have a different situation in Macedonia but it seems that this is not only the case with our country. If one looks at other economies in this area it is difficult to say whether there is better work quality or better investments in it elsewhere and so it happens that laws[16] are passed whose regulations demand fees if the owner's dog does not relieve itself within the certain park zone or if the citizen uri-

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[16] http://www.moepp.gov.mk/default-MK.asp?ItemID=B22EF3F504797B4DBA1360BEBFCCE102

nates somewhere, without beforehand creating legal, i.e. technical preconditions for these things not to happen. Actually there are cities in this area that have no functional public toiletts. Bioethical consciousness and human right to live his/her life on a certain level of quality include not only housing problem (conditionally stated), but also conditions for satisfying one's biological and pysiological needs at the given moment without being afraid of punishment.

I mentioned this example because of its reversed effect the authorities have on citizens, which caused the police-and-thief game between the citizen and the state. This seems not to be the problem only in Macedonia but also in other countries. It is familiar that man is always in conflict with the state. If this state rejects him in that measure that he has to suppress a part of himself, he will certainly find a way to retaliate. This automatically excludes the bioethical consciousness of adapting and conforming characteristic behaviour not only to the minimum of some so-called civilization or polite behaviour but to the bioethical thinking in general.

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There are many similar examples, comparisons and implications. Unfortunately, the problem lies not within the truth of their remark or implication. What creates controversy is that one talks about bioethics and that all authorities have heard of the UNESCO declarations and documents related to these problems. But this does not mean that they imply them or that they adapt their legislation to their regulations. Even they play the police-and-thief game. This is upheld by the fact that if one utters some of the remarks mentioned beforehand the usual answer one gets is that *that would probably be contrary to the state's constitution!* This opens an important question related to bioethics and its relation to the state, both on a local and on global level.

Namely in each constitution of newly founded countries one can find an article about rights and obligations for a clean environment[17]. The problem is that these constitutions had been formed as a temporary answer to some political problems and not as a conceptualization of state development to perceive world as a space in which conditions for enrichment as well as for planned spending of bioresources and biopotentials on our planet are enabled by sustaining human, biological and natural diversity.[18]

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[17] http://www.moepp.gov.mk/default-MK.asp?ItemID=A038221BBA291A4BB62D2B32407D076C

[18] http://www.moepp.gov.mk/default-MK.asp?ItemID=D899B34D32D2AF4DB2CABE9B6AA3B79C

I would like to add one more digression related to this context. Even with efforts to adapt the constitution to such needs and to make the content of the law more obligatory, unfortunately, one faces a certain type of lobbying in the interest of profits.

This implies another fact. The way of lobbying in favour of bioethics or the UNESCO declarations and documents, which are both declarative and obligatory, is problematic. This suggests that even those who are devoted to such problems and who try their best to solve them, come across the situation. I've experienced that in the area where I come from, where they build a house starting with the roof. In other words, the way of education independent of state or area in which one lives has to undergo changes to avoid documents and declarations being applied only formally or generally, whereby the whole worth systems in economy, politics, society and thereby in ethics are neglected.

Therefore, we do not have to lobby for a more human design of health institutions, but above all create worth systems within men based on bioethical way of thinking and existence.

This means that each state tending to become systematic part of globalization, in this sense of ethic globalization, should above all approach its economy and education and especially laws dealing with these problems, in a way that it enables bioethical orientation and realization, not only declaratively but realistically as well.

Translation/prijevod: Katja Dobrić, BA.

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Unreviewed abstracts/ Nerecenzirani sažeci

Violeta Beširević[*]

From Nuremberg to UNESCO: informed consent to medical treatment or exam

ABSTRACT

The informed consent to a medical treatment or participation in medical research is nowadays considered a fundamental standard of everyday practice and scientific research in medicine. However, accepting this standard, both in medical ethics and law, is not uniquely viewed upon in terms of its content or necessity. Starting from basic principles – human dignity and individual autonomy – UNESCO's International Committee for Bioethics has offered in sketches of three bioethics declarations unique rules which must be followed in the application of this institute, and which were consequently adopted by consensus by all UNESCO state members. Following a short historical overview, this presentation examines the standards of patients' consent to a medical measure or exam contained in UNESCO's bioethics declarations, namely: Universal Declaration on Human Genome and Human Rights, International Declaration on Human Genetic Data and Universal Declaration on Bioethics and Human Rights. The presentation will show that declarations hold only minimum standards that protect patients or participants in medical exams from self-willing treatment or research and that the authors of these documents missed the opportunity to set rigorous and explicit rules for the applications of this institute. However, bearing in mind that most countries' domestic legal regulations are not sufficiently elaborated in regards with biomedicine and that the existing domestic laws differ in many aspects, the author shall show that the UNESCO's bioethics declarations are a useful source and signposts for the domestic systems in defining ethical and legal regulations regarding biomedicine. Besides, even though these documents are not legally binding, one should bear in mind that declarations of this type are the first step towards the necessary protection of human rights with regards to biomedicine worldwide and they promote a new approach to solving bioethical dilemma based on the international law on human rights.

Key words: UNESCO, bioethics, patient's consent, human dignity, autonomy, international law on human rights

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Jasminka Katić Bubaš*, Ervin Jančić**

Ostvarivanje namjere Opće deklaracije o bioetici i ljudskim pravima u radu bolničkih etičkih povjerenstava

Opća deklaracija o bioetici i ljudskim pravima od 19. listopada 2005. godine u članku 19. promiče rad i namjeru etičkih povjerenstava kao neovisnih, multidisciplinarnih i pluralističkih etičkih odbora koji se trebaju osnivati, promicati i podržati na svim odgovarajućim razinama kako bi:

(a) izvršili procjenu relevantnih etičkih, pravnih, znanstvenih i socijalnih pitanja koja se odnose na istraživačke projekte koji uključuju ljudska bića;

(b) pružili savjete o etičkim problemima u kliničkom okruženju;

(c) izvršili procjenu znanstvenog i tehnološkog razvoja, formulirali preporuke i doprinijeli pripremama smjernica o pitanjima koja se nalaze u području primjene Deklaracije, te

(d) poticali rasprave, obrazovanje i podizali javno mnijenje te sudjelovanje i angažiranost u području bioetike.

Slijedom članka 22. citirane deklaracije, države bi trebale poduzeti sve odgovarajuće mjere bez obzira da li su zakonskog, upravnog ili drugog karaktera, kako bi provele načela postavljena ovom deklaracijom u skladu s međunarodnim zakonom o ljudskim pravima. Takve mjere podržat će aktivnosti u sferi obrazovanja, obučavanja i javnog informiranja. Isto tako države trebaju dati poticaj osnivanju neovisnih, multidisciplinarnih i pluralističkih etičkih odbora kako bi se ostvarila namjera navedena u članku 19. Deklaracije. Nastavljajući navedenu namjeru, a sukladno Zakonu o zdravstvenoj zaštiti (Narodne novine, 150/08), etičko povjerenstvo zdravstvene

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ustanove jest tijelo koje osigurava obavljanje djelatnosti zdravstvene ustanove na načelima medicinske etike i deontologije.

Etičko povjerenstvo imenuje upravno vijeće i čini ga najmanje pet članova, od toga najmanje 40% članova suprotnog spola, s time da najmanje jedan član etičkog povjerenstva treba biti predstavnik nemedicinskih struka i najmanje jedan član koji nije radnik zdravstvene ustanove. Upravno vijeće imenuje i zamjenike članova etičkog povjerenstva. Broj članova i sastav etičkog povjerenstva uređuje se statutom zdravstvene ustanove.

Etičko povjerenstvo donosi poslovnik o svome radu. Etičko povjerenstvo zdravstvene ustanove: prati primjenu etičkih i deontoloških načela zdravstvene struke u obavljanju djelatnosti zdravstvene ustanove, odobrava znanstvena istraživanja u zdravstvenoj ustanovi, nadzire uzimanje dijelova ljudskog tijela nakon obdukcije u medicinske i znanstveno-nastavne svrhe, rješava i druga etička pitanja u obavljanju djelatnosti zdravstvene ustanove. (2)

Uvidom u godišnje izvješće 2005. godine, Opća bolnica Karlovac imala je 889 zaposlenih, ukupan broj postelja 429, a popunjenost - iskorištenost bolničkih postelja 80,24%, broj liječenih bolesnika je bio 16 878, koji su ostvarili 125 641 dana bolničkog liječenja, te godine u polikliničko konzilijarnoj zaštiti učinjeno je 210 416 pregleda i pruženo 217 086 usluga. (3)

Od imenovanja, 02. studenog, 2004. godine, Etičko povjerenstvo održalo je 32 sjednice. Većina predmeta rasprave Etičkog povjerenstva činili su zahtjevi za donošenje etičke suglasnosti provođenja završnih faza kliničkih ispitivanja ili kliničkih istraživanja za potrebe stručno-znanstvenog rada, te za potrebe izrade doktorskih disertacija, raspravljalo o prijavama nuspojava lijekova koje su se dogodile tijekom odobrenih istraživanja, o pritužbama pacijenata i bolničkih liječnika, komunikacijskim problemima liječnik-pacijent, zaštiti tajnosti podataka, potrebi edukacije osoblja i potrebi bioetičkih konzultacija.

Navedeni najčešći predmeti rasprave potvrđuju već ranije definirane tri do četiri osnovne funkcije institucionalih etičkih povjernstava; edukacija, potpora i savjetovanje (4,5), odnosno edukacija, utvrđivanje politike djelovanja, konzultiranje i ocjenjivanje pojedinačnih slučajeva te, u nekim slučajevima, teološke refleksije. (6)

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Achieving purpose of The Universal Declaration on Bioethics and Human Rights in the work of hospital ethics committee

The Universal Declaration on Bioethics and Human Rights, adopted on 19 October 2005, in Article 19 promotes the work and purpose of ethics committees as independent, multidisciplinary and pluralistic ethics boards that are to be founded, promoted and supported at all appropriate levels so they can:

(a) assess relevant ethical, legal, scientific and social issues regarding research projects which involve human beings;

(b) provide advice on ethical problems in clinical environment;

(c) assess scientific and technological development, formulate recommendations and contribute to preparations of guidelines on issues that the Declaration is applicable to, and

(d) encourage discussions, education and affect public opinion and participation and engagement in the field of bioethics.

Resulting from Article 22 of the cited Declaration, states should take all appropriate measures regardless of their being of legal, administrative or any other type, in order to carry out principles set in this Declaration in accordance with the international law on human rights. Such measures shall support activities related to education, training and dissemination of information to the public. States should also encourage establishing independent, multidisciplinary and pluralistic ethics committees in

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order to achieve the purpose stated in Article 19 of the Declaration. By continuing the aforementioned purpose, and in accordance with the Health Care Act (Official Gazette 150/08), the ethics committee in a health facility is a body that ensures the work in a health facility is based on principles of medical ethics and deontology.

Ethics committee is appointed by the governing council and it consists of minimally five members out of which at least 40% of the members must be of the opposite gender, and at least one member must be a representative from a field not related to medicine and at least one member must not be a health facility employee. The governing council also appoints deputies of the ethical committee members. The number of members and structure of the ethics committee is governed by the health facility statute.

Ethics committee adopts rules of procedure. Its function is to monitor the application of ethical and deontological principles of health profession in the work of the health facility, approves scientific research in the health facility, monitors removal of body parts for scientific and educational purposed after the autopsy and resolves other ethical issues arising in the work of the health facility. (2)

Insight into the annual report from 2005 has shown that Karlovac General Hospital had 889 employees, 429 beds and occupancy rate was 80.24%, the number of treated patients was 16 878, who accounted for 125 641 days of hospital treatment. There were 210 416 polyclinic exams and 217 086 health services were provided. (3)

From its appointment on 2 November 2004, the ethics committee has held 32 sessions. Most discussions revolved around requirements for the approval to conduct final phases of clinical experiments or clinical research for purposes of professional and scientific work and doctoral dissertations. Reported side effects of medications during approved experiments were discussed, as well as patients' and hospital doctors' complaints, doctor-patient communication problems, confidentiality of data, necessity for employees' education and necessity for bioethical consultations.

These examples corroborate earlier defined three out of four basic functions of the institutional ethics committees; education, support and counseling (4, 5), i.e. education, establishing work policy, consultations and assessment of individual cases, and, in some cases, theological reflections. (6)

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Miscellanea/ Slobodne teme

JAHR | Vol. 1 | No. 1 | 2010

UDK: 175:791.43
Original Scientific Article/Izvorni članak
Received/Primljeno 01/03/2010

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Etika i film: Od identifikacije do moralne edukacije u filmskoj umjetnosti

SAŽETAK

Različita umjetnička djela raspolažu različitim potencijalom identifikacije publike sa sadržajem. Ovaj potencijal, koji može biti namjerno odabrani autorski pristup ili, pak, posljedica nepredviđenih korelacija, u konačnici se nerijetko interpretira i analizira kao poruka moralnog, pa i moralno-edukativnog karaktera. Iz neurofizioloških razloga, identifikacijski je kapacitet najnaglašeniji u mediju filma.

Ovaj rad pokušava analizirati iz više perspektiva mehanizme i fenomenologiju identifikacije na nekoliko primjera filmova »novije« produkcije (dakle, nastalih unatrag dvadesetak godina – *Dances with the Wolves*, *Titanic*, *Schindler's List*, *La vita è bella*, *Lilja 4-ever* i dr.), kao i hipotetski negativne primjere moralno-edukativnog učinka (*Independence Day*, *Rane*, *Bure baruta*, *Fine mrtve djevojke, Requiem for Dreams, Gegen die Wand* i dr.).

Rezultat ove analize je formiranje obrasca »filma s moralno-edukativnim ambicijama«, kao i ukazivanje na neke opasnosti zanemarivanja moralno-edukativnog aspekta filmskih scenarija.

Ključne riječi: etika, moral, identifikacija, edukacija, film

Uvod

Tko je posjetio crkvu Sv. Marije na škrilinah (kamenim pločama) nedaleko Berma, u središnjoj Istri, zasigurno se sjeća dobro očuvanih fresaka koje se pripisuju radionici Vincenta iz Kastva, majstora iz druge polovine XV. stoljeća. Među uobičajenim motivima iz života Krista nalazi se i »Pokolj nevine djece« koji nadzire figura Hero-

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da, očiju naknadno ispunjenih vezujućom masom. Zidne slike su, naime, za nepismen narod kasnoga srednjeg vijeka, služile kao *Biblia pauperum*, pa se taj narod, koji je freske očito doživljavao prilično živo, osvetio zločincu Herodu iskopavši mu oči.

Tko je, opet, pogledao film *Shakespeare in Love* (SAD; 1998.; režija: John Madden),[1] sjeća se dobro dočarane atmosfere elizabetinskog kazališta početkom XVII. stoljeća u Londonu, kada publika »participira« u svim zbivanjima na sceni, uzdiše s glumcima i plače. U našim se kinima takva atmosfera mogla doživjeti još neposredno nakon Drugoga svjetskog rata, kada su revniji gledatelji redovito upozoravali glumce s platna na »opasnosti« koje im prijete. Još 1960-ih se u gradskim knjižnicima moglo doći do primjeraka romana poput *Love Story* Ericha Segala, na čiju su poleđinu dopisivana imena onih čitatelja koji su pod utjecajem priče zaplakali.

Freske, kazalište, knjiga – mediji koji su, svaki u svoje vrijeme, bili popularnima (plebs Londona Seičenta daje za predstavu posljednji peni) pa stoga i utjecajnima, imali su, očito, moć provociranja identifikacije sa sadržajem predstavljanog.[2] U današnje vrijeme, teško da bi se našlo ikoga tko bi na srednjovjekovni način bio podložan interagirati s freskama, a bili bi razmjerno rijetki i oni koji bi priznali da u dubljoj mjeri suosjećaju s kazališnom ili knjiškom pričom. Međutim, dok je odmak od identifikacije postao moguć i uobičajen u slučaju starih medija, identifikacija je u naše doba postala karakterističnim obilježjem novijeg medija, filma. (Hoće li identifikacija zauvijek ostati vezana uz film, teško je reći: premda je moguće da je ljudska neurobiologija pronašla u filmu optimalan medij komunikacije poruka, nije nemoguće zamisliti hologramske ili neke druge medije koji će u budućnosti podignuti prag identifikacije.) Temeljna teza ovoga rada je da bi film, s obzirom na raskošan identifikacijski potencijal kojim raspolaže, trebao obraćati na nj više pažnje, pa i ciljano ga koristiti za razvitak pozitivnih moralnih stavova i praksi,[3] izbjegavajući istovremeno opasnost prenošenja negativnih etičkih poruka.

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[1] Temeljne reference za većinu filmova spominjanih u ovom članku mogu se naći u *Variety Portable Movie Guide – Updated Edition* (New York: Berkley Boulevard Books, 2000) i S. J. Schneider, ur., *1001 Movies You Must See Before You Die* (London: Cassell, 2007).

[2] Identifikacija (od lat. *idem* = isto, dakle, »poistovjećivanje«) se u kolokvijalnim okolnostima povremeno rabi kao sinonim za suosjećanje, sućut, simpatiju i empatiju, što, međutim, ni etimološki ni terminološki ni povijesno često nije ispravno.

[3] Usporedi slično razmišljanje o zadaći filma u: T. Vuković, »Snimanje filma je etički čin: razgovor s filmskim redateljem Brankom Ištvančićem,« *Glas Koncila* 14, br. 1763 (2008): 1-3. Općenito o području primjenjivosti morala u odnosu na umjetničko djelo (fabulistički moralizam, izlagački moralizam, moralna odgovornost za posljedice djela, stvaralačko-ekspresijska moralnost i profesionalni moral) vidi, primjerice, u: H. Turković, *Suvremeni film: djela i stvaratelji, trendovi i tradicije* (Zagreb: Znanje, 1999); R. Eldridge, »Art and morality,« u: *Introduction to the Philosophy of Art* (Cambridge: Cambridge University Press, 2003); N. Carroll, »Art, Narrative, and moral understanding« i »Moderate moralism«, u: *Beyond Aesthetics* (Cambridge: Cambridge University Press, 2001); M.

Od identifikacije do empatije

Osim medijske animacije (koja je, kako je dosad rečeno, ovisna o edukaciji pojedinca i vremenu), identifikacija supsumira još jednu komponentu – empatiju (grč. *en* = u + *pathos* = bol, trpnja, strast; *empathes* = strastven). Ova »ostrašćenost«[4] zapravo je sinonim za razumijevanje i preuzimanje tuđeg afektivnog stanja, odnosno, kada se radi o percepciji medija, uživljavanje u priču (njem. *Einfühlung*), poistovjećenje s njenim likom ili potkom. Kada je riječ o dimenzijama empatije, Gallo[5] razlikuje kognitivnu i afektivnu dimenziju, pri čemu bi prva razumskim argumentima približavala tuđe osjećanje vlastitom.

Kao termin, empatija je u engleski jezik ušla tek početkom XX. stoljeća, zahvaljujući psihologu Edwardu Titcheneru (1867.-1927.), dok je u njemačkim filozofskim krugovima bila prisutna i ranije, osobito među estetičarima. Theodor Lipps (1851.-1914.) je, primjerice, objašnjavao empatiju kao rezonancu naše percepcije i vanjskog objekta (unutarnju imitaciju): percepcija lijepoga, po Lippsu, uzrokovana je pozitivnom, a ružnoga negativnom empatijom.

Osim u estetici, empatija je osobito proučavana u socijalnoj psihologiji, budući da se vjeruje da pogoduje razvoju prosocijalnih stavova i ponašanja. I doista, mnogobrojna dosadašnja istraživanja fenomena empatije otkrila su da u pozitivnoj korelaciji s razvitkom empatije u djece stoji neautoritativno ponašanje majke,[6] dok prijetnje i fizičko kažnjavanje djece,[7] kao i njihovo zanemarivanje ili izloženost obiteljskom nasilju,[8] negativno utječu na razvoj empatičkog potencijala. Kada se radi o edukativnim postupcima s ciljem uvećanja empatičke sposobnosti, dobri rezultati su postizani sa zadaćama koje su fokusirale pažnju djece na sličnosti između njih i drugih osoba, odnosno osobito u slučajevima kada se od djece (ili odraslih) zahtijevalo da preuzmu ulogu druge – stvarne ili fiktivne – osobe i da zamisle njene

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Kieran, »Art and morality,« u: The Oxford Handbook of Aesthetics, uredio J. Levinson (Oxford/New York: Oxford University Press, 2003) i dr.

[4] Bratoljub Klaić, iznenađujuće, spominje samo »nestrpljivost, želju, žudnju« i »netrpeljivost, nepodnošljivost; trzavice«. B. Klaić, *Rječnik stranih riječi* (Zagreb: Nakladni zavod Matice Hrvatske, 1986).

[5] D. Gallo, »Educating for empathy, reason, and imagination,« *Journal of Creative Behavior* 23, br. 2 (1989): 98-115.

[6] N. Eisenberg i P. Mussen, »Empathy and moral development in adolescence,« *Developmental Psychology* 14, br. 2 (1978): 185-6.

[7] P. Clarke, »What kind of discipline is most likely to lead to empathic behaviour in classrooms?,« *History and Social Science Teacher* 19, br. 4 (1984): 240-1.

[8] F. S. Hinchey i J. R. Gavelek, »Emphatic responding in children of battered mothers,« *Child Abuse and Neglect* 6, br. 4 (1982): 395-401.

osjećaje ili se ponašaju u skladu s njima.[9] Ova procedura, poznata u anglosaksonskoj literaturi kao *role-taking* i *role-playing*, nije ništa drugo do identifikacija s likovima priče. U suglasju s ovime su i nalazi da empatijski potencijal uvećava vježbanje percipiranja tuđeg gledišta i izloženost snažnim emotivnim podražajima (tuđa nesreća, gubitak, nelagoda).[10]

Moderna psihologija smatra korisnim razlikovati reaktivne emocije prema tome jesu li okrenute sebi ili drugome.[11] »Emotivna zaraza« (*emotional contagion*) u djece ili mase bi, prema tome, bilo obično preuzimanje emotivnog stanja od okoline, bez razumijevanja uzroka. Afektivna empatija, pak, već je pravo uživljavanje u osjećaje drugih, premda ne neminovno imajući razloga za takvo osjećanje. Simpatija je suosjećanje s nečijom negativnom emocijom, a, ukoliko tuđa nesreća ne poluči druge reakcije do li lošeg osjećaja (dakle, orijentiranog prema sebi), govori se o osobnoj tjeskobi (*personal distress*).[12]

U novije vrijeme, empatija je dobila i neurofiziološku osnovu, prvenstveno otkrićem tzv. zrcalnih neurona (*mirror neurons*).[13] Naime, pokazalo se da skupine živčanih stanica u premotornoj kori čeonog režnja majmuna reagiraju na promatranje kretnje na način da misaono »opetuju« istu kretnju. Naknadno je potvrđeno da sličan obrazac vrijedi i za prepoznavanje (i »ponavljanje«) tuđih emocija na osnovu izraza lica. (Intrigantno zvuči činjenica da je u blizini premotorne kore, u orbitofrontalnom korteksu, locirano i funkcionalno područje povezano s usvajanjem moralnih stavova: naime, pri oštećenju ove zone javljaju se poremećaji poput koprolalije, nemogućnosti inhibiranja socijalno neprihvatljivog ponašanja, pojačana impulsivnost i sl.)

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[9] H. Black i S. Phillips, »An intervention program for the development of empathy in student teachers,« *Journal of Psychology* 112 (1982): 159-68.

[10] M. A. Barnett, J. A. Howard, E. M. Melton i G. A. Dino, »Effect of inducing sadness about self or other on helping behavior in high- and low-emphatic children,« *Child Development* 53, br. 2 (1982): 920-3.

[11] K. Stueber, *Rediscovering Empathy: Agency, Folk Psychology, and the Human Sciences* (Cambridge, MA: MIT Press, 2006).

[12] Usporedi i razvojne razine empatije, koje odgovaraju stadijima kognitivnog razvoja (globalna empatija, egocentrična empatija, empatija za osjećaje drugih, empatija za nečije životne uvjete): Z. Raboteg-Šarić, »The role of empathy and moral reasoning in adolescents' prosocial behaviour,« *Društvena istraživanja* 6 (1997): 493-512; Cf. također Z. Raboteg-Šarić, »Empathy and moral development: Implications for caring and justice,« *Contemporary Sociology* 30 (2001): 487-8.

[13] G. Rizzolatti, L. Craighero i L. Fadiga, »The mirror system in humans,« u: Mirror *Neurons and the Evolution of Brain and Language*, ur. A. Stamenov i V. Gallese (Amsterdam/Philadelphia: John Benjamins Publishing Co., 2002), pp. 37-59.

Od empatije do morala

Ako pretpostavimo da empatija, kao stanje afektivnog približavanja drugome, pogoduje razvoju odnosno jačanju kooperativnosti, altruizma,[14] ne-izazivanju i/ili ublažavanju tuđih trpljenja, zaštiti drugoga, darežljivosti i toleranciji prema drugačijemu, onda je jasno zašto je McCollough empatiju usporedio s »moralnom imaginacijom« koju obrazovanje treba promicati, a građani pretvarati u politiku.[15] Batson serijom eksperimenata dokazuje da empatija potiče pomaganje drugima ne iz egoističkih, već altruističkih poriva.[16] Hoffman u empatiji vidi biološku predispoziciju za altruističko ponašanje[17] ali, uz empatiju, kao izvorište moralne prakse naglašava i poznavanje apstraktnih moralnih načela.[18]

Ako je, po svemu sudeći, empatija povezana s razvojem »zdravih« (prihvatljivih) moralnih stavova i praksi, prvo pitanje koje se nameće jest kako izbjeći nametanje moralnih principa i poticati razvoj empatije na manje nametljiv, pa i neprimjetan način? Istraživanja su, naime, pokazala da djeca bolje usvajaju vrijednosti koje nastavnici sami modeliraju nego kada su samo poticana da se ponašaju na određeni način.[19] Gadamer[20] ispravno upozorava da nas, pri čitanju Shakespearea ili Platona, ne zanima primarno što su oni rekli već što govore sami njihovi tekstovi. Hans Christian Andersen pisao je i priče koje su imale očitu namjeru da oblikuju stav javnosti, ali je najveći učinak u (re)generiranju moralnih stavova polučio pričom koja vjerojatno uopće nije bila »hotimično educirajuća.«[21] Za *Priče iz davnine* Ivane Brlić-Mažuranić i *Pinocchia* Carla Collodija se kaže da su među rijetkim primjerima u kojih »didakticizam nije ugušio umjetničko djelo«.[22] Da bi se postigao bolji učinak formiranja poželjnih moralnih stavova, te stavove, dakle, ne treba **nametati** već in-

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[14] Raspravu o altruizmu u životinja i njegovoj evoluciji prema sebičnosti vidi u: F. de Waal, *Prirodno dobri: podrijetlo ispravnog i pogrešnog kod ljudi i drugih životinja* (Zagreb: Naklada Jesenski i Turk, 2001).

[15] T. E. McCollough, *Truth and Ethics in School System* (Washington, DC: Council for Educational Development and Research, 1992).

[16] C. D. Batson, »Self-other merging and the empathy-altruism hypothesis: reply to Neuberg et al.,« *Journal of Personality and Social Psychology* 73 (1997): 517-22.

[17] M. Hoffman, *Empathy and Moral Development* (Cambridge: Cambridge University Press, 2000).

[18] O ideji objašnjavanja morala kao evolucijsko-biološke kategorije, vidi u: M. Ruse, »Evolucijska etika: čemu nas prošlost može naučiti?«, u: *Evolucija društvenosti*, ur. J. Hrgović i D. Polšek (Zagreb: Naklada Jesenski i Turk, 2004), pp. 433-51.

[19] A. Kohn, »Caring kids: the role of the schools,« Phi Delta Kappan 72, br. 7 (1991): 496-506. Vidi također: S. Težak, *Metodika nastave filma* (Zagreb: Školska knjiga, 2002), 60.

[20] H.-G. Gadamer, *Truth and Method* (New York: Crossroad Publishing, 1989).

[21] Cf. A. Muzur, »Bajke kao (re)generatori morala: primjer Djevojčice sa žigicama H. Ch. Andersena,« u: *Ars speculandi: lektira kao izgovor za razmišljanje* (Rijeka: Izdavački centar Rijeka, 2004), pp. 57-85.

[22] D. Težak i M. Čudina-Obradović, *Priče o dobru, priče o zlu: priručnik za razvijanje moralnog prosuđivanja u djece* (Zagreb: Školska knjiga, 2005), 11.

direktno **razvijati**, empatijom. Pritom je, zbog svog većeg identifikacijskog potencijala i bolje prihvaćenosti (popularnosti konzumacije) u našem vremenu, najprihvatljiviji »vehikl« priče filmski medij.[23]

O specifičnostima filma kao medija prenošenja (poruke) pisano je mnogo. Burch,[24] primjerice, naglašava »dijegetičku snagu« filma, tj. njegovu sposobnost da dokazuje »prizornom dojmljivošću,«[25] glazbom i zvukom, glumačkim i drugim kvalitetama koje mogu biti analizirane iz različitih točaka gledišta.[26] Postavlja se, međutim, pitanje na koji način strukturirati (filmsku) priču kako bi ona mogla biti u funkciji poticanja empatije i, konačno, razvoja prihvatljivih moralnih stavova.

Temeljeći se na empirijskim psihološkim pravilima, Propp, analizirajući bajke, zagovara univerzalne simbole i elemente koji mogu biti prenijeti iz jedne bajke u drugu bez modifikacija.[27] Štoviše, po njemu, u analizi bajki bitna je akcija (funkcija), s vrlo malobrojnim postojećim obrascima, a ne protagonisti i detalji (koji mogu biti iznimno brojni u okvirima istog funkcionalnog obrasca).[28] Slijed funkcija uvijek je isti. Uzimajući za primjer pučke magičke priče, Propp razlikuje početnu situaciju (upoznavanje s licima, obitelji, junacima); odlazak od kuće; nametanje zabrane junaku; junakovo opiranje zabrani; itd.[29] Lévi-Strauss, štoviše, smatra da je mitski oblik zapravo preteča sadržaja bajke, i da je ponavljanje elemenata (slijeda) potrebno radi prikaza i naglašavanja mitske strukture.[30] Sve je to bez sumnje značajno za razmatranje strukture,[31] ali očigledno nije ono što podrazumijevamo pod razvojem identifikacijskog (empatičkog) potencijala priče uopće, pri kojemu primarnu ulogu ima ipak sadržaj.

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[23] O »hladnom voajerizmu« nove generacije režisera i trendu snimanja filmova s »odmakom od ljudi«, »bez emotivnog stava« vidi: V. Simičević, »Današnji filmovi nemaju emotivnog stava« (razgovor s Rajkom Grlićem), *Novi list – Mediteran*, 27. srpnja 2008.

[24] N. Burch, *Life to Those Shadows* (Berkeley/Los Angeles: University of California Press, 1990).

[25] N. Gilić, *Uvod u teoriju filmske priče* (Zagreb: Školska knjiga, 2007), 114-5.

[26] O točkama gledišta, kao i drugim elementima analize filma i filmske priče, vidi u: F. Casetti i F. Di Chio, *Analisi del film*, 15. izd. (Milano: Bompiani, 2007), 228-33.

[27] V. J. Propp, *Morfologia della fiaba*, prev. i ur. G. L. Bravo (Torino: Giulio Einaudi, 1966), 12.

[28] Ibid., 26.

[29] Ibid., 31.

[30] C. Lévi-Strauss, *Antropologia strutturale*, prev. Paolo Caruso (Milano: Arnoldo Mondadori, 1992), 229 i 257.

[31] O strukturi filmske priče (prostoru, trajanju i dr.) vidi: Gilić, *Uvod u teoriju filmske priče*, 41-113.

Od morala do etičke edukacije filmom

Premda zasigurno i dokumentarni i eksperimentalni rod filma mogu pobuditi empatiju,[32] u pravilu, najveći učinak polučuje igrani film,[33] neovisno o vrsti (kratkometražni, dugometražni, serija) i žanru (vestern, horor i dr.).[34] Ovdje ćemo se dotaknuti nekoliko proizvoljnih primjera različitih žanrova kako bismo poduprli tezu o filmskom pobuđivanju empatije i posljedičnim učincima na moralne stavove (i praksu).

> *Dances with Wolves* (SAD/V. Britanija; 1990; režija: Kevin Costner)
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> Priča o časniku američke sjevernjačke vojske koji, s manirima viteške časti i poštenja, otkriva Granicu i identificira s Indijancima. Unatoč priličnom stupnju kontrasta u oslikavanju dobra i zla, zahvaljujući vjernosti prikaza (priroda, indijanski govor i dr.) i brojnim vrhunsko modeliranim sporednim likovima, ovaj film provocira snažnu empatiju.
>
> *Lilya 4-ever* (Švedska; 2002; režija: Lukas Moodysson)
>
> Glavni prigovor filmu je upravo prevelika pretencioznost i »nepotrebno opterećenje retorikom lošeg didaktičkog filma«.[35] Film pripovijeda o ruskoj tinejdžerki koja, napuštena od svih, postaje prostitukom i žrtvom trgovine ljudima, a obilježen je naturalističkim prikazom silovanja i silovatelja, koji u gledatelja rezultiraju prvenstveno tjeskobom.
>
> *Schindler's List* (SAD; 1993; režija: Steven Spielberg)
>
> Baziran na istinitoj priči, film oslikava preobrazbu njemačkog industrijalca iz bešćutnog poslovnog čovjeka u spašavatelja Židova od nacističkih progona. Intrigantna ali ne nužno i ispravna je Žižekova psihoanalitičarska ideja da je »tajni motiv koji prožima sve ključne Spielbergove filmove ponovno pronalaženje oca, njegova autoriteta« i da se Schindler tijekom filma otkriva svoju očinsku dužnost prema Židovima i pretvara se u »brižnog i odgovornog oca«.[36] S druge strane, Rosenbaum[37] prigov-

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[32] O etičkim aspektima dokumentarnog filma, vidi: K. Bakker, »Dobro, loše i dokumentarac,« prevela Diana Nenadić, *Zarez* 226 (2008): 5-6.

[33] Zanimljivo je pitanje koji sve izražajni elementi filma, osim priče, mogu pobuditi empatiju. Usporedi, na primjer: C. Plantiga, »Scene empatije i ljudsko lice na filmu, » prevela Dunja Krpanec, u: *Passionate Vievs: Film, Cognition, and Emotion*, uredili Carl Plantiga i Greg M. Smith (Baltimore/London: John Hopkins University Press, 1999), 24-37.

[34] Detaljnije o rodovima, vrstama i žanrovima u. N. Gilić, *Filmske vrste i rodovi* (Zagreb: AGM, 2007).

[35] D. Rubeša, »Izgubljeni anđeli«, *Vijenac* 265 (2004): 1.

[36] S. Žižek, *Pervertitov vodič kroz film*, prev. S. Horvat i dr. (Zagreb: Antibarbarus/HDP, 2008), 11.

[37] J. Ros(enbaum), »Schindler's List,« u: Schneider, ur., *1001 Movies You Must See*, 831.

ara Spielbergu da je zanemario nekoliko zanimljivosti istinite teksture, svjestan, međutim, da bi, da je bilo drugačije, film »izgubio ponešto od svoje moralne izravnosti čak i ako bi dobio na moralnoj kompleksnosti.« U svakom slučaju, odlična gluma, glazba i poveznica s poviješću daju visok stupanj empatije.

Titanic (SAD; 1997; režija: James Cameron)

I ovdje je povijesna utemeljenost tragičnog potonuća »nepotopivog« broda, kombinirana s kvalitetnom romantičnom mezalijansom i suosjećanjem s putnicima nižih razreda, dovela do uspješne mobilizacije empatijskog potencijala. (Ima i drugačijih gledišta: Žižek, primjerice, optužuje Camerona za »površni holivudski marksizam« i prenaglašeno simpatiziranje nižih klasa uz karikiranje egoizma bogatih.[38] Berryjeva,[39] opet, locira *Titanic* negdje »na pola puta između *Posejdonove avanture* i *Broda ljubavi*.«)

La vita è bella (Italija; 1997.; režija: Roberto Benigni)

Po Žižeku, filmu se može zamjeriti »podržavanje etičkog stava nečije iluzije«, poput, primjerice, filma *Good bye, Lenin!* (Njemačka; 2003.; režija: Ulrich Becker).[40] Međutim, prava (empatička) vrijednost filma je u neuobičajenom komičnom aspektu (otac prikazuje sinu zatočeništvo u logoru kao igru) tragične, istinom prožete, potke (holokaust).

Independence Day (SAD; 1996.; režija: Roland Emmerich)

Napad vanzemaljaca na Zemlju dočekuju Amerikanci i, predvođeni osobno svojim Predsjednikom, pobjeđuju. Primjer kako nekritična antipatična egzaltacija i glorifikacija rodoljubnog patosa, naglašavanje (moralne) superiornosti, osrednja gluma, unatoč dobrim posebnim efektima, mogu svaki empatijski potencijal ostaviti neiskorištenim.

Rane (Srbija; 1998.; Srđan Dragojević) i *Bure baruta* (Srbija; 1998.; režija: Goran Paskaljević)

Beogradsko podzemlje, oslikano naturalističkim prikazima nasilja, ubojstava, konzumacije droga. Provocira obilje frustracija i nikakvu slutnju bijega ili popravka.

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[38] Žižek, *Pervertitov vodič kroz film*, 13.

[39] J. B(erry), »Titanic«, u: Schneider, ur., *1001 Movies You Must See*, 880.

[40] Ibid., 61.

Fine mrtve djevojke (Hrvatska; 2002.; režija: Dalibor Matanić)

Priča o lezbijskom paru iz zagrebačkog predgrađa. Sve je primitvno, crno, neprijateljsko i kulminira tučom i silovanjem. Tjeskoba potpuna, prostora za empatiju nema.[41]

Requiem for a Dream (SAD; 2000.; režija: Darren Aronofsky)

Odlična gluma vodi gledatelje kroz trpljenje nekoliko ovisnika o drogama, njihove krize, mentalna stanja i različite sudbine. Drama koja zbog prevelike plastičnosti rezultira prije hororskom tjeskobom nego empatijom.

Gegen die Wand (Njemačka; 2004; režija: Fatih Akin)

Priča o Turčinu koji se opija i otuđuje, zbližava, vjenčava i udaljava od žene koju maltretira obitelj. »Socijalni angažman« primjereniji dokumentarnom filmu, priča lišena perspektive i rezolucije.

Zaključak

Iz navedenih primjera moguće je izvući nekoliko preporuka za »film-koji-bi-imao-moralno-edukacijske-ambicije«:

Nulto, moralne stavove ne valja nametati već se služiti empatijom kao neusporedivo boljim putem usvajanja prihvatljivih stavova i praksi.

Prvo, preveliku plastičnost u oslikavanju trpljenja (nasilje,[42] osobito seksualno, kao kombinacija sile i poniženja, fizičke i psihičke boli), treba izbjegavati i zadržati se eventualno na aluzijama, budući da u suprotnom rezultat nije empatija već tjeskoba, okrenuta prvenstveno sebi.[43]

Drugo, poticati empatiju ne znači nužno poticati i društvenoangažirano djelovanje, već tek pridonijeti sazrijevanju moralnih stavova. Stoga ekstremizacija (karikiranje) socijalne situacije ne polučuje željeni učinak, čak i ako se približava realnosti.

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[41] Govoreći o svom najnovijem filmu, *Kinu Lika*, Matanić sam naglašava da se orijentira prema »iskrenosti« i a «autentičnosti«, približavajući svoj igrani film dokumentarnom žanru. V. Simičević, »Život je uvijek luđi od fikcije« (razgovor s Daliborom Matanićem), *Novi list*, 31. kolovoza 2008.

[42] O posljedicama promatranja nasilja na ekranu, međutim, postoje različita mišljenja. Premda, naime, prevladava eksperimentalno provjerena teza da su ljubitelji agresivnih scena skloniji počinjanju takvih čina i u svakodnevici, ima i onih koji tvrde da gledanje nasilja na ekranu rezultira katarzom i pogoduje borbi protiv nasilja u stvarnosti. Usp. Težak, *Metodika nastave filma*, 17.

[43] Cf. Stueber, *Rediscovering Empathy*, 24.

Treće, *happy end* može zatomiti empatiju, ali, ukoliko priča sretno završava nakon veće napetosti, kod publike se sprečava zadržavanje osjećaja gorčine, nemoći i frustracije, pa je u tom slučaju *happy end* poželjan i, s aspekta uvećanja empatije, koristan.[44]

Četvrto, efekt *chiaro-scuro* nije nužan: modeliranje »pozitivnih« i »negativnih« likova može biti složen, a još uvijek polučivati visok stupanj empatije. Savršenost i nepobjedivost, dapače, mogu biti antipatičnima i stoga bitno umanjiti empatiju.[45]

Peto, radi većeg identifikacijskog učinka korisno je iz priče eliminirati bilo kakve fantastične elemente: što je potka bliža realnosti (i/ili istinitosti), to je stupanj identifikacije veći.

Napokon, treba napomenuti da je, kao i pri gledanju filma, pri razvoju moralnih/etičkih stavova vrlo izražen element očekivanja i okolnosti (*set and setting*) koji neke od nabrojenih »preporuka« mogu uvelike modificirati. Ukoliko nismo larpurlartisti, ostaje, u svakom slučaju, opravdana težnja da specifičan medij filma »iskoristimo« za trajniju zadaću od kratkotrajnog šoka ili zabave.

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[44] Muzur, »Bajke kao (re)generatori morala,« 83.

[45] O otklonu djece od filmskog junaka vidi: Težak, *Metodika nastave filma*, 49.

JAHR | Vol. 1 | No. 1 | 2010

UDK: 175:791.43
Original Scientific Article/Izvorni članak
Received/Primljeno 01/03/2010

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Ethics and film: from identification to moral education in film art

Introduction

Those who have visited the Church Sv. Marija na škrilinah (St. Mary on the Rocks) near Beram in central Istria, surely remember well-preserved frescoes that are put to credit of the workshop of Vincent of Kastav, Master who lived in the second half of the 15th century. Among usual motifs from the life of Christ, there is also »The Slaughter of Innocent Children« that is overseen by the figure of Herod, whose eyes were subsequently filled with binding mix. Wall paintings served as *Biblia pauperum* for the illiterate people of late Middle Ages, so those people, who obviously experienced the frescos rather lively, revenged on Herod by poking his eyes out.

And then, those who have seen the film *Shakespeare in Love* (USA; 1998; directed by John Madden),[1] remember well depicted atmosphere of the Elizabethan Theater in the early 17th century in London, in which the audience »participates« in all developments happening on scene, sighs with the actors and cries. In our cinemas such atmosphere could have been experienced immediately after the World War II, when eager moviegoers regularly warned the actors on screen of »dangers« that threat them. As late as in 1960s it was possible find in public libraries copies of nov-

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[1] Basic references for most films mentioned in this article can be found in Variety Portable Movie Guide – Updated Edition (New York: Berkley Boulevard Books, 2000) and S. J. Schneider, ed., 1001 Movies You Must See Before You Die (London: Cassell, 2007).

els such as *Love Story* by Erich Segal on whose back one could find list of names of those readers who cried because moved by the story and added their names.

Frescoes, theater, book – media that had been, each in its time, popular (plebeians of the 16th century London would give their last penny for plays) and consequently influential, obviously had the power to induce identification with their content.[2] Nowadays, it would be difficult to find anyone who would be susceptible to the medieval manner of interaction with the frescoes, as well as those who would admit to deep sympathies with the story of a play or a book. However, whereas detachment from identification has become possible when it comes to old media, identification has today become a characteristic feature of a newer medium, film. (Shall identification always remain related to film, it is difficult to say: even though it is possible that human neurobiology has found in film an optimum medium to communicate messages, it is not impossible to imagine holographic or other types of media which shall, in future, raise the threshold of identification.) The main thesis of this paper is that film, considering its enormous identification potential, should pay more attention to it, and even use it on purpose for the development of positive moral viewpoints and practices,[3] and at the same time avoid the danger of conveying negative moral messages.

From identification to empathy

Apart from media animation (which depends, as already stated, on individual's education and time in history), identification includes another component – empathy (from Gk. *en* = in + *pathos* = pain, suffering, passion; *empathes* = passionate). This »passionness«[4] is really a synonym for understanding and assuming another person's emotional state, i.e., when related to the media perception, feeling into the story (G. *Einfühlung*), identifying with its characters or concept. When speaking about

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[2] Identification (lat. *idem* = the same) is sometimes colloquially used in the meaning of sympathy, compassion, empathy, which is often neither etimologically, terminologically nor historically correct

[3] Compare similar reflections on the task of the film in: T. Vuković, »Film making is an ethical act: interview with a film director Branko Ištvančić« *Glas Koncila* 14, No. 1763 (2008): 1-3. Generally on the application of morality in relation to a work of art (plot moralism, presentation moralism, moral responsibility for the consequences of one's work, creational-expressional morality and professional morality) see in:: H. Turković, *Suvremeni film: djela i stvaratelji, trendovi i tradicije* (Zagreb: Znanje, 1999); R. Eldridge, »Art and morality,« in: Introduction to the Philosophy of Art (Cambridge: Cambridge University Press, 2003); N. Carroll, »Art, Narrative, and moral understanding« i »Moderate moralism«, in: *Beyond Aesthetics* (Cambridge: Cambridge University Press, 2001); M. Kieran, »Art and morality,« in: The Oxford Handbook of Aesthetics, edited by J. Levinson (Oxford/New York: Oxford University Press, 2003) et al.

[4] Bratoljub Klaić, surprisingly, mentions only »impatience, wish, desire« and »intolerance, unbearableness, strains; ». B. Klaić, *Rječnik stranih riječi* (Zagreb: Nakladni zavod Matice Hrvatske, 1986).

dimensions of empathy, Gallo[5] differs cognitive from emotional dimension, whereby the first dimension would use rational arguments to bring another person's feeling closer to one's own.

As a term, empathy entered the English language in the early 20th century, owing to the psychologist Edward Titchener (1867-1927), whereas in German philosophical circles it had been present earlier than that, particularly among aestheticists. For example, Theodor Lipps (1851-1914) described empathy as a resonance of our perception and external objects (inner imitation): the perception of beautiful is, according to Lipps, caused by positive, while the perception of ugly is caused by negative empathy.

Apart from the aesthetics, empathy has been particularly studied within the field of social psychology, since it is believed that it facilitates development of pro-social attitudes and behaviors. And indeed, numerous studies of the empathy phenomenon conducted thus far have shown that mother's non-authoritative behavior correlates positively with child's development of empathy[6], whereas threats and corporal punishment of children,[7] as well as neglect or exposure to family violence,[8] have a negative effect on the development of emphatic potential. When it comes to educational methods whose objective is to increase emphatic abilities, good results have been achieved by using tasks aimed at drawing children's attention to similarities between themselves and other persons, especially in cases where children (or adults) were asked to take the role of another – real of fictitious – person, imagine their feelings or act according to them.[9] This procedure, known in Anglo-Saxon literature as *role-taking* or *role-playing*, is nothing but the identification with the characters in a story. In accordance with that are study findings that empathic potential can be increased by practicing perceiving other people's viewpoints and exposure to strong emotional stimuli (other person's ill-fortune, loss, uneasiness).[10]

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[5] D. Gallo, »Educating for empathy, reason, and imagination,« *Journal of Creative Behavior* 23, No. 2 (1989): 98-115.

[6] N. Eisenberg and P. Mussen, »Empathy and moral development in adolescence,« *Developmental Psychology* 14, No. 2 (1978): 185-6.

[7] P. Clarke, »What kind of discipline is most likely to lead to empathic behaviour in classrooms?« *History and Social Science Teacher* 19, No. 4 (1984): 240-1.

[8] F. S. Hinchey and J. R. Gavelek, »Emphatic responding in children of battered mothers,« *Child Abuse and Neglect* 6, No. 4 (1982): 395-401.

[9] H. Black and S. Phillips, »An intervention program for the development of empathy in student teachers,« *Journal of Psychology* 112 (1982): 159-68.

[10] M. A. Barnett, J. A. Howard, E. M. Melton and G. A. Dino, »Effect of inducing sadness about self or other on helping behavior in high- and low-emphatic children,« *Child Development* 53, No. 2 (1982): 920-3.

Modern psychology finds it useful do differ reactional emotions according to whether they are oriented towards self of another.[11] *Emotional contagion* in children or mass would, therefore, be simply assuming the emotional state of one's environment, without understanding the cause. On the other hand, emotional empathy means true identification with other person's emotions, which does not necessarily mean that there are reasons for such emotions. Sympathy is compassion to somebody's negative emotion, and if another person's ill-fortune does not induce other reactions besides a dismal feeling (self-oriented), it is defined as a *personal distress*.[12]

Recently, neurophysiologic base for empathy has been discovered, primarily the discovery of so called *mirror neurons*.[13] It has been shown that groups of nerve cells in premotor frontal cortex in monkeys react to observing motion in a way that they cognitively »repeat« the same motion. It was subsequently confirmed that similar pattern is also valid for recognition (and »repetition«) of others' emotions based on facial expressions. (It sounds intriguing that in the vicinity of the premotor cortex, in orbitofrontal cortex, a functional area related to internalizing moral views has been located: if this area is damaged, disorders such as corpolalia, inability to inhibit socially unacceptable behavior, enhanced impulsiveness, etc. appear.)

From empathy to morality

If we suppose that empathy, as a state of emotional reaching out to another person, encourages development of co-operation, altruism, non-provoking and/or easing the suffering of others, protection of others, generosity, tolerance for the different, then it is clear why McCollough has compared empathy with »moral imagination« that should be promoted through education and turned into a citizens' policy.[14] Through a series of experiments, Batson proved that empathy encourages helping others in a manner motivated not by egoism but altruism.[15] Hoffman sees in empa-

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[11] K. Stueber, *Rediscovering Empathy: Agency, Folk Psychology, and the Human Sciences* (Cambridge, MA: MIT Press, 2006).

[12] Compare also cognitive levels of empathy, which correspond to the stages of cognitive development (global empathy, egocentric empathy, empathy for the feelings of others, empathy for somebody's living conditions) Z. Raboteg-Šarić, »The role of empathy and moral reasoning in adolescents' prosocial behaviour,« *Društvena istraživanja* 6 (1997): 493-512; Cf. also Z. Raboteg-Šarić, »Empathy and moral development: Implications for caring and justice,« *Contemporary Sociology* 30 (2001): 487-8.

[13] G. Rizzolatti, L. Craighero and L. Fadiga, »The mirror system in humans,« in: Mirror *Neurons and the Evolution of Brain and Language*, ed. A. Stamenov and V. Gallese (Amsterdam/Philadelphia: John Benjamins Publishing Co., 2002), pp. 37-59.

[14] T. E. McCollough, *Truth and Ethics in School System* (Washington, DC: Council for Educational Development and Research, 1992).

[15] C. D. Batson, »Self-other merging and the empathy-altruism hypothesis: reply to Neuberg et al.,« *Journal of Personality and Social Psychology* 73 (1997): 517-22.

thy a biological predisposition to altruistic behavior[16] but, along with empathy, he also emphasizes the knowledge of abstract moral principles as a source of moral practice.[17]

If, as it seems, empathy is related to the development of »healthy« (acceptable) moral views and practices, the first question that arises is how to avoid the imposing of moral principles and encourage the development of empathy in a less imposing, even invisible manner? Research has shown that children internalize values better when teachers are models for such values than when they are just encouraged to behave in a particular manner.[18] Gadamer[19] correctly cautions that while reading Shakespeare or Plato, we are not primarily interested in what they have said, but what has been said by their texts. Hans Christian Andersen wrote stories whose obvious purpose is to shape public views, but his greatest success in creating moral views was achieved through a story which was most likely not »educational on purpose« at all.[20] It is said for *Croatian Tales of Long Ago* by Ivana Brlić-Mažuranić and *Pinocchio* by Carlo Collodi that they are the best examples of works in which »didacticism has not stifled the work of art«.[21] In order to achieve better effect in forming desired moral views, those views must, therefore, not be **imposed** but indirectly **developed** through empathy. In order to do so, because of its growing identification potential and better acceptance (popularity of consummation) in this day and age, the most acceptable »vehicle« for conveying the story is a film medium.[22]

A lot has been written on specific qualities of film as a medium of conveying the message. Burch,[23] for instance, emphasizes the »diegetic force« of the film, i.e. its ability to make a point through »impressive scenes«,[24] music, sound, acting and oth-

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[16] M. Hoffman, *Empathy and Moral Development* (Cambridge: Cambridge University Press, 2000).

[17] On the idea of explanation of morality as an evolutionary and biological category see in: M. Ruse, »Evolucijska etika: čemu nas prošlost može naučiti?«, in: *Evolucija društvenosti*, ed. J. Hrgović and D. Polšek (Zagreb: Jesenski i Turk, 2004), pp. 433-51.

[18] A. Kohn, »Caring kids: the role of the schools,« *Phi Delta Kappan* 72, No. 7 (1991): 496-506. See also: S. Težak, *Metodika nastave filma* (Zagreb: Školska knjiga, 2002), 60.

[19] H.-G. Gadamer, *Truth and Method* (New York: Crossroad Publishing, 1989).

[20] Cf. A. Muzur, »Bajke kao (re)generatori morala: primjer *Djevojčice sa žigicama* H. Ch. Andersena,« in: *Ars speculandi: lektira kao izgovor za razmišljanje* (Rijeka: Izdavački centar Rijeka, 2004), pp. 57-85.

[21] D. Težak and M. Čudina-Obradović, *Priče o dobru, priče o zlu: priručnik za razvijanje moralnog prosuđivanja u djece* (Zagreb: Školska knjiga, 2005), 11.

[22] On »cold voyeurism« of the new generation of directors and the trend of making films »detached from people«, »without the emotional statement« see: V. Simičević, »Films nowadays have no emotional statement« (interview with Rajko Grlić), *Novi list – Mediteran*, 27 July 2008.

[23] N. Burch, *Life to Those Shadows* (Berkeley/Los Angeles: University of California Press, 1990).

[24] N. Gilić, *Uvod u teoriju filmske priče* (Zagreb: Školska knjiga, 2007), 114-5.

er kinds of qualities which may be analyzed from different points of view.[25] However, there is the question of the manner in which to structure a (film) story in order for it to encourage empathy and, finally, encourage the development of acceptable moral views.

Basing it on empirical psychological rules, Propp expresses, after fairytales analysis, his favor for using universal symbols and elements that can be transposed from one fairytale into another without modifications.[26] Moreover, according to him, analysis of fairytales has shown the importance of action (function) with few existing patterns, and not of protagonists and details (which may be very numerous within the framework of the same functional pattern).[27] The order of functions is always the same. Taking as example folk magic stories, Propp distinguishes the initial situation (introducing characters, families, heroes); leaving home; imposing ban on the hero; hero's resistance to the ban; etc.[28] Lévi-Strauss suggests that myth is the predecessor of fairytale content and that the repetition of elements (order) is necessary in order to show and emphasize the structure of the myth.[29]

All this is, without a doubt, significant for studying structure,[30] but it is obviously not what we mean by the development of identification (emphatic) potential of the story in general, and where content's role is of primary importance.

From morality to ethical education through film

Even though documentaries and experimental films may provoke empathy as well,[31] in general the best effect is achieved through feature films,[32] not depending on type (short-film, feature-length, TV-series) or genre (western, horror, etc.).[33] We shall mention here several arbitrary examples in order to support the thesis on empathy induced by films and consequences to the moral views (and practice).

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[25] On points of view and other elements of film analysis and analysis of a film plot, see in: F. Casetti and F. Di Chio, *Analisi del film*, 15th edition. (Milano: Bompiani, 2007), 228-33.

[26] V. J. Propp, *Morfologia della fiaba*, translated and edited by G. L. Bravo (Torino: Giulio Einaudi, 1966), 12.

[27] Ibid., 26.

[28] Ibid., 31.

[29] C. Lévi-Strauss, *Antropologia strutturale*, translated by Paolo Caruso (Milano: Arnoldo Mondadori, 1992), 229 i 257.

[30] On the structure of the film story (space, length, etc.) see: Gilić, *Uvod u teoriju filmske priče*, 41-113.

[31] On ethical aspects of the documentaries, see: K. Bakker, »Dobro, loše i dokumentarac,« translated by Diana Nenadić, *Zarez* 226 (2008): 5-6.

[32] The intriguing question is which film elements, apart from the plot, can induce empathy. Compare: C. Plantiga, »Scene empatije i ljudsko lice na filmu,« translated by Dunja Krpanec, in: *Passionate Vievs: Film, Cognition, and Emotion*, edited by Carl Plantiga and Greg M. Smith (Baltimore/London: John Hopkins University Press, 1999), 24-37.

[33] More details on genres in: N. Gilić, *Filmske vrste i rodovi* (Zagreb: AGM, 2007).

Dances with Wolves (USA/Great Britain; 1990; directed by Kevin Costner)

Story about a Union Army Officer who, with manners of knightly honor and honesty, discovers a Frontier and identifies with the Indians. Despite strong contrast in depicting good and evil and as a result of a faithful presentation (nature, Indian speech, etc.) and numerous exceptionally well defined supporting roles, this film provokes deep empathy.

Lilya 4-ever (Sweden; 2002; directed by Lukas Moodysson)

The main objection to this film is its great pretentiousness and »unnecessary burdening with the rhetoric of a bad didactic film««.[34] The film tells a story of a Russian teenager who, abandoned by everyone, becomes a prostitute and a victim of trafficking in human beings and the film is characterized by a naturalistic depiction of rape and a rapist, which provokes primarily anxiety in viewers.

Schindler's List (USA; 1993; directed by Steven Spielberg)

Based on a true story, the film depicts a transformation of a German industrialist from a callous businessman into a savior of the Jews from Nazi persecution. Intriguing, but not necessarily correct, is Žižek's psychoanalytical idea that »the secret motif that permeates all Spielberg's key films is re-discovery of a father, his authority« and that throughout the film Schindler re-discovers his fatherly duty towards the Jews and transforms into a »caring and responsible father«.[35] On the other hand, Rosenbaum[36] raises an objection to Spielberg stating that he had ignored several curiosities of true texture, aware, however, that, had it been differently, the film would have »lost some of its moral directness even if it gained moral complexity.« Nevertheless, superb acting, music and link to the past ensure a great level of empathy.

Titanic (USA; 1997; directed by James Cameron)

This film also combines historical basis of the tragic sinking of the »unsinkable« ship with a quality romantic union of lovers unequal in status as well as with the empathy for lower class passengers, which has successfully arose empathy potential. (There are also different views;

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[34] D. Rubeša, »Izgubljeni anđeli«, *Vijenac* 265 (2004): 1.

[35] S. Žižek, *Pervertitov vodič kroz film*, translated by S. Horvat et.al. (Zagreb: Antibarbarus/HDP, 2008), 11

[36] J. Ros(enbaum), »Schindler's List,« in: Schneider, ed., *1001 Movies You Must See*, 831.

Žižek, for instance, accuses Cameron for »superficial Hollywood Marxism« and over-sympathizing with lower classes along with overemphasizing the egoism of the rich.[37] And Berry,[38] places *Titanic* somewhere »half-way between *The Poseidon Adventure* and *The Love Boat*.«

La vita è bella/Life is Beautiful (Italy; 1997; directed by Roberto Benigni)

According to Žižek, this film can be criticized for »supporting the ethical view of someone's illusion«, such as, for instance, film *Good bye, Lenin!* (Germany; 2003; directed by Ulrich Becker).[39] However, the real (empathic) value of this film lies in its unusual comic aspect (father presents his son their captivity in a concentration camp as a play) of the tragic and true underlying thread (holocaust).

Independence Day (USA; 1996; directed by Roland Emmerich)

Alien invasion on Earth is resisted by Americans and with their President as a leader, they win. This is an example of how uncritical, unlikable exaltation and glorification of patriotic pathos, emphasis of (moral) superiority, mediocre acting, despite good special effect, can leave the emphatic potential unfulfilled.

Rane/The Wounds (Serbia; 1998; directed by Srđan Dragojević) and *Bure baruta/Cabaret Balcan* (Serbia; 1998; directed by Goran Paskaljević)

Belgrade underground with naturalistic depiction of violence, murders, drug use. It provokes great frustration and no hope of escape or betterment.

Fine mrtve djevojke/Fine Dead Girls (Croatia; 2002.; directed by Dalibor Matanić)

Story of a lesbian couple from Zagreb suburbs. Everything is primitive, dark, unfriendly and culminates with a fight and a rape. Strong anxiety without any space for empathy.[40]

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[37] Žižek, *Pervertitov vodič kroz film*, 13.

[38] J. B(erry), »Titanic«, in: Schneider, ed., *1001 Movies You Must See*, 880.

[39] Ibid., 61.

[40] Speaking of his most recent film, *Kino Lika*, Matanić states that he is oriented towards »honesty« and »authenticity«, nearing his feature film to a documentary. V. Simičević, »Life is always stranger than fiction« (interview with Dalibor Matanić), *Novi list*, 31 August 2008.

Requiem for a Dream (USA; 2000; directed by Darren Aronofsky)

Superb acting leads viewers through suffering of several drug addicts, their crises, mental states and different destinies. This drama, because of its great plasticity, results in a horror anxiety rather than empathy.

Gegen die Wand/Head-On (Germany; 2004; directed by Fatih Akin)

Story of a Turk who is an alcoholic and alienates himself, becomes close to, marries and alienates from a woman abused by her family. »Social engagement« would be more appropriate for a documentary, story is void of perspective and resolution.

Conclusion

Given examples may be used to formulate several recommendations for the »film with moral and educational ambitions«:

Zero, moral views should not be imposed, use of empathy is a much better method of internalizing acceptable views and practices.

First, depicting suffering too plastically (violence,[41] especially sexual violence, as a combination of force, humiliation, physical and mental pain), should be avoided and one should keep perhaps only allusions because in the contrary, the result is not empathy but the self-oriented anxiety.[42]

Second, to encourage empathy does not necessarily mean to encourage socially engaged behavior, but only to contribute to maturing of moral views. That's why extreme depiction of a social situation does not have the desired effect, even if it gets close to the reality.

Third, happy ending may suppress empathy, but, should the story end happily after a great tension, the audience does not retain the feelings of bitterness, powerlessness and frustration so in these cases a happy ending is desirable and, as for encouraging empathy, useful.[43]

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[41] There are different views on cosequences of TV violence. The prevailing opinion, corroborated by experiments, is that fans of such scenes are more likely to commit such acts in everyday life, but there are also those who claim that watching violence on screen results in chatarsis and helps fighting the violence in real life. Compare: Težak, *Metodika nastave filma*, 17.

[42] Cf. Stueber, *Rediscovering Empathy*, 24.

[43] Muzur, »Bajke kao (re)generatori morala,« 83.

Fourth, *chiaro-scuro* effect is not essential: creating of »positive« and »negative« characters can be complex, and still evoke a high level of empathy. Perfection and invincibility may even be unlikable and seriously diminish the feeling of empathy.[44]

Fifth, for the purpose of greater identification effect it is useful to eliminate fantastic elements from the story: the closer the story is to reality (and/or truthfulness), the greater the level of identification.

Finally, it should be stated that, just as with watching a film, during the process of development of moral/ethical views, the element of set and setting is prominent, which can largely modify some of the listed »recommendations«. Unless we are followers of art for art's sake, there is a reasonable aspiration to »use« the specific film medium for a task more permanent than just a short-term shock or fun.

Translation/prijevod: Snježana Volarić

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[44] On detachment of children from a film hero, see: Težak, *Metodika nastave filma*, 49.

Partner institutions/ Institucije-partneri

Judit Sándor*

Center for Ethics and Law in Biomedicine, CEU (Budapest, Hungary)

CELAB is not just an Acronym. It represents the Center for Ethics and Law in Biomedicine in Budapest and it embraces manifold activities conducted by lawyers, philosophers, anthropologists, ethicists and other social scientists in the Center. In 2005 the idea behind establishing CELAB was related to the recognition of a new and increasingly developing interdisciplinary field: the ethical, legal, and social implications of biotechnological advances. Life sciences, especially biomedicine, traditionally focused on the restoration of health and 'normality'. However, entering the age of the human genome project, biobanks, stem cell research, and nanotechnology the role of biomedical science has shifted toward the purposeful transformation of various human capacities. For instance, while the new reproductive technologies could overcome some problems of infertility, they also pose new questions of what sexuality, gender, and kinship mean in our contemporary societies. We also have to realize that the technologies of genetic testing and preimplantation diagnosis allow for enhancement. And all these changes force the various social sciences and the practice of governance to rethink decision-making in science policy, the way resources are allocated, and the ethical and legal concerns related to the various uses of genetic data. Our Center has focused on these issues in the framework of different European research projects funded by the European Union, European Science Foundation and by UNESCO.

Our first year of operation (the 2005-2006 academic year) was dedicated to setting priorities, developing networks and creating a biomedical-legal database. In the sec-

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ond year we submitted numerous applications to various research grants, and within a short time we started two new research projects. During our third year of research activities, the network of CELAB partners, associates and collaborators have become truly international, which is accentuated by our participation in five European research projects. Our small research team has been consequently expanded, and together with our new colleagues and research associates, we are working on a wide range of academic and administrative tasks. Regardless of this necessary institutional expansion, our staff has been able to preserve its original enthusiasm to work in the exciting cross-disciplinary domain of biomedical law and ethics.

CELAB works on the national, regional, and international levels. In European research consortia knowledge about the Hungarian and Central European legal system is often required while it is also essential to be familiar with other European legal and ethical approaches. Nevertheless, as international research projects have become increasingly global in their scope, we have also developed a wider comparative perspective in our work that includes studies of North American and East Asian legal and ethical discourses.

Moreover, we seek to integrate the results of these research projects into our academic teaching curricula. Therefore, we have organized workshops and seminars, film screenings and policy debates that are open to the CEU community and beyond. We also participate in legal policy development activities and provide research tools for the international scientific community. For instance, in 2007 we launched the new version of the Biolaw Database that makes it possible for researchers and students to study legal instruments and ethical norms in the field of biomedicine and biotechnology more systematically, or just to learn about the possible directions of future comparative research. In addition, we update our CELAB website on a daily basis.

At the beginning of 2008 we received a UNESCO grant. Within less than a year we completed a very ambitious project: the promotion of implementing the three bioethics-related Declarations of UNESCO in five countries – Croatia, the Czech Republic, Italy, Hungary, and Serbia. This project required legal policy work but it also gave us an opportunity to develop and reaffirm further professional contacts in the region with similar centers and scholars. As a result, CELAB published a series of booklets in five languages and organized a workshop with lectures and panels to discuss the possible methods to implement these instruments in teaching and to influence national legislation in the field of bioethics and related human rights. Although the working language of CELAB is English, this UNESCO funded project gave us the opportunity to learn about different cultural approaches to working in the field of bioethics and human rights.

Since 2007 we have also participated in the Francophone network of biomedical lawyers. This network, which has been expanded since its establishment, currently works on several thematic issues of bioethics and biomedical law and in each interdisciplinary workshop panel the participants seek to explore and understand the cultural differences behind the formulation of various bio-legal norms. The first workshop in Rennes, organized by Professor Brigitte Feuillet-Liger, was a big success and the first publication of the network on Assisted Reproduction and Anonymity has been already published. The next workshop of the network was held in Kyoto in 2009 and focused on the bioethical problems in the field of health care provided to adolescents. The third theme will elaborate the ethical issues of the death and dying with the family.

The EU project that is perhaps in the most advanced stage is called *PRIVILEGED* (Privacy in Law, Ethics and Genetic Data). The aims of this project were to make recommendations for research practice and public policy-making, including regulatory options at the national, regional, and European levels. PRIVILEGED has sought to identify, analyze and compare plural ethical, cultural, and social concepts of legitimate privacy interest engaged by research using genetic databases and biobanks. It articulates the relation between such concepts and the current regulation of research using genetic data and biobanks. PRIVILEGED focuses on the various privacy interests, particularly grounded within intimate and familial relationships in various research areas, especially in the so-called biobanking applications. This is a mega-project in which representatives of no less than thirty-two universities participate, among them not only European experts but also lawyers from Japan, Taiwan and Israel. As part of the project, two major reports have already been submitted.

The second project focuses on the governance of the so called gene-banks and the European legal and ethical framework to regulate their activities (Acronym: *GeneBanC*). Our team focuses mainly on the cases of countries that joined the European Union in 2004, most of which have not adopted legislation or guidelines in the field of classical biobanks, or have done so relatively recently without extensive experience.

In 2008 we started our third research project in this field, *TISS.EU*, mobilizing the resources of ten universities in Europe. The major aim of this project is to carry out a high-quality interdisciplinary comparative analysis of European health policies in order to assess the impact of EU legislation and to explore the relevant ethical and legal situation across the European Union. The first TISS.EU project meeting was held in Göttingen, Germany and focused on the ethical and legal challenges to conduct research on human tissues. Our Center organized the next workshop in Budapest in 2009.

Another EU funded project, *NANOPLAT* (Framing the Deliberative Process on the Responsible Development of Nanoscieneces and Nanotechnologies) also started in 2008, focusing on 'deliberative processes' in nanotechnology because these may be seen as useful, although possibly highly problematic regulatory forms supplementing democratic mechanisms. On the other hand, the conceptual shift from 'government' to 'governance' might allow for more participatory forms of shaping public policy.

The fifth EU funded research project we participate in is *RemediE* (Regenerative Medicine in Europe: Emerging Needs and Challenges in a Global Context). This project focuses on the present and future role of regenerative medicine in the health care industry, especially on the relevant intellectual property rights and patent issues. Therefore, the contributors to this project will explore and analyze international and regional policies regarding the patentability of living organisms, human genes and stem cells, as these are highly critical areas of research where market interests and ethical concerns frequently collide.

The academic year of 2008–2009 was a very intensive period for the Center for Ethics and Law in Biomedicine (CELAB). We participated, simultaneously, in five European Commission funded research projects (GeneBanC, NANOPLAT, Privileged, RemediE and the TissEu), and contributed to three more EU projects as consultants. In addition to working on these European programs, CELAB also completed a UNESCO financed project on the implementation of the three bioethics declarations in five countries of the wider Central European region (Croatia, Czech Republic, Hungary, Italy, and Serbia).

Among the EU sponsored research projects, perhaps one of the biggest achievements was to complete and publish a comparative survey of the available legal regulations of biobanks in eleven European Union member states (Cyprus, Czech Republic, Estonia, Greece, Hungary, Italy, Latvia, Lithuania, Malta, Poland and Romania). Research within the GeneBanC project required the application of interdisciplinary methods: collection of data through desk research, compiling and administering detailed questionnaires, conducting fieldwork and interviewing relevant experts in the region.

In addition to the fields in which we had conducted research before, we have developed expertise in some new research areas, such as the social-ethical aspects of nanotechnology and the intellectual property aspects of regenerative medicine.

Participation in the NANOPLAT project prompted us to accumulate knowledge on the recent advances in nanotechnology, even outside of our traditional research interest in the ethics and law of life sciences. This short but very intense project focused on the deliberative processes in shaping the contours of policies in the field of nanotechnologies.

In 2008 we started to work on another new topic within the framework of the RemediE project, which lies at the intersection of ethics and biotechnology. The emergence of biotechnology and the extension of the scope of patent rights have by now become a public concern. From genes through genetically modified plants and animals to human cells, each stage of accretion of patentability in this arena has been contested. Much of this opposition arises from cultural concerns about the moral appropriateness of property rights being applied to living, especially to human-derived cells. Because of these ethical controversies, this EU funded research project gives us an opportunity to understand the process in which biotechnological research becomes increasingly commercialized and lucrative new markets for technological advances are created.

The workshop CELAB organized in the framework of the TissEu Project was a successful event as the international experts invited analyzed a new and often misinterpreted perspective on biobanking: the questions of tissue anonymization.

During the last academic year, we also participated as consultants in several other EU projects, namely *From GMP to GBP* (From GMP to GBP: Fostering Good Bioethical Practices (GBP) in the European Biotech Industry), *NMD–Chip* (Development of Targeted DNA Chips for High Throughput Diagnosis for Neuromuscular Disorders) and *BBMRI* (Biobanking and Biomedical Resources Infrastructure).

I am very grateful to be able to work in such an inspiring field and with motivated colleagues.

Rut Carek*

Croatian Commission for UNESCO (Zagreb, Croatia)

The Croatian Commission for UNESCO was created as an advisory body of the Government in July 1992. Since 2004 it is attached to the Ministry of Culture and its department for UNESCO, which operates within the Directorate for International Cultural Cooperation.

The Croatian National Commission consists of the following bodies:

- The General Assembly
- The Executive Committee, which is composed of 7 members (Chairperson, Deputy Chairperson, and Chairpersons of the Programme Committees of the Commission)
- Five Programme Committees dealing with:
    - Education
    - Natural Sciences
    - Social Sciences and Humanities
    - Culture
    - Communication and Information

The National Commission is composed of 17 members representingvarious governmental departments and ministries, institutions, agencies and individual experts. The Commission meets in plenary more than five times a year. The President of the

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* Secretary-General/Croatian Commission for UNESCO, Ministry of Culture, Zagreb, Croatia

Commission is Academician Vladimir Marković, and the Secretary General is Rut Carek.

Besides being active in all fields of UNESCO, we consider the organisation's normative work very important and have been working on promoting and facilitating the ratifications of UNESCO conventions and declarations:

- Convention on the Protection of the Diversity of Cultural Contents and Artistic Expression (ratified in May 2006)
- Convention on the Protection of the Intangible Heritage of Humanity (ratified in May 2005)
- Convention on the Protection of Underwater Cultural Heritage (ratified in December 2004)
- Convention against Doping in Sports (ratified in October 2007).

Activity Report for the Department of Social Sciences and Medical Humanities at University of Rijeka School of Medicine for 2009

Academic affairs: Members of the department currently hold around 50 mandatory and over 30 elective courses, which makes up for the total of near 4000 quota hours annually. All teachers fulfill the required quota and most of them even overfulfill it. A new mandatory course was launched, *Business Ethics* (in the fourth year as a part of Graduate studies, Study of Organization and Health Management), as well as several new elective courses. Teaching *An Introduction to Scientific Research* class was assumed for the following studies: Study of Medicine, Study of Dental Medicine, Study of Organization and Health Management, Study of Sanitary Engineering, as well as the Methodology of Research at the postgraduate doctoral program study in *Biomedicine*.

A. Muzur was one of the teachers of the *Abuse of addictive substances: epidemiology, etiology and phisiology* and *Development, early detection and treatment of addiction and other high-risk behavior of children and youth* courses at the speciality graduate studies in the field of *Promotion of health and prevention of addiction* (TEMPUS program with the participation of the Teaching Institute of Public Health at Primorsko-Goranska County and the University of Rijeka.

I. Sorta Bilajac and A- Gjuran Coha began teaching at the Biotechnology Studies (University of Rijeka), and M. Štifanić, M. Brkljačić Žagrović and E. Jančić at the Study of Nursing, established by our School at the Three-Year College of Karlovac.

In May 2009, the 11th Days of Bioethics were held at University of Rijeka School of Medicine, with about 15 participants from Croatia, Hungary, Serbia and Macedonia.

The dissertation with the topic on the hospice movement was defended (M. Brkljačić Žagrović). The University of Zagreb Senate has approved the doctoral dissertation on bioethical institutionalizatio in the European Union (I. Rinčić). Members of the Department actively participated at over 40 international and national scientific and professional conferences (Fifth International *Conference* on *Clinical Ethics* and Consultation, Taichung, Taiwan; 8th Lošinj's Days of Bioethics; The 11th Days of Bioethics, Rijeka; 3rd International Summer School of Integrative Bioethics, Mali Lošinj; The Expert Conference of Ethics Teachers, Zagreb; Round Table *Equalization of Rights for the Deaf in the Light of the UN Convention – acknowledging the Croatian sign language*, Zagreb; 15th regular conference of the IBC at UNESCO, Paris; 8th Bioethics Spring Symposium at the Croatian Medical Chamber, Zagreb; 11th Congress of the European Association of Palliative Care, Wienna; International Cognitive Linguistic Conference, Dubrovnik; Conference *Through Languages and Cultures*, Herceg Novi; 8th Alpe-Adria Sports Conference, Opatija; 18th Summer Kinesiologists' School, Poreč; 1st Eco World Fest, Opatija; Adriatic Conference for Endoscopic Surgery, Dubrovnik; International Scientific Coference *Croats and Iliric provinces (1809-1813)*, Zagreb-Zadar; Round Table *Infectious Diesases in Istria at the turn of the 20th Century*, Izola; Scientific *Conference St. Francis and the Franciscans – 800 year in the medical history*, Rijeka; Interdisciplinary Scientific Symposium *Church and Medicine at the Challenge of Alternative Healing Techniques,* Zagreb; Symposium *Democracy at the Turning Point – freedom, equality, equity: with the 150 anniversary of John Dewey's birth*, Zagreb; Round Table *Trans-border Cooperation in Health Care*, Trieste).

Members of the Department published two books (*English Language 1 for the Students of Dentistry* by A. Krišković and *Culture of Dying, Death and Mourning* by M. Štifanić), one proceedings books (*Bioethics and Medical Law* edited by I. Sorta-Bilajac), over 50 articles, out of which 5 indexed in the *Current Contents* database, around thirty other full scientific and professional papers and around twenty overviews and abstracts.

The Department announced its joint candidacy, with the support of the University of Rijeka and with other institutions from Croatia (University of Zagreb) and aborad (Universities of Eichstätt-Ingolstadt, Sarajevo, Ljubljana, Novi Sad, Sofia and Tirana) for TEMPUS project *Integrative Bioethics: development of the excellence center and joint doctoral program*, as well for the DAAD project of starting a joint MA program *Integrative Bioethics*.

Other activities: Members of the Department were awarded several grants by the University of Rijeka Foundation and the Ministry of Science, Education and Sports (for publishing activities, conference organization and participation at conferences) as well as one ERASMUS scholarhip for seven day research stay at the University of Knowlege in Sweden (I. Rinčić).

I. Šegota was awarded, at the recommendation of the Medical School in Rijeka, a Life Achievement Award by the City of Rijeka.

A. Muzur was awarded the order of knighthood *Commendatore della Stella della solidarietà italiana*.

I. Rinčić became a member of the steering committee of the Croatian Philosophical Society.

I. Sorta Bilajac became a member of the UNESCO Unit of Bioethics and Law at the University of Zagreb.

I. Šegota and A. Muzur were members of the Science Committee for the International School of Psychiatry and Cognitive Neuroscience (Rab, November 2009), I. Sorta Bilajac became a member of the Organizational Board of the 18th International Congress on Medical Law (Zagreb, 2010).

Professor Michael Cheng-tek Tai, the president of the International Society for Clinical Bioethics and the dean of the Faculty of Medical Sociology and Social Work at the Chung Shan Medical University in Taiwan, visited the Department in May 2009.

A. Muzur and I. Rinčić visited the Center for Applied Ethics of the Institute of Philosophy at the Chinese Academy of Social Sciences in Beijing in August 2009 and they renewed contact with the deputy of the director of the Center, and the vice-president of the Asian Society for Bioethics for China, professor Yanguang Wang.

While visiting Umeå University in Sweden (ERASMUS scholarship), I. Rinčić attended the course *Research Ethics* at the Department of Clinical Pharmacology (prof. Rune Dahlquist). At the same time A. Muzur developed cooperation with a scientometrist prof. Olle Person (Department of Sociology), a historian of neuroscience Kenneth Ögren (Department of Culture and Media), neuroscientist prof. Lars Nyberg (Department of Radiation Science) and neurotheologist Arne Rasmusson, Ph.D. (Faculty of Arts).

Thanks to the activities of the members of the Department, particularly N. Gosić as the head of the subsidiary, several forums were organized by the Croatian Bioethics Society – Rijeka subsidiary with bioethics and health care topics.

A. Muzur was appointed mentor to Danijela Tomić, M.A. for her Ph.D. thesis *Elements from the History of Medicine in Istrian Sacral Heritage*.

Department members were mentors for five diploma theses.

Amir Muzur, M.D., Ph.D., Associate Professor

Izvješće o radu Katedre za društvene i humanističke znanosti u medicini Medicinskog fakulteta Sveučilišta u Rijeci za 2009. godinu

Nastava: Članovi Katedre trenutno drže nastavu iz oko 50 obveznih i preko 30 izbornih kolegija, ili ukupno blizu 4000 norma-sati godišnje. Svi nastavnici ostvaruju predviđenu normu, a većina i njen prebačaj. Pokrenut je novi obvezni kolegij, *Etika u poslovnim odnosima* (4. godina Sveučilišnog studija Organizanje, planiranje i upravljanje u zdravstvu), kao i nekoliko novih izbornih kolegija. Preuzeto je držanje nastave iz *Uvoda u znanstveni rad* za studijske smjerove Medicine, Dentalne medicine, Organizanje, planiranje i upravljanje u zdravstvu i Diplomiranji sanitarni inžinjeri, kao i *Metodologija znanstvenoistraživačkog rada* na Poslijediplomskom doktorskom studiju *Biomedicine*.

A. Muzur je bio jedan od nositelja kolegija *Zloupotreba sredstava ovisnosti: epidemiologija, etiologija i fiziologija* te *Razvoj, rana detekcija i tretman ovisnosti i drugih rizičnih ponašanja djece i mladih* na specijalističkom poslijediplomskom studiju iz područja *Promocije zdravlja i prevencije ovisnosti* (program TEMPUS s participacijom Nastavnog zavoda za javno zdravstvo Primorsko goranske županije i Sveučilišta u Rijeci).

I. Sorta Bilajac i A. Gjuran Coha počele su predavati na studiju Biotehnologije (pri Sveučilištu u Rijeci), a M. Štifanić, M. Brkljačić Žagrović i E. Jančić na studiju Sestrinstva koji naš Fakultet organizira pri Veleučilištu u Karlovcu.

Znanost: Sredinom svibnja 2009., na Medicinskom fakultetu u Rijeci održani su 11. bioetički dani s petnaestak sudionika iz Hrvatske, Mađarske, Srbije i Makedonije.

Obranjena je disertacija s temom o hospicijskom pokretu (M. Brkljačić Žagrović). Senat Sveučilišta u Zagrebu prihvatio je temu doktorske disertacije o bioetičkoj institucionalizaciji u Europskoj uniji (I. Rinčić). Članovi Katedre su aktivno sudjelovali na preko 40 međunarodnih i domaćih znanstvenih i stručnih skupova (5. međunarodna konferencija o kliničkoj etici i konsultacijama, Taichung, Taiwan; 8. lošinjski dani bioetike, Mali Lošinj; 11. bioetički dani, Rijeka; 3. međunarodna ljetna škola integrativne bioetike, Mali Lošinj; Stručni skup nastavnika etike, Zagreb; Okrugli stol *Izjednačavanje prava gluhih u svjetlu konvencije UN-a – priznavanje hrvatskog zna-*

kovnog jezika, Zagreb; 15. redovita sjednica Međunarodnog povjerenstva za bioetiku (IBC) pri UNESCO-u, Pariz; 8. bioetički proljetni simpozij HLZ, Zagreb; 11. kongres Europskog udruženja za palijativnu skrb, Beč; Međunarodna kognitivnolingvistička konferencija, Dubrovnik; Konferencija *Kroz jezike i kulture*, Herceg Novi; 8. konferencija o športu RZ Alpe-Jadran, Opatija; 18. ljetna škola kineziologa RH, Poreč; 1. Eco World Fest, Opatija; Jadranska konferencija o endoskopskoj kirurgiji, Dubrovnik; Međunarodni znanstveni skup *Hrvati i Ilirske provincije (1809-1813)*, Zagreb-Zadar; Okrugli stol *Zarazne bolesti u Istri između 19. i 20. stoljeća*, Izola; Znanstveni skup *Sveti Franjo i franjevci – 800 godina u medicinskoj povjesnici*, Rijeka; Interdisciplinarni znanstveni simpozij *Crkva i medicina pred izazovom alternativnih iscjeliteljskih tehnika*, Zagreb; Simpozij *Demokracija na prekretnici – sloboda, jednakost, pravednost: uz 150. obljetnicu rođenja Johna Deweya*, Zagreb; Okrugli stol *Prekogranična suradnja u području zdravstva*, Trst).

Članovi Katedre publicirali su dvije knjige (*Engleski jezik 1 za studente stomatologije* A. Krišković i *Kultura umiranja, smrti i žalovanja* M. Štifanića), jedan zbornik radova (*Bioetika i medicinsko pravo* urednice I. Sorte Bilajac), te preko 50 članaka, od čega 5 radova indeksiranih u bazi *Current Contents*, tridesetak drugih cjelovitih znanstvenih i stručnih radova te dvadesetak prikaza i sažetaka radova.

Katedra je, uz podršku Sveučilišta u Rijeci, zajedno s drugim institucijama iz Hrvatske (Sveučilište u Zagrebu) i inozemstva (sveučilišta u Eichstätt-Ingolstadtu, Sarajevu, Ljubljani, Novom Sadu, Sofiji, Skopju i Tirani, podnijela zajedničku kandidaturu za TEMPUS-projekt naslovljen *Integrativna bioetika: razvitak Centra izvrsnosti i zajedničkog doktorskog programa*, kao i DAAD-u za projekt pokretanja skupnog MA-programa *Integrativna bioetika*.

Ostale aktivnosti: Članovima Katedre dodijeljeno je više potpora Zaklade Sveučilišta u Rijeci i Ministarstva znanosti, obrazovanja i športa (za izdavačku djelatnost, organizaciju skupova i sudjelovanje na skupovima), kao i jedna stipendija ERASMUS za sedmodnevni studijski boravak na Sveučilištu Umeå u Švedskoj (I. Rinčić).

I. Šegoti dodijeljena je, na prijedlog Medicinskog fakulteta u Rijeci, Nagrada Grada Rijeke za životno djelo.

A. Muzuru dodijeljen je viteški red *Commendatore della Stella della solidarietà italiana*.

I. Rinčić postala je članicom Upravnog odbora Hrvatskog filozofskog društva.

I. Sorta Bilajac postala je članicom jedinice UNESCO Katedre za bioetiku i pravo Sveučilišta u Zagrebu.

I. Šegota i A. Muzur bili su članovima Znanstvenog odbora *Internacionalne škole iz psihijatrije i kognitivne neuroznanosti* (Rab, XI. 2009.), I. Sorta Bilajac postala je članicom Organizacijskog odbora 18. svjetskog kongresa o medicinskom pravu (Zagreb, 2010.).

U svibnju mjesecu 2009. Katedru je posjetio profesor Michael Cheng-tek Tai, predsjednik Međunarodnog društva za kliničku bioetiku i dekan Fakulteta za medicinsku sociologiju i socijalni rad Medicinskog sveučilišta Chung Shan na Tajvanu.

A. Muzur i I. Rinčić posjetili su u kolovozu 2009. Centar za primijenjenu etiku Instituta za filozofiju Kineske akademije društvenih znanosti u Pekingu i obnovili kontakt sa zamjenicom ravnatelja Centra i zamjenicom predsjednika za Kinu Azijskog društva za bioetiku, profesoricom Yanguang Wang.

Prilikom posjeta Sveučilištu Umeå u Švedskoj (stipendija ERASMUS), I. Rinčić pohađala je tečaj *Znanstvenoistraživačke etike* pri Odjelu za kliničku farmakologiju (prof. Rune Dahlquist), a A. Muzur je istodobno uspostavio suradnju sa scientometričarem prof. Olle Personom (Odjel za sociologiju), povjesničarem neuroznanosti dr.sc. Kennethom Ögrenom (Odjel za kulturu i medije), neuroznanstvenikom prof. Larsom Nybergom (Odjel za znanost o zračenju) i neuroteologom dr.sc. Arneom Rasmussonom (Fakultet umjetnosti).

Aktivnošću članova Katedre, a osobito N. Gosić kao voditeljice Podružnice, održano je više tribina Hrvatskog bioetičkog društva – Podružnice Rijeka na aktualne teme iz bioetike i zdravstva.

A. Muzur imenovan je mentorom izrade doktorske disertacije na temu *Povijesnomedicinski elementi u istarskoj sakralnoj baštini* pristupnice mr. sc. Danijele Tomić.

Članovi Katedre su bili mentori pri izradi pet diplomskih radova.

Izv. prof. dr. sc. Amir Muzur, dr. med.
Pročelnik Katedre za društvene i humanističke
znanosti u medicini
Head of the Department of Social Sciences

Publications/Publikacije

Books

Krišković A. 2009. *English in Physiotherapy.* Rijeka: Sveučilište u Rijeci/Medicinski fakultet.

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Full papers

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Brkljačić M. 2009. Bioetika i boetički aspekti palijativne medicine [Bioethics and bioethical aspects of palliative medicine]. Medicina 44 (2), 146-51.

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Rinčić I. 2009. Ante Čović, Nada Gosić, Luka Tomašević (ur.): Od nove medicinske etike do integrativne bioetike: posvećeno Ivanu Šegoti povodom 70. rođendana (prikaz knjige) [Ante Čović, Nada Gosić, Luka Tomašević (eds.): From new medical ethics to integrative bioethics: Festschrift to Ivan Šegota's 70th birthday (book review)]. *Filozofska istraživanja* 29 (2): 789-92.

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Šubat-Dežulović M, Pelčić G, Flajšman-Raspor S, Pelčić G, Sorta Bilajac I. 2009. The influence of medical and nonmedical factors to the progression of renal osteodystrophy. *Collegium Antropologicum* 33 (4): 1405-8.

Diploma thesis defended at the Department of Social Sciences and Medical Humanities at University of Rijeka School of Medicine (includes period from 1 January 2009 to 1 May 2010)

Zora Modrić: The role of a nurse in relation to HIV patients.

On 23 September 2009, Zora Modrić, a student of the Study of Nursing, successfully defended her diploma thesis **The role of a nurse in relation to HIV patients**, and she acquired the title of baccalaurea in nursing.

The aim of the research was to examine the frequency of contact between nurses and HIV patients, to examine the viewpoints of nurses on keeping the professional secret regarding the HIV patients and determine the viewpoints of nurses regarding education related to HIV in their own profession. As part of the research, a survey was carried out among nurses in Clinical Hospital Center Rijeka. Among the most important findings, one should point out the following: the significant number of participants (43%) witnessed the discrimination of HIV positive patients (by other patients), and 27% had knowledge of cases of revealing professional secrets regarding HIV positive patients. The results also showed that nurses believe that all patients deserve equal quality of health care, including HIV positive patients and that in their work they abide by the principles prescribed in the Code of Ethics by the Croatian Nurses Association. Mentor for the diploma thesis was Iva Rinčić, B.Sc., M.A. and the members of the committee also included Amir Muzur, Ph.D., Associate Professor and Mirko Štifanić, Ph.D., Associate Professor

Marija Matković: Blood-free treatment of Jehovah's Witnesses as a challenge for nurse's work

On 24 February 2010, a student of the Study of Nursing Marija Matković defended her diploma thesis **Blood-free treatment of Jehovah's Witnesses as a challenge in nurse's work** before the committee whose members included Iva Rinčić, B.Sc., M.A. (mentor), Mirko Štifanić, Ph.D., Associate Professor (member), Amir Muzur, Ph.D., Associate Professor (member), thus fulfilling conditions to acquire a title of baccalaurea in nursing.

The main purpose of this paper was to examine the specific elements in treatments of Jehovah's Witnesses while providing them health care, with emphasis on the issue of refusal of blood transfusion. The survey was carried out in Clinical Hospital Center Rijeka and it included 50 subjects. The aim was to establish the frequency of contacts of nurses with patients who are Jehovah's witnesses, the level of knowledge on the issue of blood-free treatment of Jehovah's witnesses, the level of familiarity with the existing legal regulations and ethical standards, establishing nurses' viewpoints regarding blood-free treatment of Jehovah's Witnesses.

The results have shown relatively low frequency of contacts and providing health care to patients who are Jehovah's Witnesses. It has also shown that there is certain vagueness regarding professional topics, legal regulations and ethical standards. Thus, the conclusion emphasizes the importance of continual education of nurses concerning specific conditions of treatment of patients who refuse certain procedures, including the blood-free treatment of Jehovah's Witnesses.

Diplomski radovi obranjeni pri Katedri za društvene i humanističke znanosti u medicini Medicinskog fakulteta Sveučilišta u Rijeci (1. siječanj 2009. – 1. svibanj 2010.)

Zora Modrić: Uloga medicinske sestre u odnosu s pacijentima oboljelim od HIV-a

Dana 23. rujna 2009. godine studentica stručnog studija sestrinstvo Zora Modrić obranila je diplomski rad **Uloga medicinske sestre u odnosu s pacijentima oboljelim od HIV-a**, te je promovirana u stručnu prvostupnicu sestrinstva (baccalaurea). Cilj istraživanja bilo je ispitati učestalost kontakata medicinskih sestara s pacijentima oboljelim od HIV-a, ispitati stavove medicinskih sestara oko čuvanja profesionalne tajne o HIV pacijentima, te utvrditi stavove medicinskih sestara oko educiranosti vlastite profesije u vezi HIV-a. U okviru istraživanja provedana je anketa s medicinskim sestrama/tehničarima u Kliničkom bolničkom centru Rijeka. Među najvažnijim rezultatimo treba istaknuti: značajan broj ispitanika/ca (43%) svjedočio je diskriminaciji HIV pozitivnih pacijenata (od strane od drugih pacijenata), a 27% upoznato je sa slučajevima otkrivanja profesionalne tajne o HIV pozitivnim osobama. Rezultati su ujedno pokazali da medicinske sestre/tehničari smatraju da svi pacijenti zaslužuju jednaku kvalitetu zdravstvene skrbi, uključujući i oboljele od HIV-a, te da se u radu sa spomenutim pacijentima pridržavaju načela propisanih Etičkim kodeksom Hrvatske udruge medicinskih sestara. Mentorica pri izradi diplomskog rada rada bila je mr. sc. Iva Rinčić, prof., a članovi povjerenstva bili su dr. sc. Amir Muzur, izv. prof. i dr. sc. Mirko Štifanić, izv. prof.

Marija Matković: Beskrvno liječenje Jehovinih svjedoka kao izazov u radu medicinske sestre

24. veljače 2010. godine, studentica stručnog studija sestrinstvo Marija Matković obranila je pred povjerstvom u sastavu mr. sc. Iva Rinčić, prof. (mentorica), dr. sc. Mirko Štifanić, izv. prof. (član) i dr. sc. Amir Muzur, izv. prof. (član) diplomski rad **Beskrvno liječenje Jehovinih svjedoka kao izazov u radu medicinske sestre**, stekavši time uvjete za promoviranje u stručnu prvostupnicu sestrinstva (baccalaurea).

Glavni cilj izrade ovog rada bilo je istražiti specifičnosti liječenja Jehovinih svjedoka u okviru pružanja zdravstvene njege, s naglaskom na problematiku odbijanja transfuzije krvi. Istraživanje je provedeno u Kliničkom bolničkom centru Rijeka na 50 ispitanika/ca, u okviru kojeg se nastojala utvrditi učestalost kontakata medicinskih sestara/tehničara s pacijentima Jehovinim svjedocima, razina poznavanja problematike beskrvnog liječenja Jehovinih svjedoka, razina poznavanja postojeće zakonske regulative i etičkih standarda, utvrđivanje stavove medicinskih sestara prema beskrvnom liječenju Jehovinih svjedoka

Rezultati su kod ispitane populacije pokazali relativno nisku razinu učestalosti kontakata, kao i pružanja zdravstvene njege pacijentima Jehovinim svjedocima, ali i postojanje određenih nejasnoće u pogledu stručnih pitanja, pravne regulacije, kao i etičkih standarda. U zaključku je stoga istaknuta važnost kontinuirane edukacije medicinskih sestara/tehničara o specifičnim uvjetima liječenja pacijenata koji odbijaju pojedine postupke, uključujući beskrvno liječenje Jehovinih svjedoka.

Bioethics calendar/ Bioetički kalendar

Aktualni trenutak hrvatskog zdravstva i njegove prakse

Mjesto i vrijeme održavanja: Medicinski fakultet Rijeka, 22. siječnja 2010.

Organizatori:

Hrvatsko bioetičko društvo – podružnica u Rijeci
Medicinski fakultet u Rijeci – Katedra za društvene i humanističke znanosti u medicini

Organizacijski odbor:

Nada Gosić i Amir Muzur (supredsjedatelji), Mirko Štifanić, Iva Sorta-Bilajac, Morana Brkljačić Žagrović, Iva Rinčić (članovi)

Skup je kategoriziran kao stručni i odgovarajuće bodovan pri Hrvatskoj liječničkoj komori.

Polazišta:

S krizom sustava zdravstva susreću se mnoge države. Zdravstvo postaje tromo, zapleteno u birokraciju, a istodobno postaje odlično mjesto za skrivanje različitih anomalija. Nezadovoljni su i liječnici i pacijenti. To je osobito ozbiljan problem u zemljama u tranziciji, uključujući Hrvatsku, koji otežava ostvarivanje temeljnih ciljeva javnoga zdravstva. Metode ostvarivanja ovih ciljeva, pitanja javno-privatnog partnerstva, normativna i stvarna pozicija liječnika, drugih zdravstvenih djelatnika i pacijenata, upravljanje krizom u zdravstvu, afirmacija profesionalizma i etičnosti te mogućnosti za unapređenje kvalitete zdravstvenog sustava Republike Hrvatske, samo su neke od tema kojima se bavio okrugli stol, pristupajući problemima iz znanstvene, stručne, društvene, etičke i kulturne perspektive.

Program skupa:

10.30 – 11.00	Prijava sudionika
11.00 - 11.15	Otvaranje skupa i najava teme
11.15 – 11.30	**Mirko Štifanić** (Katedra za društvene i humanističke znanosti u medicini Medicinskog fakulteta Sveučilišta u Rijeci): *Politizirano zdravstvo*
11.30 – 11.45	**Vibor Delić** (Uprave za medicinske poslove Ministarstva zdravstva i socijalne skrbi RH): *Osnove odlike reforme zdravstvenog sustava RH*
11.45- 12.00	**Renato Mittermayer** (Agencija za kvalitetu i akreditaciju u zdravstvu): Kvaliteta u zdravstvu kao cilj
12.15 – 12.30	**Dražen Gorjanski** (HZZO Podružnica Osijek): *Komercijalizacija zdravstva*
12.30 – 12.45	**Zvonko Bošković** (Hrvatsko bioetičko društvo – Podružnica Rijeka): *Pogled u normativno i stvarno u zdravstvenom sustavu*
12.45 – 13.00	**Nela Gašpar** (Katolički bogoslovni fakultet u Rijeci): *Bioetika i zdravlje u kršćansko-teološkoj perspektivi*
13.00-14.00	Pauza uz domjenak
14.00 - 16.00	Rasprava i zatvaranje skupa

Post festum:

Za okruglim stolom referiralo je četvero izlagača (V. Delić i R. Mittermeyer su u posljednji čas odustali). U publici se okupilo oko 60 sudionika iz Rijeke, Rovinja, Požege, Zagreba, Klenovnika, Novog Marofa, Osijeka, Popovače i Zadra, među kojima i dvoje saborskih zastupnika, prodekan Medicinskog fakulteta u Rijeci, ravnatelji KBC Rijeka i najveće privatne poliklinike u regiji, pročelnici odjela za zdravstvo i socijalnu skrb PGŽ i Grada Rijeke, republički čelnici sindikata zdravstva i udruga za prava pacijenata, pravnika u zdravstvu i mnogih drugih. Skupu je nazočilo i dvadesetak studenata V. godine studija Organizacije, i upravljanja u zdravstvu (OPUZ) koji se na taj način predstavio širem forumu. *Novi list* je sljedećeg dana donio o održavanju okruglog stola afirmativnu vijest na oko pola stranice.

Rezultat:

Organizatori su, temeljeći se na iznijetim referatima i dinamičnoj diskusiji, sastavili »Riječki apel« (u prilogu) i odaslali ga na adrese sudionika skupa, donositelja odluka u zdravstvu, sredstava javnog informiranja i drugih subjekata zdravstvenog sustava, čime se željelo potaknuti oživotvorenje moralnih dimenzija u zdravstvu i socijalnoj skrbi.

Riječki apel za racionalno i etično zdravstvo

Suglasni da hrvatsko zdravstvo proživljava težak trenutak obilježen tranzicijom političkih, gospodarskih, društvenih i moralnih vrijednosti, sudionici Okruglog stola *Aktualni trenutak hrvatskog zdravstva i njegove prakse* zalažu se za sljedeća načela:

1. sustav javnog zdravstva je, za razliku od privatnog, **neprofitan** sustav;
2. svi subjekti sustava javnog zdravstva – institucije i pojedinci, zdravstveni radnici i pacijenti – dužni su ponašati se **racionalno** u potrošnji materijala i vremena;
3. osnov i mjerilo načela racionalnosti ne može biti unaprijed zadani financijski limit, već **optimalna korist za pacijenta** koja podrazumijeva najbolji mogući stručni i etički tretman;
4. **racionalizacija** se, između ostaloga, postiže i inzistiranjem na prevenciji (uključujući i nagrađivanje liječnika za postizanje nižeg pobola i eliminaciju štetnih navika, a ne manju potrošnju materijala);
5. budući da su temeljne vrijednosti društva **zdravlje, obrazovanje i rad**, država mora iznaći dostatna sredstva za zdravstvo, bilo revizijom troškova i kvalitetnijom organizacijom, planiranjem i upravljanjem unutar sustava javnog zdravstva, bilo preraspodjelom iz drugih izvora;
6. **ulogu pacijenta** i **moralnog, humanog liječnika** treba konstantno osnaživati u sustavu zdravstva (unapređivanjem komunikacije i transparentnosti sustava), a zdravstvene usluge unapređivati prikupljanjem sugestija, pritužbi i pohvala korisnika;
7. treba naglašavati i promicati kako **odgovornost** liječnika, tako i odgovornost pacijenta (redoviti preventivni i kontrolni pregledi i sl.), kao i njihov suradnički odnos;
8. liječnik i zdravstveni sustav u cijelosti trebaju težiti što boljem i stalnom **educiranju i informiranju** pacijenta;
9. treba težiti kompletiranju **dugoročnog sustava zakonskih i podzakonskih akata** u području zdravstva i socijalne skrbi, u čijem će formuliranju ravnopravno sudjelovati struka, udruge pacijenata i politika;

10. sredstva javnog informiranja imaju nezaobilaznu ulogu u procesu unapređivanja sustava javnog zdravstva: umjesto generiranja senzacionalizma i prenaglašavanja afera, međutim, njihova uloga trebala bi biti **sustavno promicanje pozitivnih vrijednosti** (primjerice, ugleda liječničke profesije, poštovanja prava pacijenata, popularizacija prakse doniranja organa i sl.).

Amir Muzur
Medicinski fakultet u Rijeci, 22. siječnja 2010.

The current moment of Croatian health system and its practice

Venue and time: Medical School in Rijeka, 22 January 2010

Organizers:

The Croatian Bioethics Society – Rijeka subsidiary
The Department of Social Sciences and Medical Humanities at University of Rijeka School of Medicine

Organizational Committee:

Nada Gosić and Amir Muzur (co-chairpersons), Mirko Štifanić, Iva Sorta-Bilajac, Morana Brkljačić Žagrović, Iva Rinčić (members)

The conference is categorized as professional and appropriate points are received by the Croatian Medical Chamber.

Starting points:

Health systems in many countries face the crisis. Health system is becoming sluggish, entangled in red tape and at the same time perfect for hiding different anomalies. Both physicians and patients are dissatisfied. This is a particularly serious problem in transitional countries, including Croatia, and it complicates the achievement of fundamental goals of public health. Methods of achieving these goals, issues of public and private partnership, normative and real position of physicians and other health workers and patients, health crisis management, affirmation of professionalism and ethics and possibilities to enhance the quality of the Croatian health system are only some of the Round Table topics, with the scientific, professional, social, ethical and cultural approach to the issues.

Conference:

10.30 – 11.00	Accreditation
11.00 - 11.15	Opening of the Conference and topic announcement
11.15 – 11.30	**Mirko Štifanić** (The Department of Social Sciences and Medical Humanities at University of Rijeka School of Medicine): *Politicized Health System*
11.30 – 11.45	**Vibor Delić** (Department of Medical Affairs at the Ministry of Health and Social Welfare): *Basic Characteristic of Croatian Health System Reform*
11.45- 12.00	**Renato Mittermayer** (Accreditation Agency in Healthcare Quality System): Quality in a Health System as a Goal
12.15 – 12.30	**Dražen Gorjanski** (Croatian Institute for Health Insurance, Osijek subsidiary): *Health Care Commercialization*
12.30 – 12.45	**Zvonko Bošković** (Croatian Bioethics Society – Rijeka subsidiary): *Look into the Normative and Real in the Health Care System*
12.45 – 13.00	**Nela Gašpar** (Catholic Theological Faculty in Rijeka): *Bioethics and Health from the Christian-Theological perspective*
13.00-14.00	Refreshments
14.00 - 16.00	Discussion and closing of the conference

Post festum:

There were four presenters at the Round Table (V. Delić and R. Mittermayer quitted at the last moment). Audience consisted of about 60 participants from Rijeka, Rovinj, Požega, Zagreb, Klenovnik, Novi Marof, Osijek, Popovača and Zadar, including two representatives in the Croatian Parliament, vice-dean of Medical School in Rijeka, general managers of the Clinical Hospital Center Rijeka and the biggest private polyclinic in the region, heads of the county's and city's departments of health and social welfare, heads of the health care union and the association for the promotion of patients' rights, jurists in the health care system and others. There were also around twenty 5th year students of Organization, Planning and Management in Health Care System Study, which was thus presented to the larger forum. The following day Novi list published a half-page affirmative article concerning Round Table.

Result:

Organizers have drafted »Rijeka Appeal« (enclosed) and sent it to the addresses of the conference participants, health care system decision makers, media and other subjects within the health care system with the aim to implement moral dimensions in health and social care.

Rijeka Appeal For Rational And Ethical Health Care System

In agreement that the Croatian health care system is going through a difficult moment marked by a transition of political, economic, social and moral values, the participants of the Round Table *The current moment of Croatian health system and its practice* promote the following principles:

1. public health care system is, as opposed to the private one, a **non-profit** system;
2. all subjects in the public health care system – institutions and individuals, health care workers and patients – must spend both time and materials **rationally**;
3. the basis and criterion of the rationality principles may not be the financial limit set in advance, but the **optimal benefit for the patient** which implies the best possible professional and ethical treatment;
4. **rationalization** is, among other, achieved by insisting on prevention (including rewarding physicians for achieving lower number in illnesses and elimination of bad habits, and not for the reduction in use of materials);
5. considering the fact that the main values of the society are **health, education and work**, the state must ensure sufficient funding for the health care system, whether by reviewing costs and better organization, planning and managing within the public health system or by redistribution from other sources;
6. **the role of the patient and the moral, humane doctor** must continually be empowered within the health care system (by promoting communication and system transparency) and health care services should be improved by collecting suggestions, complaints and commendations;
7. the **responsibility** of both doctors and patients should be emphasized and promoted (regular check-ups) as well as their co-operation;
8. a doctor and the health care system have to aim at better and continual **educating and informing** of a patient;

9. long-term system of legal acts on health care and social welfare should be completed and professionals, patients' associations and politics shall participate equally in its formulation;
10. media have an essential role in the process of improving the public health care system: instead of generating sensationalism and drawing attention to affairs, they should **systematically promote positive values** (for instance those regarding the dignity of doctor's profession, respecting patients' rights, popularization of organ donation, etc.).

Amir Muzur
School of Medicine in Rijeka, 22 January 2010

First Video Conference Bioethics Education - Sharing Various Experiences

First Video Conference BIOETHICS EDUCATION - SHARING VARIOUS EXPERIENCES was organized by Bioethics Society of Serbia and University of Belgrade School of Medicine on 29 January 2010.

Participant from four different centers (Belgrade - Serbia, Zagreb - Croatia, Udine - Trieste and Nijmegen - Netherlands) »meet« in cyber space at the common IP address (147.91.120.50.)

After *Welcome speech* by Karel Turza (School of Medicine, University of Belgrade, Serbia), the first session started. The lecture entitled *Bioethics Education in Croatia* was held by Nada Gosić (School of Medicine, University of Rijeka, Croatia), Iva Rinčić (School of Medicine, University of Rijeka, Croatia) gave a lecture *The Rijeka Model of Bioethics Education*, while Hrvoje Jurić (Faculty of Humanities and Social Sciences, University of Zagreb, Croatia) presented the lecture named *Ethics and Bioethics Education in Secondary School in Croatia*. After first session the participants from all four centers took place in a short discussion regarding the current questions in bioethics education.

The Moderators of the second sessions were Francesco Saverio Ambesi Impiombato (University of Udine, Italy) and Evert van Leeuwen (St. Radboud University, Nijmegen, Netherlands). On behalf of Dejan Donev (Center for interactive bioethics, Kumanovo, Macedonia) Sandra Rađenović (School of Medicine, University of Belgrade, Serbia) presented *The Bioethical Themes in the Ethical Lessons for the Younges*. With Karel Turza (School of Medicine, University of Belgrade, Serbia) Sandra Rađenović also delivered the lecture *Bioethics at the School of Medicine, University of Belgrade*. Zoran Todorović (School of Medicine, University of Belgrade, Serbia) was presenter of the lecture *Animal Care and Use Course: Teaching of Animal Bioethics at the School of Medicine, University of Belgrade*. The last presentation, *Ethical Committees and Drug Safety in Clinical Trials: Experiences of the Clinical Centre of Serbia* was presented by Milica Prostan (School of Medicine, University of Belgrade, Serbia).

Iva Rinčić

International Conference on Bioethics Committees in Hospitals

May 17-20, 2009, Zefat, Israel

The purpose of the Conference organized by the *UNESCO Chair in Bioethics* and *ISAS International Seminars* was to serve as an international platform for exchange of knowledge and thoughts on bioethics committees in health care institutions.

The Conference focused on definitions, composition, functions, and a general place and role of hospital ethics committees, with main aim to channel new ideas in order to provide expertise and represent different viewpoints concerning ethical issues raised in biology, medicine and the life sciences, to improve patient-centered care, to protect persons who become involved in research trials and to facilitate the acquisition and use of new knowledge directed to improving health and the delivery of health care, to benefit individual patients as well as entire societies.

Conference Topics

- The challenge and tasks of bioethics committees
- Establishing bioethics committees
- Different forms of bioethics committees
    - Policy-making bioethics committees
    - Advisory bioethics committees
    - Health professional association bioethics committees
    - Health care/hospital bioethics committees
    - Research ethics committees
- Procedures and operations
- Evaluating bioethics committees
- Programs for continuing bioethics education

10 Parallel Sessions

1 Workshop: Multicultural Considerations in Ethical Consultation

1 Poster Session

Additional info:

http://www.isas.co.il/bioethics2009/index.php

This year's conference is taking place from 2-5 May, 2010, also in Zefat, Israel. The focus is on Bioethics Education: Contents, Methods, Trends. The Conference is designed to offer **a platform** for the exchange of information and knowledge, and to hold discussions, lectures, workshops, as well as an exhibition of programs and databases.

More info at:

www.isas.co.il/bioethics2010

Iva Sorta-Bilajac

The 14th International Forum on Quality and Safety in Health Care: Supporting and energizing the movement for health and health care improvement

17-20 March 2009, Berlin, Germany

The **International Forum on Quality and Safety in Health Care** is focused on the importance of the organization of care, as well as the clinician's responsibility for the care of individual patients. This can be obtained by benchmarking, shared decision making, training for patient safety, improving both cost and quality, improvement in primary care, mental health care, open disclosure...

The Berlin Forum aimed to integrate learning about quality improvement into the learning of a health professional's core discipline, by providing a forum where practitioners, educationists, academics, and leaders could meet and learn from each other through a series of sessions where participants could debate and argue about ideas at the leading edge of safety and quality improvement – on thinking of safety in a different way, on advancing understanding of the evidence for quality improvement activities, on what constitutes leadership for quality improvement...

The Forum took place over four days, Tuesday 17 to Friday 20 March. The first day consisted of five parallel full day mini-courses on »the basics« of various aspects of quality improvement, for participants new to the subject or who wanted a refresher on a particular aspect. On Tuesday afternoon there was an optional introduction to the German health service, followed by the welcome reception for delegates. The main program then went on from Wednesday to Friday. Each day opened with a plenary talk to all delegates and then divided up into a series of parallel sessions, some of these organized as half day mini-courses, with a strong emphasis on teaching skills and knowledge. The last time slot of each day included presentations selected from the call for papers, grouped into themed topics. Finally, a final plenary talk was held on the last day, so that all delegates could join together again before departing. Two special programs were also organized:

- for chief executives of health organizations, and
- a specific student-teacher program.

All together there were:

- 4 Plenary Sessions,
- 73 Parallel Sessions, and
- 16 Half day Mini-Courses.

The International Forum continues to grow in influence, and is a key meeting point for healthcare professionals with attendees from over 70 countries. The 15th Forum is taking place from 20-23 April 2010, in Nice, France. The 2010 theme of **Improving Quality, Reducing Costs** addresses the challenges brought about by global financial pressures.

Additional info: www.internationalforum.bmj.com

Iva Sorta-Bilajac

Simpozij: Etika i palijativna medicina

U organizaciji Hrvatskog katoličkog liječničkog društva dana 7. studenoga 2009. godine na Medicinskom fakultetu Sveučilišta u Zagrebu održan je Simpozij »Etika i palijativna medicina«. Već sam naziv simpozija govori o poveznici znanosti i humanosti u okviru moralnih vrijednosti te u svrhu kvalitete ljudskog života od njegovog početka do smrti.

Sukladno *Kodeksu medicinske etike i deontologije* Hrvatske liječničke komore jedno od najvažnijih obilježja medicinskog poziva pomoć je i briga (skrb) za pacijenta, poglavito onog teško bolesnog i umirućeg. Doprinos i olakšavajuće okolnosti takvog oblika pomoći dakako je napredak kako medicinskih tako i farmaceutskih znanstvenih dostignuća. Do sredine prošlog stoljeća navedene su znanosti bile relativno ograničene u suzbijanju boli i kontroli simptoma. Napredak u ljekovitoj terapiji pedesetih godina 20. stoljeća, u kombinaciji s većim razumijevanjem psihosocijalnih i duhovnih potreba umirućih bolesnika, utrli su put razvitku palijativne/hospicijske skrbi.

Utemeljen i dokazan model palijativne skrbi/medicine na kraju života jest hospicijska skrb. Započinje kada su iscrpljene klasične (kurativne) metode liječenja ili kad su znaci širenja maligne bolesti dostigli takav stupanj da ih bolesnik teško podnosi.

Primarni je cilj kurativne medicine izlječenje, a smrt zadnji neuspjeh. Naprotiv, u palijativnoj je medicini cilj olakšanje patnje, a smrt koja se desi nakon što je bolesniku olakšana patnja - uspjeh. Palijativna medicina mnogo je šira i dublja od puste simtomatologije. Termin implicira holistički pristup bolesniku, što podrazumijeva ne samo fizičku dimenziju, nego i psihološku, društvenu i duhovnu zaokupljenost.

Upravo je holistički pristup okarakterizirao predavanja na simpoziju, pa su izlagači bili liječnici: dr. sc. Morana Brkljačić Žagrović, dr. sc. Marijana Braš, Matija Rimac, Vlasta Vučevac, dr. sc. Jasminka Stepan Giljević te Zoran Lončar; potom viša medicinska sestra Kristina Vokić, te teolozi prof. dr. sc. Mijo Nikić i biskup prof. dr. sc. Valentin Pozaić.

Zaključna misao profesora Pozaića ujedno predstavlja najbolji zaključak i poruku ovog Simpozija, a glasi: Kako u svijetu tako i u Hrvatskoj, glavni problem nametanja i zahtjeva eutanazije nije prvotno teorijske već praktične naravi, traži se praktični a ne teorijski odgovor, to je hospicij kao jedna od najljepših, najhumanijih i najkreativnijih inicijativa u borbi protiv eutanazije. Preobrazba načina umiranja na zlo ostvariti će se ako prevagne eutanazijski mentalitet – kultura smrti; preobrazba na dobro, ako pobijedi hospicijski mentalitet i palijativna skrb/medicina – kultura života.

Morana Brkljačić Žagrović

Symposium on Ethics and Palliative Medicine

Organized by the Croatian Catholic Medical Society a Symposium *Ethics and Palliative Medicine* was held on 7 November at the University of Zagreb School of Medicine. The name of the symposium itself implies a link between science and humanity in the framework of moral values and with the aim of the quality of human life from its beginning until death.

According to the Croatian Medical Chamber's *Code of Medical Ethics and Deontology* one of the most significant characteristics of medical vocation is help and care for the patient, particularly the one who is gravely ill and dying. Certainly, the contribution and alleviating circumstances of this kind of help is the result of advancement of both medical and pharmaceutical scientific achievements. Until the mid 20th century, these sciences had been relatively limited in suppressing pain and symptoms control. The advancement in medicinal therapies in the 1950s, combined with growing understanding of psychosocial and spiritual needs of the dying, paved the way for the development of the palliative/hospice care.

Founded and proven model of palliative care/medicine at life's end is hospice care. It begins when classic (curative) methods of treatment have been exhausted or when the symptoms of spreading of malignant disease have reached the level where the patient stands it with great difficulty.

The primary goal of curative medicine is healing, and death is its last failure. On the contrary, the goal of palliative medicine is to alleviate suffering and the death, which occurs after alleviating patient's suffering, is a success. Palliative medicine is much deeper than pure symptomatology. The term implies holistic approach to the patient, which includes not only physical dimension, but also his or her psychological, social and spiritual engagement.

Holistic approach was the characteristic of lectures at the symposium and lecturers included physicians: Morana Brkljačić Žagrović, Ph.D., Marijana Braš, Ph.D., Matija Rimac, Vlasta Vučevac, Jasminka Stepan Giljević, Ph.D., and Zoran Lončar; then Kristina Vokić, graduate nurse and theologists: professor Mijo Nikić, Ph.D., and bishop, professor Valentin Pozaić, Ph.D.

The final thought of professor Pozaić is at the same time the most appropriate conclusion and message of this symposium: Both in Croatia and worldwide, the main problem of imposing and requiring euthanasia is not theoretical but practical in nature, so a practical and theoretical answer must be sought, and that is the hospice as one of the most beautiful, most humane and most creative initiatives in the fight against euthanasia. The act of dying shall be transformed to evil if the euthanasia mentality prevails – the culture of death; and it will be transformed to good if the hospice mentality and the palliative care/medicine prevails – the culture of life.

Morana Brkljačić Žagrović

Prekogranična suradnja u zdravstvu: mogućnosti i perspektive

26. listopada 2009., Trst, Italija

Okrugli stol »Prekogranična suradnja u zdravstvu: mogućnosti i perspektive« (*Cooperazione transfrontaliera in sanità: Opportunità e prospettive*) održan je dana 26. listopada 2009. u Trstu, u Starhotels Savoia Excelsior Palace hotelu.

U današnjoj Europi, oslobođenoj fizičkih granica među državama, ostaju one nacionalne, socijalne, ekonomske, kulturološke... Upravo kroz proces europskih integracija, sustav biomedicine i zdravstva suočava se s novim scenarijima i mora razmišljati o perspektivama za budućnost u regionalno povezanim državama, kakve su upravo Italija, Slovenija i Hrvatska.

Ovaj okrugli stol imao je za cilj uključiti političare i stručnjake, sukobiti (ne)postojanje političke volje i praktičnu potrebu za poboljšanjem zdravstvenih usluga. Građani Europe, naime, trebaju imati pravo na najvišu razinu zdravstvene skrbi, neovisno u kojoj državi članici žele ostvariti to svoje pravo.

Sudionici okruglog stola bili su:

Luciano Bresciani, povjerenik za zdravstvo regije Lombardija,

Vladimir Kosic, povjerenik za zdravstvo i socijalnu skrb regije Friuli Venezia Giulia,

Gordana Kalan Živčec, predsjednica Slovenske liječničke komore,

Iva Sorta-Bilajac, predsjednica Povjerenstva za zaštitu prava pacijenata PGŽ,

Gabriella Clarich, predsjednica Povjerenstva za dostupnost zdravstvene skrbi Talijanskog liječničkog zbora,

Claudio Pandullo, predsjednik Talijanskog liječničkog zbora,

Giovanni Collino, Europski parlamentarac.

Moderator okruglog stola i diskusije s publikom bio je Paolo Possamai, direktor Tršćanskih novina »Il Piccollo«.

Iva Sorta-Bilajac

Trans-border cooperation in health care: possibilities and perspectives

26 October 2009, Trieste, Italy

Round Table »Trans-border cooperation in health care: possibilities and perspectives« (*Cooperazione transfrontaliera in sanità: Opportunità e prospettive*) was held on 26 October 2009 in Trieste, in Starhotels Savoia Excelsior Palace Hotel.

Todays Europe, free from physical borders between countries, is left with national, social, economic, cultural... borders. It is through the process of European integrations that the system of biomedicine and healthcare is faced with new scenarios and needs to consider perspectives for the future in the regionally connected countries, as are Italy, Slovenia and Croatia.

The goal of this Round Table was to include politicians and experts, to bring face to face the lack of political will with the practical need for the improvement of health care services. The citizens of Europe have the right to the highest level of health care, independent of the state member in which they wish to exercise that right.

The participants were:

Luciano Bresciani, the health care commissioner for Lombardia region
Vladimir Kosic, the health care and social welfare commissioner for Friuli Venezia Giulia region,
Gordana Kalan Živčec, the president of the Slovenian Medical Chamber,
Iva Sorta-Bilajac, the president of the Committee for Protection of Patients' Rights, Primorsko-goranska County,
Gabriella Clarich, the president of the Committee for the Availability of Health Care of the Italian Medical Chamber,
Claudio Pandullo, the president of the Italian Medical Chamber,
Giovanni Collino, European parliament representative.

The Round Table and discussions with the audience were moderated by Paolo Possamai, the director of »Il Piccollo«, the newspaper from Trieste.

Iva Sorta-Bilajac

18th World Congress on Medical Law

The 18th World Congress on Medical Law will take place in Zagreb, Croatia, from 8-12 August, 2010. The Congress offers an excellent opportunity to discuss new developments in medical law and ethics, and to exchange ideas with experts from all around the world.

The emphasis of the 18th World Congress is human rights based approach in health, law and ethics, since health law and human rights are an inseparable synergy. Also, the Congress will discuss current issues in medical malpractice, responsibility and insurance, legal and ethical aspects of reproductive technology and genetics, medical research, e-health, legal issues in public health, mental care, nursing practice, alternative and complementary therapies.

Topics:

1. Health Law and Human Rights. An Inseparable Synergy:
    - Human rights based approach to regulating patients' rights
    - Patient's rights representatives
    - Obligations and responsibilities of patients
    - Health personnel and human rights
    - Vulnerable persons
    - Children rights
    - Human rights issues in health law
2. Health law and medical institutions
3. Issues in medical malpractice and physicians' liability
4. Issues in medical malpractice and institutional liability
5. Medical liability and protection
6. Informed consent
7. Bioethics and legal aspects of reproductive technology and genetics
8. Abortion
9. End of life decisions
10. Organ transplantation

11. Health law and medical research
12. Legal issues in public health
13. Bioethical and legal aspects of mental care
14. Legal approach to e-health
15. Legal issues related to pharmaceutical industry
16. Nursing practice
17. Alternative and complementary therapies
18. Insurance and health care
19. Medical law; health law; bioexology: educational aspects

Student Competition:

The Competition is open to all undergraduate and graduate students of Law, Medicine or allied disciplines. This competition challenges students to explore the Congress themes - from the Human Rights Based Approach to Health, Law and Ethics - through new visions for the future. Students are invited to select a theme that puts health law issues in human rights perspective, and to develop ideas which investigate, interrogate, and propose sustainable options for the future. The paper proposals should also reveal something about the social, cultural, economic and/or political conditions related to the place a student is coming from.

Some examples of specific topics:

- Medical liability
- Patients rights
- Informed consent
- Reproductive technology and genetics
- Abortion
- End of life decisions
- Organ transplantation
- Biomedical research
- Mental care
- Pharmaceutical industry
- Nursing practice

Additional info: http://www.2010wcml.com

Iva Sorta-Bilajac

Conference announcements/Najave skupova

11. okrugli bioetički stol

Na Medicinskom fakultetu u Rijeci, 6. i 7. svibnja 2010. godine održat će se 12. dani bioetike, u sklopu kojih će Okrugli stol ove godine biti posvećen etičkim aspektima sporta i nositi naziv »Etika i sport«.

Organizatori skupa su Katedra za društvene i humanističke znanosti u medicini (Medicinski fakultet Sveučilišta u Rijeci), Hrvatsko bioetičko društvo-Podružnica Rijeka, Hrvatsko društvo za kliničku bioetiku (HDKB), Hrvatsko društvo za športsku medicinu - HLZ Podružnica Rijeka, Udruga zdravstvenih djelatnika u športu (UZDUŠ) Rijeka.

Morana Brkljačić Žagrović

11th Bioethics Round Table

Medical School in Rijeka shall be the host of the 12 th Days of Bioethics which shall be held on 6 and 7 May 2010. This year's Round Table is dedicated to ethical aspects of sport and is entitled »Ethics and Sport«.

The organizers of this conference include The Department of Social Sciences and Medical Humanities at University of Rijeka School of Medicine, The Croatian Bioethics Society – Rijeka subsidiary, The Croatian Society for Clinical Bioethics, Croatian Sports Medicine Society – Croatian Medical Association (Rijeka subsidiary), Association of Health Professionals in Sports Rijeka.

Morana Brkljačić Žagrović

Religijske sljedbe i alternativna medicina na Zapadu: bioetički, pravni i medicinski aspekti

Mjesto i vrijeme održavanja: Medicinski fakultet u Rijeci, 26. 11. 2010.

Organizatori:
Medicinski fakultet u Rijeci – Katedra za društvene i humanističke znanosti u medicini
Pravni fakultet u Rijeci
Centar za informiranje o sektama i kultovima (CISK) kao hrvatska podružnica udruge European Federation of Centres of Research and Information on Sectarianism (FECRIS)

Polazišta:

Centar za informiranje o sektama i kultovima (CISK) je osnovan u Hrvatskoj prije dvije godine kao odgovor na potrebe žrtava s kojima se Zapadni svijet suočio pred dvadesetak godina. Zasnivajući svoj rad na Europskoj konvenciji za ljudska prava, neutralan pristupom, CISK, kao podružnica europskog FECRIS-a, prati organizirane međunarodne grupacije totalitarnih tendencija koje pod izgovorom da se bore za mir, blagostanje i čovjekovo zdravlje nude nove modele i preobrazbu u zdravstvu, edukaciji, ekonomiji, ekologiji, prehrani i poštivanju ljudskih prava. Upitne psihoterapije i sumnjivi medicinski tretmani koji su dosegli znatne razmjere, sastavni su dio ove »preobrazbe«. Takav organizirani i manipulativni segment društva odveo je najranjivije skupine (mlade, starije, labilne i bolesne) u svijet izolacije, ovisnosti, psiho-fizičkih oštećenja i prijevara te unesrećio mnoge obitelji kršeći opće priznata ljudska prava i prava djeteta. Na pojavu ovog problem Zapadno je društvo reagiralo mehanizmima u Europskom parlamentu, Vijeću Europe, pa i zakonodavstvom, poput Francuske. Ideja je da Medicinski fakultet u Rijeci otvori ovu temu u Hrvatskoj ne bi li se znanost, javnost i političke strukture senzibilizirale u cilju eventualnog donošenja nužnih zakonskih okvira. Potporu djelatnosti CISK-a odnosno održavanju okruglog stola dali su pravobraniteljica za zaštitu djece Republike Hrvatske Mila Jelavić, dipl. iur. i zastupnik u Hrvatskom saboru prof. dr. sc. Miljenko Dorić (Medicinski fakultet u Rijeci), a prof. dr. sc. Berislav Pavišić (Pravni fakultet u Rijeci) prihvatio je da za okruglim stolom u Rijeci objasni novi francuski zakon koji, između ostalog, pravno regulira stvaranje ovisnosti, navođenje na samoubojstvo, na mentalnu manipulaciju osobama s posebnom ranjivošću te na štete od ilegalnih medicinskih ili farmaceutskih tretmana.

Amir Muzur

Religious sects and alternative medicine in the West: bioethical, legal and medical aspects

Time and venue: Medical School in Rijeka, autumn 2010

Organizers: Department of Social Sciences and Medical Humanities at University of Rijeka School of Medicine
Faculty of Law at Rijeka University
Sects and Cults Information Centre (CISK) as a Croatian subsidiary of European Federation of Centers of Research and Information on Sectarianism (FECRIS)

Starting points:

Sects and Cults Information Centre (CISK) was founded in Croatia two years ago as an answer to the victims' need that the Western world faced around twenty years ago. CISK, as a subsidiary of the European FECRIS bases its work on the European Convention on Human Rights, has a neutral approach, follows organized international groups with tendencies towards totalitarianism who, under the pretences of fight for peace, well-being and health of a human being, offer new models and changes in health, education, economy, ecology, nutrition and human rights. Questionable psychotherapies and suspicious medical treatments reached significant extents and are essential parts of this »transformation«. This organized and manipulative segment of society has led the most vulnerable groups (the young, the old, the unstable and the sick) into the world of isolation, addiction, psycho-physical damages and deception and has brought distress to many families by breaking generally acknowledged human rights and rights of the child. The Western Society has reacted to this phenomenon through mechanisms in the European Parliament, Council of Europe, and even legal regulations, such is in France. The Medical School in Rijeka wishes to initiate the discussion of this topic in Croatia with the purpose of motivating the scientific and general public, as well as political structures, to possibly develop necessary legal framework. CISK has received support for its activities and for holding a Round Table by the Croatian Ombudswoman for Children Mila Jelavić, and a representative in the Croatian Parliament Professor Miljenko Dorić, Ph.D. (Medical School in Rijeka) and a Professor Berislav Pavišić, Ph.D. (Faculty of Law in Rijeka) has agreed to explain the new French law which, among other, determines legal regulations on creating addiction, persuasion to suicide, mental manipulation with particularly vulnerable persons and damages caused by illegal medical or pharmaceutical treatments.

Amir Muzur

Reviews/
Prikazi

Michele Aramini:

Uvod u bioetiku

Kršćanska sadašnjost, Zagreb, 2009., 443 str.

Suvremenoj znanosti treba i suvremena etika. Znanstveno-tehnološki napredak s jedne strane, te ograničena materijalna sredstva s druge, naprosto nameću nove kategorije odnosa pojedinac - društvo - okolina. Javlja se potreba za redefiniranjem tih odnosa i preraspodjelom odgovornosti.

U tom kontekstu sustav biomedicine i zdravstva postaje sve složeniji, opterećeniji. Naime, nekoć prihvaćeno mišljenje kako je poznavanje medicinskih znanja i vještina dovoljno jamstvo da će konačna odluka o onom što se smatra medicinski indiciranim djelovanjem u najboljem interesu za pacijenta biti ispravna, danas zahtijeva i znanstveno i stručno preispitivanje, jer svaka medicinska procjena u sebi uključuje i skup vrijednosnih procjena ili normi koje se nalaze izvan okvira medicinskih vrijednosti. Medicinska kompetencija više nije jedina kompetencija pri donošenju medicinski ispravnih odluka, jer svaka medicinska odluka u sebi sadrži i medicinsko-tehničku i moralnu komponentu. Upravo bioetika, kao međudisciplinarna, višedisciplinarna i dijaloška, pluriperspektivna i integrativna znanost, pruža adekvatan okvir za donošenje medicinski i moralno ispravnih odluka, kako za zdravstvene djelatnike, tako i za pacijente i sve ostale koji su u to odlučivanje uključeni, a na koje tradicionalna »Hipokratova« medicinska etika više nema adekvatnog odgovora.

Na tragu tih razmatranja potrebno je osvrnuti se na novi udžbenik koji se pojavio na hrvatskoj bioetičkoj akademskoj sceni. Radi se o prijevodu drugog izdanja talijanskog sveučilišnog udžbenika iz bioetike »Uvod u bioetiku«, autora Michelea Araminia, profesora bioetike na Katoličkom sveučilištu »Sacro Cuore« u Milanu. Kako se i naglašava u Predgovoru knjige - »...objavljivanje jednog novog uvoda u bioetiku, namijenjenog liječnicima, profesorima i studentima raznih učilišta, opravdava se nastojanjem da se ponudi znanstvena informacija, jasna i što potpunija... Nadalje, uzimajući u obzir razna etička stajališta koja se pojavljuju u bioetici, u ovoj su knjizi za svaku pojedinu temu ponuđeni različiti etički sudovi i njihove argumentacije. Tako se čitatelju želi ponuditi mogućnost da izgradi vlastito uvjerenje.«

Prijevod ovog, drugog izdanja, predstavlja upravo kolaborativnu, dijalošku bioetiku u praksi, obzirom da sam autor ističe kako veliku zahvalnost duguje upravo svojim studentima, koji su prihvatili ovu knjigu kao radni materijal i svojim ju prijedlozima obogatili i doveli do sadržajnog i strukturnog oblika koji ovdje prikazujemo.

Knjiga je podijeljena u dva dijela. Prvi dio, koji nosi naslov »Opća bioetika«, sadrži pet poglavlja: Korijeni bioetike i metoda načelâ; Razvoj bioetike i etika kreposti; Aktualni pregled (posebno valja naglasiti pod-poglavlja: Laicistička bioetika, Bioetika katoličkog nadahnuća, Problem etičkog pluralizma, Kvaliteta života ili svetost života); Što je bioetika?; Dostojanstvo ljudske osobe. U Drugom dijelu, pod naslovom »Bioetički problemi«, kroz dvadeset i dva poglavlja raspravlja se o: Zdravlju i bolesti; Tjelesnoj boli i trpljenju u čovjeku; Pravima bolesnika; Kliničkom i farmakološkom ispitivanju na ljudima; Genetskom inženjeringu; Kloniranju; Ontološkom i moralnom statusu ljudskog embrija; Potpomognutoj oplodnji; Pobačaju; Spolnosti i značenju ljudskog rađanja; Presađivanju organa; Moždanoj smrti; Eutanaziji, terapijskom nasilju i smrti dostojnoj čovjeka; Palijativnoj skrbi i alternativama eutanaziji; Ovisnosti o drogi; Alkoholizmu; Sindromu stečenog gubitka imuniteta; Patologiji sporta: »dopingu«; Samoubojstvu mladih; Bioetici i okolišu; Pravima životinja i znanstvenom eksperimentiranju; Ekonomiji i zdravlju. Knjiga također sadrži Dodatke: Mišljenje državne bioetičke komisije, te Dokumente crkvenog učiteljstva Katoličke i Evangelističke crkve, te Talijanske židovske zajednice. Na kraju se nalazi bogata Bibliografija.

Ova knjiga svojom strukturom, sadržajem i pristupom kojim raspravlja o svevremenskim filozofsko-teološkim razmatranjima, ali i »gorućim«, kontroverznim pitanjima suvremene znanosti i tehnologije (u medicini, pa i šire, zadirući u ekologiju, ekonomiju i društvo u cjelini), vodi čitatelja na put ka upravo samom sebi svojstvenom, osobnim moralom utemeljenom, te jasno znanstveno potkrijepljenom bioetičkom promišljanju, s didaktički i metodološki primjereno postavljenim »smjerokazima«. Pri tome pokušava dati odgovore na jedno od vječnih pitanja: »Je li medicina umijeće ili znanost? Je li to humanistički poduhvat sa znanstvenom komponentom ili znanstveni poduhvat sa humanističkom komponentom?«, koje danas sve više dolazi do izražaja.

Bioetika je u proteklih 40-ak godina proživjela vrlo bogatu i kompleksnu povijest. S vremenom je doživjela transformaciju iz skupa poprilično krutih pravila u profesionalnom djelovanju, stvorenih dominantno od strane same medicinske struke, u široko polje znanstvenog i društvenog interesa. Da bi se dodatno istaknulo mjesto i važnost Araminijeve knjige, potrebno je naglasiti kako su među prvima koji su reagirali na »nova« pitanja u »novoj medinskoj etici« bili upravo teolozi. Tako je još 1950. dekan harvardskog Teološkog fakulteta Willard L. Sperry objavio svoja predavanja održana u Općoj bolnici u Massachusettsu u knjizi pod naslovom »Etički temelji medicinske prakse«. U knjizi progovara o pitanjima govorenja istine, produženja života i eutanazije u kontekstu izazova nove medicinske tehnologije. Četiri godine kasnije (1954.) izlazi knjiga »Moral i medicina« koja će ostaviti dubok trag u povijesti bioetike, a koju mnogi bioetičari ocjenjuju »pionirskim radom nove medicinske etike«. Autor joj je Joseph Fletcher koji ovdje čini neuobičajen odmak od teoloških rasprava o npr. eutanaziji, ili abortusu i raspravlja o individualnim slobodama i pravima pacijenata. Šesnaest godina kasnije (1970.) Paul Ramsey, profesor religije s Princeton sveučilišta objavljuje knjigu koja se danas smatra temeljnom u bioetici kao znanstvenom polju. U knjizi »Pacijent kao osoba« on prikazuje pacijenta kao aktivnog, slobodnog i autonomnog subjekta zdravstvene skrbi, koji ima određena prava i time se suprotstavlja ideji tradicionalnog liječničkog paternalizma.

Spomenuvši samo najvažnije, postavlja se pitanje tako intenzivnog prisustva teologa u raspravi o »novim« etičkim pitanjima u »novoj« medicini. Međutim, gledana kroz prizmu brige o životu (uključujući dvije vječite ljudske stvarnosti: *etiku* i *život*, tj. moralno razmišljanje o životu i svim njegovim sastavnicama), bioetika sadržajno nije velika novina u kršćanskoj moralnoj teologiji. Profesor Michele Aramini tako nastavlja niz teologa koji su dali veliki doprinos promišljanju bioetičkih tema, čineći to, što se iz knjige »Uvod u bioetiku« iščitava, religijski neopterećeno, a opet religijski utemeljeno. Takav pristup omogućava zasigurno i njegova znanstvena izobrazba u domeni bioetike i političkih znanosti. Autor je brojnih bioetičkih publikacija, posebice na temu eutanazije, gdje predstavlja jednog od vodećih analitičara i kritičara nizozemskog zakona o eutanaziji. Također je znanstveni direktor »Fondazione Mirasole« Sveučilišta u Milanu, te predsjednik Etičkog povjerenstva Klinike »San Pio X« u Milanu (Camilliani).

Stoga se prijevod drugog izdanja knjige »Uvod u bioetiku« s pravom može ocijeniti - kako to čini dr. Mario Palmaro - »novim udžbenikom talijanske bioetike«. Upravo pokušaj da se bioetika približi čitatelju kroz jasnu i što potpuniju znanstvenu informaciju, te pluriperspektivizam religijskih gledišta na pojedine, čak i kontroverzne bioetičke teme, čini ovu knjigu jednako zanimljivom i hrvatskim čitateljima. Knjiga je prevedena i na španjolski jezik, dok je autorica hrvatskog prijevoda mr. sc. Ana Volarić Mršić s Hrvatskih studija Sveučilišta u Zagrebu, inače dugogodišnja izvršna tajnica Centra za Bioetiku Filozofsko-teološkog Instituta Družbe Isusove, Zagreb.

Konačno, ova knjiga zaslužuje da bude prepoznata kao vrlo kvalitetan i sveobuhvatan udžbenik iz bioetike za studente biomedicine i srodnih studija, ali i sve one koji se u svom poslovnom (pa i privatnom) bavljenju susreću s bioetičkim pitanjima i problemima.

Iva Sorta-Bilajac

Michele Aramini:

Introduction to Bioethics

Kršćanska sadašnjost, Zagreb, 2009, 443 pages.

Modern-day science requires modern-day ethics. Scientific and technological advances on the one hand, and limited material resources on the other, simply impose new categories in relation: individual – society – environment. The necessity to redefine those relations and to redistribute responsibility appears.

In that context the system of biomedicine and health becomes more and more complex, burdened. Formerly accepted opinion that having medical knowledge and skills provides adequate guarantee that the final decision on what is considered medically indicated activity in the best interest of the patient today also requires scientific and professional re-examination because every medical assessment includes in itself a collection of value assessments or norms that are outside the frame of medical values. Medical competence is no longer the only competence necessary for making medically correct decisions because every medical decision also contains a medical-technical and moral component. It is bioethics that, as an interdisciplinary, multidisciplinary, dialogue, multiperspective and integrative science, provides adequate framework for making medically and morally correct decisions, both for health workers and for patients and all other persons involved in decision-making not adequately covered by the traditional Hypocrites' medical ethics.

With this in mind, it is necessary to give a review of the new textbook that appeared in Croatian bioethics academic field. It is a translation of the second edition of the Italian university bioethics textbook »Introduction to Bioethics« by Michele Aramini, a bioethics professor at the Sacro Cuore Catholic University in Milan. As he states in the Foreword of his book: »... publishing of the new introduction to bioethics, intended for physicians, professors and students of various learning institutions, is justified by attempting to offer scientific information as clear and complete as possible... Moreover, taking into consideration different ethical views appearing in bioethics, this book offers for each topic various ethical views and their arguments. Thus, the book wishes to offer its reader the possibility to form his or her own opinion.«

The translation of this, second, edition, represents the collaborative, dialogue bioethics in practice, since the author himself points out that he owes his gratitude to his students who accepted this book as a work material and enriched it with their suggestions and gave its form a content and structure that we are presenting here.

The book consists of two parts. Part one, entitled »General Bioethics« contains five chapters: Roots of Bioethics and Principles Methods; Development of Bioethics and the Ethics of Virtue; Current Overview (following subchapters should be emphasized: Laicist Bioethics, Catholicism-inspired Bioethics, Issue of Ethics Pluralism, Quality of Life or Sanctity of Life); What is Bioethics?; Dignity of a Human Being. Part two, entitled »Bioethics Issues« discusses following topics in twenty-two chapters: Health and Sickness; Physical Pain and Suffering of a Human Being; Patients' Rights; Clinical and Pharmacological Experiments on Humans; Genetic Engineering; Cloning; Ontological and Moral Status of a Human Embryo; Artificial Insemination; Abortion; Sexuality and Significance of Human Birth; Organ Transplantation; Cerebral Death; Euthanasia, Therapeutic Violence and Dignified Death; Palliative Care and Alternatives to Euthanasia; Drug Addiction; Alcoholism; Acquired Immunodeficiency Syndrome; Pathology of Sports: Doping; Youth Suicide; Bioethics and Environment; Animal Rights and Scientific Experiments; Economy and Health. The book also contains Appendices: The National Bioethics Committee Opinion, Documents issued by the teachers of Catholic and Evangelical Church and Italian Jewish Community. It ends with rich bibliography.

With its structure, content and approach used to discuss everlasting philosophical and theological examinations and also with »burning«, controversial issues of contemporary science and technology (in medicine and beyond, touching upon ecology, economy and society in general), it takes a reader on a journey towards self-distinctive, based on personal ethics, and clearly scientifically substantiated bioethical examination with didactically and methodologically appropriately placed »signposts«. In relation to this it attempts to provide answers to one of the eternal question: »Is medicine art or science? Is it a humanistic venture with a scientific component or a scientific venture with a humanistic component?«, which nowadays becomes more and more prominent.

In the past 40 or so years bioethics has lived through a very rich and complex history. With time it has undergone a transformation from a set of quite rigid rules for professional activities, made predominantly by medical profession itself, into a broad field of scientific and social interest. In order to additionally emphasize the position and importance of Aramani's book, it is important to point out that theologists were among the first who reacted to »new« issues arising within »new medical ethics«. As far back as in 1950, the Dean of Harvard Divinity School, Williard L. Sperry, published his lectures held in Massachusetts General Hospital, entitled »The Ethical Basis of Medical Practice«. In his book he raises the issues of truth telling, prolonging life and euthanasia in the context of challenges of new medical technology. Four years later (1954) the book that has left a strong mark in the history of bioethics »Morals and Medicine« is published. Many bioethicists describe this book as the »pioneer work of new medical ethics«. Its author is Joseph Fletcher who steps away from the usual theological discussions, such as euthanasia or abortion, and discusses individual freedoms and patients' rights. Sixteen years later (1970) Paul Ramsey, a religion professor at Princeton University, published a book which is today considered to be the basis of bioethics as a field of science. In his book »The Patient as Person« he describes a patient as an active, free, autonomous subject in the health care system with specific rights and thus he opposed the idea of traditional medical paternalism.

By mentioning only the most important, the question of such strong presence of theologists in discussions on »new« ethical issues in »new« medicine arises. However, seen through the prism of care about life (including two eternal human realities: *ethics* and *life*, i.e. moral reflection on life and all its components), bioethics is not, in its content, very new in Christian moral theology. Professor Michele Aramini continues the line of theologists who made a great contribution in reflections on topics of bioethics and he does it, as can be seen in the book »The Introduction to Bioethics« religiously unburdened and yet religiously founded. Such approach is surely possible, among other, because of his scientific education in the field of bioethics and political sciences. He is the author of numerous publications on bioethics, particularly on topic of euthanasia in which he is one of the leading analysts and critics of the Dutch law on euthanasia. He is also a science director of »Fondazione Mirasole« at the Milan University and the president of the Ethics Committee of »San Pio X« Clinic in Milan (Camilliani).

That is the reason why the translation of the second edition of »Introduction to Bioethics« can be rightly termed – as dr. Mario Palmaro says - »the new textbook on Italian bioethics«. The attempt to bring bioethics closer to the reader through clear and complete scientific information and multiperspective religious views on particular, even controversial, topics makes this book equally interesting to Croatian readers as well. The book was also translated into Spanish, and the author of the Croatian translation is Ana Volarić Mršić, M.A. from the University of Zagreb, Center for Croatian Studies and long-time executive secretary in the Center for Bioethics at the Institute of Philosophy and Theology SJ, Zagreb.

Finally, this book deserves to be recognized as a quality and comprehensive bioethics textbook for students of biomedicine and related studies, but also for all those who encounter bioethics issues in their professional (and also private) life.

Iva Sorta-Bilajac

Biomedicine and Human Rights: The Oviedo Convention and its Additional Protocols

Council of Europe Publishing, Strasbourg, 2009, pp. 190.

Convention on Human Rights and Biomedicine (ETS No.164, or, by its full name, Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine) was brought in Oviedo, Spain, on April 4, 1997, by the Council of Europe and offered for signature and ratification to the member states and other international subjects. Thirteen years after, the Convention represents one of the most important documents in the realm of bioethics, being at the same time a part of the legal acquest of the European Union.

Although the Convention has originally had obligatory character and has encompassed all the important bioethical issues , it has been considered an instrument providing a framework (containing general principles and preventing rough infringing of human rights and dignity) and only minimal common standards.[1]

In order to address particular bioethical issues, but also because the dynamics of bioethics science and practice has imposed a dynamic updating of the Convention, a series of additional protocols have been compiled and signed during the last decade. Those changes and adjustments are presented in a new edition by Council of Europe Publishing from December 2009.

Beside the text of the basic Oviedo Convention, printed are the Explanatory report on the Convention on Human Rights and Biomedicine (drawn up at the request of the Steering Committee on Bioethics in 1996, to clarify the object and purpose of the Convention), Additonal Protocol to the Convention on Human Rights and Biomedicine, on the Prohibition of Cloning Human Beings (ETS No. 168; 1998),

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[1] Cf. Iva Rinčić Lerga, »Deset godina Konvencije o ljudskim pravima u biomedicini Vijeća Europe (1997.-2007.): postignuća i perspektive« [Ten years of the Convention on Human Rights and Biomedicine by the Council of Europe (1997-2007): achievements and perspectives], in: *Integrativna bioetika i interkulturalnost: zbornik radova 2. međunarodnog bioetičkog simpozija u Bosni i Hercegovini* [Integrative bioethics and interculturality: proceedings of the 2nd international symposium on bioethics in Bosnia and Hercegovina], edited by V. Valjan (Sarajevo: Bioetičko društvo BiH, 2009), pp. 297-310.

Explanatory report on the Additional Protocol to the Convention on Human Rights and Biomedicine, on the Prohibition of Cloning Human Beings (1998), Additonal Protocol to the Convention on Human Rights and Biomedicine, concerning Transplantation of Organs and Tissues of Human Origin (ETS No. 186; 2002), Explanatory report on the Additonal Protocol to the Convention on Human Rights and Biomedicine, concerning Transplantation of Organs and Tissues of Human Origin (2001), Additonal Protocol to the Convention on Human Rights and Biomedicine, concerning Biomedical Research (CETS No. 195; 2005), Explanatory report on the Additonal Protocol to the Convention on Human Rights and Biomedicine, concerning Biomedical Research (2004), Additonal Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes (CETS No. 203, 2008), and Explanatory report on the Additonal Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes (2008).

The new edition of the Council of Europe Publishing represents a dextrously designed product offering a crucial updating for all those studying bioethical standards in Europe. This user-friendly book, moreover, provides an excellent insight into the fascinating recent history of institutional deliberation and of international and intercultural harmonizing of the cardinal issues of human life.

Iva Rinčić and **Amir Muzur**

Instructions for the authors

Jahr – Annual of the Department of Social Sciences and Medical Humanities publishes previously unpublished papers. It is the aim of the editorial board to publish articles covering a wide span of topics (including ethics, bioethics, history, medical and scientific history, sociology, cultural anthropology, theology, law, etc.). The journal publishes reviewed articles as well as articles not subject to the reviewing procedure. The reviewed articles are accepted to be published after having received two anonymous positive reviews.

Reviewed articles are categorized as following:

- original scientific papers that contain new, previously unpublished results of scientific research (Original Scientific Articles, Short Communications)
- scientific articles that contain original, concise and critical presentation of a particular field or its part, in which the author himself has an active role (Review Articles). The role of author's direct contribution to the particular field in relation to already published papers needs to be emphasized, as well as the overview of those papers.
- Professional Articles that contain useful contributions from and for the profession, and they do not have to be based on original research.
- Letters to the editor

The annual also publishes uncategorized papers, i.e. overviews of bioethics and other relevant publications published in the past three years in and outside Croatia, as well as reports and announcements of upcoming bioethics events (public lectures, book promotions, scientific conferences, etc.).

By giving their consent to be published, the authors give journal the right for the paper to be published for the first time in its printed or electronic format. Authors can publish their works in other publications where there must cite the data about articles' first publication.

Layout and manuscripts

Original (scientific) articles should consist max 32 pages, short communications and review articles should consist of 8 – 16 pages and reviews and overviews should consist of 2 – 4 pages.

Page means 1800 characters with spaces, i.e. 30 lines each consisting of 60 characters.

Manuscript, in layout, must contain following elements:

- author's name and surname,
- name and address of author's mother institution,
- author's contact address (if different from mother institution's address),
- author's e-mail address,
- full title of the article (and subtitle in necessary),
- abstract (not longer than 900 characters with spaces) and keywords (not more than 10), in English and another language of choice (Croatian, German, French, Italian, Spanish).

If complete bibliographical information regarding cited works is not stated in footnotes, the author must provide a reference list at the end of the article, containing complete information on cited works.

Manuscripts are to be sent by mail in three copies to the editorial board:

Department of Social Sciences and Medical Humanities
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The editorial board does not return manuscripts.

Citation method

The editorial board recommends using footnotes as a method of citation. When a work is cited for the first time (regardless of the language the work has been published in), it should look as following:

[for book] Tristram H. Engelhardt, *The Foundations of Bioethics*, University Press, New York 1986, p. 72.

[for proceedings] Jacob D. Rendtorff and Peter Kemp (ed.), *Basic Ethical Principles in Bioethics and Biolaw, Vol. I. Autonomy, Dignity, Integrity and Vulnerability*, Center for Ethics and Law, Institut Borja de Bioètica, Copenhagen, Barcelona 2000.

[for journal article] Roberto Andorno, »The Oviedo Convention: A European Legal Framework at the Intersection of Human Rights and Health Law«, *Journal of International Biotechnology Law*, 2 (4/2005.), p. 135.

[for proceedings article or book chapter] Diego Gracia, »History of medical ethics«, in: Henk Ten Have and Bert Gordjin (ed.), Bioethics in European Perspective, Kluwer, Dordrecht 2001., p. 34.

[for electronic works of reference] http://www.legalhelpmate.com/health-care-directive-patient-act.aspx (16 June 2009)

In the second and further citations, note should contain only the initial of author's first name and his surname, title of the work (book or article) and a page number:

T. Engelhardt, *The Foundations of Bioethics*, p. 113.

R. Andorno, »The Oviedo Convention: A European Legal Framework at the Intersection of Human Rights and Health Law«, p. 138.

When work is cited consecutively, the note should contain only the abbreviation Ibid and a page number

Ibid, p. 150.

The editorial board, naturally, accepts other methods of citation as well, under the condition they are used consistently within a particular text.

Upute autorima

JAHR – Godišnjak Katedre za društvene i humanističke znanosti objavljuje neobjavljene priloge. Namjera Uredništva je objavljivati članke iz širokog raspona tema (uključujući etiku, bioetiku, povijest i filozofiju znanosti i medicine, sociologiju, kulturnu antropologiju, teologiju, pravo i dr.). Časopis objavljuje članke koji se recenziraju i one koji ne podliježu recenzijskom postupku. Članci koji se recenziraju prihvaćaju se za objavljivanje nakon provedenog recenzijskog postupka, na temelju dviju anonimnih pozitivnih recenzija.

Recenzirani članci kategoriziraju se na sljedeći način:

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Časopis objavljuje i nekategorizirane radove, odnosno recenzije i prikaze bioetičkih, ali i drugih relevantnih izdanja objavljenih u zadnje tri godine u Hrvatskoj i inozemstvu, te izvješća i najave bioetičkih zbivanja (javna predavanja, predstavljanja knjiga, znanstveni skupovi i sl.).

Svojim pristankom na objavljivanju autori daju časopisu pravo prvog objavljivanja u tiskanom i elektroničkom formatu. Radove objavljene u časopisu JAHR autori mogu objaviti u drugim publikacijama uz navođenje podataka o njihovu prvom objavljivanju.

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[za članak iz časopisa] Roberto Andorno, »The Oviedo Convention: A European Legal Framework at the Intersection of Human Rights and Health Law«, *Journal of International Biotechnology Law* 2 (4/2005.), str. 135.

[za članak iz zbornika ili poglavlje iz knjige] Hrvoje Jurić, »Princip očuvanja života i problem odgovornosti«, u: Ante Čović (ur.), *Izazovi bioetike*, Pergamena, Zagreb 2000., str. 143.

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