

European Association of Centres of Medical Ethics
EACME
25th Annual Conference

"Bioethics from a Cross-Cultural Perspective"

September 15-17, 2011, Istanbul-Turkey

in collaboration with
The Turkish Bioethics Association

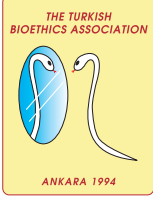


EACME
CONFERENCE

Istanbul, Turkey

2011

BOOK OF ABSTRACTS



**European Association of Centres of Medical Ethics
(EACME)**

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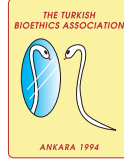
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European Association of Centres of Medical Ethics (EACME) Annual Conference



Turkish Bioethics Association

BOOK OF ABSTRACTS

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Editors

Yeşim Işıl Ülman - Muhtar Çokar

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tbd@biyoetik.org.tr - www.biyoetik.org.tr

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Tel: +90 212 260 92 32

info@catigrafik.com

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CONGRESS ORGANIZATION SECRETARIAT



Tel: +90 212 293 31 51

info@panaromaturizm.net

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FOREWORD

Dear Colleagues,

The Turkish Bioethics Association is privileged and honored to host, for the first time in Turkey, the Annual Conference of EACME in Istanbul. The Conference has been organized in collaboration with the Acibadem University School of Medicine, Medical History and Ethics Department.

The scientific programme covers a wide range of topics related to bioethics from a cross-cultural perspective, including bioethics and humanities, universal values and cultural diversity, European Biomedicine Convention, human rights and bioethics, and health care policy making.

The scope of the Conference has been designed by giving emphasis to the role of bioethics in an interdisciplinary approach with the allied fields by investigating its function in the content of human rights and its implementation in the teaching of medical humanities, in a cross-cultural perspective, keeping in close contact with conflicting issues in bioethics.

The boundaries between bioethics, health law, and human rights are increasingly blurred. These three domains become conceptually and operationally inseparable parts of the same trend towards ensuring respect for the human person in the bio-medical field. The major public health issues that we face today can be better addressed if all three disciplines work together. Bioethics can contribute to this inter-disciplinarity by accepting its Nuremberg roots and by actively engaging in a health and human rights agenda.

The human rights language is a great advantage to the construction of a universal bioethics. The central concepts that human rights are universal, inalienable, and linked to human dignity have been well articulated, widely endorsed, and publicly embraced. Consequently, harnessing the moral and rhetorical force of human rights language commands international attention to bioethics issues that impact human rights.

The aims of this Conference are to address the interaction between human rights issues and bioethics; to explore common ethical values to facilitate a cross-cultural dialogue and to discuss to what extent human rights can play the role of a *lingua franca* for international bioethics.

In addition, medical humanities offer a powerful way to convey an understanding the values that shape the physician-patient relationship. Also the European Biomedicine Convention is a very helpful document to explore these values with its special emphasis on human dignity and human rights. Lastly bioethics in conflicting issues in healthcare policy-making, in social justice and inequalities, population policy and gender policies claim to put forth novel and fruitful topics of discussion, all by keynote lectures and presentations.

We would like to extend our special thanks to Dr. Roberto Andorno, member of the Scientific Committee for his intellectual support at every stage of the Conference. We really appreciate efficient support of our colleagues in the EACME Board, Prof. Renzo Pegoraro, Prof. Dr. Chris Gastmans, Dr. Rouven Porz and Ms Angelique Heijnen, the executive secretary, with their helpful suggestions all through the process of preparation. We feel really indebted to the esteemed and eminent

bioethicists led by Prof. Dr. Jan Helge Solbakk and Dr. Antony Mark Cutter who have kindly chosen Istanbul as the venue of the Globalising Bioethics Education (GLEUBE) Summer School in order to back the EACME Istanbul Conference on the eve of the meeting. They have made a unique learning opportunity come true with the rich content of the School programme bringing American and European approaches to bioethics into discussion to search the roots of European bioethics methods and approaches in bioethics, human enhancement, converging technologies and public engagement. We express our special thanks to Heather Melanie R. Ames for all the organizational support.

We owe special thanks to the competent key-note speakers, Dr. Deborah Kirklın, Prof. Dr. Guy Widdershoven, Prof. Dr. Elmar Doppelfeldt, Ayşegül Elverış, L.L.M, Prof. Dr. Richard Ashcroft, Prof. Dr. İbrahim Ö. Kaboğlu, Prof. Dr. Nikola Biller-Andorno, Dr. Yvonne Denier who have provided the Conference its distinctive character with their sophisticated lectures to bring about the main themes into discussion. The members of the Scientific Committee who laboriously revised the abstracts deserve special appreciation by contributing to the meeting. We would like to thank the honorary presidents of the Conference, Prof. Dr. Yaman Örs and Prof. Dr. Necmettin Pamir, the Rector, and Prof. Dr. Nurdan Tözün, the Vice-Rector of Acıbadem University for their motivating and inspiring confidence in us through the making of this European Conference step by step.

This meeting has been sponsored by public and research funds granted to the projects produced by the Board of the Turkish Bioethics Association. We deeply appreciate Acıbadem University, the Turkish Prime Ministry Public Fund, the Turkish Ministry of Culture for their kind support to the Conference so as to enable the modest Conference budget accomplished. We are indebted to Panaroma Organization Firm care of Mr. Turgay Bektaş and Ms. Tuba Çeliker for their expert support to the Organising Committee; to l'Ajans for the subtle design of the Conference's visual material, to Verus for the efficient internet page of the Conference, to Mr. Ersin Bektaş, from Çatı Grafik, for the exquisite composition and printing of the *Book of Abstracts*.

On this occasion, the Turkish Bioethics Association is pleased to publish the Turkish translation of the Guide for Research Ethics Committee Members of the Steering Committee on Bioethics (CDBI) with permission of the Council of Europe to the benefit of the bioethicists and researchers in Turkey.

The main philosophy of the Board of the Turkish Bioethics Association is to function by appreciating individual labour while respecting the collective work as proven by its activities. We aimed to get the bioethicists around the world together in order to create an international academic platform for a multidisciplinary and cross-cultural interaction, and to explore the ways of collaborating and acting together led by the core values of bioethics, dignity, integrity and solidarity in a pluralistic and universalistic approach. This objective can be achieved, by your contributions in full sense; thank you for being with us in our beloved city, Istanbul.

**On behalf of the EACME 2011 Organising Committee
the Board of the Turkish Bioethics Association
Yesim Isil Ulman**

Dear Colleagues, Dear Participants of EACME Istanbul Conference,

On behalf of Acıbadem University School of Medicine and the Organising Committee it is a pleasure and honour to welcome you all in Istanbul in this prestigious Annual Meeting of the European Association of the Centres of Medical Ethics. I feel exclusively glad to open this scientific platform bringing about the main issues of bioethics and its interaction with human rights, medical education, new emerging technologies, healthcare policy making.

Last decades of the 20th century and the turn of the 21st century have witnessed a new fact and formation. Perception of world as a multifaceted prism, from social, political, cultural to scientific, technological, economical and humanitarian aspects, has necessitated a wider approach and viewpoint to assess the 21st century debates at length. The key to handle the problem has emerged as bioethics. Bioethics is an important part of this inclination as a discipline stemmed originally from the ethical philosophy, and flourished vastly in modern times. As the ethical issues have moved from being internal concerns of the professions to matters of public, political debate, bioethical decision making has immersed much more into the professional and academic resolution and analysis.

While the new medical technology and scientific developments promise a better and more comfortable way of life and facilities to men on earth, those technologies and promises are deeply questioned by philosophical debates and moral deliberation. Ethical reasoning has been an indispensable part of this discussion when it is universally accepted that any research or procedure cannot be approved unless it has been carried out within scientific and ethical boundaries. The experience of humanity during modern ages has been the struggle for the implementation of ethical standards and principles into all sorts of scientific researches and trials on human and non-humans. As a clinician and researcher I have personally been involved in and felt deep in my heart the ethical dilemmas in my professional life while seeking the best way to communicate with and set up a mutual interaction in decision-making for the benefit of my patient while doing no harm to her/him and, to handle with the complexities of truth telling without misleading or confusing my patient, and overcome the challenges of a fair and equal healthcare by keeping confidentiality and building a relationship based on trust. This has been a huge work overloaded with the clinical responsibilities and academic duties pervading twenty four hours of daily life and entire life span.

I feel excited to be a part of this academic platform thinking over not only the philosophical and moral debates but also the concrete issues of healthcare setting. I wish you an excellent congress to bring about and ponder on these matters in the background of a fabulous and inspiring Istanbul.

**Vice-Rector of Acıbadem University
Prof. Dr. Nurdan Tözün**

VALUES AND VALUE-LADENNESS IN CLINICAL ETHICS

By Yaman Örs, M. D., D. Phil.

Prof. Dr. (Ret.), Dept. of Deontology, Ankara University Medical Faculty

Welcome to everybody. I wish all of you success and a very nice time on the occasion of this congress. I thank wholeheartedly to the members of the Organizing Committee (excepting myself), and, above all of course, to Yeşim Işıl Ülman for her hard-to-believe efforts in the realization of this meeting.

I would like to thank her also for the acceptance of this concise academic speech, which is certainly not quite usual in the opening session of a congress, and for her critical evaluation of it.

The basic point in this brief presentation is the methodological distinction between moral values and moral value-ladenness, and its reflection in medical ethics, with special reference to clinical activity. (1)

More and more thinkers in related academic circles have been questioning in our time whether disease phenomena could be value-free, that is, if diseases can ever be regarded, in clinical medicine, as phenomena which could be studied, to a great extent, "objectively". Most if not all of the related points concerning the moral philosophy of medicine are considered in academic circles as well as in those of medical practice and elsewhere.

No one, on whichever side he/she may be in the related debates in this matter, could be sceptical about the basically humanistic concern on the part of the defenders of the thesis that diseases, insofar as patients are concerned, cannot be regarded as phenomena which are (morally / ethically) neutral. Of course, not only in human but also in animal medicine, obviously, pathological phenomena, clinically to be considered as illnesses, create serious moral issues. The scientific and philosophical problem here appears to be that whether pathological phenomena are value-free or value-laden depends, in principle, upon the level, whether organisational or discursive, at which we consider them: they concern different levels of empirical organisation in the living realm and in human life - biomolecular, cellular, systemic, biological, psychological and/or social...

An essentially conceptual, philosophical, and neglected, point, whose consideration would understandably contribute to the elucidation of the problem in question, is the generally omitted methodological one that the term "value", whether in philosophy or elsewhere, assumes quite different senses depending on the universe of discourse. Moral / ethical values, in medicine as well as generally, are semantically

quite different, obviously, from functional / practical, aesthetic, economic values and so on (let alone basically academic/technical ones such as mathematical or statistical values, or those in different basic sciences). Because contextually they all differ from one another, that is, ontologically speaking *they may have no significant resemblance relationship, although actually they may be interrelated* (esthetic and ethical values, economic and functional ones, and so on...). It must then be understandable that whenever we speak of our “values”, we must make clear to which “specific context” or “set” we refer.

We must also consider, in both theoretical and practical terms, to what extent different sets/subsets of pathological phenomena in medicine are *value-laden*, if they are not indeed value-neutral. We must then take into account *the important distinction between the more or less “direct” and exclusive moral concepts*, such as ‘goodness’, ‘integrity’, ‘virtue’, ‘compassion’, ‘loyalty’, ‘honesty’, ‘courage’, and so on, *on the one hand; and, on the other hand, those which represent value-ladenness*, as in the case of ‘poverty’, ‘in need of’, ‘pain’, ‘illness’ / ‘sickness’, ‘truth-telling’, or similar others, most of them with different degrees of medical relevance. We may add here, as regards one of the above points, that we should take into account different kinds of value-ladenness as well as values, whereby the term “value” as a linguistic element assumes quite different senses.

Generally speaking, in our philosophical considerations in ethics, it is evidently with reference to the values of our moral sphere that we formulate our views. When the discussants of “moral affairs” do utter moral terms, such as “goodness” or “responsibility”, or those of value-ladenness, like “patient” or “pain”, then it becomes undoubtedly clear that it is either the moral values or value-ladenness that would specifically concern us in the related contexts.

As the term “value” is mentioned more and more frequently in the philosophical literature and discussions on the ethics of clinical activity (and, certainly, in other aspects of medicine), we must be in a position to know, to the extent that this would be possible, the intensity or semantic “purity” or “centrality” / “central significance” of the related terms in a given context.

It must be evident that, so far as both moral relevance and intensity are concerned, there must certainly be a difference to be taken into account in moral discussions, concerning medical practice as well as generally speaking, between moral values and value-laden attitudes.

Ethical issues / topics in clinical medicine should possibly be understood as the sum total of the physician’s approaches, attitudes and behaviour to the patient and to the psychological, moral, and deontological aspects of his/her practice. More comprehensively, however, and judging by what can be meant by the term in the contemporary discussions on the specific aspects of medicine, we would be in a position to

observe that what is called “model” in medicine should rather denote to the overall scientific-academic, social-moral, and technical-practical commitments of the doctor within the context of clinical practice as well as medical activity as a whole. Thus, the term “model” would assume a function akin to that of “paradigm” or “conceptual framework” in the contemporary philosophy of science.

Lastly in the present context, I would like to mention an anecdote which would be related to our topic. During a coffee break in a symposium of psychiatry, I was discussing the above problem with a British colleague, a psychiatrist and philosopher. I was opposing his claims that the distinction of values in different contexts might not be really significant, and that at all events even if the opposite would be the case, psychiatrists might not be able to appreciate this philosophical point, at least “for the time being”.

Well, the accompanying picture, one of the quite interesting works of the great Catalan artist, Joan Miró (1893-1983), “The Two Philosophers” (1936)*, could perhaps be shown here relevantly. But I am certainly not in a position to tell which of these “beings”, the bird-like discussant or the long- and thin-headed one, would represent whom; I mean my British colleague or me.

* From: Roland Penrose, *miró*, Thames and Hudson, London, (1970, 1985) 1995; pp. 80-81.

(1) I owe thanks to Ms. Zümrüt Alpınar, doctoral student and my very young colleague, for her critical remarks and suggestions concerning this methodologically important point in ethics.

**Dear EACME Members,
Dear all Participants,**

It is a pleasure and an honor for me to express my warmest greetings to all of you today, on the occasion of the annual EACME Conference, which this year takes place in Istanbul.

First of all, I wish to express my particular thanks to the organizers of the event and our hosts, namely the Turkish Bioethics Association and the University of Acibadem School of Medicine in Istanbul, and in particular the colleague Prof. Yesim Ulman. My best greetings to all the authorities here present and the colleagues of Istanbul and Turkey.

I also would like to express my deep gratitude to Dr. R. Porz and Prof. C. Gastmans of the EACME Bureau and Mrs. A. Heijnen, executive officer, for all their precious work in support of the EACME so that the Association is alive and efficient promoting the dialogue and cooperation in the research on medical ethics and bioethics, and all the people who served the Association in the past years.

Geographically and historically, Istanbul is a “city-bridge”, which lies at the crossroads of great ethnic, cultural and religious traditions among Europe, Asia and North Africa. Through history, Europe and the Mediterranean basin have seen different populations and civilizations meeting and fighting, and even today this area is crossed by tensions and hopes both along the North-South axis and the East-West one. Recently, we have witnessed the outbreak of the war in Libya, the tragedy in Norway, the dramatic situation in Syria, the migration of many people and refugees. But we can also notice signs of turmoil and changes in the countries of North Africa: hopes of democracy in search of forms of greater justice and solidarity and better respect for human rights and the dignity of all men and women. Coming together is always a positive experience and, in some way, even a “surprise”, because sometimes the exchange and the discussion can lead to unexpected developments. My wish is that this tradition of the “bridge” will be confirmed by our Conference in Istanbul through the sharing of insights, taken from the cross-cultural perspective of bioethics, on the paradigm of human rights between universalism and particularism, and the role of medical humanities, thus enhancing the very rich art heritage of the European and Mediterranean world.

With this spirit and these goals in mind, I wish all of us to enjoy the EACME Conference that starts today driven by intellectual depth, positive feelings and appreciation for this beautiful city.

**Prof. Renzo Pegoraro
President of EACME**



**GLOBALISING EUROPEAN BIOETHICS EDUCATION (GLEUBE)
SUMMER SCHOOL
Istanbul, Turkey
September 11-14, 2011**

**In Conjunction with the European Association of Centres of Medical Ethics
Annual Conference, September 15-17, 2011**

"Bioethics is the philosophical study of the ethical controversies brought about by advances in biology and medicine. Bioethicists are concerned with the ethical questions that arise in the relationships among life sciences, biotechnology, medicine, politics, law, philosophy, and theology." (GLEUBE Website)

GLEUBE (Globalising European Bioethics Education) is a European Union funded project aimed at increasing the international profile of European bioethics. The project is a collaboration between five European institutions, The University of Central Lancashire (Co-coordinating institution), Cardiff University, Dublin City University, University of Helsinki and the University of Oslo.

Within the academic study of bioethics some scholars have identified the recent emergence of distinct "European" and "American" principles of bioethics. The so-called American values are represented by the Georgetown Principles. In contrast, European Principles might be seen to include autonomy, dignity, integrity and vulnerability. In addition, several „new“ principles have also proved popular in (predominantly European) bioethical debates, especially as relates to genomic technology; these include solidarity, benefit sharing and precaution. Most recently scholars have begun to identify principles that might reconcile or go beyond this apparent disparity of European and American principles. Against this backdrop, some have sought to identify similarities between the European and American principles, whilst others have questioned whether "bioethics" need be a "principles based" discipline at all.

In response to this emergence of distinct European approaches to bioethics, and the perception that current education, clinical and policy activity is dominated by American approaches, GLEUBE proposes a summer school to discuss this distinction. A different collaborating institute will present each of the four days of the summer school. Themes include the roots of European bioethics, methods and approaches in bioethics, human enhancement, converging technologies and public engagement. This is a unique learning opportunity within the realm of European Bioethics. The school will be held in English. We would like to invite all interested students both European and International (masters level or higher) to join us in Istanbul.

**www.gleube.eu
[www.twitter.com/gleube](https://twitter.com/gleube)
www.facebook.com/gleube**

This is European Bioethics: A Summer School, Istanbul 11-14 September, 2011, Program

	Sunday September 11th	Monday September 12th	Tuesday September 13th	Wednesday September 14th
9:00-9:15	<i>Opening and Welcome Address</i> Anthony Mark Cutter, Coordinator of GLEUBE Yesim Isil Ulman, Chair of the Turkish Bioethics Association	Morning Meet and Greet	Morning Meet and Greet	Morning Meet and Greet
9:15-10:00	Public engagement in converging technologies pt 1 Lecturer: Anthony Mark Cutter	Philosophical Ethics Lecturer: Matti Häyry	<i>Bioconservatism versus transhumanism</i> Lecturer: Bert Gordijn	<i>Emerging technologies and European bioethics: Part 1</i> Lecturer: Bjørn Hoffman
10:00-10:15	Break	Break	Break	Break
10:15-11:15	Public engagement in converging technologies pt 2 Lecturer: Natasha Burns	Methods and approaches in bioethics: Part 1 Lecturer: Tuija Takala	<i>Socratic debate about posthumanity</i> Dublin City University Lecturer: Bjørn Hoffman	<i>Emerging technologies and European bioethics: Part 2</i> Lecturer: Bjørn Hoffman
11:15-12:15	The importance of New Media Lecturer: Anthony Mark Cutter	Methods and approaches in bioethics: Part 2 Lecturer: Tuija Takala	<i>The Roots of European Bioethics: A view from Ancient Greek Antiquity</i> Lecturer: Jan Helge	<i>Emerging technologies and European bioethics: Part 3</i> Lecturer: Bjørn Hoffman
12:15-14:00	Lunch	Lunch	Lunch	Lunch
14:00-14:45	Web 2.0 and Research Lecturer: Natasha Burns	<i>Human enhancement in a European context</i> Lecturer: Bert Gordijn	<i>Catharsis and Moral Therapy: A Platonic approach to teaching bioethics</i> Lecturer: Jan Helge Solbakk	Student Group Work based on Oslo
14:45-15:00	Break	Break	Break	Break
15:00-15:45	Bioethics: It's scope and levels. European and other values in bioethics Lecturer: Matti Häyry	<i>Enhancement in Sports</i> Lecturer: Elizabeth Yuko	<i>Catharthis and Moral therapy: An Aristotelian approach to teaching bioethics</i> Lecturer: Jan Helge Solbakk	Student Presentations
15:45-16:00	Break	Break	Break	Break
16:00-17:00	Student Group Work based on Lancashire and Helsinki	<i>Neurotechnologies and brain computer interfaces</i> Lecturer: Bert Gordijn	Student Group Work based on Dublin and Oslo	Student Presentations
17:00-18:00	Student Group Presentations	<i>Reproductive medicine and artificial wombs</i> Lecturer: Elizabeth Yuko	Student Group Presentations	Evaluations and closing of the summer school

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"Bioethics from a Cross-Cultural Perspective"

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EACME 2011 ANNUAL CONFERENCE COMMITTEES

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Prof. Dr. Necmettin Pamir

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MAIN TOPICS

BIOETHICS FROM A CROSS-CULTURAL PERSPECTIVE

- Bioethics and Humanities
- The European Biomedicine Convention: a Platform of Dialogue
- Human Rights in Bioethics: Universalism and Particularism
- Bioethics in Conflicting Issues

MAIN TOPICS AND SUBTOPICS

I. Bioethics and Humanities

History of Bioethics for Understanding Different Ethical Traditions
Medical Humanities and Ethics Education
Comparison Between Western and Eastern Bioethics
Reason, Emotion and Bioethics

II. The European Biomedicine Convention: a Platform of Dialogue

Is There a European Bioethics?
Human Dignity and Bioethics
Bioethics and Biolaw
New Medical Technologies and Bioethics

III. Human Rights in Bioethics: Universalism and Particularism

Ethical Values for Bridging Gaps and Cross-Cultural Dialogue
Common Language for Dialogue in Bioethics?
Human Rights as a *Lingua Franca* for International Bioethics?
Bioethics in Industrialized and in Developing Countries

IV. Bioethics in Conflicting Issues

Ethics in Healthcare Policy Making
Social Justice and Inequalities in Bioethics
Population Policy and Bioethics
Gender Based Ethics

Thursday 15 September 2011				
HALL 1 (MAIN HALL)				
10:00-13:00	Registration			
12:00-13:00	Meeting of the EACME Board of Directors			
13:00-13:30	Opening Session Assoc. Prof. Yeşim Işıl Ülman, <i>President of the Turkish Bioethics Association</i> Prof. Dr. Nurdan Tözün, <i>Vice-Rector of Aciademy University</i> Prof. Dr. Yaman Örs, <i>Honorary President of EACME 2011</i> Prof. Dr. Renzo Pegoraro, <i>President of the European Association of Centres of Medical Ethics</i>			
13:30-14:30	Plenary Lecture: "Bioethics and Humanities" Key Note Speakers: Prof. Dr. Guy Widdershoven, Dr. Deborah Kirkin Moderator: Prof. Dr. Renzo Pegoraro			
HALL 1 (MAIN HALL)		HALL 2	HALL 3	HALL 4
14:30-15:45	Parallel Sessions BIOETHICS, DIGNITY AND AUTONOMY <i>Chair: Renzo Pegoraro</i> <u>Manne Sjöstrand</u> How to define decision-making competence <u>Ioana Ispas</u> My autonomy, your integrity and our dignity who should come first? <u>Jenny Slatman</u> Bodily integrity in blemished bodies <u>Murat Aksu</u> Istanbul Protocol and related training activities in Turkey	Parallel Sessions ETHICS, RESEARCH, PUBLICATION <i>Chair: Björn Hofmann</i> <u>Daniel Strech, Neema Sofaer</u> How to write a systematic review of argument-based literature <u>Gert Helgeson</u> Redundant publication in bioethics <u>Stefan Eriksson</u> Is peer review detrimental to science? On the need for more transparency <u>Péter Kakuk</u> Conflict of interests in biomedical sciences: toward a new ethical framework	Parallel Sessions BIOETHICS IN THE END OF LIFE <i>Chair: Reidun Førde</i> <u>Jan Schildmann, Daniel Strech</u> Quality of ethical guidelines on end of life decisions. reflections on a systematic review ... <u>Ralf Stutzki, Stella Reiter-Theil, Markus Weber</u> End of life issues in light of patients' religious and spiritual convictions. an explorative study with ALS /MND patients and their primary caregivers <u>Marianne K. Bahus, Reidun Førde</u> Doctors' attitudes and legal knowledge regarding patient autonomy and end-of-life decisions <u>Gürkan Sert, Tolga Güven</u> Can competent patients at the end of life refuse treatment in Turkey ? The ethico-legal aspects of the right to refuse	Parallel Sessions BIOETHICS AND HUMANITIES <i>Chair: Gerald Neitzke</i> <u>Anoja Fernando</u> A humanities course for medical students in Sri Lanka <u>Mehmet Ali Gülpınar, Mehmet Akman, Pemra Unalan, İnci User</u> Human in medicine course as an example of preclinical medical humanities programme <u>Nadi Bakırcı, Pınar Topsever, Yeşim Işıl Ülman, Muhtar Çökar</u> Medical ethics and humanities teaching: two years experience <u>Kenji Hattori</u> Substantial advantages of using drama cases in clinical ethics education
15:45-16:00	Coffee Break	Coffee Break	Coffee Break	Coffee Break
16:00-17:30	Parallel Sessions BIOETHICS AND PHILOSOPHY <i>Chair: Yaman Örs</i> <u>Zümrüt Alpınar</u> Ethics and bioethics in Prof. Yaman Örs's scientific philosophy <u>Michael ch. Michailov, Eva & Renate Neu, Manfred Holler</u> Medical philosophy incl. ethics in context of health policy <u>M. Volkan Kavas</u> Historicist approach to bioethics: an evaluation on methods and focal points	Panel Session CLINICAL ETHICS <i>Chair: Jan Schildmann</i> Panelists: <u>Jan Schildmann</u> , Germany <u>Gerald Neitzke</u> , Germany <u>Guy Widdershoven</u> , Netherlands <u>Marta Spranzi</u> , France <u>László Kovács</u> , Germany <u>Lazare Benaroyo</u> , Switzerland <u>Reidun Forde</u> , Norway	Parallel Sessions END OF LIFE <i>Chair: Bert Gordijn</i> <u>Ralf Jox</u> The progress and perils of the notion of a right to die <u>Ruth Horn</u> Euthanasia and end-of-life practices in France and Germany. what kind of autonomy for a terminally ill patient? <u>Pervin Somer, Elif Vatanoğlu</u> Home care services for geriatric patients in Turkey according to medical law and medical ethics <u>Gemma N. Balein</u> Factors associated with good death	Parallel Sessions BIOETHICS AND HUMANITIES <i>Chair: Nermin Ersoy</i> <u>Tetyana Ospanova, Valeriya Myasodov, Ievgeniia Bolokadze</u> Ethical teaching in nephrology <u>Pemra Unalan, Sibel Kalaça, Mehmet Ali Gülpınar, Mehmet Akan, Gürkan Sert</u> Implementation of a human in medicine programme in an undergraduate medical school curriculum

16:00-17:30	Marcel Mertz, Hannes Knuppel, Martina Schmidhuber Mapping disease specific ethical issues development of a framework for identifying and classifying disease specific ethical issues ..			Sefik Görkey Medicine in western painting tradition: an elective course proposal for medical humanities Tetyana Ospanova, Valeriy Myasoedov, Ievgeniia Bolokadze, Iryna Sorokina Teaching of bioethics in Kharkiv National Medical University
17:30-18:30	Parallel Sessions BIOETHICS IN CONFLICTING ISSUES <i>Chair: M. Volkan Kavas</i> Mentor Hamiti, Diturije Ismaili, Blerim Reka Internet ethics and education Yulia Chukova Scientific ethics and its particular aspects Ralf Stutzki Patients have a right to "unfiltered" media access...An audio-visual presentation	Parallel Sessions BIOETHICS AND HUMANITIES <i>Chair: Atilla Özgür</i> Mine Şehiralti, Aslıhan Akpınar Attributes of a good physician: medical students' changing opinions Dilek Özden, Şerife Karagözoğlu, Gülşay Yıldırım et al The ideas of intensive care unit doctors and nurses about futility care and treatment and the relationship between the work satisfaction and burnout level Boleslav L.Lichterman From deontology to bioethics: evolution of medical ethics in Russia		
19:00-21:30	WELCOME RECEPTION - BY THE BOSPHORUS Thursday 16 September 2011 HALL 1 (MAIN HALL)			
08:00-09:00	Registration			
09:00-10:00	Plenary Lecture: "The European Biomedicine Convention: a Platform of Dialogue" Key Note Speakers: Aysegül ELVERİŞ, LL.M, Prof. Dr. Elmar Doppelfeld Moderator: Prof. Dr. Ergun Özsunay			
	HALL 1 (MAIN HALL)	HALL 2	HALL 3	HALL 4
10:00-11:15	Parallel Sessions BIOETHICS, UNIVERSALISM AND PARTICULARISM <i>Chair: Tineke Abma</i> Bert Vanderhaegen Global bioethics is a fiction? David Fieldsend Unity in diversity: can there ever be a true European consensus in bioethics? Elvio Baccarini Cultural diversity, Medical Ethics, democracy Brigitte Feuillet Bioethics and biolaw: an established relationship	Parallel Sessions BIOMEDICAL RESEARCH <i>Chair: Jiri Simek</i> Sabine Salloch, Jan Schildmann, Jochen Vollmann Value and limitations of empirical research on peoples' moral attitudes in different cultural contexts Ioana Ispas What makes vulnerable principle unstable, in evaluation of research projects? Funda Gülşay Kadioğlu, Selim Kadioğlu Prominent topics and samples of empirical researches in Turkish medical ethics literature	Parallel Sessions BIOETHICS IN CONFLICTING ISSUES <i>Chair: Richard Nicholson</i> Erica Haimes, Ken Taylor, Ilke Türkmenbaş Women's views and experiences of an egg sharing for research scheme: does local practice have global implications? Kızılca Yürür, Murat Civaner Discrimination in healthcare: can we avoid all instances? Salvatore Pisu, Michela Pintor, Federica Demuru, Ernesto d'Aloja The right to respect the freedom and the right to protect the health: an harmony rather than a conflict	Parallel Sessions BIOETHICS IN THE BEGINNING OF LIFE <i>Chair: Yeşim Işıl Ülman</i> Marie Geneviève Pinsart Refusal of treatment of her foetus by a pregnant woman: socio-cultural aspects Tutku Özdoğan, Ebru Şenol, Sükrü Aydemir Three fetuses as patients Maria Liljas Stålhandske, Maria Ekstrand, Tanja Tydén et al Reason and emotions in conflict: existential and ethical aspects of abortion from a Swedish perspective Christina Jivkova The abortion as an instrument to control the birthrate

10:00-11:15		Serdar İzmirli, Süleyman Dere, Aşkın Yaşar The contribution of the studies to the medical science by using experimental animals (rat and mouse) in Turkey	Sükran Sevimli Bioethical concepts and applications of the concepts and practices contribute to peace	
11:15-11:30	Coffee Break	Coffee Break	Coffee Break	Coffee Break
11:30-12:45	Parallel Sessions ETHICS IN HEALTHCARE POLICY MAKING <i>Chair: Tamay Başağaç Gül</i> Juha Räikkä Public health policies and the question of feasibility Tineke Abma Policy discourses on intercultural healthcare: from paternalism to objectification Marko Ahteensuu Medical decision-making under great uncertainty Hana Horak Development of ECJ case law in the field of health services	Parallel Sessions BIOETHICS AND THE PUBLIC <i>Chair: Chuan-Feng Wu</i> Helena Siipi Ethics of engaging the public James Yeates, Natasha Browning, Ruud Ter Meulen The empirical return: a model for including public discourses in bioethics Hung En Liu What do the general public think about researchers' financial conflict of interest in biomedical research?— results of a public survey in Taiwan James Yeates, Ruud Ter Meulen Framing public discussion of enhancement: the final word?	Parallel Sessions HUMAN DIGNITY AND BIOETHICS <i>Chair: Lazare Benaroyo</i> Renzo Pegoraro Advance directives in the european debate Zehra Göçmen Baykara, Serap Şahinoğlu Assessment of nurses' professional autonomy in nursing care: a qualitative study Özge Yücel The problem of chemical castration of sexual offenders in the context of gender based ethics Zehra Göçmen Baykara - Serap Şahinoğlu New nursing law and conversion of nursing profession in Turkey	Parallel Sessions BIOETHICS, RELIGION AND ETHNICITY <i>Chair: Muhtar Çokar</i> Henry S. Perkins, Josie D. Cortez, Helen P. Hazuda Gender differences within American ethnic groups over attitudes about physicians, treatments, and the health care system Jamal S. Aljarallah Challenges facing islamic biomedical ethics Jiri Simek, Ondrej Doskocil World ethics declaration and its role in religious bioethical tradition Angeliki Kerasidou Malariaigen: an example of bioethical practice in developing countries
12:45-13:45	Lunch	Lunch	Lunch	<i>PhD-Lunch-Meeting Chair: Dr. Rouven Porz</i>
HALL 1 (MAIN HALL)				
13:45-14:45	Plenary Lecture: "Human Rights in Bioethics: Universalism and Particularism" Key Note Speakers: <i>Prof. Dr. Richard Ashcroft, Prof. Dr. Ibrahim Ö. Kaboğlu</i> Moderator: <i>Dr. Rouven Porz</i>			
	HALL 1 (MAIN HALL)	HALL 2	HALL 3	HALL 4
14:45-16:00	Parallel Sessions BIOETHICS, HUMAN RIGHTS AND DIGNITY <i>Chair: Zuhail Okuyan</i> Benedict Faneye Human dignity & human rights: a universal language for bioethics Chris Durante Agreeing to disagree in a morally diverse society: coping with religio-cultural pluralism from human rights to bioethics Friedo Zoelzer Human rights and obligations: an approach to Bahá'í bioethics Kris Dierckx, David G. Kirchhoffer Human dignity and human tissue: a meaningful ethical relationship?	Parallel Sessions BIOETHICS FROM A CROSS- CULTURAL PERSPECTIVE <i>Chair: Richard Ashcroft</i> Cristián Borgoño Is inculturation a proper paradigm for a cross-cultural bioethics? Zehra Edisan - Funda Gülay Kadioğlu Health related quality of life questionnaires and cross-cultural adaptation: an assessment from ethical point of view Gerald Neitzke Trans-cultural competencies in clinical ethics consultation Demet Tekin, Gurban Sert, Aysegül Akgül, Ani Agopyan Sportsmen's views of private life and expectations in relation with health centers and sports doctors	Parallel Sessions BIOETHICS AND HEALTHCARE <i>Chair: Yvonne Denier</i> Tim Peters, Jan Schildmann, Jochen Vollmann Interculturality at the bedside: two teaching concepts on the management of patients from different cultural backgrounds for medical students Tolga Güven, Aslihan Akpınar Why we need to "care": the problems created by promoting patient autonomy as a legal concept in Turkey's healthcare setting and the ethics of care perspective as a possible solution Lyudmila Chakarova, Sylvia Mladenova Bioethical aspects of the concept for sustainable development in healthcare	Parallel Sessions HUMAN RIGHTS IN BIOETHICS <i>Chair: İke Türkmenbaş</i> Ingemar Engstrom Three fundamental ethical perspectives – paternalism, autonomy and participation – and their relation to human rights Allane Madanamoothoo What protection for the saviour-sibling child under French law? Richard Nicholson Does humankind want to survive? Vojin Rakic Neuro-pharmacology for "cosmetic" purposes: ethical, political and cultural aspects

16:00-16:15	Coffee Break	Coffee Break	Coffee Break	Coffee Break
16:15-17:30	EACME General Assembly			
19:00-23:00	GALA DINNER - BOSPHORUS CRUISE			
Saturday 17 September 2011				
HALL 1 (MAIN HALL)				
09:00-10:00	Plenary Lecture "Bioethics in Conflicting Issues" Key Note Speakers: <i>Prof. Dr. Nikola Biller-Andorno, Dr. Yvonne Denier</i> Moderator: <i>Prof. Dr. Chris Gastmans</i>			
HALL 1 (MAIN HALL)		HALL 2	HALL 3	HALL 4
10:00-11:15	<p>Parallel Sessions BIOETHICS IN CONFLICTING ISSUES <i>Chair: Nikola Biller-Andorno</i></p> <p><u>Christian Kind</u> A hunger striker, the swiss federal court, forced feeding, and good medical practice</p> <p><u>Marie Chenik, Urban Nylen</u> Female patient beliefs and preferences about gender challenging staff determination to preserve equality between men and women caregivers...</p> <p><u>Teddy Florea, Eniko Demyeny</u> Applied Case Studies in Ethics and Medicine in Eastern Europe – the Role of Bio-Ethics in Living Organ Donations' Decision Making</p> <p><u>Hsiao-Lu Lee, Yu-Ling Bai</u> Kidney allocation priority for waiting list or younger age case</p>	<p>Parallel Sessions BIOETHICS IN CONFLICTING ISSUES <i>Chair: Ruud ter Meulen</i></p> <p><u>Francesca Bosisio, Marie Santiago, Lazare Benaroyo</u> The ethical principles versus the market logic: a Swiss-French survey on incentives for organ donation</p> <p><u>Chuan-Feng Wu</u> The right to health and healthcare, distributive justice</p> <p><u>Björn Hofmann</u> On the anxiolytic use of diagnostic tests: two case studies</p> <p><u>Anne Hambro Alnæs</u> Cultural competence: an ethical obligation for physicians exploring possibilities of living kidney donation (LKD) ...</p>	<p>Parallel Sessions BIOETHICS AND BIOLAW <i>Chair: Meral Özgüç</i></p> <p><u>Lillian Lillemoen, Elisabeth Gjerberg, Reidar Pedersen, Reidun Førde</u> Informed consent and ethical challenges in nursing homes. The experience and views of patients and next of kin</p> <p><u>Şükran Sevimli</u> Child clinic and informed consent issue</p> <p><u>Mukaddar Gün, Serap Şahinoğlu</u> Evaluation on embryonic stem cell researchs from the perspective monotheistic religions</p> <p><u>Mehmet Karataş, Özgür Karataş, Özgür Çevrim</u> Inönü Univ. School of physical education and sports school students perceptions of the use of doping and ethics.</p>	<p>Parallel Sessions ETHICAL VALUES FOR CROSS-CULTURAL DIALOGUE <i>Chair: Mine Şehiraltı</i></p> <p><u>Pamela Tozzo</u> Bioethical issues involved in disclosing misattributed paternity from different countries' perspectives</p> <p><u>Tineke Abma</u> And they are all called Mohammed." experiences of migrant students with the medical curriculum on cultural sensitivity</p> <p><u>Marta Spranzi</u> The ethical position of interpreters in the medical encounter: neutrality and medical ethics</p> <p><u>Liliane Elze Falcão Lins Kusterer</u> Bioethical issues and transcultural aspects from complementary and alternative medicine ...</p>
11:15-11:30	Coffee Break	Coffee Break	Coffee Break	Coffee Break
11:30-12:45	<p>Parallel Sessions SOCIAL JUSTICE AND INEQUALITIES IN BIOETHICS <i>Chair: Kris Dierickx</i></p> <p><u>Gülsüm Onal, Murat Civaner</u> What do patients complain about in Turkey: a retrospective study of patient rights units' documents</p> <p><u>M. Volkan Kavas</u> Performance based payment in healthcare and loss of values: transformation from lettered physician to estranged technician</p> <p><u>Erica Falkenstrom, Anna T. Hoglund, Jon Ohlsson</u> The role of emotions in the handling of ethical dilemmas</p> <p><u>Pietro Refolo, Roberta Minacori, Vincenza Mele et al</u> Patient-reported outcomes (pros): the significance of using humanistic measures in clinical trial and clinical practice</p>	<p>Parallel Sessions BIOETHICS AND NEW MEDICAL TECHNOLOGIES <i>Chair: Funda Gülay Kadioğlu</i></p> <p><u>Ayşe Yüzbaşıoğlu, Meral Özgüç</u> Biobank for Rare, Disorders and Some Bioethical Reflections</p> <p><u>Luciana Caenazzo, Renzo Pegoraro</u> Forensic DNA database in Europe: some ethical issues</p> <p><u>Gönül Peker</u> Neuroethics: what, why, how, where & for whom</p> <p><u>Atilla Özgür, Savaş Volkan Genç</u> Productive robots or life partners?</p>	<p>Parallel Sessions BIOETHICS AND NEW MEDICAL TECHNOLOGIES <i>Chair: Anne Hambro Alnæs</i></p> <p><u>Alexander McKeown</u> Controlling human enhancement technologies: the need for a heuristic approach</p> <p><u>Karsten Klint Jensen</u> Is there anything special about gene therapy?</p> <p><u>Sinan Fındık, Tuna Çakar, Yeşim Işıl Ulman</u> Ethical concerns about neuromarketing</p> <p><u>Linus Vanlaere, Trees Coucke</u> High technology in the realm of health care: a care-ethical appraisal</p>	<p>Parallel Sessions BIOETHICS IN CONFLICTING ISSUES <i>Chair: Serap Şahinoğlu</i></p> <p><u>Aimi Yusof</u> Is variation in research ethics committees' decisions acceptable?</p> <p><u>Arianna Ferrari, Christopher Coenen</u> The challenges of technological visions for the bioethical discourse: the case of cognitive enhancement</p> <p><u>Anton A Van Niekerk</u> Deliberating about race as variable in biomedical research</p> <p><u>Boleslav Lichterman, Leonid Likhterman</u> Ethical dilemmas in neurosurgery</p>

HALL 1 (MAIN HALL)	
12:45-13:00	Closing Session
POSTER PRESENTATIONS	
PP - 1	Imitative disorders in the system of modern psychology and ethics <u>A. A. Shevchenko</u>
PP - 2	Prevention of burnout syndrome in professional activity-actual problem of medical ethics <u>A. A. Shevchenko</u>
PP - 3	Prenatal diagnostics of congenital malformations of the central nervous system in children– ethical issues <u>A. A. Shevchenko</u>
PP - 4	Principles managing for dying patients in The clinic of intensive therapy: ethical and medical aspects <u>A. N. Verbitskiy</u>
PP - 5	Research ethics committees in Belarus: ethics promoters or just formal structures? <u>Andrei Famenka</u>
PP - 6	National midwifery ethic values and determination code of ethics: an example <u>Ayla Berkiten Ergin</u> , Müesser Özcan Şenses, Zeynep Acar, Nermin Ersoy
PP - 7	European epidemiology and ethics (E3) survey <u>Behnaz Schofield</u>
PP - 8	Ethical evaluation of e-health practices <u>Bilge Sözen</u> , Sevgi Şar
PP - 9	Conflict management in Bulgarian nursing practice – an empirical study results <u>Dimitrova Svetlana Metodieva</u> , G.Petrova, J.Marinova, B. Parashkevova, G. Chamova
PP - 10	The wildlife protection and improvement areas in accordance with animal protection and bioethics Gökhan Aslım, Ali Yiğit, Aşkın Yaşar, <u>Serdar Izmirli</u>
PP - 11	Clinical trials and ethics committees in Turkey <u>Hilal İlbars</u>
PP - 12	Human Dignity and Human Enhancement <u>Joanna Rozynska</u>
PP - 13	Professional ethics committee activity - reflection of ethical problems existing in the period of Bulgarian healthcare reform <u>Marinova Juliana Krumova</u> , B. Parashkevova, Sv. Dimitrova, G. Chamova, G.Petrova
PP - 14	Start to inquire about:inform consent and keeper sisterhood concepts in the Jodi Picoult's my sister's keeper novel <u>Mukadder Gün</u>
PP - 15	Patient rights and professionals: knowledge of health care workers in Istanbul on patient rights <u>Nuran Akyurt</u> , Tolga Güven, Gürkan Sert, Murat Balıkcı, Hakan Albayrak
PP - 16	Views of a group of physician in residency training on informed consent <u>Oya Ögenler</u> , Nursel Bilgin, Selim Kadioğlu, Tamer Akça
PP - 17	The senior nursing students in west black sea universities association attitudes to patient rights <u>Rahime Aydın Er</u> , Nermin Ersoy, Sevim Çelik
PP - 18	Informed Consent in Veterinary Practice <u>R. Tamay Başağaç Gül</u> , Özgül Küçükaslan
PP - 19	Patient rights and professionals: opinions of health care workers in Istanbul on patient rights <u>Tolga Güven</u> , Nuran Akyurt, Gürkan Sert, Murat Balıkcı, Hakan Albayrak

CONFERENCE SESSIONS

15 September 2011, Thursday

**HALL 1
13:30 – 14:30**

Plenary Lecture: “Bioethics and Humanities”

Key Note Speakers: **Prof. Dr. Guy Widdershoven,**
Dr. Deborah Kirklin

Moderator: **Prof. Dr. Renzo Pegoraro**

Guy A.M. Widdershoven

Guy A.M. Widdershoven (1954) is professor of Philosophy and Ethics of Medicine and Head of the Department of Medical Humanities, and senior researcher at the EMGO Institute for Health and Care Research of VU University Medical Center, Amsterdam. He published on hermeneutic ethics, and its application in empirical ethics, moral deliberation and ethics of chronic care (psychiatry and elderly care). Research topics; autonomy in chronic care, coercion in psychiatry, evaluation of moral deliberation projects, end-of-life issues, genetics and public health genomics. He is scientific director of the Netherlands School of Primary Care Research (CaRe) and president of the European Association of Centers of Medical Ethics (EACME).

EXPERTISE

- Experience in clinical ethics and facilitation of moral deliberation in healthcare institutions (general hospitals, psychiatry, elderly care)
- Member of ethical committees in healthcare institutions
- Experience in ethical analysis of case stories (both methodology and content)
- Experience in empirical ethics (both theoretical/methodological and practical)
- Experience in mixed methods research (combining qualitative and quantitative research in health care)

SELECTED PUBLICATIONS (2005-2009)

- Widdershoven, G., Abma, T., Molewijk, B. (2009). Empirical ethics as dialogical practice. *Bioethics* Vol. 23 (4), p. 236-248.
- Widdershoven, G., Molewijk, B., Abma, T. (2009). Improving care and ethics: A plea for interactive empirical ethics. *The American Journal of Bioethics* Vol. 9 issue 6 & 7, p. 99-101.
- Abma, T., Molewijk, B., Widdershoven, G.A.M. (2009). Good care in ongoing dialogue. Improving the quality of care through moral deliberation and responsive evaluation. *Health Care Analysis: Volume 17, Issue 3*, p. 217-235.
- Slatman, J., Widdershoven, G. (2009). Being whole after amputation. *The American Journal for Bioethics* 9; 1: 48-49.
- Widdershoven, G., McMillan, J., Hope, T., Van der Scheer, L. (eds.) (2008). *Empirical Ethics in Psychiatry*. Oxford: Oxford University Press
- Molewijk, A.C., Abma, T., Stolper, M., Widdershoven, G. (2008). Teaching ethics in the clinic: the theory and practice of moral case deliberation. *Journal of Medical Ethics* 34 p. 120-124
- Goldsteen, M., Abma, T., Oeseburg, B., Verkerk, M., Verhey, F., Widdershoven, G. (2007). What it is to be a daughter? Identities under pressure in dementia care. *Bioethics* 21 (1), p. 1-12
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- Widdershoven, G.A.M., Berghmans, R.L.P. (2006). Meaning-making in dementia: a hermeneutic perspective. In: Hughes, J.C., Louw, S.L., Sabat S.R. (eds.). *Dementia. Mind, meaning, and the person*. Oxford: Oxford University Press, p. 179-191.
- Abma, T.A., Widdershoven, G.A.M. (2006). Moral deliberation in clinical psychiatric nursing practice. *Nursing Ethics* 13 (5), p. 546-557.
- Ashcroft, R., Lucassen, A., Parker, M., Verkerk, M., Widdershoven, G. (Eds.) (2005). *Case analysis in clinical ethics*. Cambridge: Cambridge University Press.
- Widdershoven G.A.M. (2005). Beyond autonomy and beneficence. The moral basis of euthanasia in The Netherlands. In: Schotsmans, P., Meulenbergs, T. (eds). *Euthanasia and Palliative Care in the Low Countries*. Leuven/Paris/Dudley, MA : Peeters, p. 83-95

BIOETHICS AS HUMAN SCIENCE

Guy A.M. Widdershoven

Department of Medical Humanities, EMGO Institute for Health and Care Research,
VU University Medical Center, Amsterdam

E-mail: g.widdershoven@vumc.nl

In my presentation, I will argue that bioethics is part of the tradition of the humanities or human sciences (Geisteswissenschaften). According to philosophical hermeneutics (H.-G. Gadamer), the human sciences are moral sciences. They investigate our moral geography (M.U. Walker). The human sciences aim at moral learning (Bildung). They help us to understand our world better, and to find our way in it. This implies a combination of descriptive and normative elements. The recent trend towards empirical ethics can be seen as an actualization of the tradition of the humanities. I will illustrate this with examples from bioethics research.

Dr. Deborah Kirklin

Deborah Kirklin is a family physician in North London, a teacher at University College London. She graduated as a doctor from Oxford University in 1986 and then worked as a paediatric intern at the Massachusetts General before returning to England to complete her training in general practice. In 1998 she completed an MA in Medical Law and Ethics at King's College London, and in 2005 completed a PhD in Medical Ethics at Manchester University. From 1998 to 2006 she helped establish a programme of medical humanities at University College London, and from 2000 to 2006 was the director of the UCL Centre for Medical Humanities. In June 2008 she was appointed Editor of the BMJ journal Medical Humanities. Her research interests include the legal, ethical and social implications of the new genetics, end of life care, women's health, interpretative approaches to ethical analysis, and medical education.

MEDICAL HUMANITIES: FROM CONCEPTION TO BIRTH

Dr. Deborah Kirklin

There is a pressing need for a contemporary health and policy discourse that's rich and subtle and diverse, and informed by the insights and knowledge of as wide a range of thinkers and doers as possible. In this paper I will argue that working together, across the rich disciplinary reach of medical humanities, scholars can not only enrich each other's work, but can also create meaning to inform the here and now. I will begin by exploring different conceptions of medical humanities, and end with a practical example of how this approach can enrich the work of ethicists, using the history of mental health legislation in the UK to illustrate my point.

15 September 2011, Thursday

HALL 1
14:30 – 15:45

Parallel Sessions
BIOETHICS, DIGNITY AND AUTONOMY

Chair: **Renzo Pegoraro**

Manne Sjostrand
How to define decision-making competence

Ioana Ispas
My autonomy, your integrity and our dignity who should come first?

Jenny Slatman
Bodily integrity in blemished bodies

Murat Aksu
Istanbul Protocol and related training activities in Turkey

HOW TO DEFINE DECISION-MAKING COMPETENCE

Manne Sjöstrand

Karolinska Institutet, Centre for Healthcare Ethics, Berzelius väg 3,
11771 Stockholm, Sweden, E-mail: manne.sjostrand@ki.se

Presented at the Conference by: Manne Sjöstrand

Abstract:

The right of patients to be informed and to make their own healthcare decisions is generally acknowledged in medical ethics. In laws and regulations this typically is formulated in the form of certain requirements for informed consent. This is also acknowledged in major international conventions such as the European Council's Convention on Human Rights and Biomedicine. However, the right to have one's healthcare decisions respected presupposes the ability to make such decisions. This is often referred to as "decision-making capacity" or "decision-making competence" and is commonly held as an important element of patient autonomy. Influential definitions of competence usually list criteria such as intentionality, understanding, appreciation and reasoning. Other questions, such as whether competence also involves emotional capacities and whether competence varies with risk, are more controversial.

It is commonly recognized that competence is a normative concept. Since the assessment of patients' competence may serve to distinguish decisions that should be respected from those that need not be respected, it obviously can have important consequences for how patients are treated. Moreover, the very concept of competence is based on normative deliberations. Even if it were defined in terms of quantifiable abilities, scientific or psychological methods could neither determine which abilities were the relevant ones, nor the degree of them that should be required. These questions need to be examined in relation to more or less controversial normative assumptions. Although most bioethicists might agree upon this problem, its implications have not been properly recognized in the bioethical debate. I propose that in order to find an adequate definition of competence, we first need to decide what the purpose of the definition is. If the purpose is practical (for instance to make decisions about (in)voluntary treatment in psychiatry, or to decide whether a patient is able to consent to participate in clinical research), it may be possible to establish some general criteria that the definition should fulfil. For instance, it should be applicable in practice, it should be able to gain support from different ethical theories, it should have reasonable normative implications, etc. Different criteria will entail different results for the concept of decision-making competence, which may, in turn, imply different understandings of the concept of patient autonomy. Even if no single definition of competence can take equal account of all possible criteria, it may nevertheless be possible to arrive at one that is both normatively plausible and practically useful and that can avoid controversial ethical assumptions. The aim of this presentation is to demonstrate how such a definition can be established.

Key Words: Autonomy, decision-making competence

MY AUTONOMY, YOUR INTEGRITY AND OUR DIGNITY WHO SHOULD COME FIRST?

Ioana Ispas

Center for Applied Ethics, University of Bucharest, 204 Splaiul Independentei Blvd, Bucharest, Romania.

E-mail: ioana_isp@yahoo.com

Presented at the Conference by: Ioana Ispas

Abstract:

The research ethics committees responsible for different ethical evaluations and who are committed to give a public advice are a constant presence in democratic societies. As consequence, in these cases we could accomplish an engagement of using pluralist values. Due to the fact that we assume that taking decision at the individual level is ethically based, we could make the statement that people have different ethics to guide them. Is any unique approach which could help us to take a responsible decision? Ethical principles are universal, meaning the same thing for each person or situation, in a relevant context.

In this context the article investigates whether the ethical principles such as autonomy, integrity and dignity could be used in evaluating biomedical research projects, individually or in combinations. The methodology is based on ethical matrix elaborated by Mepham for a group of imaginary research projects which try to investigate the war consequences on the vulnerable human beings (research on prisons included). The impact of environment (on animals, plants and generally speaking on biodiversity) is also taken into account.

The ethical matrix is used to illustrate different results of ethical evaluation for different category of vulnerable people and different vulnerabilities (cognitive vulnerabilities, medical vulnerabilities, infrastructure vulnerabilities, allocation vulnerabilities). In my approach I agree with Beauchamp interpretation that vulnerability has no group specificity.

The research investigates which of these three principles offer a better coverage of the vulnerable human being interests and whether the combination of two out of three principles is useful for ethical evaluation of the projects. The interpretation of the findings is based on Romanian legislation in research ethics.

Key Words: Autonomy, biomedical research, ethical matrix.

BODILY INTEGRITY IN BLEMISHED BODIES

Jenny Slatman

CAPHRI School for Public Health and primary Care, Department Health, Ethics and Society, Maastricht University Medical Center

PO Box 616 6200 MD Maastricht

Netherlands

E-mail: Jenny.slatman@maastrichtuniversity.nl

Presented at the Conference by: Jenny Slatman

Abstract:

In this paper, I would like to present the theoretical background and the initial questions of my new interdisciplinary research project on “bodily integrity in blemished bodies”, which I currently carry out together with two PhD students in the Maastricht University Medical Center oncology ward and the Dutch National Cancer Institute in Amsterdam (with funding of a grant from the innovative research incentives program of the Dutch Organization for Scientific Research (NWO-VIDI grant)).

This project seeks to gain an understanding of bodily integrity by exploring the experience of bodily *wholeness*. It will argue that the way in which people experience their own bodies is not just a psychological fact, but that this experience also serves as the basis for making choices, and thus entails a *normative* meaning. From a theoretical perspective on ethics, this implies that this project seeks to base ethics on embodiment, or more precisely, on experiences of embodied self-experiences. Something like “best clinical practice” cannot be based upon medical possibilities, correct medical information and patients’ cognitive processing of this information only – it should also include an evaluation of the way a patient experiences her or his own body. To flesh out this phenomenological ethics of the body, this project will focus on people with disfiguring breast, head and neck cancer.

Theoretical starting point for this project is provided by phenomenological accounts on embodied self-experience, i.e. that the experience of one’s own body is double-sided. One can experience one’s own body both as an object one *has*, and as a lived through agent (or subject) one *is*. In contrast with habitual views on bodily integrity in current ethical discussion, this project starts from the view that bodily integrity or bodily wholeness is directly related to the degree in which a person is able to identify with her or his body, i.e. the degree in which a person is able to be the body s/he has. In this project, we will focus on the capacity of (re)identifying with one’s blemished body.

Pursuing a qualitative empirical study in the field of oncology care, we will investigate how to understand this process of (re)identification in cancer survivors whose bodies are (visibly) marked by cancer(s) and/or its surgical treatment (including possible reconstructions). We will explore five lines of inquiry: (1) how people experience their disfigurement; (2) which “strategies” they use to cope with it; (3) what choices and decisions they make; (4) what the impact of cultural representations is in 1, 2 and 3; and (5) to what degree their strategies and decisions actually result in

an experience of bodily wholeness. We will thus assess the relation between patients' embodied self-experience and the choices that are offered and made.

It is expected that the outcomes of this project – an empirically sound vocabulary of body experiences in oncology care – will be applied to evaluate and adjust existing decision aids, and to pave the way for a new treatment decision model.

Key Words: Bodily integrity; disfiguring cancer; phenomenological-narrative ethics

ISTANBUL PROTOCOL AND RELATED TRAINING ACTIVITIES IN TURKEY

Murat Aksu¹, Ufuk Katkıcı^{2,4}, Istanbul Protocol Education Committee*

*Bahattin Özdemir³, Berna Aydın⁴, Burhanettin Kaya⁴, Çağlar Özdemir⁴, Emre Kapkın⁴, Gürcan Altun⁴, Hakan Özdemir⁴, Halis Ulaş⁴, Hülya Üçpınar^{3,5}, Kerem Altıparmak³, Kemalettin Acar⁴, Nadir Arıcan⁴, Önder Özkalıpcı⁶, Özgür Can⁴, Serhat Gürpınar⁴, Sezai Berber⁴, Şebnem Korur Fincancı^{4,5}, Türkcan Baykal⁴, Ümit Biçer⁴, Ümit Ünüvar^{4,5}, Yasemin Balcı⁴

¹ Adnan Menderes University School of Medicine, Department of Medical Ethics and the History of Medicine, E-mail: murataksumd@gmail.com

² Adnan Menderes University School of Medicine, Department of Forensic Medicine, E-mail: ufuk.katkici@gmail.com

³ Turkish Medical Association, Master Trainer, Lawyer, Izmir, Ankara.

⁴ Turkish Medical Association, Master Trainer, MD, Samsun, Ankara, Kayseri, Izmir, Edirne, Denizli, İstanbul, Isparta, Eskişehir.

⁵ Human Rights Foundation of Turkey, Master Trainer, Lawyer, MD, Istanbul.

⁶ International Rehabilitation Council for Torture Victims, Master Trainer, MD, Copenhagen K, Denmark.

Presented at the Conference by: Murat Aksu

Abstract:

Torture is a profound concern of the world community. Torture, ill-treatment and other human rights violations, number of international legal regulations are prohibited. However, torture still exists as a worldwide practice, and nevertheless a serious problem despite the observed changes in practice of torture in Turkey after recent legal amendments and with many years in the field of human rights struggle. One of the most important documents in this area is Istanbul Protocol called “Manual on the Effective Investigation and Documentation of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment”. The Istanbul Protocol is a standard guideline for legal, and health professionals for effective investigation and documentation of torture. This document submitted to the United Nations High Commissioner for Human Rights in 9 August 1999.

“The Principles on the Effective Investigation and Documentation of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment” have been annexed to the General Assembly resolution 55/89 (4 December 2000) and the Commission Human Rights resolution 2000/43 (20 April 2000), both adopted without voting. The Protocol provides comprehensive, practical guidelines for the assessment of persons who allege torture and ill-treatment, for investigating cases of alleged torture, and for reporting the findings to the relevant authorities.

Turkish physicians, lawyers, human rights defenders provided significant and important contributions in the creation efforts of this protocol. After the starting point, Turkish physicians showed an excellent effort to fight the torture and other cruel practice with a project. This project aimed to raise physicians' knowledge and skills fighting against torture; they may also have a key role in the documentation of torture.

Between 2007-2009, Turkish Government has put an effort in training of the medical personnel on the Istanbul Protocol. This project was called "Training Programme on the Istanbul Protocol", and approximately 3500 physicians were trained by Turkish Medical Association and International Rehabilitation Council of Torture Victims as a consortium partner. This "Training Programme" can be considered as a positive step towards prevention of torture in Turkey.

Currently, it has been developed a follow-up system by a continuous training programme based on long distance training by Human Rights Foundation of Turkey. This long distance training program aims to give the conceptual framework about medical ethics and rise to knowledge of participants and get an awareness human rights and medical ethics especially torture and other cruel practice according to the Istanbul Protocol principles. The training programme is consisted with 3 sections and last for three months. First section topics cover conception of international human rights, human rights regulation and universal ethics principles. The purpose of this section is to give essential knowledge to participants and show that there are not any conflicts between universal ethical principles and international-national regulation, provided that approached the human rights basis. Second section includes principles common to all codes of health-care ethics. Subtopics of this section are consisted by the duty to provide compassionate care, informed consent, confidentiality. In this section, we aim to raise awareness among the participants so that they may develop new attitudes if they encounter a torture case. And final section focuses on health professionals with dual obligations.

In Turkey as a developing country, governmental and non-governmental organizations' collaboration with these educational efforts aim to protect human rights at the national area and support the efforts of fighting against the torture at international dimension with gained experience.

Key Words: Ethics, human rights, torture, Istanbul protocol, training, Turkey.

15 September 2011, Thursday

HALL 2
14:30 – 15:45

Parallel Sessions
ETHICS, RESEARCH, PUBLICATION

Chair: **Bjørn Hofmann**

Daniel Strech, Neema Sofaer

How to write a systematic review of argument-based literature

Gert Helgeson

Redundant publication in bioethics

Stefan Eriksson

Is peer review detrimental to science? On the need for more
transparency

Péter Kakuk

Conflict of interests in biomedical sciences: toward a new ethical
framework

HOW TO WRITE A SYSTEMATIC REVIEW OF ARGUMENT-BASED LITERATURE

Daniel Strech ¹, Neema Sofaer ²

¹ Daniel Strech, Assistant Professor, Hannover Medical School, Centre of Public Health and Healthcare , Institute of History, Ethics and Philosophy, Carl Neuberg Str. 1, 30625 Hannover, Germany. E-mail: Strech.Daniel@mh-hannover.de

² Dr Neema Sofaer, Wellcome Trust Research Fellow, Centre of Medical Law and Ethics, School of Law, King's College London, Strand, London WC2R 2LS, UK.

Presented at the Conference by: Neema Sofaer

Abstract:

Systematic reviews, which were developed to improve clinical decision-making, answer an empirical question based on an unbiased appraisal of all the relevant empirical studies. We present a model for writing systematic reviews of argument-based literature: literature that uses arguments to address conceptual questions, such as the questions of whether abortion is morally permissible or whether research participants should be legally entitled to compensation for sustaining research-related injury. As we argue elsewhere, such reviews are better tools for improving ethically relevant decisions in health care, research or policy than informal reviews or samples of literature; they can aid the identification of all the reasons relevant to a conceptual question; and they enable the setting of agendas for conceptual and empirical research necessary for sound policy-making. Our model comprises prescriptions for writing the systematic review's research question and inclusion conditions; the identification of all the relevant literature; the type of data to extract on reasons and publications; and the inference of results. We explain how to adapt the model to the research question, literature reviewed and intended readers, who may be decision-makers or academics. Obstacles to the model's application are described and addressed. We also identify the model's limitations, and present an agenda for research needed to make systematic reviews even more useful for decision-makers and academics.

Key Words: Decision making (MeSH), health policy (MeSH), systematic review

REDUNDANT PUBLICATION IN BIOETHICS

Gert Helgesson

Stockholm Centre for Healthcare Ethics
Dept. of Learning, Informatics, Management and Ethics (LIME)
Karolinska Institutet, Stockholm, Sweden
E-mail: gert.helgesson@ki.se

Presented at the Conference: Gert Helgesson

Abstract:

Most scientific journals take a clear normative stance on redundant publication: it must be avoided. Redundancy is also an important issue for the individual researcher, since a precondition for fair competition for academic positions and external funding is that everyone abides by the same rules. It is, however, not obvious what makes a publication redundant – or what is bad about redundant publication. I will try to clarify this. In doing so, I will also try to show whether there is a difference between biomedical research and bioethics in this regard.

Initially I will argue that it is important, as a starting-point for the analysis, to distinguish between two ways in which a publication can be redundant: redundant for the research community and redundant as a basis for academic merit. It is not necessarily so that these criteria always point in the same direction. I will suggest that when they clash, one should choose the alternative that is most conducive to overall research interests. Arguably this means that complementary ways to deal with academic merits will be needed.

In my talk I will present and critically evaluate different views of how to understand redundancy, and the arguments for them. This includes making a critical survey of the positions and arguments found in research ethical guidelines and in the bioethical literature. It will be of interest to see, for instance, whether there are cases of (unacceptable) redundant publication that everyone agrees about and what cases are subject to disagreement.

Finally, I will examine if there are any relevant differences as to what can be seen as (unacceptable) redundant publication in biomedicine and in bioethics. I will suggest that there are – and identify the aspects relevant for making such a distinction.

Key Words: Bioethics, redundant publication, research ethical guidelines

IS PEER REVIEW DETRIMENTAL TO SCIENCE? ON THE NEED FOR MORE TRANSPARENCY

Stefan Eriksson¹

¹ Centre for Research Ethics & Bioethics, Box 564, 751 22 Uppsala
E-mail: stefan.eriksson@crb.uu.se

Presented at the Conference by: Stefan Eriksson

Abstract:

Peer review is a means to assist editorial offices in choosing and improving scientific manuscripts so that they are useful and accurate; i.e. that they further science and scientific applications by promoting scientific exchange of information and rational debate. This is an important and fruitful endeavor; suggestions that we should make without peer-review and publish more freely would result in a state of affairs where the basis for scientific advancement would be lacking.

But does it really work? Fiona Goodle has stated that “At its worst, peer review is seen as expensive, slow, biased, open to abuse, patchy at detecting scientific flaws, and almost useless at detecting fraud or misconduct”.

I will answer this criticism by distinguishing between arguments that are 1) misinformed (e.g. reviewer bias being unavoidable), 2) true but unavoidable and acceptable (e.g. that many errors turn up on secondary reviews) and 3) those that points to a need for reform. To this last category I count the arguments that fraudulent papers have often passed review, that innovative papers often get rejected, and that reviews are of low quality; creating unfair assessments.

A first conclusion of mine is that the peer review should be more carefully shaped and steered, by detailed instructions being provided to reviewers, as well as training and example material, so that major issues are addressed and so that anyone performing reviews is competent and knowledgeable enough to address them.

A second conclusion is that some of the required judgments that reviewers need to make in order to counteract misconduct on behalf of authors and to promote good quality cannot be made without knowing the identity of the authors. For example, whether they are repeating things said elsewhere, whether their results are harder to understand and digest because they are partially published in several articles, or if they give inappropriate weight to their own previous findings, can more easily be estimated knowing of their previously published work. The risk for bias is of lesser significance than the risk for low quality reviews; it is more important to guard the scientific and ethical merit of papers than trying to counter bias. But transparency also calls for openness regarding reviewers' identities.

The third and main point is that the editorial choices made on the basis of reviews would also need to be more transparent. There is a trend to suggest that we therefore need to pre-publish early versions of articles, reviews, and editorial judgments

on the internet, Nature has now decided upon such a model. I will argue against this view and propose that a procedural system should give reviewers and authors the opportunity to engage in a closed but for them transparent dialogue with the editors. All other scientific debate and discussion are performed openly – why should we make this the exception?

Key Words: Peer review, transparency, misconduct

CONFLICT OF INTERESTS IN BIOMEDICAL SCIENCES: TOWARD A NEW ETHICAL FRAMEWORK

Péter Kakuk, MA, PhD

Assistant Professor at Department of Behavioural Sciences
Medical and Health Sciences Center, School of Public Health
University of Debrecen, Nagyerdei krt. 98. P.O.Box 45. 4032 Debrecen/Hungary
E-mail: kakukp@med.unideb.hu

Research associate at Center for Ethics and Law in Biomedicine
Central European University
Nádor u. 15. 1051 Budapest, Hungary
www.celab.hu

Presented at the Conference by: Péter Kakuk

Abstract:

Conflict of interests (COI) issues in various dimensions of biomedicine became intensively scrutinized by policy makers and bioethicists in the recent decade, especially in the United States. For example, in 2009, the Institute of Medicine published its report that formulates major recommendations in order to avoid the problems of COI. Conflict of interests regulations are originated from the public arena, where public officials, government employees are seen as stewards of public interests. This ethical framework - based on the ethics stewardship - is highly problematic when applied to scientists. It is also problematic because it is grounded on role responsibility that is challenged by the current proliferation of different roles. The COI framework in science is also problematic because it has a sociologically simplistic conception of science as such. Thus, we have several reasons to be skeptical about the ethical adequacy of current perspectives of COI policies. First, I give an overview of the ethical problems related to COI in science, focusing on how COI as an ethical issue is constructed. Secondly, I give an overview about the major approaches in solving the ethical problem of COI in biomedicine. And thirdly, I approach to identify the major problems that a new ethical framework should be responsive to in order to provide a better alternative in assessing and managing problems related to COI in contemporary biomedical sciences.

Key Words: Conflict of interests, policy, ethical framework

15 September 2011, Thursday

HALL 3
14:30 – 15:45

Parallel Sessions
BIOETHICS IN THE END OF LIFE

Chair: **Reidun Førde**

Jan Schildmann, Daniel Strech

Quality of ethical guidelines on end of life decisions. reflections on a systematic review and application of the agree-instrument

Ralf Stutzki , Stella Reiter-Theil, Markus Weber

End of life issues in light of patients' religious and spiritual convictions. an explorative study with ALS /MND patients and their primary caregivers

Marianne K. Bahuş, Reidun Førde

Doctors' attitudes and legal knowledge regarding patient autonomy and end-of-life decisions

Gürkan Sert, Tolga Güven

Can competent patients at the end of life refuse treatment in Turkey? the ethico-legal aspects of the right to refuse treatment in the light of a recently reported case

QUALITY OF ETHICAL GUIDELINES ON END OF LIFE DECISIONS. REFLECTIONS ON A SYSTEMATIC REVIEW AND APPLICATION OF THE AGREE-INSTRUMENT

Jan Schildmann¹, Daniel Strech²

¹ Institute for Medical Ethics and History of Medicine, Ruhr University Bochum, Malakowturm-Markstr 258a, 44799 Bochum, Germany, E-mail: jan.schildmann@rub.de

² Institute for History, Ethics, and Philosophy of Medicine, CELLS – Centre for Ethics and Law in the Life Sciences, Hannover Medical School, Carl-Neuberg Str. 1, 30625 Hannover, Germany, E-mail: strech.daniel@mh-hannover.de

Presented at the Conference by: Jan Schildmann

Abstract:

End of life decisions such as the limitation of treatment, the initiation of palliative sedation treatment or the management of patients' wishes for hastening death pose clinical as well as ethical challenges to healthcare professionals. In recent years hospitals and other healthcare institutions have responded to this by the development of ethical policies or guidelines. Similar to their clinical counterpart ethical guidelines are designed to support physicians and other members of the healthcare team to manage difficult situations in a professional manner. However, in contrast to clinical guidelines the issue of quality of ethics policies so far has hardly been subject to any critical discussion. In this presentation we will explore the issue of quality of ethical guidelines based on the results of a systematic review on guidelines regarding end of life decision in medicine and the application of the AGREE (Appraisal of Guidelines for Research and Evaluation)-instrument.

Guidelines on end of life decisions were identified through a systematic search in MEDLINE and rated according to the relevance for this research by the authors using explicit criteria for inclusion and exclusion. All studies included were then assessed with the AGREE instrument. Difficulties in applying the AGREE-instrument for ethical guidelines were systematically noted. Of 103 guidelines identified, 34 were included as relevant. Application of the AGREE instrument indicated that most items of the six domains of this instrument (scope & purpose, stake-holder involvement, rigour of development, clarity and presentation, applicability and editorial independence) could be applied to ethical guidelines without problems. A majority of the ethical guidelines on end of life decisions that were included were assessed as qualitatively insufficient. Few guidelines demonstrated that a high level of quality in accordance with the AGREE criteria is also possible for ethical guidelines.

From our analysis we conclude that the AGREE instrument is suitable for an assessment of the quality of ethical guidelines in many areas. Examples in this respect are the requirements regarding transparency about funding sources or possible financial or intellectual conflicts of interest. However, to be applied in an even more adequate manner for ethical guidelines there should be adaptation of the AGREE instrument in some sub-areas. We will explore such modification taking the examples of ethical guidelines' normative basis and the moral argumentation used in these documents.

END OF LIFE ISSUES IN LIGHT OF PATIENTS' RELIGIOUS AND SPIRITUAL CONVICTIONS. AN EXPLORATIVE STUDY WITH ALS/MND PATIENTS AND THEIR PRIMARY CAREGIVERS (BASEL/ST. GALLEN, SWITZERLAND)

Stutzki, Ralf ¹, Reiter-Theil, Stella², Weber, Markus³

¹ Dept. Medical and Health Ethics, Medical Faculty / University Hospital Basel, Switzerland,
Missionsstrasse 21, CH-4055 Basel, Tel: 061 260 21 90/91, FAX: 061 260 21 95.
E-mail: ralf.stutzki@unibas.ch

² Dept. Medical and Health Ethics, Medical Faculty / University Hospital Basel, Switzerland,
Missionsstrasse 21, CH-4055 Basel, Tel: 061 260 21 90/91, FAX: 061 260 21 95.
E-mail: s.reiter-theil@unibas.ch

³ ALS Clinic/Muscle Center of the Cantonal Hospital in St. Gallen, Switzerland, Greithstrasse 20, CH-9007 St. Gallen, Tel: 071 494 35 81, FAX: 071 494 63 89.
E-mail: markus.weber@kssf.ch

Presented at the Conference by: Ralf Stutzki

Background

In the secular society of Switzerland self-determination, esp. regarding end-of-life decisions, is highly esteemed. As suicide and also assistance to suicide are not legally punishable acts (unless in cases of "selfish motivation"), health care professionals as well as family members or friends of severely ill patients are facing ethical dilemma, when the patient asks them to help terminating his / her life. This has been observed in groups of patients with malignancies and progressive diseases, including those suffering from ALS (Amyotrophic Lateral Sclerosis).

Objectives

To determine the correlation of personal faith, religious denomination and spirituality with ALS patients' views on end-of-life issues.

Methods

Explorative interview study with 34 patients and their primary caregivers; semi-quantitative questionnaire and qualitative interview study (2008-2011). Measures: Demographics; Questions on end-of-life decisions; Hospital Anxiety and Depression Scale (HADS); Idler Index of Religiosity (IIR); Schedule for Meaning in Life Evaluation (SMILE); The Neurobehavioural Rating Scale NRS on quality of life, feeling lonely, being a burden to others; semi-structured, tape-recorded interviews.

Results

34 patients and their caregivers were interviewed. The median age of the patients was 59 years. 18 patients were Roman-Catholic, 11 Protestant and 5 non-denominational. Median age of the caregivers was 56 years.

Significant differences between patients and caregivers were found in questions concerning quality of life ($p=0.004$), loneliness ($p=0.005$), religious self-assessment ($p=0.001$) and life-prolonging measures (PEG: $p=0.007$).

41% of the patients had already either thought about or discussed the option of ending his or her life with the help of a relative, close friends, pastor or medical doctor. At the same time, none of the interviewees showed any sign or interest to commit suicide or actively ask for assistance to terminate their life.

Discussion/Conclusion

Religious confessional faith does have an impact on a patient's view towards end-of-life issues. While a significant number of patients had either thought about or discussed the option of ending his or her life at the outset of the diagnosis, the data suggests that there are differences amongst denominations. However, this is statistically unproven yet.

Patient/caregiver-comparison reveals a significantly higher level of suffering and loneliness on the side of the caregivers.

Key Words: End of life, spirituality, ALS/MND

DOCTORS' ATTITUDES AND LEGAL KNOWLEDGE REGARDING PATIENT AUTONOMY AND END-OF-LIFE DECISIONS

Marianne K. Bahus, JD, PhD Student¹, Reidun Førde, MD, PhD²

¹ Center for Medical Ethics
Institute of General Practice and Community Medicine
Faculty of Medicine
University of Oslo
E-mail: marbahus@online.no

² Center for Medical Ethics
Institute of General Practice and Community Medicine
Faculty of Medicine
University of Oslo
E-mail: reidun.forde@medisin.uio.no

Presented at the Conference by: Marianne K. Bahus

Abstract:

According to Norwegian law dying patients have the right to refuse life prolonging treatment. The purpose was to study whether doctors' attitudes and knowledge are according to legal rules.

A strategic sample of 1175 Norwegian doctors, specialists in internal medicine, paediatrics, surgery, neurology and neurosurgery received a mail questionnaire about end-of-life care in hypothetical scenarios. Recipients were randomly selected from the membership roster of the Norwegian Medical Association. 640 doctors (54.5%) responded, of these 406 had experience with end-of-life decisions. The case presented here concern a critically ill 45 years old autonomous patient diagnosed with end state ALS. The patient refuses respiratory treatment.

56.1% of 394 doctors stated that ALS patients in such situations can *always* refuse life prolonging treatment, and 42.4% were of the opinion that the patient *normally* could refuse life-prolonging treatment.

The answers indicate that the principle of patient autonomy still isn't completely incorporated in end-of-life decisions in Norway. If the doctors' answers should conform completely to law, they all should have stated that the patient can always refuse life-prolonging treatment; to treat a patient without the patient's informed consent leaves the doctor at legal risk. The paternalistic approach exist therefore probably in a moderate version in medical decision making in Norway.

Key Words: Patient autonomy, ethics, law

CAN COMPETENT PATIENTS AT THE END OF LIFE REFUSE TREATMENT IN TURKEY? THE ETHICO-LEGAL ASPECTS OF THE RIGHT TO REFUSE TREATMENT IN THE LIGHT OF A RECENTLY REPORTED CASE

Gürkan Sert¹, Tolga Güven²

¹ Marmara University, Faculty of Medicine, Department of Medical Ethics and History of Medicine

E-mail: ozgurgurkan@yahoo.com

² Marmara University, Faculty of Medicine, Department of Medical Ethics and History of Medicine

E-mail: tolgaguvenc@hotmail.com

Presented at the Conference by: Gürkan Sert

Abstract:

Despite being one of the most important patient rights, the legal borders of the right to refuse treatment – particularly in the context of terminally ill patients – is still unclear in Turkey. The recent efforts of the Ministry of Health to implement patient rights have completely ignored this right to this day. The current legislation includes vague and somewhat contradictory provisions on the issue and the opinions of the law scholars vary greatly. Furthermore, instruments like advance directives do not exist in Turkey's health care system; therefore, incompetent patients' previous wishes can not be integrated in clinical decision-making. As a matter of fact, even competent but terminally ill patients may have no chance of refusing treatment in Turkey.

This problematic situation supports paternalist interventions on terminally ill patients against their will. However, it should also be noted that whether any criminal liability for the health care professionals will arise as a result of respecting a patient's wish to stop treatment (such as mechanical ventilator support) is also unclear in Turkey and vague provisions such as "euthanasia is forbidden" or "the right to life can not be waived" further complicate the issue. Therefore, the problem is not simply related with the paternalist attitude of the health care professionals in Turkey; the legal perspective also appears to have been shaped with paternalist concerns.

In the light of this background and by using a recently reported case example from Turkey, this paper aims to argue that the right to refuse treatment in Turkey (particularly for patients at the end of life) has been seriously neglected and it may be impossible for even competent patients to refuse treatment in Turkey. For this purpose, we will be reflecting on the experience of an elderly patient and her family and their unsuccessful attempt to refuse treatment. It will be concluded that in order to implement the right to refuse treatment in Turkey, the concept should first be examined in the proper context and the possible ethical and legal issues must be clarified as soon as possible.

Key Words: The right to refuse treatment, patient rights

15 September 2011, Thursday

HALL 4
14:30 – 15:45

Parallel Sessions
BIOETHICS AND HUMANITIES

Chair: **Gerald Neitzke**

Anoja Fernando

A humanities course for medical students in Sri Lanka

Mehmet Ali Gülpınar, Mehmet Akman, Pemra Ünalın, İnci User

Human in medicine course as an example of preclinical medical humanities programme

Nadi Bakırcı, Pınar Topsever, Yeşim Işıl Ülman, Muhtar Çokar

Medical ethics and humanities teaching: two years experience

Kenji Hattori

Substantial advantages of using drama cases in clinical ethics education

A HUMANITIES COURSE FOR MEDICAL STUDENTS IN SRI LANKA

Anoja Fernando, BA, MBBS, FRCP

Sri Lanka Medical Association,
6, Wijerama Mawatha
Colo,mo 7
Sri Lanka

E-mail: anojaf@yahoo.com

Presented at the Conference by: Anoja Fernando

Abstract:

While ethics education is well established in most Sri Lankan medical schools, teaching of arts and humanities is a recent innovation. This paper describes the introduction of a course on humanities to medical students in Sri Lanka for the first time. The course was conducted from 2005 to 2009 for four consecutive batches of students in the Faculty of Medicine, University of Ruhuna.

The main objective of introducing humanities to medical students was to promote certain humane attitudes that would be desirable in future doctors, such as empathy with patients and compassionate understanding of individuals in society. It was also hoped that exposure to arts subjects would encourage reflective practice and personal development. At the same time, it was decided to explore the possibility of widening the scope of medical ethics education in the faculty by using the humanities and its multicultural sources.

Topics for teaching were selected from both Western and indigenous sources. While the major proportion of the syllabus was drawn from Western sources, and taught in English, a fair amount was also drawn from indigenous and Asian sources. This approach resulted in exposing the students to a hitherto unappreciated alien culture as well as to the realization of the universality of human values, emotions and struggles of people all over the world. The paper also describes the challenges and constraints faced in delivering the course on humanities, as well as the student response which was very positive and enthusiastic. Evaluation of the course revealed that the students had deeply appreciated and enjoyed the exercise.

Key Words: Humanities, ethics, education

HUMAN IN MEDICINE COURSE AS AN EXAMPLE OF PRECLINICAL MEDICAL HUMANITIES PROGRAMME

Mehmet Ali Gülpınar¹, Mehmet Akman², Pemra C. Ünalın² & İnci User³

¹ Department of Medical Education, Marmara University Medical Faculty, Istanbul, Turkey

² Department of Family Medicine, Marmara University Medical Faculty, Istanbul, Turkey, E-mail: pcunalan@gmail.com

³ Sociology Division, Marmara University Science and Literature Faculty, Istanbul, Turkey

Presented at the Conference by: Pemra C. Ünalın

Abstract:

Introduction: Paradigmatic/methodological discussions during the twentieth century has led to a number of changes in concepts such as health status, disease modalities, perceptions of illness and health seeking behaviours. Interdisciplinary collaborations of biological sciences with humanities and social sciences have brought about a more holistic approach to medical research and education as well as to health services. This transformation in the approach to health has also necessitated a complete restructuring of the medical education process including the aims, learning objectives, learning modalities, learning environment and assessment procedures. It is believed that in all of their interactions with their patients, physicians must seek to understand the meaning of the patients' stories in the context of their beliefs, family and cultural values. As a reflection of all the above-mentioned changes, during the last decades, medical humanities programs have been added to the undergraduate and graduate curricula of a number of medical schools. Generally named as 'Human in Medicine' (HIM) programs, lectures, panels, psychodramas, community-based projects and small group discussions on educational materials like stories, poems, paintings, films are being utilized as educational techniques and materials in them.

Method: As a major part of second year's Introduction to Clinical Practice (ICP) program, the HIM subprogram consists of three main courses: 'Social Concepts in Health', 'Arts and Humanities' and 'Ethics'. A major aim of this sub-program is to enrich medical practice education with societal/cultural, ethical and artistic dimensions in order to create doctors sensible to patients' social, cultural and psychological background. Consequently, students will be more open to individual stories/experiences of patients and their feelings. In this study HIM program was evaluated by means of the student feedback and academic grades.

Results: All three courses were evaluated as excellent or good by half of the students for content, methodology and organization, whereas Social Concepts was evaluated as the least (2,6) with its effect on the medical practice. Arts and Humanities followed it with 2,7 and 3,0 (out of 4) for Ethics. On an average over the all courses of ICP program academic success of the students was very good. Only

15% of the students scored below 50 out of 100. But when we compare with the other elements of the ICP program (table), mean of the academic grades was lowest in History taking Course and it is followed by HIM course (mean:64,5±24,7 median:71).

Table: Academic Grades of the students for all of the courses in ICP program

	HT	CSL	Research	HIM	ICP-2 final note
Mean	60,56	87,42	81,17	64,52	70,77
SD	9,78	7,94	20,86	24,67	13,08
Median	61	89	87	71	73
Min-Max	19-80	36-100	0-100	4-96	14-91
%25-%75	55-68	85-92	77-96	60-79	67-80

Conclusion: We can conclude that the multidisciplinary, preclinical HIM program has been an efficient starting point to complement the biologic perspective of medical education with a social and humanistic perspective. However, it is important to continue the HIM courses with intracurricular and extracurricular various activities with interesting cases and a focus on clinical problems during clinical years in order to strengthen this perspective.

Key Words: Medical education, medical humanities, evaluation

MEDICAL ETHICS AND HUMANITIES TEACHING: TWO YEARS EXPERIENCE

Nadi Bakırcı¹, Pınar Topsever², Yeşim Işıl Ülman³, Muhtar Çokar³

¹ Acıbadem University School of Medicine, Department of Public Health,
E-mail: nadiba@gmail.com

² Acıbadem University School of Medicine, Department of Family Medicine,
E-mail: topsever@gmail.com

³ Acıbadem University School of Medicine, Department of History of Medicine and
Ethics, E-mail: yesimul@yahoo.com, E-mail: mcokar@ikgv.org

Presented at the Conference by: Yeşim Işıl Ülman

Abstract:

The CMPS programme has been designed as an initial introduction to medical professionalism. It aims to facilitate basic professional skills and competencies necessary for good medical practice as well as, to enhance personal and social development, fostering intellectual skills and humanistic values. The programme consists of four basic courses (Communication and Clinical Skills, Health and Society, Medical Ethics and Humanities, Research in Health) which continue throughout the first three years of undergraduate medical education, with a logical follow-up of themes building competencies to complement corresponding curricular topics of the accompanying biomedical subject committees.

Facilitating effective communication, along with scientific and creative thinking, paired with a humanistic approach, the CMPS programme creates a solid fundament for a competent and compassionate physician who is aware of the professional responsibilities towards society (community orientation), the patient as a suffering person (clinical communication skills, patient centeredness and holistic approach) and at the same time can attend effectively to the disease as a set of disordered biological processes (clinical problem solving skills paired with holistic approach).

The activities within the interdisciplinary Medical Ethics and Humanities course aim to widen the students' scope to perceive health as a human right and to develop a proactive responsibility for justice and equity in health respecting bioethical principles. It facilitates correlation of human rights with bioethical concepts in the context of human dignity, integrity, respect to the individual, non-discrimination, privacy, confidentiality and self-determination. The main principles of medical ethics, namely non-maleficence, beneficence, autonomy and justice are taken up in various examples dealt making use of methodology in ethical decision making namely, virtue ethics, deontological approach, utilitarian and consequentialist approaches together with the principlist theory. Philosophical roots of ethical theory exemplified in daily practices were discussed. Ethical dilemmas and underlying core values of patient rights and physician responsibilities as well as, life cycles like beginning and end of life are dealt with through this perspective.

This course is a blend of traditional humanities disciplines, namely, philosophy, history, literature, and the arts, paired with ethics, sociology, law and behavioural sciences. It provides a creative learning environment enhancing the development of intellectual skills along with the ability to recognize and solve ethical and social problems in a medical context. Initiating the discourse from the right to health within the context of human rights, this course also highlights the evolution of modern medicine from a historical point of view and provides a practice oriented learning environment to develop and incorporate ethical decision making skills into the process of clinical reasoning.

The CMPS programme adopts a student-centered, practice- and community-based and experiential learning approach, where the students are required to actively involve in the learning process at all times. Blended teaching methodology with task-based learning, role play, site visits, group assignments with presentations and discussions, reflective and peer group learning experiences, literature analyses, and self-directed learning sessions are used.

Evaluation methodology is in accordance with the aims and learning outcomes, as well as, with applied teaching and learning methodologies. Log-books, standardized evaluation of group presentations of assignments and projects or performances, oral and written examinations, structured observation reports, essays, and structured feed-back forms are implemented for assessment as well, as evaluation purposes.

On a five point Likert scale (1 totally disagree – 5 totally agree), a majority of students scored positive for the programme of year I, which reviews history of medicine in an evolutionary approach and focuses on abstract concepts and ideas of human rights-right to health and aims to identify the role of the physician in society. The programme of year II, which highlights concrete issues of medical ethics like ethical argumentation and moral deliberation, physician responsibility and patient rights in the framework of legal regulations, and hot topics like new medical technologies and genetics was scored positive by 80% of the students. The programme also received good qualitative student feed-back (written formless feed-back after each lesson). In accordance with a student centered approach, the curriculum outline of the courses of the following year were planned in interdisciplinary workshops organized with facilitators and students.

In summary, the “Medical Ethics and Humanities” course within the CMPS programme at Acibadem University School of Medicine is a contemporary example for interdisciplinary integration of teaching about humanistic, ethical and professional core values in undergraduate medical education.

Key Words: Professionalism in medical education, humanities, ethics

SUBSTANTIAL ADVANTAGES OF USING DRAMA CASES IN CLINICAL ETHICS EDUCATION

Kenji Hattori

Department of Medical Philosophy and Ethics
Gunma University Graduate School of Medicine
3-39-22 Showa-machi, Maebashi, Gunma 371-8511 Japan
E-mail: hattorik@med.gunma-u.ac.jp

Presented at the Conference by: Kenji Hattori

Abstract:

To enrich clinical ethics education, improving case study is of necessity. While so many authors have struggled to establish how to solve perplexing ethical issues in cases that haunt us and we have held debates over various perspectives and methodologies, little attention has been given to the qualitative conditions of the proper cases for case study. Yet it is plausible that the poetics of the case, its structure and mode as such, affects the manner of conducting discussions and the quality of arguments in clinical ethics case study. For medical ethics case study should deal with values and all aspects of each patient's life as such, every case description should convey more detailed relevant information about the patient's personal matters and that of her/his family members. A case to be used in clinical ethics case studies should be messy and be constructed, like a literary work, with much nuanced taste (Barthes) or ambiguity, polyphonic voices (Bakhtin), and drama.

We have the following dichotomous taxonomy of cases. The first axis is that real cases versus hypothetical or fictitious cases. The second one is that thin, tamed or skeleton cases versus thick, wild or flesh-and-blood cases. And the third is that narrative or short story cases versus dramatized cases. In this paper we will shed light on the last dichotomy.

Narrative cases have several methodological problems anyway. First of all, the existence of the narrators is absolutely problematic who look through meanings of actions, minds, and relationships of characters in the cases. Examine if such a narrator exists in the real medical settings. Actually we should admit that no almighty human beings are present who could see everything like God views. On the contrary, medical practitioners often feel it difficult to know what patients actually feel and think. Second, a case story must rely on words woven by a narrator so that actions, thoughts and psychological conditions of characters in the cases must be interpreted and translated in virtue of narrator's perspectives and expressions. Therefore there must be over-interpretation or discard of subtle nuances of the cases. For example, countenances, non-verbal sentiments of characters or atmospheres of occasions must be fixed or distorted by the narrations in themselves.

As one of the solutions for these problems, we found it effective to use drama cases. So we decided to produce original dramas based on East Asian cultures and actual current circumstances. Some features of our drama cases are as follows. First,

we eliminate any narrations and explanatory words. Second, we avoid excessive affected performances to have viewers grasp matters easily. Third, we use no BGM which never exists in the actual clinical settings. Fourth, each case lasts 15-20 minutes without any eventual outcomes or endings. In this presentation, by showing a small part of one of our drama cases, we will examine the usefulness and advantages of drama cases as educational materials in comparison with narrative cases.

Key Words: clinical ethics, education, case study

15 September 2011, Thursday

HALL 1
16:00 – 17:30

Parallel Sessions
BIOETHICS AND PHILOSOPHY

Chair: **Yaman Örs**

Zümrüt Alpınar

Ethics and bioethics in Prof. Yaman Örs's scientific philosophy

Michael ch. Michailov, Eva & Renate Neu, Manfred Holler

Medical philosophy incl. ethics in context of health policy

M. Volkan Kavas

Historicist approach to bioethics: an evaluation on methods and focal points

Marcel Mertz, Hannes Knuppel, Martina Schmidhuber

Mapping disease specific ethical issues development of a framework for identifying and classifying disease specific ethical issues and two examples of its application in clinical practice guidelines

ETHICS AND BIOETHICS IN PROF. YAMAN ÖRS'S SCIENTIFIC PHILOSOPHY

Zümrüt Alpınar

PhD Candidate

Institute of Biomedical Ethics, University of Zürich

Pestalozzistrasse 24 CH-8032, Zürich, Switzerland

E-mail: zumrut.alpinar@ethik.uzh.ch

Presented at the Conference by: Zümrüt Alpınar

Abstract:

Why scientific philosophy? Is there a good reason for us to adopt the approach of scientific philosophy when ethics and bioethics are considered? According to Prof. Dr. Yaman Örs, who embraces the approach of logical empiricism and scientific philosophy, basically as defended by Hans Reichenbach, there is. In this paper, accordingly, Prof. Örs's approach to philosophy, ethics and bioethics will be discussed. For the main aim of this paper, I will discuss the contents of a book consisting of the related papers of Professor Örs in Turkish, edited by me, and which we hope will be published in the course of this year: "The Meaning and Meaninglessness of Ethics From The Perspective of a Scientific Philosopher". There are five main chapters in this book: (1) Main Lines of Yaman Örs's Approach to Scientific Philosophy, (2) His Writings on Ethics, (3) The Ethics of Philosophy, (4) His Writings on Bioethics, and (5) His Papers on Medical Ethics. Throughout this paper, I will focus on the systematics of the book and its chapters, explaining Prof. Örs's methodological approach to philosophy and ethics before signifying in detail the importance of his own specific philosophical terms in this context, such as "the ethics of philosophy or philosophizing", "the ethics of philosophers", "the problem sets in bioethics and medical ethics", and "ethics of the professions as differentiated extensions of ethics".

Key Words: Yaman Örs, scientific philosophy, ethics, bioethics, the ethics of philosophy, problem sets in bioethics, ethics of the professions as differentiated extensions of ethics.

MEDICAL PHILOSOPHY INCL. ETHICS IN CONTEXT OF HEALTH POLICY

Michael Ch. Michailov¹, Eva & Renate Neu¹, Manfred Holler^{1,2},
Michael Schratz^{1,3}, Germain Weber^{1,4}

¹ Inst. Umweltmedizin c/o Int. Council Sci. Dev./Int. Acad. Sci., Austria, Bulgaria, Germany, Slovakia & Univ. Erl.-Nürnberg & Univ. Innsbruck. ICSD e.V. Postfach (POB) 340316, D-80100 München & E-mail: eva.neu@hotmail.de

² Ex-Dean, Fac. Economics, Univ. Hamburg

³ Dean, Fac. Education, Univ. Innsbruck

⁴ Dean, Fac. Psychology, Univ. Luxembourg & Vienna

Presented at the Conference by: Michael Ch. Michailov

Introduction: The permanent increase of health/medical problems in daily life – home/working-place/school/hospital, etc. – needs new interdisciplinary models for education in these fields. Reports in this context are given during important international/European congresses (see lit.). Institutes/research units of medical ethics/philosophy (=MP) could be connected by a network building a *Global Agency for Medical Philosophy (GAMP)* via foundation of national, continental (e.g. European), international institutes, related to an *international university* (proposed by Bertrand Russell*): Common research/educational programmes, personnel, possibility for whole life work, etc. could be promoted.

On conception about GAMP: Obligatory implication of elementary **medical philosophy** (*ethics, epistemology* incl. metaphysics/scientific-theory, *aesthetics*) in education (philosophy, pedagogy, medicine, psychology, theology, etc.). This needs priority in scientific-political-financial support, similar to natural/technical sciences.

Proposals for discussion:

1. *Foundation and/or enlargement of institutes/departments/research-units for MP/ethics.*

2. Organization of regular *MP-sessions on medical philosophy* to important philosophical, medical, pedagogical, psychological, biological *congresses*.

3. Recommendation for *implication* of approaches to *MP in scientific contributions* in the fields of anthropological sciences incl. short (congress-)/normal publications, dissertations – see 2. (medical faculty of prominent West-European university declined discussion on MP in a dissertation, despite recommendation of prominent philosopher/psychologist incl. one dean).

4. Preparation of *conceptions* concerning *European/international education for medical philosophers* (post-/graduate physicians, psychologists, theologians, etc.).

5. Periodic *education for scientists and politicians in MP*, responsible for health and medicine (local boards of 2 cities and ministries/European countries declined support of new models for better health).

6. Conception on *periodic education* in ethics/medical philosophy for *personnel*, working in health centres, hospitals, schools, etc. (clinic-head of radio-oncological department to prominent West-European university declined proposal for decrease of anxiety of patients).

7. *Interdisciplinary discussions* on importance of MP for health policy could be started via *common sessions* to *congresses* of anthropological sciences under participation of *leading scientists/functionaries* from **ESPMH/EACME** (R.Andorno, N.Biller-Andorno/Suisse, Ch.Gastmans, P.Schotsmans/Belgium, B.Gordijn/Ireland, S.Holm/UK, F.Oduncu/Germany, R.Pegoraro/Italy, T.Takala/Finland, Y.I.Ulman/Turkey, S.M.Vidal/UNESCO-Uruguay, G.Widdershoven/Netherlands, etc.) and **ICSID/Int.Acad.Sci.** (M.Bishop*/USA, V.D.-Danilyan/Russia, B.Josephson*/UK, L.R.Langslet/Norway, J.-M.Lehn*/France, N.Lobkowicz, H.Michel*, J.Mittelstraß/Germany, B.Samuelson*/Sweden, K.Singh/India, S.Tonegawa*/Japan, J.v.Uexküll/Sweden-UK, etc.: The authors thank for moral support of ICSID-projects). Possibilities are given during international/European congresses for philosophy (**FISP-2013-Athens**: McBride, Moutsopoulos, Brandt, Føllesdal, Lütge, Sève,...), psychology (**IUPsyS-2012-Cape Town**: Overmier, Cooper, vonRosenstiel,...), genito-urology (**SIU-Berlin-2011**: Thüroff, Bauer, Chaussy, Desai, Hofstetter, Hohlbrugger, Madersbacher, Valiquette, Staehler,...), physiology (**FEPS-2011-Istanbul**: Pohl, Ergene, Birnir, Eisner, Hultburn, Neher*, Stühmer, Thurau, Türker, van-derVusse, Weiss,...), psychosomatics (**ICPM-2011-Seoul**: Streltzer, Kubo, Kikuchi, vonRad,...), biophysics (**IUPAB-2011-Beijing**: Steitz*, Nagayama, Smith, Govil, Grigera, etc.; **EBSA-2011-Budapest**: Yonath*, Diaspro, Pálincás, Hell, Mátyus, Sackmann,...), radiation research (**IARR-2011-Warszawa**: Cebulska-Wasilewska, ElBaradai*, Iyengar, Paretzke, Wojcik, Williams,...), toxicology (**EUROX-2011-Paris**), psychiatry (**WPA-2011-Buenos Aires**: Maj, Mezzich, Suematsu,...) [*Nobel-Laureate].

Conclusion: Scientific, political, financial support in context of proposals (1.-7.) for ESPMH/EACME/ICSID by CIOMS, ICSU, ICPHS up to UNESCO could open a new dimension in renovation of anthropological sciences, i.e. obligatory large implication of MP in topics of bio-medical congresses, research, postgraduate education in spirit of **UNO-Agenda21** for *better health, education, ecology, economy in all countries*.

Lit.: Neu/Michailov et al. to Conf./Congress-Books ESPMH Zagreb-2010/46-47, Barcelona-2005/65-66; EACME Oslo-2010/55-56, Venice-2009/61-61, Prague-2008/48; ISB/Bioethics Istria-2008/290&307; ISIM/Int.Med. Melbourne-2010: Int.Med.J. 40/1/144&145; IUPHAR Copenhagen-2010: Basic&Clin. Pharm.&Tox. 17/1/488-489).

Key Words: Ethical education, health policy, ethics in uno agenda 21

HISTORICIST APPROACH TO BIOETHICS: AN EVALUATION ON METHODS AND FOCAL POINTS

M. Volkan Kavaz, MD, PHD¹

Ankara University, Faculty of Medicine, Department of History of Medicine and Ethics

E-mail: volkankavas@yahoo.com

Presented at the Conference by: M. Volkan Kavaz

Abstract:

Today, it seems necessary to make an evaluation again on methods and focal subject areas in bioethics, which has been accepted by everybody as bearing past enough to have collected a certain amount of theoretical production and experience in praxis. It is observed that main activities of the discipline proceed towards a particular direction and intellectual frameworks constituting the ground for studies and main interest areas are becoming plainer. While mostly utilized analyzing methods are turning into a few in numbers, sets of topics studied are becoming simpler and smaller. This main path itself, through which the discipline flows and has been becoming gradually more visible both in Turkey and worldwide, needs to be tested morally.

Such an evaluation in bioethics necessitates a “meta-ethical” analysis. This refers to the inevitability of the effort to understand the social and historical function of ethics as an upper-activity. The theory of “historicism” represents the most competent framework for such an analysis.

According to the theory, ethical approaches are not absolute; they change by time. Neither this change happens spontaneously, randomly or irregularly, nor its dynamics are related with continuous clash of schools of thought “giving guidance to humanity”, which is usually balanced by the hegemony of one these schools over others. Underneath this change lie relations of production which determine the social structure and themselves change progressively by various factors in time. Relations of production (substructure) prevailing in a particular society at a certain moment create institutions such as law, politics, religion and coercion as well as forms of social conscience (superstructure), which are necessary for the persistence of those relations. The relation between sub- and superstructures depicted here is interactive. While the first determines the latter, the latter affects the first to some extent.

It is possible to entitle a thought system which exists dominantly in a society at particular historical period as “prevailing ideology”. Besides, this society, even though small in scale by means of its effect and perceived significance, covers another thought system; the ideology of a new social structure, which does not fit the current one and bears the objective of going beyond it and taking it forward (progressive ideology).

If it is accepted that ethics, as an area of intellectual activity, cannot exist entirely independent from thought systems of societies, being in accordance with the schema outlined here, it exists as *split* in a particular society at a certain historical moment: *Prevailing ethical understanding* and *progressive ethical understanding*.

Bioethics, as known well, is an activity of applied philosophy within ethics. Therefore, the function of basic analyzing methods (and of course theoretical understandings underlying them) preferred by those who produce in this field and which needs the topics of studies they conduct meet can only be understood by evaluating the main direction such studies head for. This evaluation conditions an inquiry whether bioethics predominantly follows prevailing ethics or progressive ethics of our age. This, first of all, is possible by determining the quality of the social structure we live in and its prevailing ideology.

Social structure of our age is determined by capitalist relations of production. While its prevailing ideology, on one hand, justifies negativities (inequalities, erosion of social justice, wars etc.) caused by capitalism and presents excuses for the results of market-oriented practices or denies them completely, on the other hand, it puts forth accounts reinforcing the benefit of classes who make profit over continuation of the given structure. Contrarily, besides including the idea of establishing a new social structure for the benefit of workers constituting the big part of the society by destroying capitalist relations of production, progressive ideology also emphasizes the importance of disclosing practices against working class, explaining causes, making their results visible, judging and condemning them, preventing loss of values such as equality, justice, freedom and enlightenment.

Within the scope of this study, methods, analyses, discussions and practices significant enough to suggest a certain direction of understanding will be evaluated on the ground of historicist theory; and in this context, whether (and if so to what degree) this main direction is morally defensible will be questioned.

Key Words: Bioethics, historicism, ideology

MAPPING DISEASE SPECIFIC ETHICAL ISSUES DEVELOPMENT OF A FRAMEWORK FOR IDENTIFYING AND CLASSIFYING DISEASE SPECIFIC ETHICAL ISSUES AND TWO EXAMPLES OF ITS APPLICATION IN CLINICAL PRACTICE GUIDELINES

Marcel Mertz^{1,2}, Hannes Knüppel¹, Martina Schmidhuber^{1,3}, Daniel Strech¹

¹ CELLS – Centre for Ethics and Law in the Life Sciences
Institute for History, Ethics and Philosophy of Medicine
Hannover Medical School, Carl-Neuberg-Str. 1, D-30625 Hannover
E-mail: Mertz.Marcel@mh-hannover.de

² Chair for Philosophy III, Department of Philosophy
University of Mannheim, Schloss, D-68131 Mannheim

³ Institute for Philosophy, Catholic-theological Faculty University of Salzburg,
Franziskanergasse 1, A-5020 Salzburg

Presented at the Conference by: Marcel Mertz

Abstract:

Background: Identifying and classifying ethical problems is one of the first challenges Clinical Ethics is confronted with. While established frameworks of Clinical Ethics (such as Beauchamp/Childress 2008) focus on individual ethical decision-making, frameworks focusing more on the identification of ethical issues are often absent. In a project funded by the German Research Foundation (DFG), the need for such a framework was recognized when confronted with the challenge to integrate disease specific ethical issues (DSEI) in clinical practice guidelines (CPG) for dementia and chronic kidney disease. Such CPGs aim to improve standards of clinical competence; to date, however, CPG development manuals fail in addressing methods for the systematic integration of DSEI. A general framework that allows “mapping” DSEI was required as part of such an integration. Further, it allowed for a basis for a theoretically saturated framework of DSEI for dementia and chronic kidney disease.

Methods: First, a tentative framework relying on the work of Jonson et al (2010) was used. After experiencing conceptual limitations for classifying ethical issues, esp. concerning the “graphic” systematization of DSEI, a new framework on the basis of a systematic review of clinical ethics literature on dementia and chronic kidney disease was developed. Having applied the framework explorative, its categories for classifying ethical issues were validated regarding completeness and generalizability. This content validity was reached by consensus between the project members, as well as by discussing the framework with project-extern experts for clinical ethics.

Results: The framework consists of seven categories: indication, patient information, patient decision making competence, proxy decisions, social and context related aspects, clinical conduct, and evaluation. This allows identifying and classifying ethical issues at different stages within the process of providing health care. With this framework, 26 DSEI for dementia and 18 DSEI for chronic kidney disease were produced. In the talk, we present the overall framework and the results of its appli-

cation for DSEI in the mentioned CPGs.

Discussion: The framework presented does not include weighing of principles or norms. So, it is compatible with established frameworks of Clinical Ethics. By systematically identifying and classifying (disease specific) ethical issues, such a framework should build the basis for a systematic and transparent integration of DSEI in CPGs. Further use of the framework could be envisaged in the domain of training and sensitization in Clinical Ethics.

Beauchamp, T. L. and Childress, J. F. (2008). *Principles of Biomedical Ethics*. New York, Oxford, Oxford University Press.

Jonsen, A. R., Siegler, M. and Winslade, W. J. (2010). *Clinical ethics. A practical approach to ethical decisions in clinical medicine*. New York, McGraw-Hill.

Key Words: Clinical ethics, clinical practice guidelines, disease specific ethical issue

15 September 2011, Thursday

HALL 2
16:00 – 17:30

Panel Session
CLINICAL ETHICS

Chair: Jan Schildmann

Panelists:

Jan Schildmann, Germany

Gerald Neitzke, Germany,

Guy Widdershoven, Netherlands

Marta Spranzi, France

Laszlo Kovacs, Germany

Lazare Benaroyo, Switzerland

Reidun Forde, Norway

ECEN panel session at EACME Istanbul

Preliminary programme

120 minutes

Title: Clinical Ethics Support in Europe: News from the European Clinical Ethics Network

0.00 Welcome & introduction to ECEN

0.05 Understanding each others work in CES

- Introduction to the ECEN grid (distribution of our paper) 0.05
- Case presentation in clinical ethics: 0.15
- Response from ECEN members on the case by using grid 0.25

- **Member 1 (0.25)**
- **Member 2 (0.35)**
- **Member 3 (0.45)**
- **Discussion on case & grid (0.55)**

1.05 Presentation ECEN Summercourse (PR)

1.15 Closure of panel session

1.20 Ending

Understanding European Clinical Ethics Support Services: news from the European Clinical Ethics Network (ECEN)

Chair: Jan Schmidmann

In this panel session, the ECEN will introduce themselves to you. The ECEN has been founded in 2005 and meets twice a year in order to share clinical experiences and scientific research in the field of clinical ethics support services (CESS). Meanwhile, working groups of the ECEN have produced their papers on different topics related to CESS. During this panel session, we will present 'a guideline' that has been developed and used during the ECEN meetings (and which has been published in Clinical Ethics). This guideline, also called a grid, can be used to structure presentations on CESS in order to improve the understanding of how different countries perform their CESS. The grid will get applied within the panel session, using a true clinical ethics case. Different ECEN members will apply the grid to this case. Finally, the ECEN will announce a clinical ethics summerschool that they will offer on the fall of 2012.

15 September 2011, Thursday

HALL 3
16:00 – 17:30

Parallel Sessions
END OF LIFE

Chair: **Bert Gordijn**

Ralf Jox

The progress and perils of the notion of a right to die

Ruth Horn

Euthanasia and end-of-life practices in France and Germany. what kind of autonomy for a terminally ill patient?

Pervin Somer, Elif Vatanoğlu

Home care services for geriatric patients in Turkey according to medical law and medical ethics

Gemma N. Balein

Factors associated with good death

THE PROGRESS AND PERILS OF THE NOTION OF A RIGHT TO DIE

Ralf J. Jox

Ralf J. Jox, MD PhD Institute for Ethics, History and Theory of Medicine
Ludwig-Maximilians University Munich Lessingstrasse 2
D-80336 Munich, Germany
Phone: 0049-89-5160-2620
Fax: 0049-89-5160-2712
E-mail: Ralf.jox@med.lmu.de

Presented at the Conference by: Ralf J. Jox

Abstract:

The rise of modern bioethics in Western societies is closely connected with the right-to-die movement. Ethical questions at the end of life have been the primary topic since bioethics began in the 60s of the last century, and the language of human rights has been a catalyst for the professional development of bioethics. In parallel, the right-to-die movement has been a driving force in promoting modern palliative care. Philosophically, the right to die is primarily based on the liberal notion of personal autonomy, and the right-to-die movement has led the way towards more respect for patient autonomy in medicine generally. Yet, the extent of this right is controversial in a double sense: (1) it is unclear whether the right to die only refers to death from natural causes like diseases or also to self-afflicted or self-commissioned death like suicide and euthanasia; (2) it is disputed whether the right to die is merely a negative right, e.g. the right to refuse life-sustaining medical treatment or refuse rescue after a suicidal attempt, or whether it includes positive rights, such as having the right to palliative care in dying, determining the place of death, requesting assistance in suicide or the termination of life by physicians. Moreover, as the right to die is based on the meta-ethical foundations of individual liberalism and rationalism it may be difficult to apply in non-individualist societies. It is also quite difficult to say which conditions of rationality and decision-making capacity must be met in order to qualify for the right to die. These may be some reasons why the right to die has not been explicitly stated in the major human rights formulations such as the Universal Declaration of Human Rights, the European Convention for the Protection of Human Rights and Fundamental Freedoms or the European Convention of Human Rights and Biomedicine. All of these documents, however, mention the right to life, which can be seen to include the freedom of each autonomous citizen to waive this right and accept one's own death. In addition, the right to bodily integrity and the associated obligation for each medical procedure to have the patient's informed consent logically imply the negative right to die for each autonomous individual. Although human rights documents do also state some positive rights, they do not state a positive right to die as there is considerable controversy on this question as I already mentioned. As the language of a right to die is so vague and lumps all these different aspects together, it might be prudent not to include this emotionally-laden formulation into human rights documents. We need a diligent and differentiated discussion on the various forms of the right to die, and to do this, other ethical theories than only rights-based ethics might be beneficial.

Key Words: Human rights, patient autonomy, end of life

EUTHANASIA AND END-OF-LIFE PRACTICES IN FRANCE AND GERMANY. WHAT KIND OF AUTONOMY FOR A TERMINALLY ILL PATIENT?

Ruth Horn, PhD (Marie Curie Fellow)

Centre for Ethics in Medicine University of Bristol
Canynges Hall 39 Whatley Road, Bristol, BS8 2PS
Tel: +44 (0)117 92 87308
E-mail: Ruth.Horn@bristol.ac.uk

Presented at the Conference by: Ruth Horn

Abstract:

The objective of this paper is to understand from a sociological perspective how the moral question of euthanasia, framed as the “right to die”, emerges and is dealt with in society. It takes France and Germany as case studies, two countries where euthanasia is not authorised but where there nevertheless exists a debate about end-of-life issues. I presuppose that, and explore how, each society has its own specificities in terms of practical, social and political norms that affect the ways in which they deal with these issues. The paper thus seeks to understand how requests for the “right to die” emerge in each society, through both the debate (analysis of daily newspapers, medical and philosophical literature, legal texts) and the practices (ethnographic work in three French and two German hospitals) that elucidate the phenomenon. Thus, one will see that the arguments and terms employed in the debate as well as the questions that arise with regard to end-of-life practices pertain to different problems: therapeutic “activism”, even at the end of life, in France; respect for the patient’s will, in Germany.

In spite of the differences observed between these two countries, the central issue at stake in their respective debates is however the question of the individual’s autonomy to choose the conditions in which he or she wishes to die; these conditions depend, amongst others, on the doctor-patient relationship, the organisation of end-of-life care in hospital settings, and more generally, on the way autonomy is defined and handled in the public debate.

It appears then that, in an environment, such as France, where patients are less overtly integrated in therapeutic decision making, the claims for euthanasia emerge more frequently as a radical response to the non respect of patients’ autonomy. The requests express the desire of the sick person to reaffirm, at least, their ultimate liberty in determining their own death. On the contrary, in countries, like Germany, autonomy consists rather in the liberty an individual has a propos any medical intervention and not only in the liberty to claim their own death administered by a doctor. The paper stresses that theoretical arguments alone are not sufficient to approach a moral question. Broader social, legal and historical contexts that affect the question at issue should be identified in order to contribute to discussing the moral question in a new light.

Key Words: Euthanasia, autonomy, France/Germany

HOME CARE SERVICES FOR GERIATRIC PATIENTS IN TURKEY ACCORDING TO MEDICAL LAW AND MEDICAL ETHICS

Doç. Dr. Pervin Somer*, **Yrd. Doç. Dr. Elif Vatanoğlu****

* Kadir Has Üniversitesi Hukuk Fakültesi, Kadir Has Cad. D-Blok-Cibali-
Eminönü/İSTANBUL, E-mail: pervins61@hotmail.com

** Yeditepe Üniversitesi Tıp Fakültesi, Kayışdağı/İSTANBUL

Presented at the Conference by: Pervin Somer

Abstract:

Especially for the geriatric patients, it is very important to have accessible, high quality, sustainable healthcare and long term care; providing the care so cheap or free that the need for care does not cause poverty for the patients and regardless from the economical situation are the main topics of both medical ethics and medical law. In order to provide an adequate and high quality healthcare and long term care, to make these services accessible and sustainable with the right use of economical resources, home care services are extremely important.

When we monitor the process of making policies and application of home care services in Turkey, we see that governmental authorities develop some policies without taking the opinions of the patients into consideration. Also, we can say that the related nongovernmental organizations do not have the atmosphere to express their views and wishes about the issue and also, home care services are structured according to Family Physicians Guideline in the recent months. In this paper, the home care services especially for geriatric patients will be evaluated and some proposals will be discussed.

Key Words: Home care services, geriatric patients, family physicians

FACTORS ASSOCIATED WITH GOOD DEATH

Gemma N. Balein, D.M.D., M.A., M.S.

University of the East Ramon Magsaysay Memorial Medical Center, Inc.
Aurora Boulevard Quezon City, Philippines, E-mail: gemmabalein@yahoo.com

Presented at the Conference by: Gemma N. Balein

Abstract:

The pre-eminence that Western culture places on the principle of autonomy at end of life has often been challenged by the practices, beliefs and values of the Filipinos. Bioethics needs to address, understand and practice its discipline in the Philippines according to the country's norms and culture.

Several studies abroad have already explored the factors considered important at end of life among terminally-ill patients, family members and healthcare providers. Results gathered ranged from "freedom from pain", "autonomy, control and independence", "acceptance, closure most often at home", to "medical care, sensitivity to religious and spiritual values, living well with God."

This study focuses on factors associated with good death as perceived by terminally-ill patients, family members and healthcare providers. Specifically, it aims to know what factors at end of life will be rated as extremely important by more than 70% of the survey participants and to find out which factors will be selected and ranked as five most important at end of life. Structured face to face interviews, using a modified 35-item questionnaire, were conducted among 35 patients, 41 family members and 34 healthcare providers at the Supportive Palliative and Hospice Care Clinic and the Cancer Institute, University of the Philippines- Philippine General Hospital.

Descriptive statistics and weighted mean were used to determine the perceptions regarding factors associated with good death. One-way ANOVA and Multiple Comparisons scheffe tests were used to examine the significance of specific response differences among groups.

A major finding of this study is the strong agreement among end-of-life care-participants' definitions of what constitutes a good death. One of the survey items showed consensus among all 3 groups. Survey participants overwhelmingly ranked "Come to peace with God" as the 1st most important. Regardless of role, respondents converged on the importance of spiritual support at the end of life.

The findings of this study were used as a spring board to augment the understanding of good death. A crucial part of the discussion is the revisiting of the literature review in light of the research findings and concludes with implications and potential impacts this research project has in the fields of medicine, bioethics, and society at large.

Key Words: Good death, end-of-life

15 September 2011, Thursday

HALL 4
16:00 – 17:30

Parallel Sessions
BIOETHICS AND HUMANITIES

Chair: **Nermin Ersoy**

Tetyana Ospanova, Valeriy Myasoedov, Ievgeniia Bolokadze
Ethical teaching in nephrology

Pemra Ünalán, Sibel Kalaça, Mehmet Ali Gülpınar,
Mehmet Akan, Gürkan Sert
Implementation of a human in medicine programme in an undergraduate medical school curriculum

Şefik Görkey
Medicine in western painting tradition: an elective course proposal for medical humanities

Tetyana Ospanova, Valeriy Myasoedov, Ievgeniia Bolokadze,
Iryna Sorokina
Teaching of bioethics in Kharkiv National Medical University

TEACHING OF BIOETHICS IN KHARKIV NATIONAL MEDICAL UNIVERSITY

Tetyana Ospanova¹, Valeriy Myasoedov¹, Ievgeniia Bolokadze¹, Iryna Sorokina¹

¹ Kharkiv National Medical University, 4, Lenina pr, 61022, Kharkiv, Ukraine;
E-mail ; t.ospanova@mail.ru

Presented at the Conference by: Prof. Tetyana Ospanova

Abstract:

Over the past few years bioethics has become an integral part of medical education in Ukraine. Starting from 1990s, syllabi of undergraduate and post-graduate medical education have included some bioethics issues in the course of undergraduate and postgraduate medical education, and special training modules and courses in bioethics have been designed.

Kharkiv National Medical University involves into teaching bioethics interdepartmental teams including clinicians. Medical ethics lectures and seminars start in the first year on the department of Philosophy, serving as an introduction for students to the field of ethics and topics such as "Psychology of communication", "Modern civilization and culture", "Life", "Humanity", "Culture and valuables" are covered. While these topics are introduced at a basic level in the first year, an intense schedule within the Medical Deontology module is offered to second year students on the Internal Medicine Department and diverse issues in bioethics, such as patient rights, informed consent, patient-physician relationship, informed consent, privacy and confidentiality in health care, life and death, abortion, reproductive medicine, the right to refuse treatment are covered. In courses of 'Bioethics' and 'Medical deontology' that are offered the third year students educational objectives have defined for students' knowledge, skills and attitudes. Students of the 4th-5th and 6th year and postgraduates under the supervision of a member of the department are more willing to analyze and discuss real cases presented by physicians in sessions during their clinical training which include internal medicine, surgery, paediatrics, obstetrics, pathology and etc. Syllabi imply discussing bioethical problems (experimental medicine, reproductive technologies, euthanasia; ethical problems in transplantology and medical genetics, HIV, ethics in psychiatry, moral problems in allocating health-care resources and etc.). E.g., in Paediatrics topics include the nature of the patient-practitioner relationship, research with child participants, and the developing autonomy of the child, the child's "best interests," and consent; in Pathology course specific information related to pathology resident education in ethics and identification of important ethical issues in the current practice of pathology are discussed. When teaching autopsy-biopsy course we pay special attention to ethical standards when interacting with the relatives of the dead person for whom the death is a tragedy. We emphasize that the body should be dissected without any damage to the open parts of the body, which can be noticed when burying. When making a diagnosis of cancer by biopsy, the psychological condition of the patient should be considered to prevent undesirable events (such as suicide).

We decided that an interdisciplinary group of teachers has been shown to be an effective model. Philosophers can be rightly expected to have a greater command over ethics but medical practitioners with knowledge of medical ethics, the upcoming breed of medical ethicists, are perhaps best suited to teach medical students and postgraduates. They have experience of the issues and are also armed with the knowledge how of ethics to be able to deal with the real problems faced in the clinical environment by the students and clinicians.

Key Words: Medical education, bioethics, teaching

IMPLEMENTATION OF A HUMAN IN MEDICINE PROGRAM IN AN UNDERGRADUTE MEDICAL SCHOOL CURRICULUM

Pemra C. Ünal¹, Sibel Kalaça², Mehmet Ali Gülpınar³, Mehmet Akman¹, Gürkan Sert⁴

¹ Department of Family Medicine, Marmara University Medical Faculty, Istanbul, Turkey, E-mail: pcunalan@gmail.com

² Department of Public Health, Marmara University Medical Faculty, Istanbul, Turkey

³ Department of Medical Education, Marmara University Medical Faculty, Istanbul, Turkey

⁴ Department of Deontology and Medical Ethics, Marmara University Medical Faculty, Istanbul, Turkey

Presented at the Conference by: Pemra C.Ünal

Abstract:

Since 2000, an "Introduction to Clinical Practice (ICP)" program was implemented in the Marmara University Medical Faculty curriculum. Today it covers exactly 15% of the whole curriculum of phase 1, which means the first 3 years of medical school. Its main objective is to acquire medical students who develop behaviors and attitudes to provide medical care to the patients and proxies in a humanistic, holistic and professional manner. To achieve that kind of behavioral style this program is applied in small groups in an interactive manner.

ICP is an original multidisciplinary program. It is coordinated by Family Medicine, Medical Education and Public Health departments mainly, lasts for 3 years, continues for 26 weeks in each year and each element recognizes the program of the previous year like a spiral. Main elements of the program are; communication skills, group dynamics and introduction to research skills and "First Aid Course" in the first year, clinical skills laboratory sessions about procedural activities, student research course and mentoring about academic skills, medical interviewing and history taking course, human in medicine program and out-patient clinics experiences in the second year, essential physician skills and primary care visits are added to the program in the third year.

When we look at the order of the courses we see that "Medical Interviewing and History Taking Course" follows the communication skills and group dynamics study of the first year and this essential clinical skill teaching is completed with general physical examination practices in clinical skills lab of the third year. A "Combining Medical Practices Session" enriched with geriatric case discussions is another complementary element of the last year. Besides all these multidisciplinary, small group teaching activities, students visits primary care centers with an individual log book to observe the physician-patient relation. "Human in Medicine Course" of the second year supports this learning environment with a social sciences and humanities perspective. Also second year research activities with "Health and Society" theme and "Our Patients and Their Diseases" theme for the third year is an other complementary element of the ICP program (Figure).

All of these courses are integrated either horizontally or vertically to offer an opportunity to the students to get a clue about the relation of each topic with another and also the place of it in daily medical practice.

Conclusion; Basic medical skills and attitudes that should be acquired at the end of undergraduate medical education are defined as universal standards. Education programs which begin before clinical years, learner centered, problem solving, integrated, community based, interdisciplinary, aimed at skill teaching in a systematic manner are accepted to be effective in teaching basic practice of medicine. In this article, a program that is developed with this philosophy to integrate the “science” and “art” sides of medicine appropriately to the essential principles described previously and applied in Marmara University Medical School since 2000 with the name of Introduction to Clinical Skills Program (ICP) is presented.

Y	COMMUNICATION SKILLS & INTRODUCTION TO MEDICAL INTERVIEW	M
E	INTRODUCTION TO FIRST AID	A
A	INTRODUCTION TO STUDENT RESEARCH and COMPUTER	R
Y	BASIC CLINICAL SKILL-I	M
E	(History Taking and Introduction to the Physical Examination, Clinical Skill Lab Activities, Outpatient Clinical Experience)	A
A	HUMAN IN MEDICINE	R
~		A
Y	CLINICAL SKILL LAB	S
E	(General Physical Examination)	T
A	BASIC MEDICAL PRACTICE	U
R	(Advanced Communication Skills,	D

Figure: **Spiral of Introduction to Clinical Practice Program in Marmara University Medical Faculty**

Key Words: Medical education, program introduction, integrated

MEDICINE IN WESTERN PAINTING TRADITION: AN ELECTIVE COURSE PROPOSAL FOR MEDICAL HUMANITIES

Sefik Gorkey

Marmara University, Faculty of Medicine, Department of Medical Ethics and History of Medicine

E-mail: sgorkey@marmara.edu.tr

E-mail: gorkey@superonline.com

Presented at the Conference by: Sefik Gorkey

Abstract:

Medical Humanities is one of the interesting areas in academic field and a new concept in Turkey. It seems that literature is used much more frequently in medical humanities, whereas music and paintings (including miniatures) are utilized less. However, Western painting tradition also has numerous scenes related with medicine. Those scenes can be seen both in religious and secular topics, which can be summarized as follows:

- Miraculous healings scenes of Jesus Christ (and Saints) in Frescoes (mostly in Italian frescoes in late medieval period and in early renaissance period (miraculous leg transplantation etc.)
- Disabled people and the accessories they used.
- Diseases and particularly epidemics (specifically plague), other infectious diseases, dermatological diseases such as leprosy, favus etc.), parasites (Murillo), hormonal anomalies (Ribera, Tiepolo, Veronese), obesity, prognati inferior (Bosch), depression / psychiatric illnesses (Goya, Lautrec, Edvard Munch) elephantiasis, testis tumors, paralysis,
- Birth scenes as seen in religious (Birth of Virgin Mary etc; Pintorichio, Massacio, Ghirlandaio, Ugolino di Prete Ilario, Pietro Cavallini, Paulo Uccello, Bartholomeo di Giovanni) or secular (Chagall) paintings.
- Patient – physician relationship (especially in Dutch paintings) (Jan Steen, Gabriel Metsu, Gerrit Dou and others)
- Dissection scenes (especially in Dutch paintings; Rembrandt, Aert Pieters, Thomas de Keyser, Nicolaes Elias, Adrian Backercornelis Troost, Jan van Neck, Enrique Simonet) and medical education scenes (Andre Brouillet, Johann Zoffany, Thomas Eakins,)
- Rheumatism (Rubens, Frans Hals, Rembrandt, etc), surgery (David Teniers,)
- Dentistry (Antonio Vivarini, Piero della Francesca, Gerrit van Honthorst, Gerrit Dou, Jan Steen, Adriaen van Ostade, Theodor Rombouts, Peter Jansz Quast, Cornelis Bega, David Ryckaert, David Teniers, Jan Victors, Pietro Longhi, Eduard Villard and others)
- Spectacles (El Greco, Ribera, Murillo etc), cataract (Picasso)
- Treatment methods through the ages (bandages, uroscopy etc.)
- Death / death room (religious, dance of death, plague pestilence, (secular / modern period, Edvard Munch)

The so-called “biomedical model” today in medical education approaches the practice of medicine in terms of tissues and organ systems. Unfortunately, this approach fails to evaluate patients as a whole and does not emphasize the concept of illness as a human experience. As a result, physicians trained with this model tend to see diseases entirely as biomedical entities and neglect the human dimension of medical practice. Integrating medical humanities into medical education can avoid this problem by drawing the medical student’s attention to the other non-biomedical, but humanistic aspects of medicine. The elective course proposal that will be detailed in this presentation aims to serve this purpose with a particular emphasis on Western painting and this paper aims to open this proposal to debate in this academic platform.

Key Words: Medical humanities, medicine in art

ETHICAL TEACHING IN NEPHROLOGY

Vladimir Lesovoy¹, Tetyana Ospanova¹, Ganna Lisova¹, Tamara Iermolenko¹

¹ Kharkiv National Medical University, 4, Lenina pr, 61022, Kharkiv, Ukraine;
E-mail: t.ospanova@mail.ru

Presented at the Conference by: Prof. Tetyana Ospanova

Abstract:

Rapid and dynamic increase of the number of patients that need different forms of renal replacement therapy can be noticed all over the world. Nephrology teaching in medical schools is particularly suited to demonstrating the interactions between technology and care. Chronic haemodialysis was one of the starting points for the birth of applied bioethics. Ethical issues relating to renal replacement therapy are drawing increasing attention within the nephrology community. Better medical care is helping patients live longer but, at the same time, is raising ethical questions.

The medical student and postgraduates will be trained to recognize the psychosocial aspects of life threatening and chronic diseases, and to provide support and education to patients and their families.

Ethical issues in Nephrology and Transplantology in Kharkiv National medical University are discussed during the Medical Deontology module that is offered to second year students on the Internal Medicine Department, such as patient rights, informed consent, withdrawal or withholding of renal replacement therapy, dialysis and transplantation in elderly, the problems of living organ and post- mortal donation, and etc. Students undertake a course in Nephrology during the fifth year. Teaching methods include rounds with the nephrology /dialysis/or transplant faculty member, attendance at the conference, and small group discussion. The humanities, the patient/physician relationship and ethical problems are discussed in lectures and interactive small group teaching, as well as in the dedicated optional seminars. Cases that illustrate ethical dilemmas are presented to the group for discussion. These case presentations may include review of clinical data, urinalysis, review of pathologic specimens, imaging data and treatment decision. Ethical issues surrounding end-of-life decision-making, futility and withholding dialysis, and organ donation/procurement, quality of patients' life are discussed on the sessions.

At the conclusion of a bioethical training program in Nephrology, students should be competent to provide an independent consulting and management service for the care of patients with kidney disease. They will develop an understanding of ethical, socioeconomic, medical/legal, and cost containment issues as they apply to the provision of patient care and graduate medical education. This teaching method helps us to explore students' existing knowledge and ideas; assess students' thinking about benefits and risks of science and technology and assess awareness of multiple views and influences on decision-making.

Key Words: Medical education, bioethics, nephrology

15 September 2011, Thursday

HALL 1
17:30 – 18:30

Parallel Sessions
BIOETHICS IN CONFLICTING ISSUES

Chair: **M. Volkan Kavas**

Mentor Hamiti, Diturije Ismaili, Blerim Reka
Internet ethics and education

Yulia Chukova
Scientific ethics and its particular aspects

Ralf Stutzki
Patients have a right to “unfiltered” media access - lessons to be learned from an award-winning alternative radio project. an audio-visual presentation.

INTERNET ETHICS AND EDUCATION

Mentor Hamiti¹, Diturije Ismaili², Blerim Reka³

¹ South East European University & E-mail: m.hamiti@seeu.edu.mk

² South East European University & E-mail: d.ismaili@seeu.edu.mk

³ South East European University & E-mail: b.reka@seeu.edu.mk

Presented at the Conference by: Mentor Hamiti

Abstract:

Today the internet represents a global virtual space where a large number of different users are meeting. They are different ages, belonging to different social strata, vary by level of education, culture, tradition, race, religion, and by geographical space where they are geographically located and other supporting features. To all of them in the same manner it is offering the possibility of information, communication, entertainment, education and performing many other daily and professional activities, which are an inseparable part of contemporary society.

But unfortunately, against all these advantages and benefits that human society has from the internet, always remains open also the possibility that the Internet to be misused by different users. In this context the role and importance of Internet ethics is undeniable. Particularly to advice and suggest users for fair and correct usage of resources that Internet offers but also provides answers about the resolution of ethical dilemmas arising from the use of the Internet.

In this context, based on the fact that education represents a fundamental component of ethical education of the Internet users, a case study was carried out by Macedonian Unit of the International Network of the UNESCO Chair in Bioethics, in the South East European University. The primary purpose of the research has been finding the real situation regarding the ethical perceptions of students, as a massive category of internet user's and resulting conclusions for further cooperation in support of Internet ethics.

Key Words: Ethics, internet, education

SCIENTIFIC ETHICS AND ITS PARTICULAR ASPECTS

Yu. P. Chukova

Krasnopresnenskiy Ecological Fund. Moscow. Russia. y.Chukova@mtu-net.ru

Presented at the Conference by: Yu. P. Chukova

Abstract:

Ethics of a scientist has much in common with ethics of other groups of the population in case of relationship between the persons, that is to say in a realm, where there are man-made laws. However, when a problem concerns an analyze of ambient actuality, new aspects appear. These aspects are more acute specially in the realm of medicine and physiology. This particular ethics of a scientist is determined by gradual, progressive knowledge of living systems, which essentially lags behind knowledge of nonliving objects because of complexity of living systems.

Modern medicine and physiology exists in conditions of inexact knowledge. The lack of knowledge is filled (is compensated) by agreement of scientists among themselves. As the positive part of this situation now it is necessary to consider own fact, when scientists recognize and aloud say about this one. The role of the negative part is much more significant. Such agreement has allowed to discredit the Weber – Fechner law (the main law of sensory physiology), though attempt to repeal this law in 1960 has failed. Now we know, that the Weber-Fechner law is a part of more general thermodynamic law [1]. It means, that the Weber-Fechner law will never be repealed, because the energy conservation law will never be repealed. Analogical consensus of scientists complicates an acceptance of scientifically substantiated standards of safety of electromagnetic radiation and selection of doses in medicamental medicine.

This aspect of ethical behavior in scientific work is very important for future development of medicine and physiology. The social laws can be any, agreement of scientists among themselves too (especially). But the laws of nature (base of all medical and physiological processes) do not depend on desire and free will of scientists. And if the scientific ethics neglect this simple true, the development of medicine and of physiology will go by a zigzag way with an apparent reverse back, just as it happened in the realm of sensory physiology.

Reference

1. Yu.P. Chukova. The Weber-Fechner law. To the 150-th anniversary of the publication of the book “Elemente der Psychophysik” by G.T. Fechner. Moscow, 2010, 180p, ZAO MP “Gigiena”, ISBN 978-5-904207-07-6,

Key Words: Nature laws, scientific consensus

PATIENTS HAVE A RIGHT TO “UNFILTERED” MEDIA ACCESS - LESSONS TO BE LEARNED FROM AN AWARD-WINNING ALTERNATIVE RADIO PROJECT. AN AUDIO-VISUAL PRESENTATION.

Ralf Stutzki

Dept. Medical and Health Ethics, Medical Faculty, University Hospital Basel, Switzerland, Missionsstrasse 21, CH-4055 Basel, Tel: 061 260 21 90/91, FAX: 061 260 21 95. E-mail: ralf.stutzki@unibas.ch; <http://medethik.unibas.ch>

Presented at the Conference by: Ralf Stutzki

Background and aim

“DU bist Radio” (“YOU are radio”) is a newly developed radio format which has first been broadcast in Switzerland in March 2009.¹

For the first time ever, five patients suffering from devastating Amyotrophic Lateral Sclerosis/Motor Neuron Disease get together to produce a radio program. They talk about their lives before being diagnosed and about the impact the disease has had on them and their families since the disclosure. Suffering from this incurable motor neuron disease and facing death possibly in the near future, this one-hour-program gives remarkable insight into five biographies which are dominated by suffering, yet guided by hope.

The aim is to allow and enable them to speak for themselves, as a possible paradigm case for encouraging the inclusion of patients’ and relatives’ “unfiltered” voices in clinical ethics consultation as well.

Approach

“DU bist Radio” (DBR) follows closely the concept of dialogical philosophy as developed for example by Martin Buber: *“I become through my relation to the Thou.”* DBR hands over the microphone to vulnerable groups (patients, prisoners, disabled or terminally ill adults, children in a hospice and drug addicts) and teaches them radio skills and craft. The final product - the radio show - including all content is solely created by the DBR groups.

Results and discussion

The project showed that the ‘experimental’ approach worked out well: ALS patients were able to communicate important messages to a large audience stimulating awareness for their needs and problems such as neglect for patients, esp. after retirement; the need to restart communication processes e.g. in their families; the need to formulate and realize dreams and goals.

This means that a radio program in which no “journalistic filter” is being applied and no journalistic questions are asked, is a fruitful media setting: it seems to be particularly the absence of the investigative approach which allows for unexpected answers and authentic insights. The impact of this experience shall be put to discussion in the context of clinical ethics consultation.

Conclusion

If we don't ask questions we will receive different answers; this rather unusual statement apparently sums up the DBR experience so far. Especially when working with patients, questions and questionnaires oftentimes emphasize the interviewer's quest for knowledge (which includes his / her attitude and prejudice). Thus, the degree of authenticity of the interviewee's answer is at least questionable. Providing a setting where patients claim their rights to be solely responsible for the content of a discussion will lead to greater insight into their overall condition – and this may also be true for clinical ethics consultation.

Key Words: Media, patients, ALS/MND

¹It has been awarded with the "Deutscher Alternativer Medienpreis" (German Alternative Media Award) and has been nominated for Europe's most influential continental media award "Prix Europa".

15 September 2011, Thursday

HALL 2
17:30 – 18:30

Parallel Sessions
BIOETHICS AND HUMANITIES

Chair: **Atilla Özgür**

Mine Şehiraltı, Aslıhan Akpınar

Attributes of a good physician: medical students' changing opinions

Dilek Özden, Şerife Karagözoğlu, Gülay Yıldırım, Eda Tabak

The ideas of intensive care unit doctors and nurses about futility care and treatment and the relationship between the work satisfaction and burnout level

Boleslav L.Lichterman

From deontology to bioethics: evolution of medical ethics in Russia

ATTRIBUTES OF A GOOD PHYSICIAN: MEDICAL STUDENTS' CHANGING OPINIONS

Mine Şehiraltı¹, Aslıhan Akpınar²

¹ Kocaeli University, Medical School, Department of History of Medicine and Ethics, E-mail: msehir@gmail.com

² Kocaeli University, Health Sciences Institute, Department of History of Medicine and Ethics, E-mail: aslyakcay@yahoo.com

Presented at the Conference by: Aslıhan Akpınar

Abstract:

There has been increased interest to investigate how medical students developed professional attributes including virtues of physicians and their communication skills during the undergraduate medical education. However changing descriptions on 'being a good physician' of the medical students in that time has not been investigated widely until today.

Understanding whether and how medical students' perception of good physician changes during medical education can be a useful starting point when considering how to incorporate aspects of professional behaviour into the medical curricula. Thereafter we may explore effects of students' values, clinical encounters, ethics education etc. on their 'good physician' concept. With this background we aimed to explore changes in medical students' perception of good physician over medical education.

We conducted a prospective longitudinal study and we looked at the views of medical students about good physician at Kocaeli University, Medical School when they were at fourth and sixth class (2008-9 and 2010-11 academic years). The students completed their theoretical ethics education until fourth year and we assumed that the students were naïve in terms of "actual physician-patient" relation. In following years they had inpatient and outpatient contacts under the supervision of the faculty and residents as main "role models". To determine the changing attributes, if any, when the fourth year students became interns, they were asked an open-ended question as 'What, in your opinion, are the attributes a good physician should have?' The answers were classified by the researchers in the method defined in our formerly published manuscript.*

In the fourth year 92 students and in the sixth year 99 interns were enrolled into the study. Sixty two of the fourth year students participated and their answers were evaluated. Sixty one interns responded until now and the forthcoming responses will be obtained in a month. Although data processing has not been completed yet, the primary findings showed that the given importance to 'interpersonal relations and communication' skills slightly decreased during internship. Attributes related to 'sustaining professional integrity' and 'scientific knowledge and medical practice' seemed not change during that time. However the interns more often emphasised 'being able to connect well with colleagues' and 'medical records should be obtained care-

fully' among attributes concerning professional integrity.

* Sehiralti M, Akpinar A, Ersoy N. Attributes of a good physician: what are the opinions of first-year medical students? J Med Ethics. 2010 Feb;36(2):121-5.

Key Words: Undergraduate medical education, virtues, medical ethics

THE IDEAS OF INTENSIVE CARE UNIT DOCTORS AND NURSES ABOUT FUTILITY CARE AND TREATMENT AND THE RELATIONSHIP BETWEEN THE WORK SATISFACTION AND BURNOUT LEVEL

Dilek Özden¹, Şerife Karagözoğlu¹, Gülay Yıldırım², Eda Tabak³

¹Cumhuriyet University, Faculty of Health Sciences, Nursing Department. Sivas,Turkey. & E-mail: dozden2002@yahoo.com

²Cumhuriyet University, Faculty of Medicine, Department of Deontology and History of Medicine. Sivas,Turkey. & E-mail: gyildirim@gmail.com

³Cumhuriyet University, Faculty of Health Sciences, Department of Nursing, Graduate Student.

Presented at the Conference by: Gülay Yıldırım

Abstract:

Aim: The aim of this study was to evaluate the ideas of intensive care unit doctors and nurses about futility care and treatment and to show the relationship between the work satisfaction and burnout level.

Material and methods: The universe of the study was composed of intensive care unit patients from two Central Anatolia University Hospital between 15 May-15 July 2010. The sampling unit was consisted of 176 person, 108 nurses and 68 doctors. The datas were collected by the datas from sociodemographic properties, career datas, a survey containing 19 sociodemographic questions about futility care and treatment, a 42 hypothesis "the ideas of doctors and nurses about futility care and treatment" form, Maslach Burnout inventory (MBI) and Minnesota satisfaction scale (short form). The datas were analysed by SPSS (version 14 for Windows) by percentage distribution, student t test, Mann Whitney-U test, Kruscall Wallis test ve variance analyse.

Results: The average age of the participants was 30.35±5.23(22-48), 72.2 % was female and 56.3% was married. The 61.4 % was nurse and 38.6 % doctor. The 81.05% of participants specified the futility care or treatment in their intensive care unit and 26.1 % with a frequency of everyday or every month. The causes of futility care and treatment were denoted as 58.0% doctor request, 43.6 family, 36.9% hospital management, 35.8% life protection work, 34.4% euthanasia equivalence, with a lower ratio 13.1% religious belief, 24.4% effectiveness principle, 12.5, justice principle. The 38.1% of participants determined the decision of futility care should be given by ethics committee, 22.2 % crew, 19.9 the responsible doctor. In the 42 hypothesis survey 68.5% of nurses noted the prolong of pain by futility care, the demoralisation according to this (66.7 %), the futility care to especially brain death or vegetative state (64.8 %), the importance of the decisions of patient and patient relatives (63.9 %), the deficient communication between the crew personel (48.1%), the ethics dilemma (70.4 %), the attention of "benefit but not harm" principle (85.2%). The 70.6 of doctors determined the importance of clinical principles about futility care. In this hypothesis, there was a statistical difference between doctors

and nurses ($p < 0.05$). The average work satisfaction of doctors were 68.01 ± 12.30 , and 57.04 ± 14.78 for nurses. The burnout level in doctors was 22.60 ± 4.42 and 19.94 ± 4.84 in nurses and there was significant difference between two groups. The relationship between the work satisfaction and burnout level was poor ($r = 0.378$, $p = 0.000$) and positive.

Conclusion: In conclusion, there is a futility care and treatment in intensive care units and especially nurses live ethics dilemma. Furthermore, the work satisfaction of nurses and doctors is normal but the burnout level of nurses was low.

Key Words: Futility care, work satisfaction, burnout

FROM DEONTOLOGY TO BIOETHICS: EVOLUTION OF MEDICAL ETHICS IN RUSSIA

Boleslav L.Lichterman

The Burdenko Neurosurgery Institute, Moscow, Russia;
E-mail: lichterman@hotmail.com

Presented at the Conference by: Boleslav L.Lichterman

Abstract:

Evolution of medical ethics in Russia was determined by several factors. First, it developed relatively late. Russian medical doctors with university degrees appeared only in the XV11th century after the politics of westernization by Peter the Great (1672-1725). Medical ethics starts from Dr. Matvei Mudrov (1776-1831) who was a first interpreter of Hippocratic works from Ancient Greek into Russian. His credo was «to treat not a disease but a patient». Second, after serfdom had been abolished in 1861 medical care in rural regions was provided by zemstva (local elected councils). Zemskie medical doctors had idealistic views of self-sacrificing for the service to the society and to the people. Medicine as money-making activity was criticized and ridiculed in Russian literature (see Chekhov's novels, for example). On the other hand, while dealing with illiterate peasants paternalism was a necessity. Third, Russian medical ethics bears a heavy mark of seven decades of Communist regime. In 1918 Health Care Commissariat (ministry) was formed. Common interests were declared superior to the private ones and medical confidentiality was viewed as a bourgeois survival. On the other hand, diagnosis was normally not disclosed to a patient in case of an incurable disease (especially cancer). The term «medical ethics» had been avoided until late 1930ies when it was replaced by «deontology» (the word was coined in the beginning of XIX century in England by J. Bentham). There were five All-Union conferences on medical deontology since 1969. Finally, «medical deontology» was abandoned in favor of «bioethics» in post-communist Russia. National Committee on Bioethics was formed but ethical committees at local level (at hospitals and research institutions) are nearly non-existent. A brief overview of ethical problems related to modern clinical trials will be provided.

Key Words: Medical ethics. history of Russian medicine; clinical trials

16 September 2011, Friday

HALL 1
09:00 – 10:00

Plenary Lecture: “The European Biomedicine Convention: a Platform of Dialogue”

Key Note Speakers: **Ayşegül Elveriş, LL.M,**
Prof. Dr. Elmar Doppelfeld

Moderator: **Prof. Dr. Ergun Özsunay**

Ayşegül Elveriş, LL.M

Aysegul Elveris completed her Bachelor of Laws (LL.B.) degree at Galatasaray University in Istanbul, Turkey in 2002. Upon graduation, she attended Université Paris 1 Panthéon-Sorbonne in Paris, France to do her masters degree in law (LL.M.). At Sorbonne, she focused on criminal law. She subsequently obtained a second masters degree in law at Robert Schuman University in Strasbourg, France, where she focused on human rights law. For the last four years, she has been working at the Council of Europe and the European Court of Human Rights as a legal officer. Currently, she is working at the Directorate General of Human Rights and Legal Affairs of the Council of Europe, in the department of Social Charter. She specializes in human rights law.

THE EUROPEAN BIOMEDICINE CONVENTION: A PLATFORM OF DIALOGUE

Ayşegül Elveriş, LL.M

Secretary of the Group of Specialists on Human Genetics

Email: aysegul.elveris@coe.int

The Convention on Human Rights and Biomedicine, which was opened for signature in Oviedo (Spain) in April 1997, is the first legally binding international instrument in this area. The Oviedo Convention was assigned two main tasks: firstly, to lay down the ethical and legal principles that apply to any medical act and, secondly, to identify a number of principles that could be applied to the new biomedical techniques.

The principles of autonomy, confidentiality, beneficence/non-maleficence and justice, which are all based on the broader notion of human dignity, are elaborated on in the Oviedo Convention. Moreover, in its thinking, the Convention retains a close kinship with the European Convention of Human Rights, from which it borrows several key concepts and terms with the aim of preserving the coherence of the European legal system.

In structural terms, the Oviedo Convention is a framework convention, whose provisions are supposed to be built on by means of additional protocols, each dealing with a separate sphere of biomedical activity. To date, four additional protocols have been opened for signature: One prohibiting the cloning of human beings (1998), one on transplantation of organs and tissues of human origin (2002), one on biomedical research (2005) and one – the last one for the time being – on genetic testing for health purposes (2008).

The Oviedo Convention had an impact on the legislation of many European countries, which adapted their provisions to its principles. The principles established by the Convention have also had an influence on the drafting of certain other international documents with universal scope such as UNESCO's Universal Declaration on Bioethics and Human Rights.

The Oviedo Convention and its additional protocols have also yielded tangible results where it comes to laying down the rules for the protection of patients in the areas of medical research, the transplantation of organs and tissue and even genetics, despite the highly changing nature of this field.

Prof. Dr. Elmar Doppelfeld

Elmar Doppelfeld as physician and Professor of Nuclear Medicine at the University of Bonn joined in 1980 a group of German academics interested in research ethics. They initiated a forum for exchange of information and harmonisation for the work of Ethics Committees, as established by the Faculties of Medicine, the Medical Associations and some States Governments in the German States since the late seventies. Prof. Doppelfeld became secretary general of this group. Since 1994 he has been elected several times as chairman of that "Permanent Working Party of Research Ethics Committees in Germany". Up to now, there is no National Ethics Committee for medical research in Germany, therefore this group ("Arbeitskreis Medizinischer Ethik-Kommissionen in der Bundesrepublik Deutschland") is accepted as an important consultancy for the public, governments and parliaments.

In 1992, Prof. Doppelfeld – scientific editor of the *Deutsches Ärzteblatt* (1988-2004) – was appointed by the German Government as a member of the German delegation to the Council of Europe's Steering Committee on Bioethics (CDBI). He was a member of the Working Party which prepared the additional protocol to the Convention of Oviedo concerning biomedical research, opened for signature on 25 January 2005 by the Committee of Ministers of the Council of Europe. He served as chairman of the Working Party which elaborated the recommendation on research using biomaterials of human origin, adopted by the Committee of Ministers on 15 March 2006. Vice chair of the CDBI since 2003, Prof. Doppelfeld was elected chair of the "Steering Committee on Bioethics" (CDBI) of the Council of Europe on 28 April 2005 and held this position until the end of the regular 2-years period of chairpersons in June 2007. Since June 2007 he chaired the working party to elaborate a guide for members of research ethics committees. This guide was accepted by the CDBI in December 2010.

THE EUROPEAN BIOMEDICINE CONVENTION: A PLATFORM OF DIALOGUE BIOMEDICAL RESEARCH

Prof. Dr. Elmar Doppelfeld

University of Bonn

The Convention on Human Rights and Biomedicine underlines the freedom of research subject to its or other protective provisions for research participants. Among these protective provision free and informed consent of the individual to be involved in a research project plays an important role. Any research project has to fulfill the widely accepted criteria scientific quality, conformity with law and ethical acceptability. Specifically risks and expected benefits may not be disproportionate. The researcher has to submit the intended project before its begin to a multidisciplinary ethics committee for an assessment. The mentioned criteria may be proved all by the ethics committee or separately by other competent bodies. As a principle the Convention requires that an approval by a competent body, if foreseen by national law, may only be given after the assessment by the ethics committee. The Convention provides specific protective provisions for research on persons not able to consent such as minors or victims of traffic accidents. The permission to include those persons into a research has to be given by the legal representative in conformity with national law. The legal representative has to base his decision on an appropriate information and has to take into account the understanding of the represented person and any objections. Such an authorisation may only be given for research projects which cannot be carried out on persons able to consent. In principle the representative may only authorise research projects with a potential direct benefit for the represented person. However, exceptionnally and under protective conditions prescribed by law the representative may agree to research projects without an expected direct benefit for the participant. Those projects may only entail minimal risk and minimal burden for the involded individual as absolute limitations.

Within this framework provisions have been elaborated to adopt the content of the Convention in more detail to the needs of research: The additional protocol concerning biomedical research (legally binding), the recommendation for research using biological material of human origin and recently the guide for members of research ethics committees. The latter is specifically dedicated to the implementation of the protective provisions to the field of medical research.

The provisions of the Convention and the additional instruments, even not yet accepted or ratified by all European states, are considered as leading contributions to the ongoing discussion how to balance freedom of research and the protection of human rights and fundamental freedoms of research participants.

16 September 2011, Friday

HALL 1
10:00 – 11:15

Parallel Sessions
BIOETHICS, UNIVERSALISM AND PARTICULARISM

Chair: **Tineke Abma**

Bert Vanderhaegen
Global bioethics is a fiction?

David Fieldsend
Unity in diversity: can there ever be a true European consensus in
bioethics?

Elvio Baccarini
Cultural diversity, Medical Ethics, democracy

Brigitte Feuillet
Bioethics and biolaw: an established relationship

GLOBAL BIOETHICS IS A FICTION?

Bert Vanderhaegen,

University Hospital Ghent, De Pintelaan 185, 9000 Gent (Belgium).

E-mail: bert.vanderhaegen@uzgent.be

Presented at the Conference by: Bert Vanderhaegen

Abstract:

The main tool in mainstream bioethical debate is secular reason. Despite perennial disagreements there are proclamations of moral consensus. The Declaration on Bioethics and Human Rights of UNESCO (2005) can be seen as such a proclamation of a universal/global bioethics. But can it ever function as the foundation of a truly global bioethics? In my opinion the critiques on secular reason which comes from postmodernity and from authorities within institutionalized religions are not seriously dealt with. Since a few decades reason itself has become under suspicion. Philosophers and sociologists like Lyotard have noted the non-availability of a universal moral narrative. MacIntyre and others have elaborated on this issue in the domain of ethics. Because of the Reformation in the sixteenth century Western Christendom was fragmented. Against this fragmentation the Western philosophers reached back to a cardinal element to overcome this tragedy: the role of reason. They believed that secular moral thought could still disclose a unity through rational moral reflection. Philosophers were very optimistic about the fact that secular rationality would disclose a common morality. Secular morality could be one. The modern philosophical project of grounding morality in reason eventually led to the fully secular, moral aspirations of the Enlightenment (and in the 20th century to the emergence of contemporary secular bioethics). But the project of the Enlightenment failed. For most intellectuals the secular hope for a perpetual peace grounded in a secular rationality was buried in the trenches of the First World War. At the end of the 20th century it became clear that secular rationality via sound rational argument alone could not transcend the diversity of moral visions with their pluralities of (bio)ethics. For several scholars it is clear that by reason alone secular morality cannot establish a content-full morality. Critics of this vision may point out that secular bioethics have secured a common moral vision to bind all. Principlism for example can reach common decisions when they approach diverse clinical cases, despite divergent theoretical commitments and backgrounds. This bioethics is neutral but still content-full. For some this whole enterprise of principlism is a complete fraud because it can only work if the participants in the debate are ideologically close enough to each other. Once the diversity among the participants is too big there is no content-full consensus possible. Therefore secular morality is procedural. This has serious consequences for what 'good' in our day and age means. The good life is not found in submitting to and being determined by the good and the true (content-full). Autonomy instead becomes integral to the good (content becomes arbitrary). The time has come that we better than ever can value the true but limited powers of reason. There is no other instrument for humanity than reason to help us live together in a moral way. But reason alone is not enough. It would be a very big step forward if all bioethicists would 'disclose' their worldview. But this

is not 'done'. It is their worldview which gives them their orientation, not only secular reason. It is time that it comes at the public forum of the bioethical debate. Maybe then the Declaration on Bioethics and Human Rights of UNESCO (2005) can function as the foundation of a global bioethics?

Key Words: Global bioethics critique

UNITY IN DIVERSITY: CAN THERE EVER BE A TRUE EUROPEAN CONSENSUS IN BIOETHICS?

David Fieldsend,

CARE for Europe/Centre for Bioethics & Public Policy, 57 Rue Archimède, 1000-Brussels, Belgium & E-mail: david.fieldsend@careforeurope.org

Presented at the Conference by: David Fieldsend

Abstract:

Drawing on a decade of experience of interaction with the European Institutions (both the European Union and the Council of Europe) as representative of CARE for Europe and the Centre for Bioethics and Public Policy, the author will explore the extent to which it has been possible to develop a truly European bioethics and how the different perspectives of these international institutions and the diverse cultural, religious and academic approaches of individual member states have interacted with each other.

The presentation will draw on the various Conventions and Protocols of the Council of Europe – particularly the Oviedo Convention on Human Rights and Biomedicine - and the extent to which it has been possible to secure national ratification of them, as well as the Opinions of the European Group on Ethics in Science and New Technologies (EGE) which advises the European Commission. It will also refer to debates surrounding the development of key pieces of EU legislation with bioethical implications, especially within the European Parliament. The relationship between the EU's genesis as a primarily economic and commercial governance entity – with its accompanying emphasis on the harmonisation of technical standards - and its approach to diversity in national bioethical perspectives will also be examined.

The attempt will be made to draw conclusions as to the relative success of the European consensus process in bioethics and the degree to which there may still be a problem, more or less residual, of the impossibility of trying to reconcile the irreconcilable.

CULTURAL DIVERSITY, MEDICAL ETHICS, DEMOCRACY

Elvio Baccarini

University of Rijeka Faculty of Humanities and Social Sciences
Slavka Krautzeka bb 51000 Rijeka, Croatia
E-mail: ebaccarini@ffri.hr

Presented at the Conference by: Elvio Baccarini

Abstract:

Do parents have the right to oppose on religious and cultural base life saving treatment of their children? Do they have the right to practice genital mutilation of their children, in accordance with the tradition of their community? What about issues of personal and public health, like those associated with sexual education relevant as a form of prevention of early pregnancies, as well as in connection to issues of public health, for example the prevention of AIDS?

Among the reactions in front of these divisive issues, one of the extremes is represented, for example, by Brian Barry who sees the possibility to establish a common standard for the resolution of the issues on the base of universal human rights. The other extreme is represented, for example, by Chandran Kukathas. In his opinion there are not and cannot be common standards of evaluation of moral issues and issues of justice. This is the reason why there is no legitimacy in intervening in the relations established in free associations of people on the base of their conscience.

In the space in-between extremes as those shown in the two examples, there are various forms of identity theories, as well as theories that want to establish common standards of rights and moral values through a democratic deliberative process.

There are theoreticians of democracy who say that we cannot establish in advance standards of justice and human rights. They are the matter of democratic decision making. However, in conditions of deep moral differences even democracy itself is a disputed subject matter. The question that appears is why does one have to renounce to demands of her conscience in order to respect the authority of democratic decisions?

Robert Talisse says that we must accept the authority of democratic decisions even when we are deeply dissatisfied by their content because we implicitly accept epistemological norms that can be satisfied only in democratic orders.

All of the three indicated proposals face serious problems. As regards Barry, it is difficult to find consensus (and, therefore, liberal legitimacy) for a system of norms that regulates deep moral conflicts. As regards Kukathas, a problem appears with human beings that are the subjects of other people's decisions because they are not able to exercise free conscience (children are the paradigmatic case). Who has the authority to make decisions regarding them? As regards Talisse, the problem is represented by the absence of consensus on epistemological norms that his theory

requires. In general, the same people that refuse the moral values as the ground of democracy tend to refuse the epistemological norms that Talisse remarks.

The appropriate solution is represented by attributing authority to democratic decisions, provided they are made not on mere procedural grounds, but after a serious exchange of reasons among citizens with the status of peers. But the foundation of the legitimacy of such deliberative democracy is represented by the civic virtue of equality among citizens, understood as the minimum condition for life in a common political society.

Key Words: Multiculturalism, liberalism, deliberative democracy

BIOETHICS AND BIOLAW: AN ESTABLISHED RELATIONSHIP

Brigitte FEUILLET, Professor of Law, University of Rennes; Membre of Institut Universitaire de France

Faculté de droit 9, rue Jean Macé 35700 RENNES / FRANCE

E-mail: brigitte.le-mintier@univ-rennes1.fr

Presented at the Conference by: Brigitte Feuillet

Abstract:

Examining the relationship between bioethics and biolaw goes back to studying the respective roles that ethics and law play in life sciences and exploring the links that exist between these two tools. This subject naturally leads to an examination of the relationship between two normative systems that differ from one another in their objectives (to provide social order for the Law and to enforce that behaviour complies with ethics) and in their binding forces (unlike law, ethics allows individuals freedom to act on their own). There appears to be an ongoing back-and-forth between bioethics and law, a give-and-take that symbolises a mutual relationship or even a connection. This presentation seeks to demonstrate that bioethics is a tool for adapting law to the needs of our modern society and that biolaw is the cornerstone for bioethics. In fact, this established relationship (rightfully) forces law to listen to bioethics and bioethics to listen to law.

Biolaw listens to bioethics because it thrives on bioethics to adjust to the new world. Even when biolaw changes, bioethics continues to watch and grow from it. Ethical discussion is at the root of transformations in the Law. Bioethics is one of creative forces of law found in medicine. However, to protect the pluralism that bioethics must convey, we must adopt a wide-ranging view of bioethics. To understand biomedical progress, ethical thinking should be based on the essential explanations from scientists and on the opinions of anthropologists, philosophers, theologians, sociologists, economists, and even jurists, in order to fully comprehend the human, economical, and social issues of biomedical practices. Bioethics must therefore be viewed as the set of all teachings from all disciplines combined, focusing on biomedicine, a doctrine that will highlight the values being threatened and those we need to stress.

At the same time, bioethics listens to biolaw. Bioethics reflects how our society should behave in number of situations. Such thinking can take place only by considering what governs (or regulates) this behaviour, namely law. Bioethics must therefore incorporate existing legal data (including the guarantees provided by law, such as our fundamental rights). In addition, bioethics can listen to the law only if it respects its organisation (what it is), its contents (what it provides), and its authority.

Key Words: Bioethics, biolaw, relationship

16 September 2011, Friday

HALL 2
10:00 – 11:15

Parallel Sessions
BIOMEDICAL RESEARCH

Chair: **Jiri Simek**

Sabine Salloch, Jan Schildmann, Jochen Vollmann
Value and limitations of empirical research on peoples' moral
attitudes in different cultural contexts

Ioana Ispas
What makes vulnerable principle unstable, in evaluation of research
projects?

Funda G. Kadioğlu, Selim Kadioğlu
Prominent topics and samples of empirical researches in Turkish
medical ethics literature

Serdar İzmirli, Süleyman Dere, Aşkın Yaşar
The contribution of the studies to the medical science by using
experimental animals (rat and mouse) in Turkey

VALUE AND LIMITATIONS OF EMPIRICAL RESEARCH ON PEOPLES' MORAL ATTITUDES IN DIFFERENT CULTURAL CONTEXTS

Sabine Salloch, Jan Schildmann, Jochen Vollmann

Institute for Medical Ethics and History of Medicine, Ruhr University Bochum, Germany, E-mail: Sabine.Salloch-s52@Rub.de

Presented at the Conference by: Sabine Salloch

Abstract:

An increasing number of empirical studies on peoples' moral attitudes towards ethically challenging topics is currently published in bioethics journals. Such research indicated repeatedly the association of moral attitudes with the study participants' cultural backgrounds. However, the impact which peoples' culture dependent moral stances have for ethical evaluations is often not made explicit. Therefore, in our contribution, we will use the growing popularity of attitudes research in bioethics as a starting point for a more detailed analysis of the value as well as the limitations of this kind of research for bioethical reasoning in different cultural contexts.

In our analysis we will start with selected empirical as well as normative challenges of attitudes research in bioethics. One point of critique here is that it often remains unclear what kind of data is exactly collected in empirical research on peoples' moral attitudes (emotions, intuitions, considered judgments etc.) and in which ways methodical distinctions in empirical research (for example, quantitative versus qualitative methodology) are relevant for its possible contributions to bioethical reflection. Another point we will dwell on is the seeming lack of external critical assessment of attitudes which are elicited as part of empirical research and which are often used as a basis for formulating normative guidelines in different contexts. Here, we will defend the position that empirical data about peoples' moral intuitions are able to deliver worthwhile contributions to normative reasoning in bioethics but have to be integrated into a broader theoretical framework in order to fulfil their specific functions. We will then give a short sketch of the different ways how empirical data about peoples' moral attitudes can be integrated into models of ethical justification as provided in different ethical theories.

In our final part, we will apply our analysis to the field of inter-cultural bioethics. We will consider different possibilities how empirical data about peoples' moral attitudes in different cultural contexts can be integrated into the debates on ethical challenges of modern health care. In this context we will focus on concrete research on peoples' culture dependent moral values using the example of empirical studies about peoples' attitudes towards end-of-life practices. Based on the analysis we will conclude with some concrete suggestions regarding the planning and conducting of moral attitudes research which aims to contribute to the debate on ethical issues in different cultural contexts.

Key Words: Attitudes research, empirical ethics, inter-cultural bioethics

WHAT MAKES VULNERABLE PRINCIPLE UNSTABLE, IN EVALUATION OF RESEARCH PROJECTS?

Ioana Ispas

Center for Applied Ethics, University of Bucharest, 204 Splaiul Independentei Blvd, Bucharest, Romania.

E-mail: ioana_isp@yahoo.com

Presented at the Conference by: Ioana Ispas

Abstract:

Biomedical research on human subjects was always very sensitive. A lot of instruments have been created to help the guidance in this area starting with Nuremburg code. Even more, at European level, Kemp in a project funded by European Union, advanced more and identified vulnerable principle as an European principle important for post conventional culture of human rights.

Vulnerability as concept is far from being clear and in consequence during medical research is difficult to be offered to research subjects in an appropriate way. Legal requirements in this area are focused mainly on limited capacity of informed consent. On the other hand so many groups are considered to be vulnerable that the principle of vulnerability became weak. The article investigates the applications of vulnerable principle in evaluation of research projects based on the guidance note for evaluation of research projects elaborated by European Commission for The Seventh Research Framework Programme and how Barcelona Declaration has been implemented in European Union ethical evaluation of research projects. The different categories of vulnerabilities are investigated: allocation vulnerability, vulnerability of infrastructure, medical vulnerability, juridical vulnerability. The findings show that many times it is difficult to make the difference between facts and norms in case of vulnerable principle.

Key Words: Vulnerability, medical research.

PROMINENT TOPICS AND SAMPLES OF EMPIRICAL RESEARCHES IN TURKISH MEDICAL ETHICS LITERATURE

Funda G. Kadioğlu¹, Selim Kadioğlu²

¹ Cukurova University, Faculty of Medicine Department of Medical Ethics
E-mail: fgkadioglu@cu.edu.tr

² Cukurova University, Faculty of Medicine Department of Medical Ethics
E-mail: selimkad@cu.edu.tr

Presented at the Conference by: Funda Kadioğlu

Abstract:

Background: In last two decades, in medical ethics literature, it is emphasized that empirical researches are necessary to identify and explain the normative structure of a concrete fact in certain medical situations. These researches examine the values and ethical principles underlying clinical decision making, and also investigate how these principles are used, by whom and under what conditions.

Objective: The aims of this study were to determine subjects and participants of the empirical ethics researches in Turkish medical ethics literature and to compare the study findings with the results of the previous studies in general medical ethics literature.

Method: In the study, data were collected from different sources representing the Turkish medical ethics literature. This retrospective and descriptive study included only the medical ethics research reports. All reports were investigated and classified by the publication source, publication year, study topics and samples.

Results: A total of 1205 articles were published in Turkish medical ethics literature. The study was performed on 161 empirical researches published between January 1994 and December 2009. In Turkish medical ethics literature, the most investigated study topics were patient rights (11.2%), transplantation (9.9%) and informed consent (8.7%), while the most studied samples were physicians (16.8%), medical students (13.7%), and nurses (11.8%).

Conclusion: Empirical studies in Turkish medical ethics literature have become more noticeable like in general medical ethics literature. Among the most studied three subjects in both ethics literature, the informed consent was the common topic. Patients, physicians, nurses and students were the most commonly studied samples of both these literatures.

Key words: Medical ethics literature, Turkish medical ethics literature, Empirical ethics research.

THE CONTRIBUTION OF THE STUDIES TO THE MEDICAL SCIENCE BY USING EXPERIMENTAL ANIMALS

(Rat and Mouse) in Turkey

Serdar İzmirli¹, Süleyman Dere¹ and Aşkın Yaşar¹

¹ Department of History of Veterinary Medicine and Deontology, Veterinary Faculty, University of Selcuk, Konya, TURKEY, E-mail: sizmirli@selcuk.edu.tr

² Department of Animal Science, Veterinary Faculty, University of Selcuk, Konya, TURKEY

Presented at the Conference by: Serdar İzmirli

Abstract:

Whilst it is acknowledged that research has progressed as a result of using animals, such as rats and mice, there is still growing concern among animal activists demanding that the scientific community minimize the pain and distress of animals used in experimental processes. They are used in the experiments which have been discussed in the science community and the public. Their contribution to the medical science has been worried a lot. Although the parameters of the valuableness of a scientific study is not clear, the number of citations and impact factor of the journal are generally accepted the parameters of the scientific valuableness. There is a positive relationship between high citation numbers and quality research in terms of highly cited articles.

This study aimed to introduce the contribution of the studies to the medical science with the above parameters by using rat and mouse. In brief, this situation is critically important for animal and research ethics.

ISI "Web of Science" has used to present the data about the studies which are related to rat and mouse. The citation rate is one of the important criteria of journals that are indexed by ISI. The study covered a ten-year period from 1997 – 2006. Correlation statistics was used to introduce the relationship between the citations', references and authors numbers. It was also utilized SPSS 15 version for Descriptive Statistics for appearance of the variables means.

The total rat studies were 1012 whereas it was 332 for mouse at this time. Furthermore, the average citation of the rat studies was 7.26 however this was 9.64 for mouse studies. The studies by using rats and mice mostly introduced at the area of pharmacology. The most citations have been received at the toxicology field for rat studies whilst it was medical chemistry for mouse studies.

The studies with rats were mostly published at the journal of Pharmacological Research and they have received 8.49 average citation. Furthermore, the studies by using rats which were published at the journal of Brain Research were most widely-cited studies by 12.92 in this field.

However, the studies with mice were mostly published at the Turkish Journal of Veterinary and Animal Sciences by getting 1.81 average citations. In addition, the studies by using mice which were published at the European Journal of Pharmacology were most widely-cited studies by 12.13.

Consequently; most remarkably, the numbers of the studies by using mice were more than the numbers of studies by using rats in Turkey. In contrast with these numbers, the citations of the mouse studies were more than rat studies. It's obvious that the contribution level to the medical science by using mice is more than the studies that conducted over rats concerning with getting citation. However, it should be researched with further studies for what reasons rats more preferred than mice by scientists' in terms of animals and research ethics.

Key Words: Rat, mouse, citation, impact factor, Turkey

16 September 2011, Friday

HALL 3
10:00 – 11:15

Parallel Sessions
BIOETHICS IN CONFLICTING ISSUES

Chair: **Richard Nicholson**

Erica Haimes, Ken Taylor, İlke Türkmendağ

Women's views and experiences of an egg sharing for research scheme: does local practice have global implications?

Kızılca Yürür, Murat Civaner

Discrimination in healthcare: can we avoid all instances?

**Salvatore Pisu, Michela Pintor, Federica Demuru,
Ernesto d'Aloja**

The right to respect the freedom and the right to protect the health:
an harmony rather than a conflict

Şükran Sevimli

Bioethical concepts and applications of the concepts and practices
contribute to peace

WOMEN'S VIEWS AND EXPERIENCES OF AN EGG SHARING FOR RESEARCH SCHEME: DOES LOCAL PRACTICE HAVE GLOBAL IMPLICATIONS?

Erica Haimes, Ken Taylor and Ilke Turkmendag

Policy, Ethics and Life Sciences Research Centre, Newcastle University, UK.

Presented at the Conference by: Erica Haimes

Abstract:

To advance our agenda of exploring the benefits empirical social science research can bring to, and derive from, normative research in ethics, we present findings from a UK project exploring women's experiences of a scheme in which volunteers 'share' their eggs with somatic cell nuclear transfer (SCNT) research in exchange for reduced IVF fees (the 'ESR scheme'). The ESR scheme has attracted critical comment including concerns that: the reduction of fees acts as an inducement to participate in research; this in turn affects the ability of volunteers to give 'proper' informed consent; the scheme is exploitative of impoverished women; it introduces money inappropriately into the doctor/patient relationship, in a socio-economic context where healthcare is free at the point of need; it contributes to the commodification of human tissue. Nonetheless, there is a local demand for the scheme and its advocates suggest that it simply replicates more widespread practices such as egg sharing for treatment, but with ethically less challenging consequences. However, these debates lack insights from women and couples who volunteered for the ESR scheme. We argue that it is necessary to explore the views and experiences of volunteers to understand fully the socio-ethical aspects of SCNT research.

We structure our discussion through three questions: (i) what is the background to controversies over the ESR scheme; (ii) what are the views and experiences of volunteers for the ESR scheme; (iii) how does this local study contribute to global debates on the provision of human reproductive tissue (hRT) to scientific research? Ongoing analysis of women's views of the ESR scheme suggests a number of trends. The volunteers regard the scheme as providing opportunities for treatment that otherwise might not be available. Money is seen as central to IVF in general and to the relationship between patients and clinics, so the suggestion that the ESR scheme 'introduces' money inappropriately is not seen as a valid concern. Providing eggs for research rather than for the treatment of other couples, as a way of accessing cheaper treatment, is preferable for those who cannot contemplate having a genetically related, but unknown, child 'out there'. Interviewees reject the idea that the ESR scheme is exploitative as they equate 'exploitation' with 'coercion'. Nonetheless, most describe their desperation for a baby and their willingness to do anything to achieve this.

Such findings offer insights into wider debates on the provision and acquisition of hRT to science and medicine. Local practices and global trends are mutually influential. However well implemented and regulated, local schemes both contribute to,

and are affected by, the ethos of global markets in human tissue, particularly when associated with the therapeutic promises of stem cell research. The findings from empirical social research can suggest how to identify and apply best practice whilst avoiding the worst offences and harms to patients.

Key Words: Egg sharing; stem cells; human tissue acquisition.

DISCRIMINATION IN HEALTHCARE: CAN WE AVOID ALL INSTANCES?

Kızılca Yürür¹, Murat Civaner²

¹ Istanbul University School of Medicine, Dept. of Medical Ethics, Istanbul, Turkey /
E-mail: kizilca2002@yahoo.com

² Uludag University School of Medicine, Dept. of Medical Ethics, Bursa, Turkey /
E-mail: mcivaner@gmail.com

Presented at the Conference by: Kızılca Yürür

Abstract:

In this presentation, we are going to focus on a number of cases from Turkey, where access to health care services is hindered due to discriminative behaviour from the side of the care provider. Using those concrete examples, we will approach the issue of discrimination as lived in patient-doctor encounters from the perspective of medical ethics and law. How are limits of personal choice to be drawn in the health profession, when people from different faith, ethnic belonging and culture face each other in an uneven position of power, the service provider having the professional know-how and facilities on his side? On the other hand, can a patient demand self-less behaviour and total service from the care provider, who may have difficulties communicating with someone who is hostile, indifferent or unable to cooperate with him/her, due to cultural, ethnic or religious differences? Where does discriminative behaviour begin in the field of medicine, when the doctor and patient come from totally different value systems or even can not speak or understand each other's language? How does Turkish law respond to the challenge of daily medical practice in Turkey, where cultural identities are numerous and are strong determinants in social interactions? Seeking answers to the above mentioned questions, we will base our analysis on concepts of right to healthcare and professional values in medical practice. We will also discuss in how far the emerging ideals are supported in the present legal framework.

Key Words: Discrimination, healthcare, medical ethics

THE RIGHT TO RESPECT THE FREEDOM AND THE RIGHT TO PROTECT THE HEALTH: AN HARMONY RATHER THAN A CONFLICT

Salvatore Pisu^{1,2}, Michela Pintor^{1,2}, Federica Demuru², Ernesto d'Aloja^{1,2}

¹ Department of Forensic Medicine, University of Cagliari, Cagliari, Italy

² Mediterranean Clinical Bioethics Center, University of Cagliari-Sardegna Ricerche, Cagliari, Italy

Presented at the Conference by: Salvatore Pisu

Abstract:

The paradigm of individual autonomy has been dominant in bioethics until recently. Certainly we are aware that the new model imposed itself to contrast an unacceptable paternalism. Anyway, we consider that the concept of individual autonomy (mainly based on principlism) is an insufficient and not convincing starting point for ethics within medical practice. Besides, it doesn't represent the best way to honor the patient's autonomy and respecting human dignity at the same time.

We, also, believe that taking into account the autonomy as a separated principle from beneficence, since both of them have the same value, at least *prima facie*, it has been the most important philosophical mistake, mainly contributing to establish the "tyranny" of autonomy in bioethics.

We are not arguing against autonomy in itself, or the right of refusing treatment. Every patient has the right to decide about his/her own health, according to his/her values, even if the decision seems to be done merely on a whim, when the patient is competent. We are worried about the rhetoric of autonomous choice represents a fundamental shift from beneficence-based medicine to a wish-based medicine, a perilous relationship founded mainly on the patient's wish. In fact, if we consider autonomy and beneficence as a similar principle, having the same importance, the patient's wish becomes the only guide of the doctor affecting the fundamental task of medicine, that is to protect the health of the patient, frustrating the responsibility of the physician. We are convinced that another point of view could be taken into account.

The patient-physician relationship is an encounter between two responsibilities, rather than an engagement between two different autonomies. The first model needs to consider beneficence as the fundamental principle of the medical enterprise. And autonomy is considered as a fundamental condition to reach the beneficence of the patient. The rule could be described in this way: a doctor cannot do the best of the patient without respecting his freedom, he cannot constrict the patient to do what he doesn't want to do.

If beneficence is the goal of medicine and has an inherent objectiveness, that is to cure and to care, the autonomy of both patient and physician is intrinsically limited: the doctor cannot operate against beneficence, and the patient cannot pretend something that is contrasting with the same principle. The patient has the negative

right to refuse a treatment, but he doesn't have the positive right to pretend any kind of treatment. The patient has no the power to unilaterally decide the role of beneficence in medicine and has no the power to decide the beneficence for him self disregarding the best clinical practice. The best clinical practice remains the only ideal that the physician must pursue in clinical settings. The consequences for the relationships are clear, and the approach with the bioethical issues (The beginning and the end of life, ethics in health care policy making, the concept of disease and health, the informed consent, the enhancement in medicine and so on) could change dramatically.

Key Words: Autonomy, beneficence, right

BIOETHICAL CONCEPTS AND APPLICATIONS OF THE CONCEPTS AND PRACTICES CONTRIBUTE TO PEACE

Assistant Professor Şükran Sevimli

100. Year University Medical Faculty Medical History and Ethics Dept. Van/Türkiye

E-mail: sukransevimli@gmail.com

E-mail: ssevimli@gmail.com

Presented at the Conference by: Şükran Sevimli

Abstract:

Bioethics, direct discussions about the future includes concrete. Thus contributed to an understanding of the size of a concrete expression of abstract concepts. Therefore, an important point that intersects with the world of philosophy has become concrete, in this context has a coverage area of bioethics into everyone. Live the life of Bioethics also requires an interdisciplinary approach because of acquisition. Interdisciplinary approach is needed, scientists in different disciplines to understand each other, no doubt contribute significantly. for example, bioethics, technology, politics, science and the ethical relations between the network and draws attention to the importance of this network.

Human life and to recognize himself, in parallel to release details of the concept of live and dead, many concepts such as necessity or a need to review and identify needs only. The development of human competition, such as to destroy its own existence, on behalf of the indispensable necessity of change in circumstances indicate that he perceives. In this context, the concept of bioethics and the content re-cat people, their beliefs, the evaluation of the existence of the path to peace for thousands of years to understand why yet also leads to adware.

As a result, bioethics concepts and practices play an important role to prevent monopolization, in other words, live life, scientific, technical, and helps to grasp the philosophical. In this context is an important element of education in bioethics regarding the evaluation and more efforts are required.

16 September 2011, Friday

HALL 4
10:00 – 11:15

Parallel Sessions
BIOETHICS IN THE BEGINNING OF LIFE

Chair: **Yeşim Işıl Ülman**

Marie Geneviève Pinsart

Refusal of treatment of her foetus by a pregnant woman:
socio-cultural aspects

Tutku Özdoğan, Ebru Şenol, Sükrü Aydemir

Three fetuses as patients

**Maria Liljas Stålhandske, Maria Ekstrand, Tanja Tydén,
Marlene Makenzius, Margareta Larsson**

Reason and emotions in conflict: existential and ethical aspects of
abortion from a Swedish perspective

Christina Jivkova

The abortion as an instrument to control the birthrate

REFUSAL OF TREATMENT OF HER FOETUS BY A PREGNANT WOMAN: SOCIO-CULTURAL ASPECTS.

Pinsart Marie-Geneviève

Chairman of the Belgian Advisory Committee on Bioethics
4, Rue de l'Autonomie B-1070 Brussels, Belgique
E-mail: gpinsart@ulb.ac.be

Presented at the Conference by: Pinsart Marie-Geneviève

Abstract:

The refusal of treatment of her foetus by a pregnant woman is relatively unusual but it raises ethical questions directly linked with the cultural pluralism and the Human rights.

We will start with three cases: the refusal by a HIV-infected woman to receive herself a treatment and thus to prevent her foetus from infection; the refusal by a woman of an *in utero* blood transfusion of her foetus; the refusal by a woman of a caesarean section that will protect the health or the life of her foetus.

Ethical analysis of these cases shows different types of conflict: conflicts of power, interests, principles, intentions, values, and representations – where the status of the woman and of her decision are at stake.

Key Words: Refusal of fetus's treatment, mother's socio-cultural background, conflict of interests

THREE FETUSES AS PATIENTS

Tutku Özdoğan¹, Ebru Şenol², Şükrü Aydemir², Fehmi Yazıcıoğlu³, Celal Yola³

¹ Institutional Address & E-mail: Marmara University Neonatology Department
(Associate Prof.) E-mail: tutkuozdogan@yahoo.com

² Institutional Address & E-mail: Süleymaniye Maternity Hospital Department of
Pediatrics E-mail: drebrusenol@gmail.com

³ Institutional Address: Süleymaniye Maternity Hospital Department of Perinatology

Presented at the Conference by: Tutku Özdoğan

Abstract:

There is limitations of obstetric estimation of neonatal outcome in extremely premature newborns. Predicting outcomes, survival, and morbidity are often uncertain, such as in cases of extreme prematurity, certain fetal anomalies, intrauterine growth restriction (IUGR) and intrauterine infection. Ethical issues in clinical practice is often challenging. Informed consent, truth telling, the maternal-fetal conflict, decision making and the fetus as a patient are the cornerstones of medical ethics.

The fetus is a patient “when it is presented to the physician and there exist medical interventions, whether diagnostic or therapeutic, that are reliably expected to result in a greater balance of clinical good over harm for the fetus and the child it is expected to become.”

In the light of those knowledge here we report 3 cases of obstetric patients to discuss.

CASE 1: Our patient is a 30 year old female, married for 10 years , admitted to the perinatology for observation of 18 6/7 weeks of first IVF pregnancy, oligo-hydramnios, hypertension and severe fetal IUGR. She yearned the baby very much. On the 61th day of hospitalization she gave birth to a 500 gr dead fetus. On her post-partum period depression was detected and she was discharged on anti-depressants.

CASE 2: This patient is a 39 year old female, married for 15 years. She applied with abdominal pain and minimal vaginal bleeding on 13 weeks of pregnancy. She had 8 pregnancies and 8 miscarriages before this one .This was an IVF pregnancy in which 3 embriyos were placed, and one was reduced 10 days ago, and when the heart beat of one of the remaining two fetuses was negative she was admitted to perinatology with the diagnosis of missed abortion. There were no signs of infection on her admittance and follow-ups and she was hospitalized for 15 days and then discharged with one healthy 15 week fetus. She was admitted to perinatology for early rupture of membranes on 20 w 4/7 of her pregnancy. On her 5th day of hospitalization, she had laboratory signs of infection and she was recommended for termination of pregnancy because of high maternal risks; the family didn't accept termination. She was started on a new antibiotic regimen on which her lab values diminished to normal. 10 days after this attack, she again had an infection and ter-

mination was recommended, but family again didn't accept termination and yet she was started on another antibiotic regimen. 20 days after this second attack, on 26 2/7 of her pregnancy, she had another chorioamnionitis attack and this time fetal distress was detected, she had an urgent C/S and gave birth to a 900 gr female baby. The baby was hospitalized in NICU for 59 days and now she is a healthy 15 month old girl with no sequela of prematurity.

CASE 3: Our patient is a 26 years old female married for 7 years. She had an IVF pregnancy on which 8 embriyos were placed. On 11 5/7weeks of her pregnancy she was admitted for fetal reduction. Her fetal count was reduced to two.

Key Words: Fetus, obstetric ethics

REASON AND EMOTIONS IN CONFLICT: EXISTENTIAL AND ETHICAL ASPECTS OF ABORTION FROM A SWEDISH PERSPECTIVE

Maria Liljas Stålhandske¹, Maria Ekstrand², Tanja Tydén², Marlene Makenzius³, Margareta Larsson³

¹ Uppsala Religion and Society Research Centre, Uppsala University, Box 511, SE 751 20 Uppsala, Sweden

² Department of Public Health and Caring Sciences, Uppsala University, Sweden

³ Department of Women's and Children's Health and Department of Public Health and Caring Sciences, Uppsala University, Sweden.

Presented at the Conference by: Maria Liljas Stålhandske

Abstract:

From a global and cross-cultural perspective, abortion is a highly controversial issue. In Sweden, however, the abortion legislation is liberal and the issue is rarely debated – most Swedes endorse the right to free abortion. In fact, according to the World Values Survey, few populations are so positive about abortion as the Swedish. But does this mean abortion is an uncomplicated experience to Swedish women and men?

This paper presents results from a study investigating more closely the existential aspects of unwanted pregnancy and abortion in the Swedish context. The objective of the study was to explore and investigate the prevalence of existential experiences and needs among Swedish women and men involved in induced abortion. The study used a combination of quantitative and qualitative methods. A questionnaire was used to collect information from 499 women and 371 men involved in an abortion. We also performed individual in-depth interviews with 24 women with previous experience of unwanted pregnancy and abortion.

The results are interesting, given the Swedish cultural context with its low level of religiosity and high level of acceptance for abortion. Existential experiences and needs were common both among women and men, even though women reported a significantly higher degree. For example, existential thoughts about life and death, meaning and morality were closely related to the abortion experience for 61 % of the women and 41 % of the men. A higher degree of existential experiences and needs were also correlated to difficulty of abortion decision and poor psychological well-being after the abortion. Analysis of the interviews showed a similar distribution of experiences, varying from those who found the abortion simple to go through, to those who experienced it as an existentially demanding life event. Some of the interviews also displayed a struggle between reason and emotion. Women who were positive about abortion in general found it difficult to face an abortion in their own lives, and some of them described how they rationally thought abortion was the right thing to do, while simultaneously feeling that it was wrong. Almost all women in the interview study were, however, satisfied with their abortions, and thought in the end that they had made the right choice. Many also expressed gratitude for the possibil-

ity to choose if and when to become mothers.

Our conclusion is not that the Swedish abortion legislation is too liberal. Rather, even when abortion is culturally accepted, women's experiences of abortion vary and can in many cases include existential thoughts about life, death, meaning and morality. This challenges both abortion personnel and researchers to treat abortion as a complex situation beyond the issue of ethics and political rights. It also places demands on abortion care to develop new forms for meeting the physical, psychological and existential needs of each patient – allowing women to experience abortion both as a simple and as a challenging life event.

THE ABORTION AS AN INSTRUMENT TO CONTROL THE BIRTHRATE

As. Prof. Christina Jivkova, Ph.D.

Department of Social medicine and Health Management, section "Medical ethics and History of Medicine", Medical Faculty, Medical University, Sofia, Bulgaria
E-mail: hr_jiv@yahoo.com

Presented at the Conference by: Christina Jivkova

Abstract:

The dream of the more families is to control and manage the childbirth and the number of the children in the family. How this is going in Bulgaria can be seen from the conducted investigation of the birthrate and abortions during the period 1980-2004. The investigation show, that the basic instrument for control the birth rate was the abortions. Since 1980 to 2000 year, the abortions are more, than the births. After 2000 year abortions are lower, than the births.

Births and abortions of 1000 women in fertile age

Year	1980	1985	1990	1995	2000	2001	2002	2003
Births	60,4	56,6	49,2	35,2	37,0	36,0	35,2	35,9
Abortions	72,9	62,5	67,2	47,2	30,6	26,8	26,7	25,4

The information about the sexually transmitted diseases, which rich young people by the way of mass media, films and family conversations influence the sexual behaviour of the young people. During the last years, the use of contraceptives has increased and the number of abortion after year 2000 has decreased.

In the number of abortions have been included the social abortions, the spontaneous abortions and abortions on medical indications. The social and medical abortions are made only with the consent of the mother.

The decision for abortion depends and from traditions in the ethnic group. The Romanies women never make abortion, even at proven lesion fetus. Every mother has a right to take decision to make abortion when the fetus has malformations or to give birth. After the birth they give the child in the States homes, because they don't want to take care for ill child, or use the child for begging.

Important factor who influence over the decision for birth or abortion is demographic politics in the country. In Bulgaria the State pays two years of the mother to take care for the child after birth. This is the cause some girls to become pregnancy on 13 years old and to give birth to child every second year. 87% of them are single mothers, because the State gives more social help to single mothers. This mothers and their partners never work and use to live from the money which the State gives to their children.

Arise many ethical and social questions from the taxpayers...

16 September 2011, Friday

HALL 1
11:30 – 12:45

Parallel Sessions
ETHICS IN HEALTHCARE POLICY MAKING

Chair: **R. Tamay Başağaç Gül**

Juha Räikkä

Public health policies and the question of feasibility

Tineke Abma

Policy discourses on intercultural healthcare: from paternalism to objectification

Marko Ahteensuu

Medical decision-making under great uncertainty

Hana Horak

Development of ECJ case law in the field of health services

PUBLIC HEALTH POLICIES AND THE QUESTION OF FEASIBILITY

Juha Räikkä

Affiliation: Department of Behavioural Sciences and Philosophy, University of Turku, Finland

Address: Assistentinkatu 7, 20014 University of Turku, Finland

E-mail: jraikka@utu.fi

Presented at the Conference by: Juha Räikkä

Abstract:

Public health policies differ on national grounds. While health equity understood as an equal access to health services may be the main goal of the public health policy of one country, it need not be considered important at all in another country. The purpose of the present paper is not to defend any particular goal that a public health policy may strive for. Instead, I will analyze a particular argument that is often presented against such defences. The argument I have in mind is the claim that a public health policy that is seen desirable (in a particular country) is nonetheless unrealistic and infeasible. A worry concerning the feasibility of political suggestions is common in many political contexts, but the argument is targeted against public health policies particularly often, as such policies typically require a lot of resources – too much, the critics tend to say. Of course, whether this criticism is convincing depends on what exactly is the policy we are talking about. However, in my presentation I aim to say something general about the “question of feasibility”.

I will claim that while the claims concerning feasibility of certain policies are often presented as factual claims, they are in important respects normative. Therefore, the critics who say that certain public health policies are “unrealistic” should defend their claim with normative, that is moral, arguments – at least in good many cases. The question of desirability and the question of feasibility are not as separate matters as is often assumed. Very often, to say that a particular public health policy “is a utopian project”¹ is to make a normative (as opposed to factual) claim, and not only in the self-evident sense that these kinds of claims are relevant to our final judgment on what policy we should adopt.

Key Words: Public health policy, feasibility, realism, normative aspects

POLICY DISCOURSES ON INTERCULTURAL HEALTHCARE: FROM PATERNALISM TO OBJECTIFICATION

Tineke A. Abma

Institutional Address & E-mail

Professor T.A. Abma VU Medical Centre, Dept Medical Humanities, Amsterdam

E-mail: t.abma@vumc.nl

Presented at the Conference by: Tineke A. Abma

Abstract:

Since the '90 intercultural healthcare has become subject of discussion and research in the fields of anthropology, psychology and organization studies. This discussion is, however, grounded in the practice of healthcare for migrants. The purpose of this presentation is to give an overview of transitions in policy discourses on intercultural aspect of healthcare. It is based on a discourse analysis of policy documents produced by the Dutch government over the period from 1980-2010.

Three discourses can be distinguished. In the '80 the discourse is characterized by a paternalistic attitude, and stemming from the idea "that we need to do something good for labour immigrants from Turkey and Morocco." This discourse emphasizes the provision of information and education of professionals. Later, attention for the communication between caregiver and care provider is added. The second discourse is social critical. The emphasis shifts to adjustments required in the care and organization of care. Instead of a cultural static approach, as in the first discourse, the idea is that cultures are dynamic and never homogeneous. The most recent discourse can be considered as objectifying. Characteristic is the attention for epidemiology and scientific research onto the effectiveness of interventions for immigrant populations. In a normative analysis and discussion I will compare the three discourses and conclude that the inter-cultural approach of the second discourse is the most ethically sound as it prevents stigmatization and opposition between cultures, and fosters dialogue across cultures, ethnicities and other relevant dimensions of difference. Yet, this is also the discourse that comes most close to our identities.

Key Words: Policy Discourse, government, cross-cultural dialogue

MEDICAL DECISION-MAKING UNDER GREAT UNCERTAINTY

Dr Marko Ahteensuu

Public Choice Research Centre (PCRC), Assistentinkatu 7, 20014 University of Turku, Finland
E-mail: mataah@utu.fi

Presented at the Conference by: Marko Ahteensuu

Abstract:

Medical decisions are typically made under epistemic uncertainty. The outcome of a treatment is not known for a fact. In many cases information on frequencies of the possible outcomes is available. Scientific studies may indicate that a drug causes a particular side effect, such as tachycardia, in less than 1 of 10 000 cases. This can be translated into decisions by applying the “maximise expected utility” principle – a common but not unproblematic strategy. In other cases information on frequencies is absent. When the first human heart transplant operation was undertaken in 1967, it was impossible to assign meaningful frequentist probabilities to the successful or unsuccessful outcome beforehand. Results from animal experiments however provided some basis for extrapolation and, consequently, for subjective probabilities.

This paper is concerned with the latter kind of situations in medical decision-making. In particular, I will analyse how different epistemic responses to the lack of information on frequencies can be, and should be, translated into decision-making? The decision parameters include high stakes (i.e. adverse health effects/death) even in the case of inaction and sparse or conflicting information resulting in impossibility to assign probabilities to the possible outcomes. The epistemic question: what should one believe in these situations? One option is suspension of judgement. Precautions may be taken without forming definite/probabilistic beliefs on the outcome(s). One might decide as if some things were true. However, if subjective probabilities are not applied, this strategy may lead to inconsistent decisions over time. Decision theory provides action-guidance that does not require knowledge about probabilities. (The possible outcomes however need to be well-defined.) The maximin rule may be employed, and the dominance rule is applicable in some cases. Another option is to assign subjective probabilities on the basis of “non-frequency” evidence. In the total absence of evidence, the principle of indifference might be applied. What decision rule should then be applied?

In the most well-known expression of the principlism *Principles of Biomedical Ethics* (2001, 5th edn.), Tom L. Beauchamp and James F. Childress emphasise the importance of balancing risks, benefits and costs. They give an impression that one normally arrives at a conclusion about the right course of action, i.e. treatment, after careful consideration. However, they do not provide a detailed account on how the decisions under uncertainty are reached in practice.

Key Words: Medical decision-making, great uncertainty, epistemic response

DEVELOPMENT OF ECJ CASE LAW IN THE FIELD OF HEALTH SERVICES

Prof.dr.sc. Hana Horak ¹, Kosjenka Dumančić, mr.spec. ²

¹ Faculty of business and economics, University of Zagreb, Trg J.F. Kennedyja 6, 10000 Zagreb, Croatia & E-mail: hhorak@efzg.hr

² Faculty of business and economics, University of Zagreb, Trg J.F. Kennedyja 6, 10000 Zagreb, Croatia & E-mail: kdumancic@efzg.hr

Presented at the Conference by: Hana Horak

Abstract:

Health services are one of the most important services in the field of free movement at European Market guaranteed by the Treaty on Functioning of the European Union (TFEU). Health services make the great part of market weather as an economic or non-economic activity. Health policy is directly in hands of national authority and European rules on internal market intervene only in the case that the health service is within the economic activities. The main instrument of the harmonization in this area is a Proposal for a Directive of the European Parliament and of the Council on the application of patients' rights in cross-border healthcare which deals with health-care services weather they are provided within the private or public healthcare institution. This Proposal is a result of a huge number of cases in the area of free movement of patients and their right to get a healthcare service cross the border. Directive also deals with e-health services provided via Internet. Authors will show recent judgments of the ECJ and their influence to the Proposal of the Directive. The accent will especially be given at newest judgments dealing with patients from "new" Member Countries that seek medical help in "old" Member States and influence of these judgments into the national social security system as are the recent judgment in the case Watts, Hartlauer, Stamatelaki and Elchinov. These judgments show approach to the healthcare and free movement of patients as their right to get medical treatment anywhere in the EU.

Key Words: Health services, ecj case law, patient rights

16 September 2011, Friday

HALL 2
11:30 – 12:45

Parallel Sessions
BIOETHICS AND THE PUBLIC DEBATE

Chair: **Chuan-Feng Wu**

Helena Siipi
Ethics of engaging the public

James Yeates, Natasha Browning, Ruud Ter Meulen
The empirical return: a model for including public discourses in
bioethics

Hung En Liu
What do the general public think about researchers' financial conflict
of interest in biomedical research?— results of a public survey in
Taiwan

James Yeates, Ruud Ter Meulen
Framing public discussion of enhancement: the final word?

ETHICS OF ENGAGING THE PUBLIC

Helena Siipi

Department of Behavioural Sciences and Philosophy, 20014 University of Turku,
Finland, E-mail: helena.siipi@utu.fi

Presented at the Conference by: Helena Siipi

Abstract:

Several studies have reported increasing public scepticism about biotechnological and biomedical innovations in Europe in last few decades. Onora O'Neill (2002) famously notes that, reported public trust in science and even in medicine has faltered despite its success, despite increased efforts to respect persons and their rights, despite stronger regulation to protect the environment and despite the fact that environmental concerns are taken far more seriously than they were a few years ago.

The scientific community has found the negative attitudes disturbing and sought ways of communicating and co-operating with the public. The early phrase "public understanding of science" procedures contained solely top-down science education, whereas the latest public engagement procedures allow more active participation of the members of the public. However, the ethical justification and the aims of public engagement often remain obscure. Why should the public be engaged? Or to put it another way around, why is it justified to engage the public?

Claims that it is (ethically) necessary or at least desirable to engage the public in decision-making concerning new biotechnologies and biomedical innovations are common. Appeals on greater general agreement, consensus and trust between the public, scientists, and decision-makers rely on psycho-social benefits reached by engagement procedures. Sometimes the public engagement is even seen as a method for finding better answers to factual and moral questions. General justifications of this kind, however, omit to pronounce which kind of changes will lead to the described states of harmony and mutual understanding. Nature of those changes, nevertheless, is central to ethics of engaging public.

The justifications given to public engagement procedures can be divided into technology based and human based ones. The technology based justifications see the technology as fixed and public engagement as a tool for avoiding negative public responses. The starting point may then be in the technological imperative: Since the technological possibilities will realize anyway, opposing attitudes are going to cause many kind of problems. Alternatively the technology based justifications may lie in the view that new technologies are going to do some good for the society. The opposition will hinder that good from realizing. Negative attitudes are then seen as a kind of anomaly or mistaken – as something that needs to be modified and "corrected".

The human based justifications emphasize the importance of developing the technologies to meet the ethical views of the general public. The starting point is then moral views prevalent in the society. Public engagement serves democracy and

public good (and even some special rights the public may have regarding new biotechnologies) by bringing lay persons' views into the decision making regarding science and technology. In short, public engagement is seen desirable because it enables citizens' moral to influence the science.

I argue that since different public engagement procedures can have fundamentally different aims, their ethical basis should always be made explicit to the participants. However, this is seldom done today.

Key Words: Public engagement, new biotechnologies

THE EMPIRICAL RETURN: A MODEL FOR INCLUDING PUBLIC DISCOURSES IN BIOETHICS

James Yeates

Natasha Browning, Ruud ter Meulen
Centre for Ethics in Medicine, University of Bristol
E-mail: James.Yeates@bristol.ac.uk

Presented at the Conference by: James Yeates

Abstract:

In recent years, bioethics has witnessed an “empirical turn” in which empirical work, using sociological and public engagement models, have increased their “market share” of the academic work and influence in public decision-making. This has raised various questions about how – and whether – such empirical work should be used in ethics-based policymaking. Solutions to the empirical turn question include arguments for the exclusion of sociological data, usually based on a dichotomisation (e.g. is–ought or facts and values), with arguments for deriving “ethical” policy from public views dismissed as examples of a natural fallacy. Usually such positions defend the sole or hegemonic use of “philosophical bioethics”, divorced from any contingent descriptions of individuals’ opinions. At the other extreme, some argue that policy should be based solely on public opinion. In some cases, this is from anti-theoretical positions; in other cases this is defended by appeals to democratic ideals or process.

On the one hand, no position can be said to exclude any normative content. In at least an almost trivial way, the justification and defensibility of the use of public opinion must involve some normative concepts. Indeed the arguments against using bioethics must, in part, involve bioethical reasoning. Furthermore, the advocacy of using empirical data necessarily raises the question of how that data is to be used, and answers to this question are again normatively based. Thus any use of empirical data necessary has a philosophical component. On the other hand, it is impossible to consider “philosophical bioethics” as being without any empirical component. In very general terms, most philosophical theories have been based on some empirical evidence. More generally, ethicists’ “ontological” efforts to describe possible ethical values and approaches are an empirical exercise in describing what values exist. In this way, perhaps the ‘is’ and the ‘ought’ are inevitably linked – unless, of course, we are recommitting a naturalistic fallacy.

A way-out of this dilemma is to look at the role of bioethics in relation to societal debates. Bioethics can be modelled as a means of *solving disagreements*. There are many different ways in which disagreements can be resolved, but all involve both empirical and philosophical elements. Some involve a philosophical defence of an operational use of public opinion (e.g. referenda). Some involve more complex constructs, such as maximising satisfied preferences, which need empirical information to determine their application. Some involve using socially-defensible reasoning methods (e.g. conceptual analysis) or debate (e.g. discourse ethics) to

resolve disagreements. How can a choice be made about what method to resolve debates? Ultimately, defensibly resolving disagreements requires a “real” concordance at a fundamental level within public policymakers. Perhaps such agreement can be reached about general methodologies of reasoning – and perhaps many of those used in philosophical bioethics. In this way bioethics, and healthcare policymaking, can be re-grounded in empirical facts.

Key Words: Bioethics, ethics, empirical turn, methodologies, sociology

WHAT DO THE GENERAL PUBLIC THINK ABOUT RESEARCHERS' FINANCIAL CONFLICT OF INTEREST IN BIOMEDICAL RESEARCH?— RESULTS OF A PUBLIC SURVEY IN TAIWAN

Hung-En Liu

Assoc. Professor of Law
National ChengChi University, Taipei 116, Taiwan
E-mail: markliu@nccu.edu.tw

Presented at the Conference by: Hung-En Liu

Abstract:

In the past three decades, biomedical research collaborations between industry and academia have been increasing substantially. Since more and more studies are sponsored by pharmaceutical companies and other for-profit entities, and some researchers hold significant financial interests in the results of their studies, the notion of conflict of interest becomes more relevant than ever. Nevertheless, whether the researchers should disclose their funding sources and financial interests to potential subjects in the informed consent process remains a controversial issue. Furthermore, due to insufficient empirical data, little is known about the perspectives of the general public on relevant topics. In 2009 and 2011, the author of this paper collaborated with Academia Sinica using Taiwanese Household Registry Database to conduct two face-to-face surveys of a random sample of 3,000 Taiwanese adults. Survey questions were designed to discover the following matters: (1) whether the general public know of the facts that many medical studies nowadays are funded by industry and that some researchers hold financial interests in the results of their studies; (2) whether they think the researcher should disclose these facts to them before asking them to participate; (3) whether their willingness to participate in research may be affected by these facts; (4) whether their trust in the results of medical research may differ because of these facts. Survey results show that 71.1% of the subjects responded that they knew many medical studies nowadays are funded by industry. Among those who were willing to participate in medical research, 50.2% said that they might hesitate if they had been told the medical study was funded by industry, and 68.7% might hesitate if they had been told the researcher held financial interests in the results of the study. In addition, respondents' trust in the results of medical research decreased significantly if they had been told those information.

Key Words: Conflict of interest

FRAMING PUBLIC DISCUSSION OF ENHANCEMENT: THE FINAL WORD?

James Yeates ¹, Ruud ter Meulen ²

¹ Centre for Ethics in Medicine, University of Bristol,
E-mail: James.Yeates@bristol.ac.uk

² Centre for Ethics in Medicine, University of Bristol,
E-mail: r.termeulen@bristol.ac.uk

Presented at the Conference by: Ruud ter Meulen

Abstract:

Human Enhancement is a rapidly emerging and advancing field. It challenges the concepts of medicine, the role of science and technology and the boundaries between authentic human and synthetic capacities. Human rights discourse, bioethics, technology assessment, sociology and biolaw can all play a part in determining what, when and how enhancement technologies can be applied to patients. Several of these disciplines come together in setting agendas and terminology for international conventions and their interpretation and application into national law.

The issue of human enhancement is still largely within the domain of bioethics and technology assessment, with relatively little analysis from human rights, sociological or legal fields. Yet these are a core part of how international and national regulation might be achieved. The 1997 European Convention on Human Rights and Biomedicine (ETS No. 164) specifically prescribes public discussion about fundamental questions of biology and medicine. Its Preamble explicitly recognises the importance of public debates, and Article 28 states that Convention parties will ensure appropriate public discussion and consultation, in order to ascertain society's views (Explanatory note to Article 28). It is to this end that the European Conference of National Ethics Committees (Cometh) resolved to 'promote, on a pluralist basis, public debate on ethical issues raised by progress in the fields of biology, medicine and public health' (Resolution No 1. Article 3).

This public debate, both within and without Ethics Committees, is one framed by rhetoric, idealist language and emotive language. This rhetoric reaches to the very fundamental aspects of the debate, including the definition of enhancement itself, and the question of "what is enhancement" or "what does enhancement". Often the categorisations and definitions of enhancement are linked to arguments that suggest something is acceptable (e.g. if conventional) or substantively different to acceptable interventions (e.g. treatment versus non-therapeutic enhancement interventions). Influentially, the term "enhancement" often appears to tacitly imply that the intervention is intrinsically good, making basic arguments for enhancement appear as analytical truths. In this paper, we reconsider various distinctions. But, finding no distinction to be successful in its aims, we do not suggest an alternative definition. Instead, we suggest a number of "rules" by which terminology should be responsibly employed within public debates on enhancement. These include

- a- Retaining the term “enhancement” as a useful “place-holder”
- b- Not leaving the term unexplained
- c- Producing an operational definition
- d- Not excluding or including any cases *a priori*
- e- Identifying and clarifying how stakeholders are using the term
- f- Transparent uses of the terms
- g- Consistency in how terms are used throughout a given document
- h- Not drawing any normative arguments from the definition, directly or indirectly.

It is anticipated that these rules may allow richer and more productive public discourses on human enhancement.

Key Words: Ethics, enhancement, public debate, human rights

16 September 2011, Friday

HALL 3
11:30 – 12:45

Parallel Sessions
HUMAN DIGNITY AND BIOETHICS

Chair: **Lazare Benaroyo**

Renzo Pegoraro

Advance directives in the european debate

Zehra Göçmen Baykara, Serap Şahinoğlu

Assessment of nurses' professional autonomy
in nursing care: a qualitative study

Özge Yücel

The problem of chemical castration of sexual offenders in the
context of gender based ethics

Zehra Göçmen Baykara, Serap Şahinoğlu

New nursing law and conversion of nursing profession in Turkey

ADVANCE DIRECTIVES IN THE EUROPEAN DEBATE

Renzo Pegoraro¹, Luciana Caenazzo², Daniele Rodriguez³

¹ Fondazione Lanza, Via Dante 55, 35139 Padua (Italy)

² Department of Environmental Medicine and Public Health, Legal Medicine Unit, University of Padova, Via Falloppio 50, 35121, Padua (Italy) – Fondazione Lanza Via Dante 55, 35139 Padua (Italy)

³ Department of Environmental Medicine and Public Health, Legal Medicine Unit, University of Padova, Via Falloppio 50, 35121, Padua (Italy)

Presented at the Conference by: Renzo Pegoraro

Abstract:

Advance directives in healthcare allow the patient to express wishes concerning future treatments in case of incapability of making decisions with the purpose of preserving the patient's right to self-determination. Very simply, an advance directive may specify what treatments the patient wishes to receive or refuse and/or it may designate a specific person (trusted person) whom that patient authorizes to make medical decisions on behalf of himself or to interpret his/her written advance directives. The provisions regarding this subject are different among the European Countries and even if in those countries where legal provisions have been established, not everything is completely resolved and some clinical-ethical implementations still seem to be necessary. The referring European document, basic for these issues, is the "Oviedo Convention" (European Council, April 1997), which in Art.9 asserts an important aspect: "*The previously expressed wishes relating to a medical intervention by a patient shall be taken into account*"; but it does not seem to provide enough conditions for deriving univocal legal solutions in the European countries legislations. In this paper the Authors explore the distinct legal contexts and the role that advance directives play in them in the different European countries. All the European countries which already have provisions regarding the advance directives seems to have a common perspective regarding proper respect guarantees of the individual's autonomy. Furthermore, particular attention must be paid to the following aspects:

- the patient consciousness at the act of advance directives formulation,
- the importance of complete information to the patient,
- importance and role of the trusted person,
- how to contextualize the advances directive in the current medical condition
- periodic revision of the advance directives.

The foresaid considerations lead to the following observations. The binding nature of the advance directives, implies two possible solutions: the strict obligation for the health professional to respect the patient's will; or the possibility for the practitioner to decide the best for the patient, taking into account the moral duty to respect the patient's indications in the advance directives. The role of the trusted person, specifically appointed to make decision on behalf of the patient when he/she will no longer have the capacity to make healthcare decisions, is extremely interesting. In fact, the trusted person has the possibility to express his/her opinion/decisions which should represent the patient's wishes regarding their health treatments, therefore contextu-

alizing the advance directives. Should all the health treatments in the advance directives (including for example artificial hydration and nutrition) be considered as a choice in the indication of the patient or should there be a limitation in the choice? Advance directives constitute an important aspect not only referring to their clinical implementation in very different contexts, but also, from an ethical point of view, they imply the necessity of further debate for cultural interpretation and adaption including more appropriate legal instruments.

Key Words: Advance directives, trusted person, autonomy

ASSESSMENT OF NURSES' PROFESSIONAL AUTONOMY IN NURSING CARE: A QUALITATIVE STUDY

Öğrt. Gör. Zehra Göçmen Baykara¹, Doç. Dr. Serap Şahinoğlu²

¹ Gazi Üniversitesi Sağlık Bilimleri Fakültesi Hemşirelik Bölümü
E-mail: gocmenzehra@yahoo.com

² Ankara Üniversitesi Tıp Fakültesi Deontoloji Anabilim Dalı Öğretim Üyesi
E-mail: serapsahinoglu@yahoo.co.uk

Presented at the Conference by: Doç. Dr. Serap Şahinoğlu

Abstract:

Scientific and technical developments and new applications in the health field have led to increased healthcare complexity and differentiation. Nurses therefore need to have the appropriate knowledge, skills and experience for the era and should be able to make correct decisions quickly. This has made the expansion of nurse authority and autonomy mandatory. Nursing care has a very important place in expanding the professional autonomy spectrum of nursing.

This thesis is a qualitative study to evaluate the professional autonomy of nurses from an ethical standpoint.

The study universe consisted of intensive care, orthopedics and neurology clinic nurses working at Gazi University Medical Application and Research Center, Numune Training and Research Hospital and Private Bayındır Hospital. The study data were obtained from the nurses using the in-depth interview method. Percentages, the Mann-Whitney U test, the Kruskal-Wallis test and content analysis were used for data analysis.

Quantitative data from the study show that 50% (15/30) of the nurses had been working as a nurse for less than 10 years, 83.3% (25/30) were happy with their profession, and 50% (15/30) were members of a professional organization. The percentage receiving courses on ethics during their professional training was 66.7% (20/30) while 73.3% (22/30) had not participated in a scientific program regarding ethics and professionalization. The nurses' mean score was 68.06 ± 20.36 for the sociotropic personality feature and 87.20 ± 15.90 for the autonomous personality feature.

The qualitative data we obtained from the study showed that all nurses could independently decide on nursing care while some stated that they sometimes could not convert these into action after making the decision. The nurses felt that professional autonomy increased the quality of nursing care while the increased quality of care expended the borders of professional autonomy.

We found that professional autonomy in nursing was limited by many factors both related and unrelated to the profession. The nurses stated the following as factors

affecting professional autonomy negatively: nursing procedures dependant on the physician with enforcement by law, traditional beliefs and habits that prevent professionalization, unfavorable institutional working conditions, working constantly under intensive inspection and pressure, inadequate professional standards, undefined responsibilities, inadequately developed professional consciousness, and unwillingness and inadequacy in making professional decisions and assuming responsibility.

Our study results indicate that the following are necessary: correct presentation to other healthcare professionals and the community of the nurse and nursing care concept and its importance, increased membership in professional organizations, increasing the professional education level, rearranging the professional education process to make it emphasize nursing care, developing areas of specialization, increasing professional knowledge accumulation and introducing ethical training directed into graduate and postgraduate programs.

Key Words: Nursing care, autonomy, ethics.

THE PROBLEM OF CHEMICAL CASTRATION OF SEXUAL OFFENDERS IN THE CONTEXT OF GENDER BASED ETHICS

Research Assistant Özge Yücel¹

¹ Atılım University Faculty of Law, Department of Civil Law, Kızılcaşar Mah. İncek/Gölbaşı/Ankara, E-mail: oyucel@atilim.edu.tr

Presented at the Conference by: Özge Yücel

Abstract:

Approaching this issue from different aspects and determining legislation politics by analyzing problem scientifically are required. In this article, the problem will be approached from feminist theory, human rights and patient rights. Punishment or treatment of sexual offenders brings discussions on gender based ethics along. Justification of criticisms differs upon replies to the question, whether judging chemical castration of offenders is punishment or treatment. If the fact, what is the reason of rape or other sexual crimes, is explained with biological impulses, female body can hardly be removed from sovereignty of legislator. On the other hand, imposing a definite treatment method by law on patient and doctor violates patient rights. Also chemical castration violates human dignity, because it denies human will. Apart from these ideas, chemical castration is not a remedy for sexual offences. In our article the reasons why it is not remedy will be viewed. Firstly the only reason of sexual offences is not pedophilia. In addition to this reason, antisocial personality disorder is often viewed among sexual offenders according to studies. Disorders can be treated by cognitive therapies; chemical castration is not a real method of treatment. For this reason, chemical castration is a punishment or a temporary prevention rather than a treatment. For a permanent prevention, real methods of treatments and rehabilitations or security measures should be applied. Also compatibility with human dignity and effects of treatment should be taken into account while choosing the method of treatment. From different perspective, aggression should not be concerned with sexuality. Sexual offences appear by sex but arise from aggression or paraphilia. According to reason attitudes should be varied, humanist penalty policies and protective measures focused on human and human dignity should be followed.

Key Words: Chemical castration, sexual offences, treatment

NEW NURSING LAW AND CONVERSION OF NURSING PROFESSION IN TURKEY

Zehra Göçmen Baykara MD¹, Serap Şahinoğlu MD, PhD²

¹Gazi Üniversitesi Sağlık Bilimleri Fakültesi Hemşirelik Bölümü

E-mail: gocmenzehra@yahoo.com

²Ankara Üniversitesi Tıp Fakültesi Deontoloji Anabilim Dalı Öğretim Üyesi

E-mail: serapsahinoglu@yahoo.co.uk

Presented at the Conference by: Serap Şahinoğlu

Abstract:

Nursing has struggled for progressed for their occupational since Florenge Nightingale. A profession, itself, the profession needs to complete the process for its professional. So they must do the criteria fully profession in their practise. Nursing education, nursing autonomy and professional conduct can be considered as criteria for nursing professionals. No doubt, as nurses with all these legal framework can make it easier.

A law has been adopted regarding as the nursing profession in 1954. However, this law constitutes a barrier to nursing process and nursing profession. In 2007, new arrangements have been made in the nursing law and thus authority and responsibilities of nurses was revised according to today's needs. Definition of nurses has been changed, basic vocational training of nurses has been brought to the undergraduate level, specialization in nursing have been addressed from a legal perspective. Thus, the nurses have a legal basis will have more autonomous decision-making power. So the nurses have a legal basis will have more autonomous decision-making power.

As a result of these important changes in the nursing law in Turkey, the nursing profession will provide an important alternation.

Key Words: Nursing, professionalization, nursing law.

16 September 2011, Friday

HALL 4
11:30 – 12:45

Parallel Sessions
BIOETHICS, RELIGION AND ETHNICITY

Chair: **Muhtar Çokar**

Henry S. Perkins, Josie D. Cortez, Helen P. Hazuda
Gender differences within American ethnic groups over attitudes
about physicians, treatments, and the health care system

Jamal S. Aljarallah
Challenges facing Islamic biomedical ethics

Jiri Simek, Ondrej Doskocil
World ethics declaration and its role in religious bioethical tradition

Angeliki Kerasidou
Malariagen: an example of bioethical practice in developing
countries

GENDER DIFFERENCES WITHIN AMERICAN ETHNIC GROUPS OVER ATTITUDES ABOUT PHYSICIANS, TREATMENTS, AND THE HEALTH CARE SYSTEM

Henry S. Perkins, M.D.,¹ Josie D. Cortez, M.A.,² Helen P. Hazuda, Ph.D.³

¹ The University of Texas Health Science Center at San Antonio, Texas, U.S.A.;

E-mail: perkins@uthscsa.edu

² The Intercultural Development Research Association, San Antonio, Texas,

U.S.A.; E-mail: jsiempre@aol.com

³ The University of Texas Health Science Center at San Antonio, Texas, U.S.A.;

E-mail: hazuda@uthscsa.edu

Presented at the Conference by: Henry S. Perkins

Abstract:

Purpose: American health care reform should address relevant gender-based attitudes, but many are poorly characterized. We, therefore, began exploring such attitudes towards physicians, treatments, and the health care system.

Methods: We conducted in-depth interviews with 26 Mexican Americans (MAs: 14 men, 12 women), 18 Euro-Americans (EAs: 7 men, 11 women), and 14 African Americans (7 men, 7 women) and content-analyzed responses for attitudes in the three topic areas.

Results: All topic areas showed noteworthy (and sometimes surprising) similarities and differences between genders within the ethnic groups.

Physicians: Among MAs men and women alike tended to trust physicians (expressing trust more than distrust: 50% versus 36% for MA men, and 58% versus 33% for MA women). Among EAs and AAs men also tended to trust physicians (expressing trust more than distrust: 57% versus 43% for EA men, and 57% versus 29% for AA men), but women tended to *distrust* physicians (expressing distrust more than trust: 73% versus 64% for EA women, and 43% versus 29% for AA women). Accordingly, among AAs more men than women claimed to trust physicians for their expertise (57% versus 29%), but among EAs and AAs more women than men claimed to distrust physicians for doubts about their competence (55% versus 29% for EAs, and 43% versus 0% for AAs).

Complaints about physicians also differed by gender. Among MAs and AAs, more women than men expressed complaints (58% versus 36% for MAs, and, 57% versus 14% for AAs). Yet among EAs women and men expressed complaints nearly equally (36% and 43%, respectively). The most common complaint was insensitivity to patients' wishes, needs, or feelings (cited by 29% of EA men, 36% of EA women, and 29% of AA women).

Treatments: Potential harms from treatments were acknowledged by nearly equal percentages of MA men and women (42% versus 50%, respectively), by more EA

men than women (57% versus 36%), and by more AA women than men (86% versus 14%). Most AA women (71%) specifically mentioned patient suffering.

The Health Care System: Among all three ethnic groups more women than men complained about the health care system (33% versus 29% for MAs, 45% versus 14% for EAs, and 29% versus 0% for AAs). The most common complaints were too many professional care-givers (cited by 25% of MA women and 33% of EA women) and poor organization (cited by 25% of EA women).

Conclusions: The genders within ethnic groups may differ in their attitudes about key aspects of American health care. Men appear to trust physicians and to voice few complaints about care. However, women—especially EA and AA women—appear to distrust physicians and harbor complaints about care. Success in American health care reforms may require addressing such gender differences explicitly.

Key Words: Satisfaction with care, gender differences, trust In physicians

CHALLENGES FACING ISLAMIC BIOMEDICAL ETHICS

Jamal S.Aljarallah

Department of Family and Community Medicine, College of Medicine, King Saud University, Riyadh, Saudi Arabia

E-mail: jaljarallah@ksu.edu.sa, jaljarallah@gmail.com

Presented at the Conference by: Jamal S.Aljarallah

Abstract:

Bio-technological advances are continuously expanding the field of medical practice and as a result, medical practitioners, the legal profession, and society are faced with legal and ethical situations of increasing complexity. Islamic Scholars (Shareia Ulema) were able, individually or through Fatwa Academies and Councils, to issue Fatwas related to contemporary ethical issues in the medical field. The Islamic legal methodology is rational and not arbitrary and therefore, relatively easy to understand and apply. Despite that, Islamic Bioethics is facing challenges which include, but are not limited to the following: (1) Differences in the interpretation of the Islamic principles and their application, (2) Discrepancies within and sometimes contradictions among fatwas, which may create confusion among practitioners and may open a gate for personal judgment. (3) Fatwas and not always incorporated in the legal system which makes it difficult to convince people about their application, (4) Different Islamic countries may adopt different Fatwas, which may add to the confusion among medical practitioners, (5) There is less interest in issues related to health policies and public health issues, (6) Islamic bioethics is only taught in few universities and colleges in Islamic countries. The paper will discuss the above-mentioned challenges using as examples contemporary ethical issues related to brain death and withdrawal of life-prolonging treatment. It will conclude by suggesting methodological approaches to dealing with the challenges.

WORLD ETHOS DECLARATION AND ITS ROLE IN RELIGIOUS BIOETHICAL TRADITION

Jiri Simek¹, Ondrej Dosekocil ²

¹ University of South Bohemia, Faculty of Health and Social Studies. Address: J. Boreckeho 27, 370 11, Ceske Budejovice, Czech Republic.

E-mail: jr.simek@volny.cz

² University of South Bohemia, Faculty of Health and Social Studies. Address: J. Boreckeho 27, 370 11, Ceske Budejovice, Czech Republic.

E-mail: doskon@centrum.cz

Presented at the Conference by: Ondrej Dosekocil

Abstract:

Many various religious traditions meet in contemporary global world. In the area of ethics they all face rivalry of secular discursive ethics. That rivalry forces members of religious societies to search a common language to preserve transcendental principles in bioethics. An important result of this process was elaboration of the Declaration of the World Ethos which was accepted by the Parliament of World Religions in Chicago in 1993. The Declaration was never amended as e.g. Declaration of Helsinki. Representatives of religious groups refer to the Declaration only rarely and they do not use it in their religious practices. The fate of the Declaration of the World Ethos shows difficultness and weakness of agreements between world's religions. Cultural diversities are too big and common principles are not concrete enough to apply them in solutions of local problems. Therefore intercultural and interreligious dialog must continue as the base of all attempts to reach common agreements. General declarations or interreligious platforms could be only epiphenomenon on this basic process.

We can apply experiences from religious area on secular principles included in American principlism or Helsinki Declaration. We are convinced that specific local interpretations of general principles must be elaborated. If not, the danger of so called ethical imperialism of Euro-Atlantic culture could be real.

Key Words: World ethos declaration - intercultural and interreligious dialog -

MalariaGEN: AN EXAMPLE OF BIOETHICAL PRACTICE IN DEVELOPING COUNTRIES

Angeliki Kerasidou

The Ethox Centre, University of Oxford

E-mail: angeliki@well.ox.ac.uk

Presented at the Conference by: Angeliki Kerasidou

Abstract:

Malaria is an infectious disease caused by a parasite known as *Plasmodium* and it is spread through the bite of an infected female mosquito. Malaria has largely been eradicated from Europe and North America, but it is still a primary cause of infant mortality in tropical countries. In 2006 it caused the deaths of nearly 1 million children under the age of five. Environmental conditions, poor healthcare and poverty are the main contributing factors to the spread of malaria.

MalariaGEN was established in 2005 as a consortium project with the goal to use genomic approaches such as genome-wide association studies (GWAS) to investigate the biological mechanisms underlying susceptibility to malaria to help the development of a vaccine. MalariaGEN is led by Oxford University with partner institutions in 21 countries, most of which are malaria-endemic.

There are a number of ethical concerns associated with genomic research requiring the collaboration and partnership of high and low income countries. The main ethical issues include ensuring valid consent from the research participants, fair data-release and data-sharing policies, as well as, what has come to be known as 'benefit sharing'. These concerns are not exclusive to GWA studies. Yet, social and economic imbalance between the participant countries adds an extra ethical dimension to these considerations.

MalariaGEN has been conducting research and developing policies to promote ethical and fair genomic research in low income countries. Although still a work-in-progress, MalariaGEN is an example of a consortium genomic project that endeavours to bring science and ethics together in order to promote and achieve high quality scientific but also ethical and fair research. The paper is going to explore of ethical issues that specifically relate to GWA research in lower income countries and discuss how MalariaGEN has addressed them. The scope is to present the 'MalariaGEN approach' to social inequality and bioethics and stimulate dialogue on better or alternative ways to approach this issue.

16 September 2011, Friday

HALL 1
13:45 – 14:45

Plenary Lecture: “Human Rights in Bioethics: Universalism and Particularism”

Key Note Speakers: **Prof. Dr. Richard Ashcroft,**

Prof. Dr. İbrahim Ö. Kaboğlu

Moderator: **Dr. Rouven Porz**

Richard E. Ashcroft MA PhD FHEA FSB

Current Position:

Professor of Bioethics, School of Law, Queen Mary, University of London (since September 2007)

Previous Positions:

Professor of Biomedical Ethics, School of Medicine and Dentistry, Queen Mary, University of London (2006-7)

Lecturer/Senior Lecturer/Reader in Biomedical Ethics, Faculty of Medicine, Imperial College London (2000-2006)

Lecturer in Ethics in Medicine, Faculty of Medicine, University of Bristol (1997-2000)

Research Fellow, Department of Philosophy, Liverpool University (1995-1996)

Degrees and Honours

Fellow of the Society of Biologists, 2009

Fellow of the Higher Education Academy, 2002

PhD, History & Philosophy of Science, University of Cambridge, 1995

BA (Hons) (First Class), Mathematics, History & Philosophy of Science, University of Cambridge, 1990

Professional Achievements

Deputy Editor, Journal of Medical Ethics

Member, Ethics of Research and Public Involvement Committee, Medical Research Council

Member, Tobacco Advisory Group, Royal College of Physicians of London

Past member, Gene Therapy Advisory Committee

Past member, Ethics Committee, Royal College of Obstetricians and Gynaecologists

Past member, board of the European Society for Philosophy of Medicine and Healthcare

Past Treasurer, Society for Applied Philosophy

Principal Books

Principles of Health Care Ethics, 2nd Edition, London: Wiley-Blackwell, 2007 (editor in chief, with John McMillan, Heather Draper, Angus Dawson)

Case Analysis in Clinical Ethics, Cambridge: Cambridge University Press, 2005 (editor, with Michael Parker, Guy Widdershoven, Marian Verkerk and Anneke Lucassen)

HUMAN RIGHTS: A *LINGUA FRANCA* FOR BIOETHICS AND BIOLAW?

Prof. Dr. Richard Ashcroft

The challenges of contemporary medicine and the life sciences are universally acknowledged. But, arguably, that is the only thing that is universally acknowledged about them. Debates about euthanasia, abortion, stem cell research, access to essential medicines, medical participation in interrogations are strongly contested everywhere, and the competing claims of community, culture, moral traditions, philosophical schools, and political and legal contexts make these debates fascinating and at times seemingly intractable.

Since the end of the Second World War, however, international human rights have often been proposed as the standard for personal and social protection of human interests, welfare and dignity. And they have increasingly been cited in bioethical debate and policy-making at clinical, municipal and international levels – by the professions, academics, states, non-governmental organisations and international bodies.

Two issues arise, of particular interest: can human rights provide a normative framework for the analysis and resolution of bioethical debates? And can human rights provide a common language for discussion of these issues? The mediaeval *lingua franca* was a language of trade and commerce used around the Mediterranean world by speakers of many other natural languages to permit communication about issues of common concern in commercial life. Can human rights give us such a vehicle for discussing bioethical issues whatever our cultural, religious, political or moral commitments? In this lecture I will explore this concept of human rights as *lingua franca*, and consider its merits for the practice of international bioethics.

İbrahim Ö. Kaboğlu

Education

- Faculty of Law, Ankara University, 1974
- Master of Public Law, Ankara University, 1977
- Doctorate of Public Law, Limoges University, 1981
- Associate Professor, Inter-university Council, Ankara 1987
- Full Professor of Constitutional Law, Marmara University, 1994

Professional Activities

- Professor of Constitutional Law at Marmara University. Teach constitutional law and the Law of Freedoms.
- Visiting Professor at several European universities, in particular in France.

Human Rights Activities

- President of the Human Rights Center of the Istanbul Bar Association (1998-2001)
- Founding president of the Human Rights Research and Application Center of the Union of Bar Associations of Turkey (2001-2005)
- Member of the National Committee on Human Rights Education (2001-2004)
- President of the Human Rights Advisory Board (2003-2005)

Professional Volunteer Activities

- Member of the Istanbul Bar Association
- Member of the Institut de Droit de l'Expression et de l'Inspiration Françaises
- Member of the Executive Committee of the International Association of Constitutional Law
- Member of the Association for the Support of Contemporary Living
- Member of the Institute of Human Rights Foundation

Publications (Books)

- Kolektif Özgürlükler (Collective Liberties) Diyarbakır: Dicle University Press, 1989
- Çevre Hakkı (Environmental Rights, 3rd Edition) Ankara: İmge Kitabevi, 1996
- Dayanışma Hakları (Solidarity Rights) Ankara: TODAİE, 1996
- Türkiye'de Düşünce Özgürlüğü (Freedom of Thought in Turkey) İstanbul: TÜGİK, 1997
- Anayasa ve Toplum (Constitution and Society) Ankara: İmge Kitabevi, 2000
- Özgürlükler Hukuku (Law of Freedoms, 6th Edition) Ankara: İmge Kitabevi, 2002
- Anayasa Hukuku Dersleri (Textbook of Constitutional Law, 6rd Edition) İstanbul: Legal Yayınevi, 2010
- Anayasa Yargısı (Constitutional Justice, 4th Edition) Ankara: İmge Kitabevi, 2007
- Değişiklikler Işığında 1982 Anayasası, Halk neyi oylayacak? (1982's Constitution in perspective of its modifications, What the people will vote?) Ankara, İmge Kitabevi 2010.

Publications (Edited Works)

- Bağımsız İdari Otoriteler (Independent Administrative Authorities; Turkish-French) İstanbul: Alkım, 1998
- Laiklik ve Demokrasi (Laicity and Democracy; Turkish with French summary) Ankara: İmge Kitabevi, 2001
- Kopenhag Kriterleri (The Copenhagen Criteria; partially trilingual: English, French, Turkish) İstanbul: İstanbul Barosu İnsan Hakları Merkezi, 2001
- Azınlık Hakları (Minority Rights: In National, Supranational and International Law (United Nations, European Union, Council of Europe and Treaty of Lausanne) İstanbul: İstanbul Barosu İnsan Hakları Merkezi, 2002
- İnsan Hakları Danışma Kurulu Raporları (The Reports of the Human Rights Advisory Council; with K. Akkurt) Ankara: İmge Kitabevi, 2006

Publications (Articles)

- In Turkish, several articles on human rights, public law and political science
- In French, several articles on human rights, constitutional law and environmental law
- In French, several contributions to books of collected works on human rights, environmental rights and constitutional law
- In English, four articles (one translated from the original Turkish)
- In Italian, three articles (translated from the original French)
- In Arabic, one article (translated from the original French)

HUMAN RIGHTS IN BIOETHICS: UNIVERSALISM AND PARTICULARISM

Prof. Dr. İbrahim Ö. Kaboğlu

Marmara Üniversitesi, Hukuk Fakültesi, 34766 Haydarpaşa, İstanbul, TURKEY
Professor of Constitutional Law Chair of the Department of Constitutional Law
Faculty of Law Marmara University (İstanbul)
E-mail: ikaboglu@marmara.edu.tr

General Plan of the Lecture

- I. Triangle of the theory of Human Rights: freedom, equality and dignity
- II. Bioethics in the classification of Human Rights
- III. Bioethics in the national system of Human Rights(HR):

Example from the Constitution of the Republic of Turkey

- A) Arrangements concerning bioethics
- B) Two main principles : the spirit (essence) of human rights and proportionality
- C) Bioethics facing internationalization of Human Rights (Article 90, Constitution of 1982 as amended on 2004)

IV. European and international guarantees of Human Rights and bioethics

- A) First degree of the protection of HR and bioethics: Declarations on bioethics..
- B) Second degree of the protection of HR and bioethics:
 - 1.- Conventions on bioethics and the measures taken by the United Nations
 - 2.- European Convention on Human Rights and Biomedicine 1997
 - 3.- Steering Committee on Bioethics of the Council of Europe
- C) Third degree of the protection of HR and bioethics: European Court of Human Rights and bioethics

-Examples of cases in which bioethical issues have been raised.

Conclusion

16 September 2011, Friday

HALL 1
14:45 – 16:00

Parallel Sessions
BIOETHICS, HUMAN RIGHTS AND DIGNITY

Chair: **Zuhal Okuyan**

Benedict Faneye

Human dignity & human rights: a universal language for bioethics

Chris Durante

Agreeing to disagree in a morally diverse society: coping with religio-cultural pluralism from human rights to bioethics

Friedo Zoelzer

Human rights and obligations: an approach to Bahá'í bioethics

Kris Dierickx, David G. Kirchhoffer

Human dignity and human tissue: a meaningful ethical relationship?

HUMAN DIGNITY & HUMAN RIGHTS: A UNIVERSAL LANGUAGE FOR BIOETHICS

Benedict Faneye

West African Bioethics Training Program
University of Ibadan, Oyo State
Nigeria, West Africa
E-mail: Bfaneye1@yahoo.com

Presented at the Conference by: Benedict Faneye

Abstract:

One of the aims of the *Universal Declaration on Bioethics and Human Rights* (UNESCO) is to “promote respect for human dignity and protect human rights”. Here are two overarching principles at work, ensuring that the biomedical sciences fulfill their task within an ethical framework. The principle of respect for human dignity is a universal moral concept, meant to be applied in human encounters. Protecting human rights underscores the legal principle of not only affirming the fundamental equality of all human beings, but equally safeguarding it. These two principles are universally defined, but are ordinarily specified by the particular value system of individual cultures in which they are employed. It is in this particular cultural application that their relevance stands out.

The thrust of this paper is that, since principles are general action guides, they actually constitute a universal language for the analysis and evaluation of all human conduct. However, there is also recognition of the fact that moral contexts vary from culture to culture, and that while the scope of the two principles above is not restricted by any particular culture, it is indeed those cultural specifics of each moral context that constitute the framework within which the principles become operational.

As general action guides, I will argue that these principles lack moral relevance outside of those particular cultural settings wherein they are contextualized. Without such relevance, these principles become meaningless mantras. I will further show that such principles do not merely uphold values informed by particular cultures, but they are an embodiment of values inherent to human nature in general. Consequently, these principles do not just serve as instruments for addressing issues peculiar to “Western bioethics” or any other particular cultural setting in an exclusive sense, but are also used for moderating bioethics discourse that transcend particular cultural boundaries. I will further explain that such universal discourse is potentially instructive with regards to how cultural universals are viewed in relation to the cultural particulars, and that this discourse essentially becomes a *lingua franca* for cross-cultural dialogue in bioethics.

AGREEING TO DISAGREE IN A MORALLY DIVERSE SOCIETY: COPING WITH RELIGIO-CULTURAL PLURALISM FROM HUMAN RIGHTS TO BIOETHICS

Chris Durante

Faculty of Religious Studies, McGill University,
Montreal, QC, CA / E-mail: C.Durante@hotmail.com

Presented at the Conference by: Chris Durante

Abstract:

In his analysis of the adoption of human rights by various religious traditions, David Hollenbach discusses the phenomenon that although different traditions accept the same set of rights and principles each tradition interprets and applies these rights in distinct ways. Hollenbach sees this hermeneutical diversity as a potential cause of conflict and tension. Consequently, he introduces the notion of “indigenous pluralism” as a means of ameliorating potential conflict and coming to accept the inevitability of interpretive differences.

I will open with a précis of David Hollenbach’s argument in “Human Rights in the Middle East: The Impact of Religious Diversity,” as a means of introducing his notion of “indigenous pluralism.” Subsequently, I will explore the possibility of incorporating the notion of “indigenous pluralism” into bioethics as a means of understanding and coming to terms with the interpretive differences present in biomedical ethics. Once this notion’s usefulness to bioethical inquiry has been demonstrated, an analysis of indigenous pluralism’s ability to be incorporated into the actual process of creating ethical principles will be set forth.

Lastly, I will explore the viability of applying indigenous pluralism to the process of formulating policies regarding standards for determining death and will demonstrate how “indigenous pluralism” can support the enactment of conscience clauses, or similar policies, which allow for different religious interpretations of death to have a role in clinical decision-making. In conclusion, it will be maintained that indigenous pluralism is a useful tool for bioethics on a number of theoretical and practical levels. The strength of “indigenous pluralism” as a conceptual tool is its potential to effectively ameliorate tensions associated with religious diversity without requiring different religious groups to either alter their metaphysical and/or ethical positions or to look beyond the boundaries of their own traditions when coping with the difficulties faced in a pluralistic society.

Key Words: Bioethics, brain death, conscience clause, human rights, indigenous pluralism, religious diversity

HUMAN RIGHTS AND OBLIGATIONS:AN APPROACH TO BAHÁ'Í BIOETHICS

Friedo Zölzer

Faculty of Health and Social Studies, Southbohemian University in České Budějovice, Czech Republic, E-mail: zoelzer@zsf.jcu.cz

Presented at the Conference by: Friedo Zölzer

Abstract:

The Bahá'ís constitute a community of 6 – 7 million people worldwide. They are the followers of Bahá'u'lláh (1817 – 1892), whom they regard as the most recent in a line of divine messengers including Krishna, Moses, Zoroaster, Buddha, Christ, and Muhammad. The community is represented in nearly every country of the world, includes members from various cultural backgrounds, and is growing faster than most other religious communities. These demographic facts alone may be reason enough to examine Bahá'í perspectives of bioethics, but as I will argue here, the relationship between human rights and obligations is a point of particular interest.

In his writings, Bahá'u'lláh clearly speaks of the “rights of the peoples and kindreds of the earth” and relates these rights to “such aims as the welfare, security and protection of mankind and the safety of human lives”. He emphasizes that “man is noble” and that this nobility is independent of sex, race, nation or social status. “The earth is but one country and mankind its citizens”, is one of his most celebrated phrases.

Not all of Bahá'í ethics is rights-based, however. Bahá'u'lláh also puts emphasis on obligations, such as the obligation to see things “with your own eyes and not through the eyes of others”, the obligation to look after the education of your children and your own life-long learning, the obligation to work so that “you yourselves and others may profit therefrom.” His son and authorized interpreter 'Abdu'l-Bahá writes one should “consider the welfare of the community as one's own.”

As regards bioethics, the writings of Bahá'u'lláh himself, of course, do not make direct reference to current issues such as reproductive medicine or end-of-life care, but the heads of the world-wide Bahá'í community, today the democratically elected “Universal House of Justice” have addressed relevant questions in the light of the principles he announced. At the same time, they have put great emphasis on the freedom of every Bahá'í to come to his or her own conclusions, taking the holy writings as a point of reference.

The above-mentioned balance of human rights and obligations can be expected to play a role whenever Bahá'ís discuss bioethics. They will recognize the right of a couple to make use of modern medical methods when they have remained childless; but they will not agree with surrogate motherhood, because of what they perceive as a „mechanistic use of the human body“, and a possibly negative „future impact on the child itself, as well as the emotional ties” between all individuals involved. They will maintain that there is an obligation to help the sick, if necessary also through organ transplantation, but they will defend the right of a dying person

to be treated with respect and not simply as a spare parts depot. These and other examples of bioethical issues on which Bahá'í perspectives have emerged will be discussed in some detail, and their potential for cross-cultural dialogue will be assessed.

HUMAN DIGNITY AND HUMAN TISSUE: A MEANINGFUL ETHICAL RELATIONSHIP?

Kris Dierickx¹, David G. Kirchhoffer²

¹ Professor of Biomedical Ethics: Centre for Biomedical Ethics and Law, Katholieke Universiteit Leuven, Kapucijnenvoer 35 Blok D – Box 7001, 3000 Leuven, Belgium, E-mail: kris.dierickx@med.kuleuven.be

² Lecturer I Faculty of Theology and Philosophy, Australian Catholic University 1100 Nudgee Rd, Banyo, Queensland E-mail: David.Kirchhoffer@acu.edu.au

Presented at the Conference by: Kris Dierickx

Abstract:

Human dignity has long been used as a foundational principle in policy documents and ethical guidelines intended to govern various forms of biomedical research. Despite the vast amount of literature concerning human dignity and embryonic tissues, the majority of biomedical research uses non-embryonic human tissue. Hence, this contribution addresses a notable lacuna in the literature: the relationship, if any, between human dignity and human tissue. We first elaborate a multidimensional understanding of human dignity that overcomes many of the shortcomings associated with the use of human dignity in other ethical debates. Second, we discuss the relationship between such an understanding of human dignity and 'non-embryonic' human tissue. Finally we consider the implications of this relationship for biomedical research and practice involving human tissue. The contribution demonstrates that while human tissue cannot be said to have human dignity, human dignity is nevertheless implicated by human tissue, making what we do with human tissue and how we do it worthy of moral consideration.

Key Words: Bioethics, biobanks, human dignity

16 September 2011, Friday

HALL 2
14:45 – 16:00

Parallel Sessions
BIOETHICS FROM A CROSS-CULTURAL PERSPECTIVE

Chair: **Richard Ashcroft**

Cristián Borgoño

Is inculturation a proper paradigm for a cross-cultural bioethics?

Zehra Edisan - Funda Gülay Kadioğlu

Health related quality of life questionnaires and cross-cultural adaptation: an assessment from ethical point of view

Gerald Neitzke

Trans-cultural competencies in clinical ethics consultation

Demet Tekin, Gürkan Sert, Ayşegül Akgül, Ani Agopyan

Sportsmen's views of private life and expectations in relation with health centers and sports doctors

IS INCULTURATION A PROPER PARADIGM FOR A CROSS-CULTURAL BIOETHICS?

Prof. Cristián Borgoño

Prof. Cristián Borgoño, MD, PhD Bioethics, MA Philosophy.
School of Bioethics Pontifical Athenaeum Regina Apostolorum
Via degli Aldobrandeschi 190 00163 Rome ITALY
E-mail: bioethicsresearch@upra.org

Presented at the Conference by: Prof. Cristián Borgoño

Abstract:

The paper will explore the usefulness of the paradigm of inculturation as an instrument to mediate between universal human rights and cultural specific norms.

As it is well known one of the greatest challenges the human rights paradigm has to face is how to reconcile its universality with cultural diversity. There is a growing literature that seriously questions the universality of human rights especially in some specific traditions. Nevertheless, an effort in balancing both principles is clearly present in a very important document for bioethics and human rights such as art. 12 of UNESCO's Universal Declaration of Bioethics and Human Rights. This means the drafters of this documents were clearly aware of the problem and tried to give an adequate answer. Although a big effort was made, the tension still remains and there is a clear and growing perception that some adaptation is necessary in different cultural settings though we can also accept the validity of universal principles in global bioethics. The need for adaptation obviously requires some guidelines to prevent the evident dangers of cultural relativism, the very denial of universalism, and of a cultural-blind universalism. Within the Catholic Church, that faces a similar problem in adapting dogmas and moral norms to different cultures, after Vatican II there has been a substantial research on the meaning of inculturation, a concept that expresses the need for adaptation of universal norms to different cultures. The paper will explore the validity of this concept and its application to the problem of proposing a global bioethics based upon human rights.

The paper will first expose the cultural based objections to the universality of human rights especially from Islamic and Asian traditions which basically argue that human rights are an Occidental concept. Religion and culture are certainly aspects that set differences between human beings and they are also quite related with each other. Some authors, like Engelhardt have even stated that there is no possible global bioethics and have offered severe criticism of UNESCO's Declaration. Secondly, the paper will explain the concept of inculturation as it has been elaborated in catholic theology to show how it mediates between universalism and particularism. The concept offers a good amount of insights that can be usefully applied to the problem of adapting universal norms to different cultures. Finally we will explore the possibility of bridging the gap between universalism and particularism in global bioethics through the application of the concept of inculturation in the forging of culture-specific norms in bioethics. Special attention will be given to the universal principles proposed in the UNESCO's Declaration.

KEY WORDS: Inculturation, global bioethics, cross-cultural bioethics

HEALTH RELATED QUALITY OF LIFE QUESTIONNAIRES AND CROSS-CULTURAL ADAPTATION: AN ASSESSMENT FROM ETHICAL POINT OF VIEW

Zehra Edisan¹, Funda Gülay Kadioğlu²

¹ Çukurova University Faculty of Medicine Department of Medical Ethics
E-mail: zedisan@hotmail.com

² Çukurova University Faculty of Medicine Department of Medical Ethics
E-mail: fgkadioglu@cu.edu.tr

Presented at the Conference by: Zehra Edisan

Abstract:

In recent years, Health Related Quality of Life (HRQOL) and its measurability have been studied extensively. Within this scope, health related quality of life measures enables individuals to describe the experiences developed on health and diseases in a quantitative way and therefore, it aims to alter the subjective measures to objective measures.

As a result of an increased demand for measuring quality of life in health care, clinicians and researchers without a suitable health related quality of life questionnaire in their own language have a choice to develop a new questionnaire or to modify a questionnaire previously validated in another language. Generally the modifying a questionnaire method is preferred because it is seen as resource-saving strategy and, therefore, original measure is subjected to cross-cultural adaptation process. Although many approaches and guidelines are available for this process, to preserve equivalence in cross-cultural adaptation of HRQOL questionnaires, “translation, back-translation, committee review, pre-testing, and weighting of scores” steps are usually followed up.

Nowadays, there are considerable numbers of quality of life questionnaires in various languages, and some of them are validated in specific countries. As well, in our country, in the adaptation process of HRQOL questionnaires, the researchers not only make translations but also make every effort to maintain cultural equivalence. In this process, the outstanding questions are whether quality of life is measurable across nations and cultures with the same instrument and whether this process will restrict the researchers’ independent beliefs about the concept of quality of life. Researchers who execute the adaptation process should try to be faithful with the original measure for cross-cultural comparability.

In this study, the current issues confronting cross-cultural questionnaire development in Health Related Quality of Life will be introduced and accompanying problems will be discussed as focusing on concept of quality of life in health care.

Key Words: Health related quality of life; health related quality of life questionnaires; cross-cultural adaptation

TRANS-CULTURAL COMPETENCIES IN CLINICAL ETHICS CONSULTATION

Gerald Neitzke

Institute for History, Ethics and Philosophy of Medicine
Hannover Medical University Carl-Neuberg-Str. 1
D – 30625 Hannover, Germany
E-mail: Neitzke.gerald@mh-hannover.de

Presented at the Conference by the : Gerald Neitzke

Abstract:

Ethics consultation has become a new paradigm in patient care in Europe. In many countries Clinical Ethics Committees have been founded or similar services for ethics counselling on the ward have been established. From our experience, in case consultations trans-cultural conflicts regularly arise. The presentation will analyse these conflicts and make some suggestions, how to deal with trans-cultural dilemmas on a methodological and on a structural level. Finally, trans-cultural competencies will be defined as a prerequisite for ethics consultation in the borderlands of the respective culture.

The structures of an ethics consultation service need to be sensitive to cultural and inter-cultural issues. This necessitates the use of interpreters, but language alone does not cover the whole range of cultural issues. According to country-specific requirements, a consultation service should define who appropriate interpreters are for what clinical context. Under which circumstances is a family interpreter sufficient, when a member of hospital staff? What are the advantages and disadvantages of professional interpreters? Every ethics committee should include at least one member who is responsible for trans-cultural and/or inter-religious problems. Some examples will be given, who could act as "trans-cultural representative".

In German hospitals three types of trans-cultural conflicts are fairly common: 1. A religious conviction (e.g. "kismet") within the family not to interfere with end-of-life-decisions, which inhibits the clinical concept of shared decision making. 2. Different cultural conceptions of health, disease and healing. 3. Different experience and expectations of health care institutions and the health care system. Aspects of ethics counselling in these areas will be developed. As moral basis for ethics consultants a culture-sensitive moral pluralism will be discussed. A moral relativism is adequate to support consensus-finding. But in order to do so, certain procedural values are indispensable: fair access, participation, mutual respect and consensus-orientation. These procedural values will be analysed in detail.

Finally, trans-cultural competencies will be defined and discussed. Which are the qualifications, skills and attitudes of an ethics committee member, to enable him or her to act as trans-cultural representative? Some examples from German clinical ethics committees will illustrate how the concept of trans-cultural competencies can be put into practice.

SPORTSMEN'S VIEWS OF PRIVATE LIFE AND EXPECTATIONS IN RELATION WITH HEALTH CENTERS AND SPORTS DOCTORS

Demet Tekin¹, Gürkan Sert², Ayşegül Akgül³, Ani Agopyan⁴

¹ Istanbul Bilgi University, School of Health Sciences, Physiotherapy and Rehabilitation E-mail: tekindemett@gmail.com

² Marmara University, Faculty of Medicine, Department of Medical Ethics and History of Medicine E-mail: ozgurgurkan@yahoo.com

³ Yavuz Selim Bone Diseases And Rehabilitation Hospital E-mail: fzt.aysegul@hotmail.com

⁴ Marmara School of Physical University Education and Sports E-mail: aagopyan@gmail.com

Presented at the Conference by: Demet Tekin

Abstract:

The aim of the sports medicine is to maintain the health of the athletes, to prevent injuries, to increase performance and provide treatment after injury. In this context, provision of services that enhances performance and evaluates performance status differs than provision of routine health care service to athletes. In such situations, where high performance is expected and injury may be present, it is necessary to treat the sportsmen in the fastest way so that the athlete becomes beneficial to the team or the institution he represents.

In the same way, expectation of high performance requires sportsmen to be under observation all the time and even requires them to be subject to applications that enhances their performance. During all these processes a lot of information for athletes are conveyed to sports doctor or health care center. In the conventional doctor-patient and health care institution-patient relation these information should be judged as the most secret information of the areas of privacy and they should be maintained confidential in the context of the respect to privacy and within the framework of the principles of medical ethics. However, since the sports doctor and healthcare institution are responsible to the team or institution the athlete is involved with, the information is shared with the team or institution in detail and even disclosure of the health status of publicly recognized athletes to the whole public is a common situation. In this context, it is clearly seen that there are significant problems related with the confidentiality of health information during the provision of health care services to athletes. This paper aims to examine these problems within the framework of medical ethics and provide recommendations accordingly.

Key Words: Sports medicine, privacy, ethical analysis

16 September 2011, Friday

HALL 3
14:45 – 16:00

Parallel Sessions
BIOETHICS AND HEALTHCARE

Chair: **Yvonne Denier**

Tim Peters, Jan Schildmann, Jochen Vollmann

Interculturality at the bedside: two teaching concepts on the management of patients from different cultural backgrounds for medical students

Tolga Güven, Aslihan Akpınar

Why we need to “care”: the problems created by promoting patient autonomy as a legal concept in Turkey’s healthcare setting and the ethics of care perspective as a possible solution

Lyudmila Chakarova, Sylvia Mladenova

Bioethical aspects of the concept for sustainable development in Healthcare

INTERCULTURALITY AT THE BEDSIDE: TWO TEACHING CONCEPTS ON THE MANAGEMENT OF PATIENTS FROM DIFFERENT CULTURAL BACKGROUNDS FOR MEDICAL STUDENTS

Tim Peters, Jan Schildmann, Jochen Vollmann

Institute for Medical Ethics and History of Medicine, Ruhr University Bochum, Malakowturm-Markstr 258a, 44799 Bochum, Germany, E-mail: tim.peters@rub.de

Presented at the Conference by: Tim Peters

Abstract:

The professional handling of interculturality poses an increasingly important challenge in the daily life of medical staff. In the age of differing ethical and religious-cultural standards and of a multiculturally developing society, the awareness and competence of medical professionals concerning clinical-ethical questions in the contact with patients from another culture is gaining in importance. Informing the patient and eliciting informed consent, a different understanding of sex and gender or a different relation to the body and to illness are examples for challenges related to different cultures. In their clinical practice doctors and other health care professionals often experience the variations in norms and values across different cultures as conflicts – for example, during decision-making about diagnostic or therapeutical measures. In Germany as in many other countries there is hardly any teaching for medical students or young doctors to handle such situations in a professional manner.

In this contribution, we present the concept and the evaluation of two teaching modules on ethical and practical aspects of interculturality. The first module focuses on the exploration of one's own norms and values within different thematic fields. Exemplary, the areas of intimacy and sexuality, religious duties and taboos as well the role of the family concerning decision-making in medicine will be dealt with. Subsequently to the investigation of the norms and values within the group of participating students, the norms and values of different cultures will be presented, compared and critically discussed. In addition to raising awareness for the issue of cultural diversity and elaborating criteria for professional handling of this issue in medical practice, the concept of ethical relativism and the related challenges are discussed.

In the second, more practically-oriented module, a concrete case will be simulated, in which a mother of Turkish descent wants to have her hospitalized daughter's virginity checked by the treating doctor without the daughter's knowledge.¹ With the help of a standardized patient this complex intercultural situation will be simulated. In the ensuing discussion the conflict will be analyzed and discussed on the basis of the developed criteria for professional behavior in intercultural encounters.

This presentation will conclude with a reflection on the didactic concept and methods as well as on the feedback of the students participating in the facultative seminar. Furthermore, with an eye to the interdisciplinary subject of intercultural doctor-patient-relationships, the potential contribution of the subject of medical ethics to the mediation of intercultural competences will be discussed.

Key Words: Interculturality, teaching

WHY WE NEED TO “CARE”: THE PROBLEMS CREATED BY PROMOTING PATIENT AUTONOMY AS A LEGAL CONCEPT IN TURKEY’S HEALTHCARE SETTING AND THE ETHICS OF CARE PERSPECTIVE AS A POSSIBLE SOLUTION

Tolga Güven¹, Aslihan Akpınar²

¹ MD, Lecturer, Marmara University, Faculty of Medicine, Department of Medical Ethics and History of Medicine
E-mail: tolgaguvenc@hotmail.com

² PhD, Kocaeli University, Faculty of Medicine, Department of Medical Ethics and History of Medicine

Presented at the Conference by: Tolga Güven

Abstract:

Patient rights have become a rather popular topic in Turkey recently. The interest in this issue can be attributed partially to the Ministry of Health’s recent efforts to implement patient rights in health care services in Turkey. However, paternalism is still common in Turkey’s health care setting and the implications of the term “patient autonomy” in Turkey’s context is yet to be clarified. Under these circumstances, patient autonomy appears to be promoted mostly as a legal, rather than an ethical concept in Turkey.

In line with these recent developments, health care professionals in Turkey are now trying to understand and meet the requirements for informed consent. Unfortunately, but perhaps not surprisingly, fear of being sued or prosecuted appears to be the main reason for these recent efforts. Many professionals and especially physicians are now concerned about preparing consent forms and getting them signed, but it is doubtful whether this emphasis on consent forms will ensure more respect for patient autonomy. We think that this current situation is causing patient autonomy to be misunderstood only as a legal concept and is enhancing the misconception that respect for autonomy requires simply meeting a series of legal criteria.

This paper aims to argue that the ethics of care approach can help to avoid this problem and provide a better perspective for interpreting the concept of autonomy in Turkey’s context. For this purpose, we will concentrate on the care perspective as an “orientation” rather than a complete theory, as advocated by authors such as Little and Verkerk. We believe that such an orientation is not only compatible with autonomy, but it can also significantly enrich the understanding of the concept by health care professionals. For this reason, we will first argue that the current legally imposed autonomy approach in Turkey has no implied or explicit emphasis on such an orientation: Patients alone are expected to bear the responsibility of being decision-makers, while health care professionals are given the message that their first and only duty is to obtain written consent in a procedural manner. At best, such an environment can help health care professional to become aware of the problems of “intervening”, but it is doubtful whether such a minimalist interpretation is adequate to fully understand the implications of respect for autonomy. By contrast, the care

perspective can be used to emphasize the significance of improving patient-professional communication, establishing empathy and understanding the impact of illness and suffering on the patient's life experience. We will conclude that these aspects can also be compatible with the concept of respect for autonomy and they are more likely to be embraced by patients in Turkey, as opposed to the "read and sign these forms" attitude that has been gaining popularity recently among Turkey's health care professionals.

Key Words: Ethics of care, autonomy, patient rights

BIOETHICAL ASPECTS OF THE CONCEPT FOR SUSTAINABLE DEVELOPMENT IN HEALTHCARE

Chakarova, L.¹, Sylvia Mladenova²

¹ Medical University - Sofia, Chair Medical ethics and law

² Medical University - Sofia, Chair Medical pedagogy

Presented at the Conference by: Sylvia Mladenova

Abstract:

Introduction: The concept of sustainable development in healthcare is closely related to the moral categories and bioethics. The treatment and the study of sustainability problems in the medical sphere contribute to the improvement of the quality of life of mankind, environment protection and the longer use of the present natural resources. In relation to healthcare the accent is put on the preservation of health of as many people as possible and the rational usage of scarce resources in the system.

The purpose of the study is to examine in what degree the inquired persons have attitude and consciousness about the requirements and the challenges of the sustainable development in healthcare.

The method of examination is anonymous sociological questionnaire with students from the Faculty of Public Health – Sofia. Inquired were 73 students from the specialties “Public health and health management” and “Management of health care”.

Results show, that students have some common notion about the sustainable development in the medical sphere, but in relation to the change of attitudes and consciousness there is a need to put much efforts in order to reach a high quality of life and future prosperity.

Key Words: Sustainable development, environment and health protection, scarce resources

16 September 2011, Friday

HALL 4
14:45 – 16:00

Parallel Sessions
HUMAN RIGHTS IN BIOETHICS

Chair: **İlke Türkmendağ**

Ingemar Engstrom

Three fundamental ethical perspectives – paternalism, autonomy and participation – and their relation to human rights

Allane Madanamoothoo

What protection for the saviour-sibling child under French law?

Richard Nicholson

Does humankind want to survive?

Vojin Rakic

Neuro-pharmacology for “cosmetic” purposes: ethical, political and cultural aspects

THREE FUNDAMENTAL ETHICAL PERSPECTIVES – PATERNALISM, AUTONOMY AND PARTICIPATION – AND THEIR RELATION TO HUMAN RIGHTS

Ingemar Engström

Swedish Medical Society, Delegation for Medical Ethics
PO Box 738, SE-101 35 Stockholm
E-mail: ingemar.engstrom@orebroll.se

Presented at the Conference by: Ingemar Engström

Abstract:

The foundations for medical ethics may be found in different domains; anthropology, general moral philosophy, political philosophy, human rights, health law and sometimes even in religious beliefs. Certain fundamental principles like nonmaleficence and beneficence may be derived from ancient Greece and thus have their origin in early moral philosophy expressed as a form of proto-code of conduct for the medical profession. The term paternalism is often used as a description of this perspective.

During the 1900's, and particularly after WW II, the patient and his/her rights in health care were put to the fore, sometimes in addition to and sometimes in contrast to the prevailing paternalistic perspective in medical ethics. The principles of autonomy and justice are, however, based in political philosophy and could best be described in terms of relations between society and the individual. These principles thus have an obvious relation to human rights.

Since then, these two fundamental principles have existed concurrently. The emphasis in medical ethics has been on autonomy whereas medical practice still shows a considerable amount of paternalism.

Both these perspectives have a kind of unilateral character and take either the doctor or the patient as the starting point. A medical ethics that take the very relation patient-doctor as the point of departure has therefore been called for and certain steps relating to concepts of participation and/or reciprocity have been proposed as fundamental principles for a "third perspective" in medical ethics.

In this paper, these three fundamental principles for medical ethics will be reviewed and discussed in relation to human rights in general and to fundamental codes, like the Oviedo convention, in particular. Questions will be raised concerning the consequences of making use of human rights more ostentatious in medical ethics and how each of these three perspectives can accommodate human rights in different understandings.

Key Words: Human rights, participation, fundamental principles

WHAT PROTECTION FOR THE SAVIOUR-SIBLING CHILD UNDER FRENCH LAW?

Allane Madanamoothoo

Research-Professor in Law at ESC Business School of Troyes, France
E-mail: allane51100@gmail.com

Presented at the Conference by: Allane Madanamoothoo

Abstract:

Saviour-sibling refers to a child who is conceived to cure an older brother or sister suffering from a serious family genetic disease. Therefore, it is meant to give birth to a child who will provide stem cells taken from the umbilical cord or bone marrow afterwards, to treat an elder sick child in the same family.

In France, this practice authorized by the bioethical law of August 2004 is strictly regulated. The authorization is granted, among other conditions, if it is demonstrated that the incurable disease of the elder child could cause death in the first years of life and the possibility of decisive improvement in the health status of the sick child.

This technique opens up new perspectives and enormous hope. Its legalisation is certainly justified by the suffering of the parents and the sick child and to avoid that they travel to other States where the law is more flexible. However, how far the saviour child is judicially protected?

Indeed, isn't this practice where the selection of embryos is done through their genetic inheritance, contrary to the Oviedo Convention? Can France's simple signature be subjected to criticism even if it has not ratified this Convention and has therefore not implanted it into the national law? What about the principle of the child's interest claimed by the United Nations Convention on the Rights of the Child? Internally, there is also the issue of the consent of the "saviour" child when the stem cells are removed elsewhere than on the umbilical cord at birth.

Beside legal matters, lie ethical ones. The first one, is the destiny of the embryos conceived: those with a genetic "anomaly" and those which are healthy but do not meet the histo-compatibility criteria. The latter can be donated to another couple, but as the first ones they can be destroyed or donated for research. There is thus a massive destruction of embryos programmed in advance. The risk of instrumentation of the saviour-sibling child has also to be taken into account. Indeed, since its conception was originally intended mainly due to its therapeutic potential hopes, will his "mission" be to serve as a "medicine" to his elder brother or sister?

Psychological problems also exist. What will be the attitudes of the parents towards the saviour-sibling child afterwards? What will happen in case of failure regarding the weight of guilt of the saviour-sibling child towards his parents and the sick child? Conversely, in case of success, what is the moral burden of debt that will be experienced by the child who will be cured? If the latter falls sick again in adolescence or

later, will the “saviour” child be considered as a bank of stem cells for life? Will he suffer from pressure from his surroundings if he refuses to act as such.

II these issues deserve to be debated. This presentation aims at showing how far the saviour child is protected under French Law.

Key Words: Saviour-sibling, stem- cells, embryos

DOES HUMANKIND WANT TO SURVIVE?

Dr. Richard Nicholson

6 Gallia Road, London N5 1LA

No institutional affiliation; former editor, Bulletin of Medical Ethics

E-mail: bullmedeth@hotmail.co.uk

Presented at the Conference by: Richard Nicholson

Abstract:

This paper will explore the paradox that the more effort modern civilisations expend on trying to keep individual human beings alive for as long as possible, the more likely it is that the human race will not survive. This raises in turn the problem that we may need very soon to assert that the survival of the human race is a more important human right than the individual's right to life. Clearly such an assertion would raise major ethical issues in determining what types of medical practice should no longer be permitted.

The paradox arises from the development of anthropogenic global warming, and the attendant myth that if we stabilise the level of atmospheric carbon dioxide, we shall prevent runaway global heating. If, in fact, we want to stabilise global temperature, we have to ensure that the amount of radiation coming into the Earth is equal to the radiation leaving. To achieve that in a sustainable way will require much more than reducing, or even eliminating, the carbon dioxide the human race emits.

It will require recognition that, after hundreds of generations of slow growth in human population, the last 12 generations saw an exponential growth of population that mirrors growth in fossil fuel use. Like any biological system subject to exponential growth, there is likely soon to be a subtotal collapse in population. An added problem is that our lack of serious effort to control global heating will soon allow it to run away, and in a further six generations Earth will be too hot for humans to survive.

In other words, our much-vaunted 'Western' civilisation is actually a complete failure, which may bring about extinction in less than 20 generations. That requires complete re-examination of every aspect of our modern way of life to determine what is really sustainable. Modern medicine is not exempt: it uses about one-eighth of global wealth to provide four years added life expectancy for the billion wealthiest people on Earth. That is both severely inequitable and unsustainable.

In medicine, we have to make major changes. It may be necessary to close most hospitals and rely on good primary care. It is folly, in survival terms, to put so much effort into trying to cure everything, rather than ensuring that the ill are properly cared for. It is the Western desire to extend life at all costs that makes medicine so expensive and so dangerous to human survival. Voluntary euthanasia should be embraced, and all methods of artificial reproduction outlawed, since it is absurd to use technology to create extra humans in a grossly overpopulated world.

The greatest obstacle to dealing with global heating, however, is the opposition of most people to any reduction in their standard of living. Nevertheless, global heating raises a vast number of new issues for ethicists.

Key Words: Human survival

NEURO-PHARMACOLOGY FOR “COSMETIC” PURPOSES: ETHICAL, POLITICAL AND CULTURAL ASPECTS

Prof. Dr Vojin Rakić

Institute for Philosophy and Social Theory
University of Belgrade
Kraljice Natalije 45, 11000 Beograd- Serbia
E-mail: vojindrakic@hotmail.com

Presented at the Conference by: Prof. Dr Vojin Rakić

Abstract:

The focus of my paper will be on the ethical, political and cultural aspects of the utilization of neuro-pharmacological means for non-medical purposes (e.g., Ritalin as a motivation and efficiency enhancer or Prozac and some tranquilizers as “recreational” mood enhancers). This use of neuro-pharmacological means for non-medical purposes I will call “cosmetic neuro-pharmacology” or “recreational neuro-pharmacology”. The opportunities for a similar (non-medical) utilization of some forms of neurosurgery (mostly “Deep Brain Stimulation”) will be covered as well. Three different cultures of the utilization of neuro-pharmacology for cosmetic purposes will be compared and contrasted:

- the Dutch pharmaco-culture of restrictive use of drugs in general (so-called “pharmacological Calvinism”), and their use for cosmetic purposes in particular;
- the American approach that is more “liberal” than the Dutch – an approach that might be responsible for the evidence we have that indicates a higher prevalence of the use of neuro-pharmacology for cosmetic purposes in the United States than in the Netherlands;
- the Serbian pharmaco-culture in the last twenty years: one that has been markedly determined by the psychological consequences of the most recent Balkan wars among the population of Serbia, in combination with the possibility of the local population to obtain drugs in pharmacies without prescriptions – a situation that resulted in a massive utilization of mood enhancers and other drugs for cosmetic purposes.

It will be concluded that the overall consumption of medicines for cognitive enhancement is likely to increase, because of the continuous loosening of indications for their administration, as well as the widening of possibilities for their acquisition (Internet). Moreover, it will be argued that a general prohibition of such medicines is not realistic and possibly not ethical and/or politically desirable either. The case of Serbia during the 1990s and much of the 2000s will be employed, however, to arrive at an understanding of what the perceived and real dangers might be for individuals and for society when neuro-pharmacological means are used by the population without any restrictions.

Key Words: Neuro-pharmacology, ethics, culture

17 September 2011, Saturday

**HALL 1
09:00 – 10:00**

Plenary Lecture “Bioethics in Conflicting Issues”

Key Note Speakers: **Prof. Dr. Nikola Biller-Andorno,**
Dr. Yvonne Denier

Moderator: **Prof. Dr. Chris Gastmans**

Prof. Dr. med. Dr. phil. Nikola Biller-Andorno

Prof. Dr. med. Dr. phil. Nikola Biller-Andorno studied medicine at the University of Erlangen-Nuernberg as well as philosophy and social sciences at the University of Hagen, Germany. Multiple scholarships and awards allowed her to pursue her research interests at prestigious institutions such as the Hastings Center (1994), Yale University (1997) and the Harvard Medical School (1997-98). After a period of further academic qualification ("habilitation") in ethics and theory of medicine at the University of Göttingen, Germany, she worked as Ethicist at the World Health Organization (2002-2004). In 2004 she was appointed Professor of Medical Ethics at the Charité, Joint Medical Faculty of the Free and Humboldt University, Berlin, Germany. In October 2005 she joined the University of Zurich as Full Professor of Biomedical Ethics; in 2007 she became Founding Director of the Institute of Biomedical Ethics at the same University, which was designated as WHO Collaborating Centre for Bioethics in 2009. She is also directing the newly established PhD program "Biomedical Ethics and Law" (medical track) at the University of Zurich as well as the Center for Ethics of the University of Zurich.

She serves as a member of the Central Ethics Commission of the Swiss Academy of Sciences, as temporary advisor to the World Health Organization and as deputy editor of the *Journal of Medical Ethics* and is active on the boards of several professional associations (Akademie für Ethik in der Medizin, Swiss Society of Biomedical Ethics, President of the International Association of Bioethics 2009-11) as well as on a number of committees (Vice-President of the Clinical Ethics Committee of the University Hospital Zurich, Member of the Ethics Committee, University of Zurich, Vice-President of the Executive Committee of the Swiss Federal Program for Gender Equality), prize juries and advisory boards. She frequently acts as reviewer for journals, funding agencies and university appointment procedures.

Nikola Biller-Andorno has published widely in the field of bioethics. Her work so far includes more than 120 contributions to journals and book chapters, some of which have been translated into Spanish and Russian. She has co-authored or co-edited seven books, among them "Ethical Issues in Governing Biobanks – Global Perspectives" (Ashgate 2008). She has given more than 100 presentations and lectures in many different countries.

THE PROHIBITION OF ORGAN SELLING AND ITS IMPLEMENTATION

Nikola Biller-Andorno

University of Zurich

In spite of a controversial philosophical debate about concepts such as autonomy, voluntariness, instrumentalization, exploitation, equity and human dignity and their meaning in the context of organ selling, global policy has reconfirmed its prohibitive stance. Bodies such as the World Health Organization, the World Medical Association, UNESCO and the Council of Europe all concur that organ selling should be banned.

Still, global policy risks being a toothless tiger if there is no interest in its implementation. In the case of organ selling, however, professional societies – the Transplantation Society (TTS) and the International Society of Nephrology (ISN) – have taken initiative. The Declaration of Istanbul on Organ Trafficking and Transplant Tourism (2008) follows up on a resolution by the World Health Assembly urging member states in 2004 “to take measures to protect the poorest and vulnerable groups from transplant tourism and the sale of tissues and organs, including attention to the wider problem of international trafficking in human tissues and organs” (WHA57.18). In addition, an Custodian Group was established, aiming to promote the goals of the Declaration internationally (<http://www.declarationofistanbul.org>).

The presentation will 1) briefly recapitulate the controversial debate on organ selling, 2) outline current global policy on the issue, and 3) present the Declaration of Istanbul and its Custodian Group as a milestone in combatting a socially exploitative practice.

Dr. Yvonne Denier

Yvonne Denier (°1976) studied Philosophy and Applied Ethics at the KULeuven. In 2005, she obtained a Doctoral Degree in Philosophy with a study on justice in health care.

She has been visiting researcher at the Internationales Zentrum für Ethik in den Wissenschaften in Tübingen (2001-2002), and at the Hastings Center in New York (2006). She is Ethical Advisor of Zorgnet Vlaanderen, an umbrella organization for over 500 health care institutions (hospitals, nursing homes and organisations in mental health care) in Flanders (Belgium). She is also Postdoctoral Researcher at the Centre for Biomedical Ethics and Law (Faculty of Medicine, KULeuven). From October 2011 onwards, she will be Assistant Professor of Health Care Ethics at this Centre.

Her research focuses on health care ethics, organizational ethics, end-of-life care ethics, and theories of distributive justice and resource allocation. She also teaches on these subjects, has given over 50 lectures in national and international conferences, and has published in several internationally peer-reviewed journals. She also participates as an ethicist in several ethics committees on local and community level in Flanders. She is a member of the Belgian Advisory Committee on Bioethics, which advises the Federal Government in Belgium.

Selection of Publications

DENIER Y.; GASTMANS C.; DE BAL N.; DIERCKX DE CASTERLÉ B., (2010) 'Communication in Nursing Care for Patients Requesting Euthanasia: a Qualitative Study.' *Journal of Clinical Nursing* 19;23-24: 3372-3380.

DENIER, Y (2010). 'From Brute Luck to Option Luck? On Genetics, Justice and Moral Responsibility in Reproduction' *The Journal of Medicine and Philosophy* 35;2: 101-129.

GASTMANS, C.; DENIER, Y (2010). 'What if Patients with Dementia use Decision-Aids to Make an Advance Euthanasia Request?' *The American Journal of Bioethics* 10;4: 25-26.

DENIER, Y.; DIERCKX DE CASTERLÉ, B.; DE BAL, N.; GASTMANS, C (2010) "It's intense, you know." Nurses' experiences in caring for patients requesting euthanasia' in *Medicine, Health Care and Philosophy* 13;1: 41-48.

DENIER, Y (2008). 'Mind the Gap! Three Approaches to Scarcity in Health Care,' in *Medicine, Health Care and Philosophy*, 11;1: 73-87.

DENIER, Y (2007). *Efficiency, Justice and Care. Philosophical Reflections on Scarcity in Health Care*, Dordrecht: Springer.

DENIER, Y (2006). 'Need or Desire? A Conceptual and Moral Phenomenology of the Child Wish,' in *The International Journal of Applied Philosophy* 20;1: 81-95.

DENIER, Y (2005). 'On Personal Responsibility and the Human Right to Health Care' in *Cambridge Quarterly of Health Care Ethics* 14;2: 224-234.

Selection of Forthcoming Work

DENIER, Y; GASTMANS C; VANDEVELDE T (2012), *Justice, Luck and Responsibility in Health Care. Philosophical Background and Ethical Implications*. Dordrecht: Springer

AACHARYA RP, GASTMANS C, DENIER Y (2011), 'Emergency Department Triage: an Ethical Analysis.' *BMC Emergency Medicine*

PINXTEN W, DENIER Y, DOOMS M, CASSIMAN J-J, DIERICKX K (2011), 'A Fair Share for the Orphans: Ethical Guidelines for a Fair Distribution of Resources within the Bounds of the 10 Year Old European Orphan Drug Regulation.' *Journal of Medical Ethics*

DIERCKX DE CASTERLÉ B, GASTMANS C, BRYON E, DENIER Y (2011), 'QUAGOL: A Guide for Qualitative Data Analysis.' *International Journal of Nursing Studies*.

WHAT DOES JUSTICE IN HEALTH CARE MEAN? PHILOSOPHICAL REFLECTIONS AND ETHICAL IMPLICATIONS

Dr. Yvonne Denier

KULeuven – Faculty of Medicine
Centre for Biomedical Ethics and Law
Kapucijnenvoer 35 box 7001, 3000 Leuven - Belgium
E-mail: Yvonne.Denier@med.kuleuven.be

What does just health care imply? Does it mean that people have a right to health care? Does it entail that there are rights-based social obligations to provide equal access to health care for everyone? And if so, why? Why are health care interests so important that they deserve special protection? What kind of social good is health care? What are its functions and do these make different from other commodities? Furthermore, how much equality should there be in health care? What inequalities are morally acceptable and how should the burdens of achieving equality be distributed? To what extent should we allow personal responsibility to play a role in allocating health care services and resources, or in distributing the costs? And what does just health care require with regard to long-term care for the chronically ill and irreversibly dependent? Since the 90's, issues of scarcity, priority setting, and rationing lie at the centre of most current debates on health care. These are pressing issues: one way or another, limits have to be set. As such, the question of what is involved in just health care becomes much more complex. This complexity can be represented as an incompatible triad, a set of three propositions of which any two are compatible but which together form a contradiction. In the case of health care, the three rival values are: efficiency, justice, and decent-quality care. It seems to be that we can have any two but not all three. In my contribution, I will provide an overview of various existing answers to the question how health care can be incorporated into a theory of justice, while realizing an acceptable balance between efficiency, justice, and care.

17 September 2011, Saturday

HALL 1
10:00 – 11:15

Parallel Sessions
BIOETHICS IN CONFLICTING ISSUES

Chair: **Nikola Biller-Andorno**

Christian Kind

A hunger striker, the swiss federal court, forced feeding, and good medical practice

Marie Chenik, Urban Nylen

Female patient beliefs and preferences about gender challenging staff determination to preserve equality between men and women caregivers. A conflicting issue at the department of gynaecology at one Swedish University Hospital.

Teddy Florea, Eniko Demeny

Applied Case Studies in Ethics and Medicine in Eastern Europe – the Role of Bio-Ethics in Living Organ Donations' Decision Making

Hsiao-Lu Lee, Yu-Ling Bai

Kidney allocation priority for waiting list or younger age case

A HUNGER STRIKER, THE SWISS FEDERAL COURT, FORCED FEEDING, AND GOOD MEDICAL PRACTICE

Christian Kind

Central Ethics Commission of the Swiss Academy of Medical Sciences,
Ostschweizer Kinderspital, CH-9006 St. Gallen, Switzerland,
E-mail: christian.kind@kispisg.ch

Presented at the Conference by: Christian Kind

Abstract:

The Swiss Federal Court has rejected the claim of a convicted prisoner to suspend his detention for health reasons caused by his hunger strike. Consequently the physician at the prison was ordered by the local authority to forcibly feed the prisoner should necessity arise. The physician's appeal against this order is still pending but fortunately the hunger striker terminated his food refusal by his own decision.

The problem remains for Swiss physicians that the highest court of our country has stated: "Forced feeding does not disproportionately affect the personal liberty of the prisoner and does not violate the prohibition of inhuman and degrading treatment, as long as it is practiced with dignity and according to the standards of good medical practice."

This leaves us puzzled. There may well be standards of good medical practice for forced feeding of incompetent patients with psychosis or anorexia nervosa. However, the World Medical Association in its Declaration of Malta as well as the Swiss Academy of Medical Sciences in its Directives on Medical Practice for Persons in Detention state very clearly that forced feeding of a competent prisoner fasting of his own will and fully informed about the medical consequences of his behavior is against the code of ethical conduct for physicians.

How then, can an authority order a physician to forcibly feed a competent prisoner according to the standards of good medical practice? Does it intend to conceptually separate the technical aspects of good medical practice from its ethical tenets? Would this mean that only the former would be left in the sole competence of the medical profession whereas the latter could be determined, at least in part, by judiciary or administrative powers? Such an understanding could have far reaching consequences for other domains of medical practice, such as the treatment of asylum seekers, suspected terrorists and prisoners of war, but also for end of life practices.

In my opinion it is paramount for the integrity of the medical profession that its code of ethical conduct must not be separated from the scientific and technical bases of medicine. A medical practitioner with comprehensive knowledge and perfect technical skills, but who disregards medical ethical norms, cannot be called a good doctor. Only a patient who knows that his doctor adheres to the professional code of ethical conduct, can trust him enough to allow the transgressions of physical, emotional and mental boundaries that are an ineluctable part of medical practice.

Of course this code cannot be immutable. But it must not be changed by forceful societal intervention. The only means to adapt to changing societal needs can be through open ethical debate involving all relevant parties. Only physicians who are personally convinced of the validity of their code of professional ethics are able to gain the durable trust of their patients.

Key Words: Hunger strike, forced feeding, code of medical ethics

FEMALE PATIENT BELIEFS AND PREFERENCES ABOUT GENDER CHALLENGING STAFF DETERMINATION TO PRESERVE EQUALITY BETWEEN MEN AND WOMEN CAREGIVERS.

A conflicting issue at the department of gynaecology at one Swedish University Hospital

Marie Chenik¹, RN, MSc, Urban Nylen², MD, PhD

¹ Coordinator Ethical Issues, Karolinska University Hospital, Quality and Patient Safety. E-mail: marie.chenik@karolinska.se

² Karolinska University Hospital, Quality and Patient Safety.
E-mail: urban.nylen@karolinska.se

Presented at the Conference by: Marie Chenik

Abstract:

The Hospital Ethic Committee (HEC) was asked by the chief officer at the Department of Gynaecology to consider a request made by physicians and other members of the staff.

The caregivers claimed that new rules applying to patients and their families were urgently needed in order to address the increase in the number of women asking for a female medical provider. They referred to similar guidelines from 2008 established by another County Council in the south of Sweden and to a statement made 2007 by the Swedish Society of Gynaecology (SFOG). According to the staff such demands from female patients more often came at one of the hospital Emergency Gynaecology Unit, a unit welcoming patients from an area with a growing Muslim population. Sometimes it happened that patients and relatives became aggressive when their demands were denied.

The staff experienced these women's request as an obstacle to give them high quality care and as a disturbance in patient flows arguing that other patients at the Emergency Unit had to wait longer. Furthermore the demand was felt by the staff, if accepted, as a discrimination of male caregivers. Such an outcome became almost unacceptable for some of the male members of the staff and many female colleagues. They truly believed that they were acting for a good cause not meeting female patient's requests. They thought that it would solve the organizational problems at the unit and even help to change the attitude of the patients and their families making them more willing to respect equality between men and women.

All healthcare professionals in Sweden have a duty to respect the dignity of every patient and the right of the patient to decide. The new rules proposed by the staff would be meant to clearly limit the right of the female patient to choose or even to ask for a female caregiver at the Emergency Gynaecology Unit. Only chance would determine which caregiver the patient would meet even if female caregivers were on duty and available at the time.

Could the new regulation and the attitude of the staff threaten the dignity, health and wellbeing of the female patients? If the answer is yes, would it be ethically acceptable?

Should the demands of the female patients be understood as discrimination against male caregivers or on the contrary should the attitude and decisions of the staff be seen as discrimination against the female patients?

Could better knowledge of the religion and social cultures of patients give medical professionals a guarantee that they are providing the best and most comprehensive care possible? Could it enhance a caregiver's possibility to build trusting relationships with patients and avoid conflicting situations?

Is a similar conflict to be found in other countries in Europe?

Key Words: Gender, gynaecology, patient preferences

**APPLIED CASE STUDIES IN ETHICS AND MEDICINE IN
EASTERN EUROPE – THE ROLE OF BIO-ETHICS IN LIVING
ORGAN DONATIONS' DECISION MAKING**

Teddy Florea and Eniko Demeny

Center for Ethics and Law in Biomedicine (CELAB)
Central European University, Budapest
E-mail: florea_george@ceu-budapest.edu

Presented at the Conference by: Teddy Florea

Abstract:

There has been an increasing role of bioethics in legislation regulating organ transplantation in Eastern Europe. New legislative measures in public health law have stipulated the presence of bio-ethics committees in supervising the living organ donation process. One of their roles is to wither suspicions surrounding paid organ exchanges between donors and recipients and wither potential organ trafficking schemes. The relevance of their activity is enhanced in countries permitting unrelated living donations where the potential of abuse is much higher. However, the decision-making practice of such committees is far from being unitary in translating the law into practice through purely objective criteria. There is an inherent risk of the process becoming purely conveyor belt alike formal instead of following its initial task of evaluating exhaustively each case. Comparatively, certain transplantation units give the green light to such life-saving procedures at a higher percentage rate than in others even within the same country.

Consequently, in light of the suspected subjectivity of decision-making of the members present in such committees, it is interesting to evaluate their decision-making process from certain contextual variables. In this study, we hypothesise that such indicators are related to the institutional and cultural environment under which the members of the commissions operate, their heterogeneous professional background, and the longitudinal experience of commission members in evaluating such practices. The question arising out of this analysis is whether best practices of such bioethical commissions can be translated from one cultural and legislative context to another. For instance, can Dutch good practices be transposed on the same efficiency level in the Eastern European countries? In our analysis, we present case studies in the regional context by focusing on both the legislation, and the actual practice of these committees. We rely in our analysis on 45 semi-structured interviews conducted with stakeholders of organ transplantation in the region acquired during our research within the EU FP7 framework project Living Organ Donation in Europe (EULOD).

KIDNEY ALLOCATION PRIORITY FOR WAITING LIST OR YOUNGER AGE CASE

Hsiao-Lu Lee ¹, Yu-Ling Bai²,

¹ Institutional RN, MSN, Instructor, Department of Nursing, yuhing junior college health care & management, Kaohsiung City, Taiwan; National Yang Ming University Nursing School PHD Candidates, Taipei, Taiwan
Address: No.15 Lane 420 Dachang 2nd Rd. Sanmin District, Kaohsiung City 807 Taiwan (R.O.C.)
E-mail:smart@ms.yuhing. Edu.tw

² RN, MSN, Instructor, Department of Nursing, Chung Hwa University of Medical Technology, Tainan County, Taiwan
E-mail:thmoas.suen@msa.hinet.net

Presented at the Conference by: Lee Hsiao-Lu

Abstract:

In this study, a qualitative analysis has been conducted to study the principles of renal distribution, and kidney organ distribution based on of absolute factors (blood type) and relative factors such as HLA (Human leukocyte antigen) and geographical distribution in Taiwan. If matching scores are equal, then priority should be given for the younger case. In 2010, 6500 patients were waiting for a kidney transplant. Only 190 patients received kidney transplants, showing the lack of donor kidneys in Taiwan. This study interviewed 8 medical experts, 1 sociologist and 6 kidney transplant patients (3 transplant patients in Taiwan, and 3 in China.). 6 medical experts stated a younger person's body is better than old one, due to recovery quickly and higher survival rate. The remaining quality of life in older patients could not be demonstrated. One physician stated, "Age is not an absolute consideration, putting them on the waiting gives them hope". Despite equal opportunities for a transplant, doctors still gave the transplant to younger patients. Three cases, ages 50-70 years old that said they suffered from dialysis and didn't want to live this way. They understood the waiting list outlook was bleak for older patients waiting for a transplant. Therefore, they went to the mainland to look for transplants. Three cases were with transplant patients in Taiwan aged 21, 23 and 34 years old, all younger than 35 years old. For waiting lists with patients aged 50 and older, the opportunity to receive a kidney transplant is very small. At this time we should ask ourselves these questions: Is the quality of life takes precedence over the amount of life? Is it severity of illness a priority? Is the kidney organ registration and allocation system fair and ethical, such as systems using a placebo? Does being an older patient reduce the opportunity of receiving a transplant, and is it ethical? How to form a common consensus and improve the quality of life with these priorities must be addressed.

Key Words: The principles of renal distribution, waiting list, ethics

17 September 2011, Saturday

HALL 2
10:00 – 11:15

Parallel Sessions
BIOETHICS IN CONFLICTING ISSUES

Chair: **Ruud ter Meulen**

Francesca Bosisio, Marie Santiago, Lazare Benaroyo
The ethical principles versus the market logic: a Swiss-French
survey on incentives for organ donation

Chuan-Feng Wu
The right to health and healthcare, distributive justice

Bjørn Hofmann
On the anxiolytic use of diagnostic tests: two case studies

Anne Hambro Alnæs
Cultural competence: an ethical obligation for physicians exploring
possibilities of living kidney donation (LKD) in non-Western
immigrant populations

THE ETHICAL PRINCIPLES VERSUS THE MARKET LOGIC: A SWISS-FRENCH SURVEY ON INCENTIVES FOR ORGAN DONATION

Francesca Bosisio¹, Marie Santiago², Lazare Benaroyo³

¹ Interdisciplinary Ethics Unit (Ethos), Sciences-Society Interface, Health Psychology Research Centre (CerPSa), Institute of Psychology, University of Lausanne, Switzerland, E-mail: francesca.bosisio@unil.ch

² Health Psychology Research Centre (CerPSa), Institute of Psychology, University of Lausanne, Switzerland, E-mail: marie.santiago@unil.ch

³ Interdisciplinary Ethics Unit (Ethos), Sciences-Society Interface, University of Lausanne, Switzerland, E-mail: lazare.benaroyo@unil.ch

Presented at the Conference by: Francesca Bosisio

Abstract:

Background: Contemporary organ donation and transplantation social representations ensue from a socio-historic evolution that begin in the late 1960s and consolidated in the late 1980s. During these years, the key-discourses to beg organ donation to the next-of-kin turn from contributing to the development of the transplant medicine into the rhetoric of the gift. With the increasing of organ shortage in the late 1990s, several authors postulate that financial incentives would improve the organ donation rates. This line of argument was closely criticized arguing that organs cannot be considered the same way as a scarce resource.

Switzerland is often pointed out to have under-average organ donation rates compared to other European countries. Over the last few years, a growing pressure was put on the social stakeholders of transplantation to find solutions able to improve the number of available organs, in accordance with the ethical and legal framework.

Purpose and methods: In order to assess the opinion of people and anticipate the further academic debate, a broad quantitative survey about organ donation and transplantation social representations was carried out in the Vaud French-speaking Swiss Province. In this talk, we will present inhabitants' and physicians' opinions concerning direct, indirect and non-financial incentives. The main assumption is that the rhetoric of the gift, and its rear values, are core elements of the local organ donation and transplantation social representations.

Results: The data collected by this survey suggest that the Vaud French-speaking Swiss population is basically opposed to the reward of living and deceased organ donation. On the one hand, physicians consider unanimously that organ donation is a selfless act. On the other hand, inhabitants do not consider organs having a financial value. The analysis of positive answers reveals that indirect and non-financial incentives are considered the most appropriated to emphasize the act of one donating his organs. The analysis of the relation between the total gross annual household incomes and the reward option chosen suggests that people in critical financial situations are more vulnerable than people of others salary classes to direct financial incentives for

living and deceased organ donation. Both groups underestimate this risk.

Conclusion: Consistent with our initial assumption, gratuity and altruism are central values in organ donation and transplantation social representations of the Vaud French-speaking Swiss population. These data show that the commodification of body parts and the exploitation of the poor could be avoided by using indirect and non-financial incentives. Nevertheless, further studies are needed to evaluate if the introduction of this kind of reward would rather increase the organ donation rates or decrease voluntarism in the Vaud French-speaking province.

Key Words: Ethics, transplantation, financial incentives

THE RIGHT TO HEALTH AND HEALTHCARE DISTRIBUTIVE JUSTICE

Chuan-Feng Wu

Assistant Research Professor
Institutum Iurisprudentiae, Academia Sinica
128 Academia Road, Section 2, Taipei City 11529, Taiwan
E-mail: cfw@gate.sinica.edu.tw

Presented at the Conference by: Chuan-Feng Wu

Abstract:

Many international human rights documents and organizations have proposed that individuals have the right to maintain the "highest attainable standard" of physical, mental, and social health. However, when it comes to decision-making and priority-setting in healthcare policy, the right to health is often lost in a sea of other considerations. The ignorance is caused not only by scarce resources which prevent society from satisfying every citizen's healthcare needs, but also by the absence of theoretical accounts and justifications, and the vague limits of social responsibility to guarantee individuals' physical, mental, and social functioning. Therefore, this paper proposes that an applicable mechanism for addressing the scope of the right to health is the search for a political conception of healthcare distributive justice, which attempts to identify the relative significance of diverse healthcare need, and to resolve competing claims to healthcare and to other social goods. On the basis of John Rawls' theory of justice, assisted by Norman Daniels' just healthcare theory, this paper explores the relationship between the right to health and healthcare distributive justice, and argues that the society only has a "legal" (human rights) obligation to fulfill basic/fundamental healthcare needs, which are those that guarantee a minimum standard of health. This minimal health is defined on the basis of a functional definition - minimal health is that which is necessary to maintain individuals' moral powers (basic capabilities for the conception of the good and the sense of justice). It is important to require society to provide necessary institutional means to recover individuals' basic capabilities (minimal health) because these capabilities define individuals' essential capacities to function as rational, autonomous, and equal members of society. Individuals who fall below the required minimal health due to disease or disability can hardly obtain fair shares of the normal range of opportunity (meaning fair competition based on their merits) to pursue the good ends of life plans, to engage in mutually beneficial cooperation, and to honor fair terms. On the contrary, the society has only a "moral" obligation to progressively fulfill non-fundamental healthcare needs, because these needs are beyond the requirements of minimal health and are unnecessary to individuals' basic capabilities (moral powers). Based upon the minimum standard of health, this paper further provides a monitorable human rights impact assessment tool to evaluate whether regulations (or restrictions) imposed on the right to health are justified. The assessment includes four steps – (1) examining the human rights burdens that a proposed healthcare policy places on the right to health, (2) clarifying the healthcare policy's purpose, (3) evaluating the effectiveness of the healthcare policy, and (4) accessing

the trade-off relationship between the restricted right to health and the proposed public order in the healthcare policy.

Key Words: The right to health, distributive justice, minimum standard of health

ON THE ANXIOLYTIC USE OF DIAGNOSTIC TESTS: TWO CASE STUDIES

Bjørn Hofmann

¹ Center for Medical Ethics, University of Oslo,
E-Mail: b.m.hofmann@medisin.uio.no

² Section for Health, Technology, and Society, University College of Gjøvik,
E-Mail: bjoern.hofmann@hig.no

Presented at the Conference by: Bjørn Hofmann

Abstract:

There is an increasing use of diagnostic tests in the range from ordinary diagnostics to screening. There are many reasons why this happens. Increased patient autonomy and demands (1), expansion of health controls, vigorous technological development, fear of litigation, economic incentives, changes in indications, professional insecurity (2), and turf wars are but some of the explanations. One of the arguments for the extended use of diagnostic tests is their anxiolytic effects (3). Diagnostic tests are useful because they relieve people's fear of disease and alleviate their anxiety. However, do therapeutic effects of diagnostics tests justify their use? This is the key question of this paper, which uses diagnostic x-ray and first trimester ultrasound screening in prenatal diagnostics as case studies.

Hofmann B, Lysdahl KB. Moral principles and medical practice: the role of patient autonomy in the extensive use of radiological services. *Journal of Medical Ethics* 2008; 39: 446-449.

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Key Words: Futility, diagnostics

CULTURAL COMPETENCE: AN ETHICAL OBLIGATION FOR PHYSICIANS EXPLORING POSSIBILITIES OF LIVING KIDNEY DONATION (LKD) IN NON-WESTERN IMMIGRANT POPULATIONS

Dr.polit. Anne Hambro Alnæs

Center of Medical Ethics, Faculty of Medicine, Oslo University, Norway.
E-mail: ahambro@online.no

Presented at the Conference by: Anne Hambro Alnæs

Abstract:

The aim of this study is to uncover differences in attitudes and expectations towards kidney donation between health care professionals in Norway and migrant minority patients in need of renal replacement therapy. Whereas Norway's living donation rates are high (36 pmp), donations from migrants with non-Western background are reported to be low, the reasons for which remain insufficiently documented. Finding out about minority populations' arguments against living donation and organ donation in general is a pressing issue. For, according to demographic estimates the proportion of non-Western citizens will by 2060 increase from current 10% to between 21% and 31%. Do immigrants distrust the Norwegian health care system and believe that LKD is a way of cheating them out of a kidney from a deceased donor, to which they believe they have a right on a par with other health care services? At issue is whether Norwegian physicians working in an increasingly plural society, are ethically obliged to expand their communicative competence to include insight into culturally based different understandings about causes and effects of diseases. A more culturally sensitive approach might alert physicians about misunderstandings and clear the path for greater donor willingness among minority patients. A common cause for kidney failure, diabetes, is unevenly distributed in the population. An Oslo study (2005) investigating diabetes rates in a low socio-economic suburb, documented that 27.5% of women (aged 30-59) from South Asia were diabetic vs. 2.9% among Western women. For men the figures were 14.3% vs. 5.9%. On an overarching national level, patients' country of origin has until the present not been reported in official health statistics or entered into medical records. In June 2011 the Norwegian Council for Quality Improvement and Priority Setting in Health Care argued that lack of such information might result in patients of minority background not receiving appropriate health services. Method: anthropological fieldwork at three hospitals in Oslo, in depth conversations with potential donors/recipients prior to and after transplantation. Discussions with nephrologists, GPs, social workers, transplant coordinators and nurses. Material: two case studies selected from a convenience sample of 18 donor/recipient pairs, 5 GPs, 2 transplant coordinators and 6 nephrologists. Findings: Apparent linguistic fluency among supposedly well-integrated migrant minority patients masks pockets of incomprehension, misunderstandings and divergent expectations about LKD. Unforeseen cognitive and emotional obstacles against kidney donation may turn out to be modifiable if they are taken seriously and addressed, not dismissed as superstition based on ignorance.

17 September 2011, Saturday

HALL 3
10:00 – 11:15

Parallel Sessions
BIOETHICS AND BIOLAW

Chair: **Meral Özgüç**

**Lillian Lillemoen, Elisabeth Gjerberg, Reidar Pedersen,
Reidun Førde**

Informed consent and ethical challenges in nursing homes. The
experience and views of patients and next of kin

Şükran Sevimli

Child clinic and informed consent issue

Mukaddar Gün, Serap Şahinoğlu

Evaluation on embryonic stem cell researchs from the perspective
monotheistic religions

Mehmet Karataş, Özgür Karataş, Özgür Çevrim

Inönü Univ. School of physical education and sports school students
perceptions of the use of doping and ethics.

INFORMED CONSENT AND ETHICAL CHALLENGES IN NURSING HOMES. THE EXPERIENCE AND VIEWS OF PATIENTS AND NEXT OF KIN

**Lillian Lillemoen, Dr.polit, senior researcher,
Elisabeth Gjerberg, Dr.polit, senior researcher,
Reidar Pedersen, PhD, senior researcher,
Reidun Førde, PhD, professor**

Institutional Address for all authors is: Centre for Medical Ethics,
University of Oslo

E-mail: Lillian.lillemoen@medisin.uio.no

E-mail: Elisabeth.gjerberg@medisin.uio.no

E-mail: Reidar.pedersen@medisin.uio.no

E-mail: reidun.forde@medisin.uio.no

Presented at the Conference by: Lillian Lillemoen and Elisabeth Gjerberg

Abstract:

The European Biomedicine Convention emphasises the interest of the patient over the sole interest of society or science, appropriate information, the principle of informed consent, and substituted decision making for incapacitated patients. But how can such general principle be implemented in a good way in nursing homes?

Norwegian studies have recently demonstrated the prevalence and types of ethical challenges experienced by nursing home staff. Inadequate care due to lack of resources and breaches of the patient's autonomy and integrity were the most often reported ethical challenges. However, knowledge about nursing home patients' and their relatives' views on these questions is more limited.

The purpose of this study is to gain more knowledge on the experiences of nursing home patients and their relatives on information, decision making and other ethical challenges. For example, what is their experience with information sharing and participation in different kinds of decisions? Furthermore, are there similarities and difference in the views of patients and relatives on these issues?

38 patients, aged 68 to 97 years, in six nursing homes in three different counties were interviewed. Seven focus group interviews with the next of kin at the same nursing homes were carried out. The focus groups comprised 60 persons; all of them were relatives to patients who suffered from dementia or other kinds of cognitive impairments.

Most patients felt they were treated with respect, and had little to complain about. Practical issues, like meals and the possibility of variations in the provision of social activities seemed to be most important. Although they seldom complained about staff being too busy, most of them had a sort of resigned attitude to this. They were well aware of the scarcity of resources, and said that they could not expect the staff to use their limited time to talk with them beyond the necessary tasks.

The interviews demonstrated great variation in how much information the residents wanted about their health conditions. While the majority of residents were satisfied with the information and had deep confidence in the staff's ability to make the best decisions for them, some wanted full information and to participate in decision making.

Also most of the next of kin were satisfied with the nursing home, but some were concerned that the patients, due to scarce resources, lose their opportunity for a meaningful life. Neither patients, nor relatives had experienced that the nursing home had initiated preliminary conversations about the patient's preferences and participation in important ethical issues like hospitalization and end-of-life care. Most residents and relatives considered it to be acceptable to use persuasion, tricks and some coercion to provide the necessary health care to patients who are not competent to give consent and who resist receiving that kind of help.

The fact that the patients rarely seem to be asked about their views and preferences, combined with considerable variations in the residents' desire for information and participation in decision making represent considerable challenges to the nursing home staff.

Key Words: Ethical challenges, nursing homes, patient and relatives

CHILD CLINIC AND INFORMED CONSENT ISSUE

Assistant Professor Şükran Sevimli

100. Year University Medical Faculty Medical History and Ethics Dept. Van/Türkiye

E-mail: sukransevimli@gmail.com,

E-mail: mhistory.deontology.ssevimli@gmail.com

Presented at the Conference by: Şükran Sevimli

Abstract:

Objective: Children's clinics, the adequacy of informed consent as to whether our knowledge of the importance of children's size.

Design:The assistant general information about informed consent, with the fiction and experienced specialist doctors and faculty members after discussing the events were related course. Course re-evaluated after the scenarios now begin again with informed consent. Children of members of the university clinic and medical students were evaluated levels of awareness about the subject.

Result: 4 doctors (Pediatricians'), 1 internal medicine, 7 assistants' and 15 students participated. Participants did not know many details about informed consent and the question is decided. Participants, for example, the biological father, social father, and whether your account for details such as the legal father, not think or even say no.

Conclusion: Firstly, clinicians who should obtain consent for the treatment of children. Information to obtain informed consent in the context of the treatment team to identify issues. And then, these questions and information should be known by members of the treatment team. Some unwanted problems may occur if insufficient information to avoid any problems.

EVALUATION ON EMBRYONIC STEM CELL RESEARCHES FROM THE PERSPECTIVE MONOTHEISTIC RELIGIONS

Mukadder Gün ¹MSc, (RN), Serap Şahinoğlu ²MSc, PhD (MD, Assoc. Prof)

¹ Gülhane Military Medical Academy Department of Sports Medicine, Ankara, TURKEY

² Ankara University, Medical Faculty Department of Deontology, Ankara, TURKEY

Presented at the Conference by: Mukadder Gün

Abstract:

Since medicine has been changing rapidly, issues have changed accordingly. Research involving human embryonic stem cells promises the prospect of great medical benefit. The use of cloning to produce human embryonic stem cell (hESC) concerns not only researchers in health profession, but also philosophers, theologians, biologists, politicians and journalists.

This study deals with Islamic, Christian and Judaist doctrines and in view of three theologians' ideas about hESC researches in light of the principle of medical ethics. The other topics of discussion on hESC researches are not included in this review.

Reproductive cloning is banned by all monotheistic religions. Furthermore human life is valuable in Islam, Christianity and Judaism and it is necessary to respect life. An important point in this study is view on embryo's moral status in monotheistic religions. Creating embryos' for the aim of research is banned in Islam and Judaism. It is defended in this study that three celestial religions should be explained in a different manner about hESC research ethical debates.

Key Words: Embryo, religion, stem cell.

ETHICAL PERSPECTIVES OF STUDENTS TOWARDS THE USING DOPING AGENTS AT THE DEPARTMENT OF PHYSICAL EDUCATION AND SPORTS HIGHER SCHOOL

Mehmet Karataş¹, Özgür Karataş², Hakan Çevrim³

¹ Inonu University Faculty of Medicine, History of Medicine and Ethics Dept., Assist.Prof.Dr, E-mail: drkaratas@hotmail.com - mehmet.karatas@inonu.edu.tr

² Inonu University, Department of Health, Culture and Sport, Coach, E-mail: okaratas@inonu.edu.tr

³ Inonu University School of Physical Education and Sport, Coach, E-mail: hcevim@inonu.edu.tr

Presented at the Conference by: Mehmet Karataş

Abstract:

Sport organizations are supposed to be a competition among equals nevertheless dopings violate this equilibrium. The use of drugs to enhance performance in order to reach the undeserved success is considered unethical by the sport organizations. Using performance enhancing substances may have detrimental effects on the health of sportsmen. Moreover lifelong ban to attend the sportive organisations may be considered if the sportsmen are found to use doping agents.

In this study we evaluated the ethical perspective of the students by a structured questionnaire toward the use of doping agents at Inonu University Department Physical Education and Sport Higher School.

Key Words: Higher school student, doping, ethics.

17 September 2011, Saturday

HALL 4
10:00 – 11:15

Parallel Sessions
ETHICAL VALUES FOR CROSS-CULTURAL DIALOGUE

Chair: **Mine Şehiraltı**

Pamela Tozzo

Bioethical issues involved in disclosing misattributed paternity from different countries' perspectives

Tineke Abma

And they are all called Mohammed.” experiences of migrant students with the medical curriculum on cultural sensitivity

Marta Spranzi

The ethical position of interpreters in the medical encounter: neutrality and medical ethics

Liliane Elze Falcão Lins Kusterer

Bioethical issues and transcultural aspects from complementary and alternative medicine and popular medicine in Brazilian public health

BIOETHICAL ISSUES INVOLVED IN DISCLOSING MISATTRIBUTED PATERNITY FROM DIFFERENT COUNTRIES' PERSPECTIVES

Pamela Tozzo

Fellow at Legal Medicine of University of Padua, - Fondazione Lanza Padova, Italy

Presented at the Conference by: Pamela Tozzo

Abstract:

Misattributed paternity or false paternity is the condition in which it is assumed that a woman's partner is the biological father of a child but, in fact, he is not.

Nowadays, the frequency of misattributed paternity has increased to the extent that health-care professionals can sometimes discover cases of false paternity during their activity, in particular during genetic counselling for molecular genetic testing or pedigree analysis to reveal genetic disorders. In the field of consulting, information regarding the possibility to discover a misattributed paternity is not requested by families nor expected by them. The false paternity information, neither requested nor expected by the families in many cases, seems to regard only the "father" of the family, but in fact it has repercussions for the entire family. In contrast with other kind of medical information, which pertains primarily to individuals, information given by molecular genetic testing and/or pedigree analysis necessarily has implications for biologically related members of the family.

Disclosing or not a false paternity implies different situations for the subjects involved, both in biological and social matters. The ethical-deontological debate focuses on whether or not to inform the family about the necessity of a paternity test during the counselling and the counsellor's duty to reveal the results.

In this paper, starting from the experience of EACME visiting scholarship at Ethox Centre in Oxford, and considering the different perspectives and ethical arguments in the current ethical Literature, we will analyse the numerous cultural, ethical and legal dimensions involved in this field, comparing the Italian and the British contexts on medical professionals' position, particularly concerning the doctor's role in genetics counselling, in relation with bioethical directives. Considering that, these two National Health Services are similar but these two Countries have had different approaches to the Oviedo Convention of the Council of Europe (1997), from this point of view it will be interesting to consider if the Oviedo Convention articles regarding information to the person concerned (Art. 5 and 10), which underline the right to know all information of client's health and the healthcare professionals' duty to give this information, to the purpose and nature of the intervention as well as on its consequences and risks., can be seen as the beginning of a platform of dialogue to enrich the debate of such an issue.

Key Words: Genetic counselling, patient information, disclosing paternity

“AND THEY ARE ALL CALLED MOHAMMED.” EXPERIENCES OF MIGRANT STUDENTS WITH THE MEDICAL CURRICULUM ON CULTURAL SENSITIVITY

Tineke A. Abma

VU Medical Centre Dept Medical Humanities Amsterdam

E-mail: t.abma@vumc.nl

Presented at the Conference by: Tineke A. Abma

Abstract:

Background: Western European countries are increasingly becoming more diverse. Among other things this results in a more mixed student population of universities. At the VU medical centre (VUmc) in Amsterdam, The Netherlands, about 20% of the population has another ethnic, cultural and religious background. To prepare medical students for the future the VUmc aims to enhance the awareness and cultural sensitivity of the medical students. In the regular bachelor and master curriculum students are confronted with cases, instructions and textbooks on intercultural diversity.

Aim and method: The aim of our study was to explore how migrant students in the VU medical school experienced this program. We held 23 semi-structured interviews with migrant students with a diverse background. About half of them was Turkish, Moroccan or came from Suriname, the other half was from all over the world. For validation of our findings a focus group with 6 migrant students was organized. The data were collected and analyzed in collaboration with a biomedical student with a Chinese-Indonesian background.

Results: The main recurring issues included the stereotypic study cases presented, the lack of respect among students and teachers, and subtle processes of in- and exclusion. Students explained that study cases were exclusively fixed on Islam and extreme health and social problems (niece-cousin marriage, female mutilation etc). Many reported about classes in which prejudices were expressed without any critical discussion, and students felt too unsafe to speak up, resulting in painful silence. An intercultural conflict concerning bodily examinations among students as part of their training – female Muslim students did not want to male students to touch them - illustrated that teachers and students lacked the capacity to deal with such situations in an adequate, and creative way. The problem was related to culture and religion (Islam), while in fact many female students prefer to do such examinations with other females.

Conclusions: The campus climate was such that migrant students did not feel respected. Teachers acted as role models to re-establish dominant cultural norms and prejudices toward certain groups. Racial aggression, although often subtle, was part of the daily interactions. The school was shocked and has decided to act upon the findings.

Key Words: Medical school, racial aggression, stigmatization

THE ETHICAL POSITION OF INTERPRETERS IN THE MEDICAL ENCOUNTER: NEUTRALITY AND MEDICAL ETHICS

Marta Spranzi

Assistant professor of medical ethics
University of Versailles
CERSES (University of Paris Descartes)
E-mail: marta.spranzi@club.fr

Presented at the Conference by: Marta Spranzi

Abstract:

The role that an interpreter plays in the clinical encounter is at the same time crucial and sensitive (Bischoff et al., 2003). The right to informed consent is a cornerstone of clinical ethics. From that respect, as our societies become more and more inter-cultural, interpreters are bound to play an increasingly important role in healthcare facilities. The purpose of this paper is to discuss the different roles that a medical interpreter can be asked to play, and make a positive suggestion as to the proper ethical position that he/she has to assume in the clinical encounter. Community interpreters cannot be considered merely as translators of medical information. They have to ensure that a satisfactory process of communication can be maintained between patients and healthcare professionals. As a right to communication rightly replaces a right to information (Manson and O'Neill, 2005), interpreters have to make explicit information that often remains implicit. Recent advances in the domains of pragmatics and relevance theory have shown what a successful process of communication implies. This task is all the more difficult that the situations encountered in the medical domain are very often emotionally critical. A few examples will illustrate the complexity of the medical interpreters' job. Secondly, in order to fulfill their sensitive role, interpreters have to abide by an ethical code. Interpreters working in different cultural and national context do not perceive themselves as having the same role. They are portrayed in turn as cultural mediators, as patients' advocates, or as neutral go-betweens between the parties. Studies show that clients and interpreters alike may be uneasy about this multifarious role (Leanza, 2005). I would like to show that interpreters should not serve as mediators or as advocates. However, their ethical positioning should be conceived as "impartial" rather than "neutral": community interpreters in the medical domain cannot eschew engagement and ethical dilemmas of their own.

Bischoff, Alexander (et al.) (2003), « Language barriers between nurses and asylum seekers : their impact on symptom reporting and referral », *Social science and medicine*, 57, 503-512.

Leanza, Yvan (2005), « Roles of community interpreters in pediatrics as seen by interpreters, physicians and reserachers », *Interpreting*, vol. 7/2, 167-192.

O'Neal Onora, and Manson (2005), *Rethinking informed consent in bioethics* ? Cambridge University Press.

BIOETHICAL ISSUES AND transcultural ASPECTS FROM COMPLEMENTARY AND ALTERNATIVE MEDICINE AND POPULAR MEDICINE IN BRAZILIAN PUBLIC HEALTH

Liliane Elze Falcão Lins Kusterer

Titular professor

Biomorphology

Bioethics Pos-graduation in Medicine and Human Health

Escola Bahiana de Medicina e Saúde Pública- EBMSP

(School of Medicine and Public Health from Bahia). Rua Frei Henrique, n 8. Nazaré,
CEP 40050420. Salvador, Bahia, Brazil. E-mail: lilianelinskusterer@bahiana.edu.br

Presented at the Conference by: Liliane Elze Falcão Lins Kusterer

Abstract:

The paradigm of health care, in the Brazilian context, has been marked by biological and technical assistance. The incorporation of the biomedical model in medical education in 1968, the period of military dictatorship, resulted in expensive model of care focused on hospital activities and use of technology. Patients in this model lose their autonomy in health care and some of them are often excluded from treatment when not fit in biomedical diagnostic models.

Changes in this paradigm of health care occurred with the implementation of public health as a right of all Brazilian citizens in 1988. In 2004, a diagnosis was established on the use of Complementary and Alternative Medicine in the Brazilian states and in 2006, practices such as Thermalism, Acupuncture, Anthroposophic Medicine, Homeopathy and Fitotherapy were incorporated in the public health program through the National Policy on Integrative and Complementary Practices.

The aim of this work is to present a retrospective of the Brazilian health changes, their bioethics aspects in order to exploit the potential of Complementary Alternative Medicine in Brazilian Public Health Care and the role these practices when those are aggregated to biomedicine treatment on the pluralism of Brazilian culture. Also, the importance of cultural sensitivity by the health care team understanding the role of Brazilian popular practices, their bioethics and anthropological aspects, in the rescue of patient autonomy in health care will be addressed.

Key Words: Bioethics, complementary and alternative medicine, brazilian public health

17 September 2011, Saturday

HALL 1
11:30 – 12:45

Parallel Sessions
SOCIAL JUSTICE AND INEQUALITIES IN BIOETHICS

Chair: **Kris Dierickx**

Gülsüm Önal, Murat Civaner

What do patients complain about in Turkey: a retrospective study of patient rights units' documents

M. Volkan Kavas

Performance based payment in healthcare and loss of values: transformation from lettered physician to estranged technician

Erica Falkenstrom, Anna T. Hoglund, Jon Ohlsson

The role of emotions in the handling of ethical dilemmas

**Pietro Refolo, Roberta Minacori, Vincenza Mele,
Antonio G. Spagnolo**

Patient-reported outcomes (pros): the significance of using humanistic measures in clinical trial and clinical practice

WHAT DO PATIENTS COMPLAIN ABOUT IN TURKEY: A RETROSPECTIVE STUDY OF PATIENT RIGHTS UNITS' DOCUMENTS

Gülsüm Önal¹, Murat Civaner²

¹ Ministry of Health, Health Directorate of Istanbul City, Patient Rights Coordination Office / E-mail: gulsumonal@yahoo.com

² Uludag University School of Medicine, Dept. of Medical Ethics, Bursa, Turkey
E-mail: mcivaner@gmail.com

Presented at the Conference by: Murat Civaner

Abstract:

Although the legislations that could be related to some patient rights such as informed consent and confidentiality might be dated to early 20th century, the first legal regulation specific to patient rights in Turkey, named "The Patient Rights Regulation" was issued in 1998. Following the regulation, in 2003, Ministry of Health has established *Patient Rights Units* in state hospitals, in order to provide an opportunity for patient to complain about services. According to the standards of complaint evaluation, once received, a complaint is negotiated with patient and the healthcare worker in order to reach a common ground. If a settlement would not be possible, then the complaint is forwarded to patient rights committee of that healthcare institution. Every step beginning from the application is recorded throughout the complaint procedure. This data might be useful for understanding two dimensions of services provided: a) it is important to know if patients are aware and demand their rights, and b) evaluating the complaints may be useful to gain insight about the existing level of access and availability of healthcare services needed, and the implication degree of patient rights in daily services.

By taking into consideration the importance of the data mentioned, in this study, it was aimed to compile the complaint data from Istanbul, covering a seven years of period between 2004 and 2010. Data from Turkey in general was also used when available. The database consists of the age, gender, education level, occupation of plaintiffs, the unit and occupation of healthcare worker complained, the reason of complaints, and the end result of complaints. The first three reasons of complaints were "*problems related to accessing services needed*", "*not to be treated in a respectful manner*", and "*not to be informed appropriately*". As a preliminary result, it is possible to say that those three reasons compose roughly half of the complaints as a whole. We strongly believe that sharing the results in detail with the participants would enrich the discussion of the data, which is highly valuable regarding patients' priorities.

Acknowledgement: Data belonging to 2004 were presented as an oral presentation by the same authors, in an international congress in 2005, but have never been published (Önal G, Civaner M. *Patients demand their rights. Oral presentation. International Joint Bioethics Congress, Nov 14-18 2005, Şanlıurfa, Turkey*).

Key Words: Patient rights, medical ethics, health policy

PERFORMANCE BASED PAYMENT IN HEALTHCARE AND LOSS OF VALUES: TRANSFORMATION FROM LETTERED PHYSICIAN TO ESTRANGED TECHNICIAN

M. Volkan Kavas, MD, PHD

Ankara University, Faculty of Medicine, Department of History of Medicine and Ethics
E-mail: volkankavas@yahoo.com

Presented at the Conference by: M. Volkan Kavas

Abstract:

Is a cigarette factory worker responsible for the harmful effects to public health of the product which he contributes to the production of? Answer to this question cannot be given, unless how much this employee is able to carry out his autonomy as a moral agent is queried. This, in case, is directly related with the level of the person's *estrangement* towards his labor.

An example would be illustrative:

Let's say, this person, who works in that factory, has very little or no opportunity to seek and find another job; wages he earns are not more than the amount which barely allows him and other individuals in his family to go to work next day; income, which is the equivalent of products he produces in almost his entire working hours, is seized by his employer; and lastly, because of timelessness, ill health, deprivation of education facilities, and most basically, because he lives in vital difficulties, neither he has chances to improve himself nor conditions to get together with other people in similar situations for a common struggle. Apparently, a worker in such a situation has to sell his labor for very cheap and cannot worry about another matter. Therefore, he can neither interfere in determining his own working conditions nor have a voice about the production process as a whole. He cannot have a judgment on the social benefit (or harm) of a product which essentially does not correspond to anything in his life either. This worker is estranged towards his labor. This brings about him to be estranged to nearly everything he needs to realize himself.

In this example, the person's autonomy is heavily restricted or ignored. Thus, his completeness as a moral agent cannot be spoken of. On the other hand, it is not difficult to estimate that autonomy of a person working in opposite conditions from the situation exemplified above is protected, and therefore, he can be held responsible for the social benefit (or harm) of the product he produces.

When looked at the healthcare system which has been transformed in Turkey through the abstraction presented here, experience of value destruction and "estrangement" phenomenon accompanying it become obvious. As known, healthcare system in Turkey has been restructured with a plan called "Health Transformation Program". Being one important component of this program, performance based payment (performance system), has started to be implemented at universities after state hospitals. From the first moment it was brought to public

agenda, the system confronted social opposition. Currently, a great majority of healthcare professionals are deeply worried about the implementation of this system and professional bodies frequently make this issue subject to their criticisms.

Basically, performance system is based on rating number of patients seen, medical procedures done, and making a payment to healthcare professionals in proportion to the points they collect in a particular period.

Since the first moment of appearance in human history, physicians have been known as persons who perform their professions with respect to some particular values. Reliance between patient and physician, which is considered a must, and the idea that physicians would always want their patients' welfare are some examples to these values. Besides, physicians are also held responsible for the social outcomes of their practice. This is a pre-assumption of the same age as civilization and it assigns physicians with responsibilities such as thinking critically about and interfering in their own labor processes ("health" as a production outcome, working conditions, implementations related to healthcare either in micro or macro scales, etc.), following scientific knowledge, improving themselves, educating and pioneering people.

However today, performance system prevents physicians bearing these responsibilities. It makes them more estranged to their labor every day; forces them to undress the "lettered person" identity dedicated to them; and degrades them to the position of a technician who cannot be held responsible for her products just like the worker in the above example. Because of the performance system and other related implementations, physicians' loss of professional independence as a result of the fact that their life and work assurances have been under threat would mean that they become estranged towards the human being and her health, which is the most important part of their labor and that their autonomy is ignored as moral agents. Loss of values lying in the heart of medical profession can cause tragic results such as increased social health problems, and most importantly, corruption of social justice and safety.

In this study, how this system leads value loss and its results will be discussed.

Key Words: Performance, autonomy, estrangement

THE ROLE OF EMOTIONS IN THE HANDLING OF ETHICAL DILEMMAS

Erica Falkenström¹, Anna T. Höglund², Jon Ohlsson³

¹ Department of Education, Stockholm University, SE-106 91 Stockholm.
E-mail: erica.falkenstrom@edu.su.se

² Centre for Research Ethics and Bioethics (CRB), SE- 751 22 Uppsala.
E-mail: anna.hoglund@crb.uu.se

³ Department of Education, Stockholm University, SE-106 91 Stockholm.
E-mail: jon@edu.su.se

Presented at the Conference by: Erica Falkenström

Abstract:

Within ethics research it is well agreed upon that emotions can play a role in ethical decision making, in that emotions may signal that ethical values are at stake. Thereby they are primarily relevant in the phase of ethical awareness for the moral agent. However, less agreement is found concerning the function of emotions in the phase of ethical judgment and ethical behavior. Theoretically it is possible to distinguish emotions from affections and feelings. Affections can be defined as physiological reactions to a stimulus, e.g. fear. Feelings imply that a person has some level of awareness about the affections. Emotions, finally, may be regarded as cognitive value judgments.

The overall aim of this study is to explore what kind of ethical competence health care managers need in order to handle conflicts of interest and ethical dilemmas in their day-to-day work. A subsidiary aim is to investigate how such competence can be learned, developed and promoted in the health care organization. In this presentation the aim is to explore the role of emotions in the handling of ethical dilemmas. In order to study ethical competence in health care management, we investigate how managers deal with conflicts of interest; for instance when managers try to reach political and economical goals and these come into conflict with professional goals and patient safety. Qualitative, semi-structured interviews were carried out twice with 10 health care managers in the Stockholm region. The results were categorized and analyzed using a thematic, step-wise method.

Through the analysis, several examples of how managers perceive, understand and use their emotions in the perception of ethical dilemmas were displayed. For example, when realizing a group of patients were forgotten, shame was found to be an important reaction. Also anger and fear were found to play a role in the identifying of conflicts of interest in the managers' daily work. However, some informants also expressed that they needed to contain emotions, such as anger or shame, in order to make use of them in the handling of ethical dilemmas. If emotions are carefully reflected upon they can sharpen the ethical judgment, according to the informants. The analysis showed that the informants made use of emotions in the identifying of conflicts of interest in their work. However, they also expressed the need for cognitive judgment of their emotions. In order to act in an ethically responsible way the

managers need to be aware of their emotions, as well as reflect upon them. They also need to understand and integrate their emotions into sensible communication. Otherwise, the managers can be led astray, for example by his or her immediate physiological affections, denying adequate emotions, and thereby make unethical decisions. Hence, emotions may be of importance, not only in the identification of conflicts of interest, but also in ethical judgment and the handling of ethical dilemmas.

Key Words: Ethical competence, emotions, health care management

PATIENT-REPORTED OUTCOMES (PROS): THE SIGNIFICANCE OF USING HUMANISTIC MEASURES IN CLINICAL TRIAL AND CLINICAL PRACTICE

Pietro Refolo, Roberta Minacori, Vincenza Mele, Antonio G. Spagnolo

Institute of Bioethics (Director: Prof. Antonio G. Spagnolo), “Agostino Gemelli”
School of Medicine, Università Cattolica del Sacro Cuore, L.go Francesco Vito,
1 - 00168 Rome, Italy

E-mail: pietro.refolo@rm.unicatt.it

E-mail: rminacori@rm.unicatt.it

E-mail: vmele@rm.unicatt.it

E-mail: agspagnolo@rm.unicatt.it

Presented at the Conference by: Pietro Refolo

Abstract:

Patient-reported outcome (PRO) is an “umbrella term” that covers a whole range of potential types of measurement but is used specifically to refer to all measures quantifying the state of health through the evaluation of outcomes reported by the patient himself.

PROs are increasingly seen as complementary to biomedical measures and they are being incorporated more frequently into clinical trials and clinical practice.

After considering the cultural background of PROs – that is the well known patient-centered model of medicine –, their historical profile (since 1914, the year of the first outcome measure) and typologies, the paper aims at debating their methodological complexity and implementation into practice. Some clinical trials and therapeutic managements utilizing patient-centered measures will be also analyzed.

Key Words: Patient-reported outcome, trial, therapeutic management

17 September 2011, Saturday

HALL 2
11:30 – 12:45

Parallel Sessions
BIOETHICS AND NEW MEDICAL TECHNOLOGIES

Chair: **Funda Gülay Kadioğlu**

Ayşe Yüzbaşıoğlu, Meral Özgüç
Biobank for Rare, Disorders and Some Bioethical Reflections

Luciana Caenazzo, Renzo Pegoraro
Forensic DNA database in Europe: some ethical issues

Gönül Peker
Neuroethics: what, why, how, where & for whom

Atilla Özgür, Savaş Volkan Genç
Productive robots or life partners?

BIOBANK FOR RARE DISORDERS AND SOME BIOETHICAL REFLECTIONS

Ayşe Yüzbaşıoğlu¹, Meral Özgüç²

¹ Hacettepe University, Faculty of Medicine, Department of Medical Biology and DNA/Cell Bank, Ankara, Turkey, E-mail: ayuzbasi@hacettepe.edu.tr

² Hacettepe University, Faculty of Medicine, Department of Medical Biology and DNA/Cell Bank, Ankara, Turkey, E-mail: mozguc@hacettepe.edu.tr

Presented at the Conference by: Meral Özgüç

Abstract:

Biobanks are valuable infrastuctures in biomedical research where improving diagnosis and therapy of human diseases will always remain an unquestinable priority. In this presentation we want to introduce some bioethical reflections that come up in this practice and will draw attention to specific issues that we have encountered in our own experience.

Hacettepe Biobank for rare disorders was established in 1995 through a grant from TTGV (Technology Development Fund of Turkey). A major fraction of rare disorders are of genetic origin and due to high consanguinity in the Turkish population, the incidence of autosomal recessive genetic diseases are higher than in western Europe . Through the establishment of a biobank we could collect and create a repository of biological samples of high quality such as cells, DNA, RNA for research that could culminate in isolation of new phenotypes and genes so that health care applications such as genetic tests could be developed.

Since currently there are no bylaws in the national legal system that governs biobanks we needed to establish our own guidelines at three tiers that need to be taken into consideration for ethical review:

Collection - clinics, use - researchers, handling - administrator.

At these steps, basic ethical considerations such as privacy and confidentiality of the patients as well as collaborations such as over the border use of samples needed to be taken into account so that basic human rights could be respected along with ability to conduct research for the benefit of the patients.

Key Words: Rare disorders, biobank, ethical considerations

FORENSIC DNA DATABASE IN EUROPE: SOME ETHICAL ISSUES

Luciana Caenazzo¹, Renzo Pegoraro²

¹Department of Environmental Medicine and Public Health, Legal Medicine Unit, University of Padova, Via Falloppio 50, 35121, Padua (Italy) – Fondazione Lanza
E-mail: luciana.caenazzo@unipd.it

²Fondazione Lanza, Via Dante 55, 35139 Padua (Italy)

Presented at the Conference by: Luciana Caenazzo

Abstract:

Advances in DNA technology and the discovery of DNA polymorphisms have facilitated the creation of DNA databases of individuals for the purpose of criminal investigation. Therefore, a considerable range of possibilities have been opened up for criminal investigations, and if we compare the DNA profiles of biological evidence found at the crime scene, with the DNA profiles in the database, we can identify the possible perpetrator of the crime. Logically, as the number of citizens whose DNA has been analysed and included in a database increases, the probability of locating suspects also becomes greater. It became obvious that the value of a DNA database is directly related to the number of records that it contains. Depending on legislation in the country, samples and profiles may be stored permanently or for a limited time, routinely searched for matches with crime scene samples and used for familial searching. Some European countries have just legislated, or are drafting laws, with the aim of regulating databases for criminal purposes, with appropriate laws.

The reason for the different regulations surrounding a biobank designed for medical research and a biobank designed for forensic investigation is that there are, obviously, different purposes in the balance between individual rights and social interests. Forensic DNA databases can be useful in criminal investigations to identify socially dangerous individuals. However, it is important to ensure that the application of Forensic DNA databases does not contrast with individual civil rights and society liberties. Although the laws that regulate the institution of forensic DNA databases in the EU are basically similar, the Member States can still make different choices regarding the management of their national forensic DNA database. Not all of these choices are at the same time also ethical choices.

In our paper we will consider some issues of forensic DNA database management that imply specific ethical challenges and demand explicit policy choices regarding:

- the collection of the DNA samples and the question of the informed consent related to the fact that taking biological samples from persons' bodies for criminal investigation purpose can be considered as a violation of one's privacy;
- minor's profiles inclusion in forensic DNA database, considering that this category is usually regarded as a vulnerable group;
- the entry and removal criteria of the DNA profiles for the fact that almost every European database has installed its own entry and removal

criteria with provision regarding storage of suspects' profiles in the database or not; - problems related to sample retention that is considered one of the most problematic topics in forensic DNA databasing; - database access: it is important to distinguish between who has access to the database and what information they have access to. Finally, we will try to better define the role and involvement of professional healthcare in the activities related with DNA forensic database.

Key Words: Forensic biobanks, social justice, ethical issues

NEUROETHICS: WHAT, WHY, HOW, WHERE & FOR WHOM A SMALL SCALE SURVEY OF PRELIMINARY AWARENESS AND INTEREST IN A MEDICS DOMINEERING POPULATION

Gönül Ö. Peker^{1,2,3}, Egemen Kaya¹, Tunç Taşbaş¹

¹ Ege University Faculty of Medicine, Dept. of Physiology, Izmir, Turkey

² Headquarters of the Neuroscience Society of Turkey (NST=TÜBAS)

³ Turkey Chapter of Society for Neuroscience

E-mail: gonul.peker@ege.edu.tr

Presented at the Conference by: Gönül Ö. Peker

Abstract:

Introduction & Objective:

Brain is highly unique among all other organs and systems because it is capable of designing and programming the individual and the community as well as learning, ruling, creating, terminating, and questioning itself. Eventually, it has recently become inevitable to launch novel areas of reasoning, debating and researching such as neurophilosophy, neuroethics, and neuroeconomy. Neuroethics has been striving to define and flourish to become a social blueprint guideline resource and an academic discipline by itself. It engages basic and clinical neuroscientists, and behavior, philosophy, ethics, cognition, education, law, public governing, and informatics professionals and scholars.

Neuroethics exists primarily to defend and protect the “other brains and individuals” from the intentional and unintentional harm of those brains who are creators and users of science and technology. All drugs, surgical and other interventions targeting brain and behavior, all approaches and methods monitoring and affecting brain activities and behavior may turn out to be potential threats and abuse exerted by the individual him/her –self or the others. Such instances may very likely to emerge extensively and intensively varying from a setting of a disaster to intensive care wards, jural courts, schools, battle fronts, and even to questioning and inspection of individuals for security purposes. Prescription and use of stimulants and narcotics, memory and affect enhancers and erasers that are being strongly debated in terms of “indication” may bear negative outcomes such as substance addiction, failure of will and reasoning, poor control of temper, and all drives violating fair play and equity in accessing opportunity stand as the major problematic of neuroethics in this context. Moreover, concepts and procedures like brain imaging, lie detectors, free will, and debatable states of consciousness cast the primary subjects of neuroethics especially in case of jurisdiction for penalty. Since 2003, we have included “Meet the Neuroethics” into the Ege Medical Faculty 2nd year curriculum within the context of the Neuroscience Block. We intended to attract early attention and hook the junior students from the beginning. We plan to extend this course further in continuum to advanced levels. Additionally, as TÜBAS and SfN-Turkey we have always organized plenary lectures, panel discussions, and brief interviews about neuroethics in our national annual neuroscience meetings and graduate workshops and courses.

In this presentation, we aim to review neuroethics concisely, and share with you the findings of our preliminary survey conducted primarily among the medical academia and students within a small population (n=72 returning out of 115).

Population & Instrument:

This questionnaire intended to target a body with almost no knowledge of neuroethics, and detect the spontaneous immediate associations relevant to neuroethics and similar concepts by using 13 well structured MCQs and 1 open end question.

Results & Conclusion:

The results of our survey exceeded our expectations by revealing a significant level of sensitivity, familiarity, even awareness, and - more importantly – a very strong motivation and anticipation for further enlightening regarding neuroethics.

Key Words: Neuroethics, neurophilosophy, neuropsychopharmacology, brain imaging, free will, lie detector

PRODUCTIVE ROBOTS OR LIFE PARTNERS?

Atilla Özgür¹, Savaş Volkan Genç²

¹Assistant Professor, Ankara University, Faculty of Veterinary, Department of Veterinary History and Deontology

²PhD. Research Assistant, Mehmet Akif Ersoy University, Faculty of Veterinary, Department of Veterinary History and Deontology & svgenc@yahoo.com

Presented at the Conference by: Atilla Özgür

Abstract:

In a utilitarian perspective, it is impossible to convince people to give up the use of animals. Since human beings are at the center till the beginning of history, animals have lost their independence a long time ago. In human-animal relationship in this manner, it is not surprising to see the animals as commodity. Most of the time humans must use the animals for food, clothing, labor and research.

The terms used in animal production describes the terms for animals as in mechanical production. Thus; the concern for animal prosperity begins at this point. There is a general acceptance of the nonsupportive attitude of public for the farm animals' prosperity as if it differs individually and publicly.

Besides the economical values of the basic procedures for livestock breeding, the argument for animal prosperity also rises. A reasonable quality of life measures for animals, bred for food, should be taken at a market-based approach.

Precision in ecological establishment of livestock production and the practices for animal prosperity puts the producers against some difficulties. The consumer's benefit and the ethical attitude in production will have an effect in production costs, which also should be kept in mind.

Nowadays, people's expectations are not only cheap food with high nutritional value, but also healthy and safe, regional, traditional, locally produced food, organic products, animal prosperity, sustainable agriculture, protection of rural resources and the environment.

The increasing interest in animal life brought the legal arrangements made along with research on animal wellbeing as a matter of scientific debate. Modern scientific applications used in production systems are not only tools to increase efficiency per animal, but also to increase animal prosperity. Unfortunately, use of scientific applications in sustainable production and animal prosperity is progressing slowly. Animal welfare policy should be included in political decisions to examine the role of ethics and science. Many theorists support the non-human animals' moral rights and privilege. Philosophical debates, religious influences and differences in opinion are the primers of bioethical debate. While replacing the existing structure of food production for various reasons (demand, taking responsibility for market regulation, etc.) the society approach should also be discussed.

Throughout human history, the animals, the source for even intellectual products, should be protected carefully as resource, cultural, biological and ecological elements of wealth. Animal prosperity protection and respect for animal welfare either accepted sincerely, or as a way of salvation of mankind, will bring the acceptance of sanctity and beauty of life.

Many people focus on treating animals properly, try to develop and evaluate their understanding on issues related to animal rights. Hastily made decisions by politicians and scientists on scientific evaluation and validation about the welfare of farm animals may lead unexpected results. These decisions' effects on animals, producers, and all related individuals and on food prices should be taken into account.

Key Words: Animal, productive, ecology

17 September 2011, Saturday

HALL 3
11:30 – 12:45

Parallel Sessions
BIOETHICS AND NEW MEDICAL TECHNOLOGIES

Chair: **Anne Hambro Alnæs**

Alexander McKeown

Controlling human enhancement technologies: the need for a
heuristic approach

Karsten Klint Jensen

Is there anything special about gene therapy?

Sinan Fındık, Tuna Çakar, Yeşim Işıl Ülman

Ethical concerns about neuromarketing

Linus Vanlaere, Trees Coucke

High technology in the realm of health care: a care- ethical appraisal

CONTROLLING HUMAN ENHANCEMENT TECHNOLOGIES: THE NEED FOR A HEURISTIC APPROACH'

Alexander McKeown

University of Bristol Centre for Ethics in Medicine School of Social Medicine
Canynge Hall 39 Whatley Road Bristol BS8 2BS United Kingdom

Presented at the Conference by: Alexander McKeown

Abstract:

The possibility of enhancing human biological, physiological and cognitive capabilities using medical biotechnologies is growing. From temporary cognitive enhancers to germline genetic engineering, new means of enhancement are likely to become increasingly commonplace over coming decades. Whilst we can be sure of demand for enhancement technologies, there is little evidence for exactly what their developmental path will be, or how they will shape the choices and lives of future individuals and societies. These uncertainties have generated many arguments against enhancement that are trenchantly ideological and logically purist in form.

I contend that this is the wrong response to the socio-technological challenges, and that we should adopt a heuristic approach to regulating enhancement technologies, rather than making absolutist claims about their moral unacceptability. I give two reasons for this – one meta-ethical, one procedural – and show that we can justify this approach in spite of the limitations inherent to all principlist frameworks. I will demonstrate that the persistence of the meta-ethical problem (the treatment / enhancement dilemma) undermines pure logical arguments purporting to show that the use of new forms of biomedical enhancement would be inherently unethical, and show how this justifies taking a pragmatic rather than a restrictive approach to their regulation.

I will also make some more general remarks about the advantages of heuristic approaches to bioethical debates. I aim to refute some of the specious claims that have been made about the limitations of principlist ethical frameworks. I will show that it is false to claim, as some have done, that principlist approaches are too simplistic for satisfactory moral reasoning or lead to a 'watering down' of moral positions. I contend that the form of argumentation I recommend, (i.e. the kind already already embedded in legal reasoning), is equal in sophistication and subtlety to more metaphysical forms of analysis.

Finally, I will show how my argument demonstrates a duty on governments and policy makers to engage with the ethical challenges of enhancement technologies, rather than seeking to outlaw them outright. I will strengthen this by exploiting a weakness in the argument that we should not allow enhancement because we do not know what will happen. Given that it is true we do not know what will happen, and enhancement aims at improvement, it is equally possible that it could, if properly governed, produce sufficient utilitarian goods for it to be socially desirable that we regulate and control its distribution rather than ban it.

It would be undesirable for enhancement technologies to be used beneath the legislative radar, as safety could not be guaranteed and there would be no mechanism for ensuring any degree of distributive justice. In view of this I will conclude by explaining how the regulation rather than prohibition of enhancement technologies is at least the lesser of two evils, and at best may produce enough personal and societal benefits to justify governments engaging in the processes of legal control that would allow these benefits to reach people in an as equitable way as possible.

IS THERE ANYTHING SPECIAL ABOUT GENE THERAPY?

Karsten Klint Jensen

University of Copenhagen, E-mail: kkje@life.ku.dk

Presented at the Conference by: Karsten Klint Jensen

Abstract:

When the possibility of gene therapy was introduced around 1990, the ethical discussion tended to concentrate on the prospect of germ line therapy. Theoretically, it should represent a highly efficient therapy for genetic diseases; however, the ethical complexities surrounding genetic engineering on humans, even though the technical difficulties have diminished over the years, still keep many countries, at least for the time being, prohibiting germ line gene therapy on humans. In comparison, somatic gene therapy has lived a far more quiet life from the point of view of ethical attention.

The research has been allowed to proceed under strict supervision, and gradually, several hundred clinical trials have been initiated comprising selected diseases within a variety of categories (cancer, immunodeficiencies, retinal degeneration, neurological diseases etc.).

Legally, gene therapy is *defined* as special in the sense that, apart from being regulated by the directives and guidelines for clinical trials and authorization of medical products in general, it is also regulated by the directives on contained use of genetically modified organisms and on deliberate release of genetically modified organisms to the environment.

This reflects that what is special about gene therapy are the relatively large uncertainties that have surrounded it from the outset, both concerning clinical practice (efficiency and risks for the patients) and concerning unintended effects on third parties or the environment at large.

However, at some stage in the future, a number of these uncertainties are likely to be reduced, and it has to be decided whether the risk is acceptable and the efficiency sufficient to allow at least some forms of gene therapy to enter clinical practice. This paper makes the thought experiment of asking, based on the current state of the art, whether gene therapy in clinical practice still would involve a special uncertainty for the patients.

I shall use the preliminary results from research in gene therapy for retinal degeneration to contrast with the results from gene therapy for X-SCID. Since these results all stem from phase one trials, the risk-benefit balance may be better than what the results indicate.

Comparing the two cases of X-SCID and Leber's congenital amaurosis reveals large differences due to the fact that in the first case, the alternative may be early death and gene therapy offers the prospect of prolonging life as well as increasing quality of life; whereas in the second case, the alternative is not life threatening and gene therapy only offers the prospect of increasing quality of life. This is confirmed both by using Quality Adjusted Life Years and a time-relative measurement of risks and benefits.

Hence, the hypothetical perspective from the patient's point of view seems to be determined much more by the alternative to gene therapy than by the fact that both cases are common in involving gene therapy. There seems to be nothing special about gene therapy itself in this regard. What is special about gene therapy therefore seems to be located in its possible adverse consequences for third parties and the environment.

Key Words: Risk-benefit analysis, clinical trial

ETHICAL CONCERNS OF NEUROMARKETING

"I consume therefore I exist!"

Sinan Fındık¹, Tuna Çakar², Yeşim Işıl Ülman³

¹ Instructor, Acibadem University, Vocational School of Health Services, Maltepe - ISTANBUL, E-mail: sinan.findik@acibadem.edu.tr

² PhD. Candidate, Middle East Technical University, Informatics Institute, Cognitive Science Program, Çankaya Ankara, E-mail: cakar.tuna@gmail.com

³ PhD., Assoc. Prof., Acibadem University, School of Medicine, Department of History of Medicine and Ethics, Maltepe - ISTANBUL, E-mail: yesimul@yahoo.com

Presented at the Conference by: Sinan Fındık

Abstract:

This study aims to investigate the ethical consideration of neuromarketing. Neuroethics, as a subbranch of ethics, is basically concerned with the ethical reasoning in moral decisions. It searches the correlation between the neuroscience and bioethics and focuses on the use of ethical concerns in the neuroscientific researches and trials. Neuromarketing which is a practical field to make use of neurotechnologies in marketing practice is increasingly becoming the target of public attention and ethical concern. We will deal with ethical implications of neuromarketing by remarking that **the human being is not to be regarded as a mere consumer**, by giving emphasis to the primacy and dignity of human being.

Neuromarketing has attracted much attention especially by the companies since it has been assumed as a good agent to understand the customers' preferences and decision making strategies among alternatives, together with its potential uses like manipulating consumers' behaviors and preferences. It is claimed that, neuroimaging tools, having the ability to reach the "inner sanctum of private thought", can be used as a good predictor of human behavior instead of traditional questionnaires (Murphy *et al.*, 2008). This information provides with the degree of influence of the products' exhibition over customers' preferences, and it can be captured by using the biomedical devices like fMRI, EEG and eye-tracking devices. There have been plenty of studies that try to portray the significance of research in neuromarketing to determine the customer's attention. Our prior concern is questioning the reliability and validity of these trials and experiments by attracting attention to the "customer standpoint" of companies which can possibly be the underlying reason for such an interest and manipulation.

Murphy and his colleagues (2008) have suggested providing with a code of ethics for both academicians and companies by which they could ensure the non-harmful use of this technology. We argue that there are much more work to be done in order to prevent the harmful uses of this technology that convey a potential threat to the primacy and dignity of human existence. We emphasize the role of independently working research ethics committees which are devoted to the scientific and ethical review of the neuromarketing experiments. They would have a significant function

to set the standards for marketing trials before they are initiated. One necessity can be the transparency of the research findings. In other words, both scientific and ethical revision and public access to the research findings should be ensured owing to the independently functioning research ethics committees. The other crucial issue is how the manipulation of the participants from the vulnerable groups like children can be prevented.

In this study, we have tried to provide a perspective about the neuromarketing “research” as well as to point out the potential risks of this technology that may infringe the right to self-determination and vulnerability of man. We advocate that underlying values of dignity and integrity of the individual must always take precedence enhanced with the ethical principles and rules of nonmaleficence, beneficence, autonomy, confidentiality and privacy over the marketing forces which expose the peril of regarding man as a mere consumer. We also remark that vulnerable groups deserve additional care for protection against commercialization and manipulation profiting from the new emerging technologies.

Key Words: Ethics, neuroscience, neuroimaging technologies, neuromarketing, human dignity

HIGH TECHNOLOGY IN THE REALM OF HEALTH CARE: A CARE-ETHICAL APPRAISAL

Linus Vanlaere¹, Trees Coucke²

¹Centre for Biomedical Ethics and Law, KULeuven, Kapucijnenvoer 35, 3000 Leuven, Belgium, E-mail: Linus.Vanlaere@med.kuleuven.be

²sTimul: care-ethics lab, Sint-Maartensplein 13, 8560 Moorsele, Belgium, E-mail: Trees.Coucke@stimul.be

Presented at the Conference by: Linus Vanlaere

Abstract:

IBM is retrofitting Watson, the computer that defeated humanity's finest Jeopardy players in February 2011, to help doctors diagnose and treat patients. Watson could possibly turn into a doctor's assistant and could efficiently analyze a patient's medical history in order to suggest the most appropriate option. The robot Cody is another example of a new application of high technology into the realm of health care and medicine. Cody is the prototype of a robot with a compliant arm to perform wiping motions that are involved in bed baths. Experiments to evaluate the performance of Cody by measuring the ability of the robot to remove an area of debris on human skin showed a good result: the robot removed most of the debris. But what are the ethical issues that might arise in human-computer or human-robot companionship relations?

In a care-ethics perspective, other issues than cost-efficiency and quality of care come into the picture. Care ethics remains closely related to real care practices and examines the way(s) in which care responsibility takes shape: the contextual elements, the way people feel involved, the way emotions are involved. Fundamental to care ethics is the concept of empathy. Empathy as the capability of adapting to human vulnerability, is fundamental in the care relation in health care. The degree in which the computer or the robot is capable to mirror empathy is central in a care-ethical evaluation.

In this workshop, we want to focus to the concept of empathy. We make a distinction between different dimensions of empathy: an affective, a cognitive and a behavioural dimension. Out of these three dimensions of empathy, we look to human-computer or human-robot companionship relations. The contemporary technologies are ethically evaluated and care-ethical questions are raised. The statement is made that if we want to introduce high technology into the realm of health care and medicine, these questions need to be answered.

KEY WORDS: Care ethics, high technology, empathy

17 September 2011, Saturday

HALL 4
11:30 – 12:45

Parallel Sessions
BIOETHICS IN CONFLICTING ISSUES

Chair: **Serap Şahinoğlu**

Aimi Yusof

Is variation in research ethics committees' decisions acceptable?

Arianna Ferrari, Christopher Coenen

The challenges of technological visions for the bioethical discourse:
the case of cognitive enhancement

Anton A. van Niekerk

Deliberating about race as variable in biomedical research

Boleslav Lichterman, Leonid Likhterman

Ethical dilemmas in neurosurgery

IS VARIATION IN RESEARCH ETHICS COMMITTEES' DECISIONS ACCEPTABLE?

Aimi Yusof

The Ethox Centre, Department of Public Health, University of Oxford, Badenoch Building, Old Road Campus, Oxford, OX3 7LF.
E-mail: aimi.yusof@st-hildas.ox.ac.uk

Presented at the Conference by: Aimi Yusof

Abstract:

Some have suggested that variations pose a threat to the integrity of Research Ethics Committees (RECs) and studies have shown variations do exist among different RECs. These differences occur among RECs because they do not conform to one uniform guideline or constitution and creates a problem when these differences involve value judgement over which decisions are considered ethical. Despite the reality of variations, further arguments are needed on why variations are seen as a problem. Many are against variations in decision making because the possible consequences of negative outcomes namely; a hindrance to new research, game playing with researchers being able to choose their favourite RECs and unfair treatment to researchers. However, variations in decision making may not necessarily cause these problems. Variations are criticised because of the misconception of what it entails. The question is not solely on satisfying researchers. If variations in decision making do provide problems to the research world, then it is deemed unacceptable. However, if variations do not actually pose threat to research, then it is acceptable as long as research could progress ethically. Therefore, this paper aims to address the question by investigating the problem with variations, especially if there really is a problem with variations as claimed.

Key Words: Research ethics committees, variations

THE CHALLENGES OF TECHNOLOGICAL VISIONS FOR THE BIOETHICAL DISCOURSE: THE CASE OF COGNITIVE ENHANCEMENT

Arianna Ferrari¹, Christopher Coenen²

¹KIT/ITAS (Karlsruhe Institute of Technology/Institute for Technology Assessment and Systems Analysis), Germany, E-mail: arianna.ferrari@kit.edu

²KIT/ITAS (Karlsruhe Institute of Technology/Institute for Technology Assessment and Systems Analysis), Germany, E-mail: christopher.coenen@kit.edu

Presented at the Conference by: Arianna Ferrari

Abstract:

Main goal of this presentation is to challenge the (bio)ethical discourse on cognitive enhancement and to investigate whether we need a different ethical analysis when we are discussing technological visions and not yet existing and well-established technologies. With the help of the analysis of empirical data, both concerning the social relevance of cognitive enhancement technologies and the scientific evidence on these technologies (state-of-the-art), it will be shown how consistent parts of the ethical discourse of cognitive enhancement contribute to constructing the phenomena as if they were urgent issues in need of an open, public discussion and an appropriate regulation. In this way, the mainstream (bio)ethical discourse presents ethical issues emerging from cognitive enhancement as traditional problems of applied ethics, while engaging at the same time in speculative ethics. After having shown pitfalls of speculation for (bio)ethics, it will be argued that a place for ethical reflection on the future is still possible, on the condition that a different ethical analysis is provided.

Key Words: Ethics, visions, cognitive enhancement

DELIBERATING ABOUT RACE AS VARIABLE IN BIOMEDICAL RESEARCH

Anton A van Niekerk

Centre for Applied Ethics, Philosophy Department, Stellenbosch University,
South Africa
E-mail: aavn@sun.ac.za

Presented at the Conference by: Prof. Anton A van Niekerk

Abstract:

This paper investigates the issue of race as a variable in research ethics: to what extent is it morally appropriate to regard the race of research subjects as a relevant factor for research outcomes? The author analyses the challenges posed to deliberation in Institutional Review Boards (IRB's) on this matter. The first part of the paper consists of a conceptual analysis of the notion of deliberation, drawing on the work of Elster, Habermas, Rawls, Gambetta and others. Special attention is paid to the dialogical structure of deliberation. The complexities attached to the notion of race, as a social construct, are also carefully analysed. Arguments in favour and against the proposal that race is a valid variable in biomedical research are systematically distinguished. The author comes to the conclusion, based on an extensive literature, that race sometimes has to be taken into consideration, subject to clearly stated qualifications. These qualifications include the following:

1. The IRB should demand that the protocol provides a very careful cost-benefit analysis of the consideration of race as a factor in the selection of the study group. The central issue is indeed, as stated in an article by Burchard et al, whether, in spite of the "potential social costs associated with linking race or ethnic background with genetics,... these potential costs are outweighed by the benefits in terms of diagnosis and research".
2. It is quite important to establish how pivotal a factor race is, in comparison to a variety of other factors that could also be considered in terms of sample or group selection. Is race really an inherent characteristic that sample members should share, or is it of secondary importance? Is race not possibly like, for example, the side of the city on which people live, a marker for differential experiences and exposures rather than a factor inherent to the person?
3. Is race duly identified as a marker and have all other possible variables been taken into account? According to an article by Caufield, other possible variables include "socio-economic status, social class, personal or family wealth, environmental exposures, insurance status, age, diet and nutrition, health beliefs and practices, education level, language spoken, religion, tribal affiliation and country of birth."
4. Are the names assigned to groups, names that are acceptable to the groups themselves?

Finally, it will be argued that deliberation, especially about such a controversial notion such as race, is not only an arduous process, but will probably for the foreseeable future remain inconclusive. We are expecting too much of this process if we expect it to yield definitive truths. The most we can expect is a series of (hopefully) progressive settlements that represent provisional beacons of insight on which we can draw in future conversations. Race will not easily be an issue that we can settle and forget about in future; it represents a field of tension and contestation that will inevitably continue to permeate interpersonal contact and social relations for the foreseeable future.

Key Words: Race, Deliberation, Biomedical Research

ETHICAL DILEMMAS IN NEUROSURGERY

Boleslav Lichterman· Leonid Likhterman

The Burdenko Neurosurgery Institute, Moscow, Russia

E-mail: lichterman@hotmail.com

Presented at the Conference by: Boleslav Lichterman

Abstract:

Neurosurgery has to deal with direct intervention into human brain. When and to what degree it is justified? There is a contradiction between the necessity to cure and often unavoidable modification of patients' behavior as a result of brain surgery. The so-called brain-mind problem is shifting from philosophical theory into clinical practice. Implementation of modern technology into diagnosis and treatment of nervous disorders may cause alienation between a neurosurgeon and his patient. The former is often interested exclusively in results of neuroimaging (in CT and MRI pictures, etc.). Such approach is detrimental for clinical thinking. Patient's personality is often ignored. The diagnosis of cerebral death is another example of ethical dilemmas related to neurosurgery. The majority of donors for organ transplantation are (former) neurosurgical patients.

The aim of this paper is to give an overview of 1) factors that contribute to human face of modern neurosurgery; 2) factors of its dehumanization and 3) existing contradictions and possible ways of their solution. Any medical doctor (including a neurosurgeon) should be not only Homo sapiens but also Homo moralis.

POSTER PRESENTATIONS

IMITATIVE DISORDERS IN THE SYSTEM OF MODERN PSYCHOLOGY AND ETHICS

A.A. Shevchenko

SI "Institute of Pediatrics, Obstetrics and Gynecology National Academy of medical sciences of Ukraine", Kiev

E-mail: aashevchenko@mail.ru

Presented at the Conference by: A.A. Shevchenko

Abstract:

Imitative disorder (Munchausen's syndrome) belongs to the borderline psychical pathology representing one of the forms of personality disorder and behaviour disorder when an individual or parents (most commonly, mothers) address a doctor complaining of neurological and somatic symptoms, either imaginary (false) or intentionally fake, and stating that they are signs of a real distress. The main objective in the life of such "patients" is hospitalization in the absence of real organic pathological changes.

This problem is particularly urgent and acute in relation to children. The children may stop visiting school, they willingly agree to hospitalization to day and night clinics for conducting a lot of additional examinations. The mothers "inducing" illnesses in their children as a rule suffer from lack of psychological support in the family; they are unhappy in their marriages and some of them suffer from mental disorders. In the case the simulated, fictional nature of the child's sickness is revealed, they deny their involvement into infliction of harm to the child's health, even if it was proven, and refuse to acknowledge their psychological problems or to undergo corresponding treatment. These sicknesses artificially induced in children, are very difficult to cure. At present, Ukraine is lacking the appropriate legal basis for the consideration of similar situations and even the physicians can be exposed to a stress influence when treating such patients. The problem has also an ethic side in view of the fact that in all the models of interrelationship between the doctor and the patient (liberal, paternalistic, interpretational, and technological) envisage the maintenance of the basis bioethical principle – respect for the patient's autonomy, frank communication and honesty, the lack of which is expressed by "Barons Munchausen". Therefore, all the above mentioned shows the seriousness of management of such patients, as well as the necessity to work out and create legal, ethic and psychological resolutions as to the protection of health professionals from possible incidents.

Key Words: Burnout syndrome, ethics

PREVENTION OF BURNOUT SYNDROME IN PROFESSIONAL ACTIVITY-ACTUAL PROBLEM OF MEDICAL ETHICS

A.A. Shevchenko

SI "Institute of Pediatrics, Obstetrics and Gynecology National Academy of medical sciences of Ukraine", Kiev

E-mail: aashevchenko@mail.ru

Presented at the Conference by: A.A. Shevchenko

Abstract:

Burnout syndrome is one of the manifestations of professional destruction of personality as a result of prolonged influence of professional stress. This syndrome includes emotional exhaustion, depersonalization (cynicism) and deterioration of professional accomplishment. Predisposition of the younger doctors to the burnout should be noted separately. It is explained by the emotional shock they experience facing the reality which often does not meet their expectations. It can lead to the disappointment in their profession. It is accompanied by the development of negative, callous and indifferent attitudes towards patients. That is why this problem has also an ethic side, in particular, for interrelations between doctor-patient.

Professional success of a doctor and efficiency in solving set tasks much depends on the ability to communicate and develop relations with patients. Despite of the state of the patients, whether they are able to control themselves or are unconscious, it is necessary to be able to interact with them and seek solving the professional tasks. To achieve it one should make oneself a professional and a personality. It is very important to make a right choice of your profession, because key element of the burnout syndrome is disagreement between the personality and the requirements applied to it. Medical doctor should possess certain qualities and traits except moral and ethical values to keep the appropriate professional activity, specifically to prevent the development of the burnout syndrome. One of the main qualities is the feeling of responsibility and inner control. If a person does not have these traits then neither knowledge nor modern equipment or facilities can compensate it. A doctor should have ability to quickly catch the problem and make a decision. In order to do it he/she needs comprehensive knowledge in his/her specialty plus flexible intellect and constant study of the new scientific materials in his/her specialty and improvement of his/her practical skills. Timely diagnostics, correction and prophylaxis of burnout can help to stop the process which has already begun and to prevent the threat of its development keeping the doctor as an effective professional and healthy personality.

Key Words: Burnout syndrome, ethics

PRENATAL DIAGNOSTICS OF CONGENITAL MALFORMATIONS OF THE CENTRAL NERVOUS SYSTEM IN CHILDREN – ETHICAL ISSUES

A.A. Shevchenko

SI “Institute of Pediatrics, Obstetrics and Gynecology National Academy of medical sciences of Ukraine”, Kiev

E-mail: aashevchenko@mail.ru

Presented at the Conference by: A.A. Shevchenko

Abstract:

Prenatal diagnostics of congenital malformations of the central nervous system is one of the most promising directions in Perinatology. Analyzing this pathology, it should be noted that it is possible to prevent the birth of children with central nervous system defects in the case of providing timely and truthful information for pregnant women and their families about consequences of postnatal development (during prenatal diagnostics). However, it should be emphasized that in the process of diagnosis of congenital malformations of the CNS there are some ethical issues, in particular, problem of termination or continuation of pregnancy.

Ethically is necessary to provide complete, truthful information in the absence of pressure on the family, even if it waives a prenatal diagnosis or abortion in case of severe abnormalities in the fetus. Therefore, the physicians associated with prenatal diagnostics must have not only professional, but also high psychological, moral and ethical qualities. The most important principles of bioethics such as respect for human dignity, the principle of “do no harm” principle “do good”, the principle of justice, the principle of vulnerability, the principle of integrity to their implementation through policies informed consent (participation in this process in this case parents), fairness, privacy, confidentiality and loyalty. It is necessary to tell the truth during prenatal diagnostics. It is a manifestation of respect for other people, duty and ethical action. It finds expression in respect for autonomy that underlies the standard informed consent. Consent can not be autonomous if it is not based on truthful information. Models of interrelations between doctor and patient can be different - an autonomous, paternalistic, interpretation, technological. Bioethical principles allows for doctor to realize the dialogic model of doctor-patient relationship, the model of trust and understanding, and thus go to a new level of relations. Themselves prenatal diagnostics should be conducted carefully to avoid errors and incorrect predictions.

Key Words: Prenatal diagnostics, ethics

PRINCIPLES MANAGING FOR DYING PATIENTS IN THE CLINIC OF INTENSIVE THERAPY: ETHICAL AND MEDICAL ASPECTS

A.N. Verbitskiy

Institute of Neurosurgery National Medical Academy of Ukraine, Kiev-04050, 32,
P. Mayborodi str., E-mail: pitulik@mail.ru

Presented at the Conference by: A.N. Verbitskiy

Abstract:

Every patient has a fear of his disease, and every dying patient is afraid of death (given that he is conscious and able to analyze the surroundings). Thus, an doctor's goals are to take away such patient's fears and physical sufferings (pain or other disorders). When taking care of the dying patients in the clinic of intensive care, a so-called comfortable supporting method has developed. It can also be practiced in special hospital wards in the territory of the department to which a patient belongs. The components of this method are: psychological comfort (tranquilizers, relatives, a psychotherapist, a priest); proper feeding (not tube, where possible); adequate analgesia; thorough hygienic care; minimization of any diagnostic, especially invasive, tests; minimization or liquidation of infusions, transfusions, catheterizations, punctures, intubations, stimulations, etc. This way, the bioethical principle of beneficence (do good) is also realized, given that this principle accentuates attention on the need to take certain actions for preventing and/or correcting the damage or harm (i.e., pain, suffering, disability). The principle of beneficence is often combined with the principle of nonmaleficence, which requires of doctors that they do not create a harm or injury to the patient, either directly, intentionally or indirectly. Also, a physician must avoid using non-standard treatment methods. In anesthesiology and intensive care, the verbal and psychological contact between the doctor and the patient is not always possible due to patient's serious state (coma, mechanical ALV, etc.). Cardiopulmonary resuscitation also does not require patient's conscious consent, since such consent cannot be obtained technically. In such cases, there is an idea of a deferred consent, when a physician, on taking urgent medical actions, explains to a patient or his relatives what in particular happened to the patient, with further realization of requests on providing information to the patient and entering a record in the case history. In any event, when a patient is treated and examined, his personal dignity and respect must be observed regardless of his state. This is crucial for establishing a personal and psychological contact between a doctor and a patient, elimination of depersonalization in their relationship and enhancing efficiency of the treatment. In addition to this, such position will provide for the realization of bioethical principles.

Key Words: Managing, dying patients.

RESEARCH ETHICS COMMITTEES IN BELARUS: ETHICS PROMOTERS OR JUST FORMAL STRUCTURES?

Andrei Famenka

Legal Medicine State Service (Minsk, Belarus) E-mail: info@sudmed.by

Presented at the Conference by: Andrei Famenka

Abstract:

Background: despite growing interest to the issues of development and operation of ethical review systems for biomedical research in Eastern Europe, little is known about the current state, problems and perspectives of research ethics in countries of Commonwealth of Independent States (CIS). The increasing volume of health research, witnessed across the region, gives rise to concerns regarding CIS countries capacities to maintain high scientific quality of research and ensure adequate protection of subjects involved.

Aim: the aim of the study was to examine the development of the system of ethical review for biomedical research in Belarus, with special emphasis on its historical background, legal and regulatory framework, structure and functioning. The purpose of the study was also to identify its main characteristics and areas of concern, as well as to highlight some systematic features countries of CIS may share in approaches to establishment and organization of ethical review systems for biomedical research.

Methods: A questionnaire was developed and sent to Belarusian research ethics committees (RECs), operating at the moment of the study. Questions were focused at history of RECs establishment, legal provisions, accountability, composition, membership and training, workload and financial issues, as well as perceptions of RECs members about their competence in research ethics and about the most crucial problems they faced. Other sources used to collect information were legal databases, scientific publications, conferences' proceedings and mass-media reports.

Results: Belarus runs an institutional model of ethics review, with approximately 50 local RECs operating in hospitals and research institutions. Although basic elements of legislative and regulatory framework for biomedical research are established, the system suffers of many of the drawbacks typical for ethical review systems in transitional countries: lack of independence, of expertise and motivation of RECs members, of multidisciplinary and lay representation, of accountability and transparency.

Conclusions: the situation with research ethics in Belarus corresponds to the tendency of bureaucratic approach to establishment of systems of ethical review for biomedical research observed in a number of countries of Central and Eastern Europe. Social, economical and political factors of transition have major impact on capacities of the Belarusian system of ethical review to ensure adequate protection of human subjects, participating in different types of biomedical research. Given that RECs seriously lack independence, expertise, variety in opinions and broad public representation, as well as motives to work efficiently, it is evident that they are just formal structures, less capable to promote ethics in research than those created in

a more democratic way. In order to ensure ample protection of the rights and interests of research subjects, more efforts should be made to enhance effectiveness of ethical review of biomedical research in Belarus, as well as in other CIS countries. Gaps identified need to be addressed through capacity strengthening aimed at improving RECs independence, minimizing possible conflict of interests, providing adequate training and support to RECs, as well as ensuring accountability and transparency of ethical review procedures.

Key Words: Research ethics, belarus

NATIONAL MIDWIFERY ETHIC VALUES AND DETERMINATION CODE OF ETHICS: AN EXAMPLE

Assistant Professor Dr. Ayla Berkiten Ergin¹, Lecturer Dr. Müesser Özcan Şenses², Research Assistant Zeynep Acar³, Prof.Dr.Nermin Ersoy⁴

¹ Kocaeli University Kocaeli Health High School & e-mail: ayla.ergin@kocaeli.edu.tr

² Kocaeli University Health High School & E-mail: muesesser@kocaeli.edu.tr

³ Kocaeli University Kocaeli Health High School &
E-mail: zeynep.acar@kocaeli.edu.tr

⁴ Kocaeli University Medical Faculty, Head Department of History of Medicine and
Medical Ethics & E-mail: n ersoy@kocaeli.edu.tr

Presented at the Conference by: Ayla Berkiten Ergin

Abstract:

As a professional discipline, midwifery combines science, art, and strong ethical values. It is an uncommon profession with an unchanged heart from its first practitioners until today and an essential attribute is: "belief in the normal processes of pregnancy, labor, and birth" This belief is key to all international ethical codes of midwifery. Midwifery practice is rooted in professional and personal values formed by the physiological realities of birth, cultural values surrounding the processes of pregnancy and birth and responsibilities to the women (often members of a vulnerable group) and vulnerable newborn babies in their care.

So as to stress and strengthen the professional and social values frequently, professional codes have been developed. Ethic codes are not only important for the individuals who are served by the midwife but also play an important role in defining the peculiarities of a professional group for the members of the profession. In this context in the course of decision a midwife should be aware of her professional and individual values and should carry her values into her professional life. Although the values of midwifery and subsequently its codes were defined in the USA and Europe in 1980s, in our country national midwifery values and codes do still not exist today.

Aim: The aim is to define national midwifery professional values and to supplement the modern midwifery practice by forming midwifery ethics codes.

Material and Methods

In the first step of the national study has been conducted in Kocaeli as a pilot region with 8 midwives working in three different hospitals and not knowing each other. Using the method of in depth interview asking two basic questions determined beforehand, the ideas of the participants about the aim have been taken.

Results

The participants put the peculiarities of a good midwife under 29 features. The first five are; *Professional competency, being able to give suitable information, being reliable, respecting an individual/regarding one's honor and empathizing*. A total of 19 values have been determined as the basic ethic values of midwifery. *Competency, reliability, responsibility, the utmost benefit and maintaining privacy* have been given the top five priorities. The participants have also some special definitions for a good midwife.

Discussion

The event of birth as being a natural process may sometimes have some risks for the mother and the baby. Midwives gives great importances to high priorities to *competency, responsibility and the utmost benefit*. Midwives' priority-who witness a woman's most private instant on maintaining privacy overlaps the nature of the profession.

Suggestion

Midwifery ethic codes and values have been defined by ICM. But different countries have been carrying on studies related with national midwifery ethic codes and values in terms of their national conditions. In these studies the support of professionals and vocational organizations is very important. So with the support of Midwives' Organization defining national midwifery values and ethic codes immediately and sharing them with the professionals will support a great deal on ethic midwifery practices.

Key Words: Midwifery, ethic codes, ethic values

EUROPEAN EPIDEMIOLOGY AND ETHICS (E3) SURVEY

Behnaz Schofield

PhD student

Centre for Ethics in Medicine School of Social and Community Medicine

University of Bristol Canynge

E-mail: Behnaz.Schofield@bristol.ac.uk

Presented at the Conference by: Behnaz Schofield

Abstract:

Collaboration in epidemiological research in Europe is seriously hindered by a lack of understanding what aspects of epidemiological data linkage or data extraction are permissible or not in the various countries. More frequent sharing of data between countries and national institutions requires a closer look at the directives on data handling and their local interpretations. Participants must be assured that everyone involved in the study will treat the information they provide with the same care. But as many nations have either differing or no data protection laws in force, these differences in national standards and procedures and in the perceptions of both the research community and society as a whole can make collaborative epidemiological studies very difficult.

The poster will present the results of a survey among epidemiologists from across Europe facilitated by the EEF (European Epidemiology Federation). This piece of work is part of a larger study considering the ethical and societal implications of consent strategies in epidemiological studies and will contribute to a PhD thesis. In order to place consent strategies within a European context, the Chairman of the International Epidemiological Association (IEA) has been approached to request he circulates (electronically) a letter of introduction to all the members of National Societies represented in the IEA. The national members are asked to complete a web-based questionnaire to establish the regulations and practical realities of access to medical records in each of the participating countries.

The outcomes of the study may help to reach a better understanding of the various national regulations, which may facilitate European collaboration in the field of data sharing and epidemiology (for example in EU funded projects). It could also be used to facilitate discussions with national regulatory or government bodies with the power to adjust and reconsider regulations and legislation affecting epidemiological studies in each country. Issues that could be included are the role of consent, safe transfer and sharing of data and tissue, protection of the rights of individuals and other ethical and regulatory issues.

Key Words: Ethics, epidemiology, legislation

ETHICAL EVALUATION OF E-HEALTH PRACTICES

Uzm. Ecz. Bilge Sözen¹ Prof. Dr. Sevgi Şar²

¹ Ankara University Faculty of Pharmacy , Department of Management,
E-mail: bilgesozen@yahoo.com

² Ankara University Faculty of Pharmacy , Department of Management,
E-mail: sevgisar98@gmail.com

Presented at the Conference by: Bilge Sözen

Abstract:

Nowadays, using of information technologies has also become widespread on health practices as many fields. In this regard, information technologies used in the health practice can be collected under the title of “E-Health”.

Information technologies in health have been used in the fields like electronic prescription systems, electronic medical records, barcode systems and decision support systems. It is possible to decrease costs of health and to reduce medical errors by using these systems.

Security issues concerned on the electronic health records are pointing out the main ethical cases like autonomy, justice, privacy and security. Providing the privacy of the medical records, sharing informations and permission of the patient, data mining, keeping the required informations of the patients', determining the persons carried authorization to be able to enter the system are main problems faced with.

With this study, e-health practices will be evaluated in terms of ethics.

Key words: Information technologies, e-health, ethics

CONFLICT MANAGEMENT IN BULGARIAN NURSING PRACTICE – AN EMPIRICAL STUDY RESULTS

Dimitrova Sv., G. Petrova, J. Marinova, B. Parashkevova, G. Chamova

Department of Social Medicine and Healthcare Management
Medical Faculty at Trakia University, Stara Zagora, Bulgaria
E-mail: svdimitr@mf.uni-sz.bg

Presented at the Conference by: Dimitrova Svetlana Metodieva

Abstract:

Introduction: The Bulgarian health care system has been in dynamic transition for 20 years by now. The contemporary stage is developing in difficult economical, social and political circumstances. Besides the Bulgarian health system suffers from extremely low number of nurses. Many challenges have to be met by practicing health care professionals. This context predisposes difficult everyday ethical and organizational conflicts that involve nurses.

The aim of this study is to discover and analyze some of the most often and difficult conflicts and their management in Bulgarian medical practice especially in nursing health care based on opinion of nurses.

Tasks:

To identify, classify and analyze the conflicts with stressing the ethical aspects. The applied methods of managing conflicts to be described and to discuss the most preferred strategies of solving conflicts.

Methods: Content analysis of written cases has been performed. The cases are prepared by students in Nursing Health Care Management at the Medical Faculty of Trakia University – Stara Zagora and describe real conflicts in their professional experience. Ethical conflicts and complex ones that include ethical component are identified and investigated. Qualitative criteria are applied for defining the type, sources, stage, methods and strategy for managing conflict.

Results: Most of the conflicts are not clearly ethical but complex and are caused by ineffective communication. We have classified them based on type of the problematic communication. Communicational difficulties in professional relationship are due mainly to the extremely low number of nurses and working overload. The insufficient time for conversations with patients leads to mistakes and interpersonal conflicts. The team conflicts most often are connected with unclear professional roles and mutual dependant responsibilities and sometimes underestimation of nurses by physicians. For solving conflicts usually the authors of cases combine well known methods with innovative ones. Compromise and cooperation are the most preferred models. The democratic style of management and involving team members in the process of choosing the proper strategy is presented in a reasonable part of cases

that are successfully solved. Our analysis shows that in the most cases the strategies of solving conflicts are unaggressive, non-competitive and creative.

Conclusion: The issue of conflict management is a big challenge to Bulgarian nurses managers. It requires theoretical knowledge, adequate managerial skills and ethical attitude to perform the delicate activity of solving conflicts. Certain political decisions must be taken as well in the direction of reducing the sources of conflicts by the managers on strategic level.

Key Words: Conflict management, Bulgarian nursing, empirical study

THE WILDLIFE PROTECTION AND IMPROVEMENT AREAS IN ACCORDANCE WITH ANIMAL PROTECTION AND BIOETHICS

Gökhan Aslım, Ali Yiğit, Aşkın Yaşar, Serdar İzmirli

Department of History of Veterinary Medicine and Deontology, Veterinary Faculty, University of Selcuk, Konya, TURKEY, E-mail: sizmirli@selcuk.edu.tr

Presented at the Conference by: Serdar İzmirli

Abstract:

The future of environment run into risk by human activities is an important issue of present days which also covers ethics and deontological aspects. Related acts as well as ethical approaches concerning with topic will be beneficial to solve the above issue.

The process of *Wildlife Protection and Improvement Areas* has been evolved with different arrangements since 1966, in Turkey. This study aimed to evaluate the *Wildlife Protection and Improvement Areas* in terms of bioethics, animal protection and animal ethics.

The study materials consisted of animal protection and local acts of wildlife (Animal Protection Act, Land Hunting Law, *Fisheries Law*, *Decree - Law Regarding Special Environment Protection Areas*, and *National Parks Law*), as well as several Treaties Ratified by Turkey (BERN, RAMSAR, CITES and Biodiversity).

Turkey has too many protection areas in various statute, such as; National Park, Nature Park, *Natural Reserve Area*, *Natural Protected Area*, *Special Environment Protection*, *Internationally Important Wetland*, *Wildlife Protection and Improvement Areas*. In total, it was determined 109 Wildlife Protection Areas and 79 Wildlife Improvement Areas, as well. However, 14 animal species has been taken under protection in Wildlife Improvement Areas. It was also emerged that the numbers of wild animals has increased and remarkable improvements have been occurred at this period in the Wildlife Improvement Areas by launching new acts.

The wild animal species which are face to face with reducing generation or die out, are taken protection and some are being breeding in their natural area without giving harm to their ecosystem in accordance with Land Hunting Act. To fulfill respective aims, a protection of delicate natural balance and warrant of biodiversity are both necessary measures.

In conclusion, it may be expressed the national arrangements that takes into consideration the international conventions, contributes to wildlife protection. Moreover, Turkey needs to be increased concerning studies in this respect. As a result, it can be implied that zoo-centric approach which based on the value, importance and rights of the entities should be become widespread in the Turkish society.

KEYWORDS: Animal ethics, bioethics, wildlife

CLINICAL TRIALS AND ETHICS COMMITTEES IN TURKEY

Hilal İlbars, Serkan Öztürk, Ülkü Terzi, Melda Ciba, Hülya Durgut, Berna Yücel, Burcu Suna, Ahmet Emin Geciken, Ayşegül Günbey Öztekin, Hanefi Özbek

Turkish Ministry of Health, General Directorate of Drug and Pharmacy,
ANKARA/TURKEY

E mail: hilbars1970@yahoo.com

Presented at the Conference by: Hilal İlbars, PhD, Pharm.

Abstract:

In Turkey, clinical trials are regulated by General Directorate of Pharmaceutical and Pharmacy (GDPP) within the Ministry of Health (MoH). Following the approval of a clinical trial in terms of scientific and ethical point of view by an Ethics Committee (EC), an application file is submitted to the Clinical Trials Department of the GDPP for an administrative review and approval.

In Turkey the first regulation about clinical drug trials was published on 1993. According to that regulation; Ethical Committee means committee formed by the Ministry at its headquarters to examine the requests on clinical researches done on drugs, to evaluate and control clinical researches and studies from ethical point of view. And Local Ethical Committees (LECs) means committees formed under the rules of this regulation by institutions or establishments resuming drug research work. Local ethical committees are formed in training hospitals where the research will be done. In that time period (1993-2008) there was 86 LECs in Turkey.

The Turkish bylaw on clinical trials was issued at the end of 2008 by the MoH to accommodate with gradual increase of quality in clinical trials. According to the mentioned by law; Ethics committees shall be established by Ministerial approval in regions to be determined by the Ministry, in order to secure the rights, safety and well-being of the volunteers to participate in the trials so as to deliver an ethical and scientific opinion on the trial protocol, suitability of investigators, adequacy of the sites where the trial will be conducted, methods and documents to be used in informing volunteers and the consent to be received from them and in other subjects concerning trials, to achieve volunteer safety and ensure that the trial is conducted and monitored in accordance with the regulations, and to evaluate all clinical trials from an ethical viewpoint. This Regulation has been prepared on the basis of article 43 of the Decree Law Regarding the Organization and Duties of the Ministry of Health (MoH), dated 13/12/1983, with No. 181 and item (k) in clause one of Article 3 in the Fundamental Law Regarding Healthcare Services, dated 7/5/1987, with No. 3359 and in parallel with the EU Directives 2001/20/EC and 2005/20/EC for the purpose of achieving harmonization with the EU legislation concerning drugs in the conduct of clinical drug trials. According to that regulation there was 56 ECs in Turkey.

After that regulation there was a new regulation about clinical trials on 2010. And according to that regulation Ethics Committee shall mean the committees to be assembled with the designation, Ethics Advisory Committee for Clinical Trials of Drugs or Ethics Advisory Committee for Non-Drug Clinical Trials, within the Higher Council of Health with the approval of the Minister in order to provide their scientific and ethical opinion as to the trial protocol, suitability of its investigators, adequacy of the trial centers, the methods and documents used to inform the subjects and the consents obtained of subjects as well as any other aspects pertinent to the trial with a view to ensuring protection of the rights, safety and well-being of subjects involved in a trial and that the trial is conducted and followed up in accordance with applicable regulations. According to that there was 6 ECs.

On 2011 we have a new law on clinical trials. The following additional items were added on Basic Health Services Act No. 3359 (dated 07.05.1987) ;"Supplemental Article 10 –For any therapeutic tools and methods, or medicinal products or preparations, traditional herbal medicinal products or medical devices to be used in humans for scientific research purposes, even if licensed or authorized, the approval of the MoH must be obtained, and most of conditions must be satisfied". One of this conditions is the proposed study is approved by the relevant ethics committee. Research will be conducted at; University centers for application and research health, accredited centers for research and development affiliated with universities, Refik Saydam National Public Health Agency and research and training hospitals of the MoH. The MoH will establish ECs to evaluate clinical trials from an ethical perspective and to protect the rights, safety and wellbeing of subjects who will take part in clinical trial. They are composed of not less than seven and not more than fifteen member, including at least one member of a lay member (non medical profession) and one lawyer, and the majority consisting of health care professionals who are specialized or holding a post doctoral degree in a branch of medicine.

The MoH will issue a regulation to lay down the principles and procedures for scientific research in humans, as well as the establishment, mandate and operating principles and procedures of Clinical Trials Advisory Committee and Ethics Committees to be assembled in relevant areas of clinical trials.

Key Words: Ethics committee, Turkey, clinical trials

HUMAN DIGNITY AND HUMAN ENHANCEMENT

Joanna Rozynska, Ph.D.

M.Jur., MA in Phil., MA in Soc., MA in Bioethics

* University of Warsaw, Institute of Philosophy, Dept. of Ethics, Warsaw, Poland

** Warsaw University of Physical Education, Department of Rehabilitation, Institute of Philosophy of Medicine and Bioethics, Poland

E-mail: jrozyńska@gmail.com, j.rozyńska@uw.edu.pl

Presented at the Conference by: Joanna Rozynska

Abstract:

The aim of my presentation (poster) is to discuss the meanings and ethico-legal significance of the argument from human dignity in the context of contemporary debates on human enhancement. Human dignity is a core value of contemporary bioethics (especially, so called 'European bioethics'), and an axiological principium of international human rights discourse. The concept plays the central role in the Council of Europe bioethical framework, in particular, in 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 (Oviedo Convention) system.

Human dignity is often invoked by opponents of potentially '*true human nature/experience*' –affecting biomedical technologies, such as human reproductive cloning, germline gene therapy or eugenic practices aiming at the selection of persons. The critics (e.g. L. Kass, J. Habermas, M.J. Sandel) argue that those technologies violate or threaten human dignity and therefore should be banned. Their voices are echoed by the majority of global, regional, and national human rights laws, including the Oviedo Convention and its Additional Protocols. However, both philosophers and public policy makers/legislators rarely define the notion of human dignity or explain why and when it is violated by a given practice. In absence of such clarifications, appeals to human dignity remain either hopelessly vague restatements of other well know values or principles (e.g. respect for persons, respect for autonomy) or mere slogans (R. Macklin).

In my presentation I would like answer the following questions: What does the concept of human dignity actually mean in international human rights law, in particular the Oviedo Convention? Is human enhancement really incompatible with human dignity? To analyze these issues, I will use a key working model of the contemporary understanding of human dignity, differentiating three concepts of dignity and two major perspectives of subjective dignity and objective dignity, as developed by Steven Malby in 2002 (*Health and Human Rights*, 2002 6(1):102-135). I will argue that only a very specific, objective understanding of the concept of human dignity may provide an argument for an international ban on human genetic enhancement.

Key Words: Human dignity, human enhancement, International human rights discourse

PROFESSIONAL ETHICS COMMITTEE ACTIVITY - REFLECTION OF ETHICAL PROBLEMS EXISTING IN THE PERIOD OF BULGARIAN HEALTHCARE REFORM

Marinova J., B. Parashkevova, Sv. Dimitrova, G. Chamova, G. Petrova

Department of Social Medicine and Healthcare Management
Medical Faculty at Trakia University, Stara Zagora, Bulgaria
E-mail: marinova@mf.uni-sz.bg

Presented at the Conference by: Marinova Juliana Krumova

Abstract:

Introduction: The process of healthcare reform in The Republic of Bulgaria is connected with serious ethical challenges. Recently Bulgarian physicians have been working under pressure of continuing dynamic changes in healthcare system administration. All the consequences of unsuccessful efforts in this direction influence strongly their performance.

Aim: Basic ethical problems in the process of Bulgarian healthcare reform to be described by the means of analysis of the activity of the Professional Ethics Committee (PEC) at the Regional Branch of The Bulgarian Union of Physicians in the town of Stara Zagora.

Methods: The whole documentation of the committee (PEC) in the period 2007-2010 has been investigated in conformity with the requirements concerning access to documentation and information. A qualitative content analysis approach has been applied in 56 written complains. A purposive questionnaire was elaborated in order to analyze the cases on the base of contemporary concepts of patients' rights. The technique of global interpretation has been applied.

Results and discussion: Results are presented by basic features of the complainants – demographic and social. Analysis is made in accordance with the year and number of registration and the way of documents presentation as well. Patients' rights based approach is used for identification of the ethical problems that are raised in the complaints to the PEC. The number of the presenting complaints increases during the investigated period. Most of them describe ethical conflicts concerning doctor – patient relationship. Some of them address conflicts between doctors. There has been a growing tendency of complaints oriented to the system "physician – society" recently. In most cases patients or their relatives describe conflicts in connection with access to specialized medical care – both on inpatient and outpatient level. Next are the complaints that comment not-respected rights in context of physician' malpractice. We discuss the results according to the following circumstances:

the problems are defined as ethical ones and are directed to be solved by the PEC; they present the complainants point of view; and it is important to stress the authors interpretation in the limits of applied methodology.

Conclusions: The negative effects of the process of healthcare reform such as limited access to specialized medical care and problematic relationship in the system doctor – patient are connected with opportunities of solving problems on all the levels of managing healthcare system. Encouragement of good medical practices that respect the rights, interests and needs of all the participants in the healthcare system reform is highly recommended.

Key Words: Professional ethics committee, patients' rights, qualitative content analysis

START TO INQUIRE ABOUT: INFORM CONSENT AND KEEPER SISTERHOOD CONCEPTS IN THE JODI PICOULT'S MY SISTER'S KEEPER

Mukadder Gün MSc, (RN).

Gülhane Military Medical Academy Department of Sports Medicine, Ankara, TURKEY

Presented at the Conference by: Mukadder Gün

Literature and art have been a strong vehicle reflecting problems of human being since existence of humanity. In this study, "informed consent" notion which is conserving its currency and "rescuer fraternity" concept which is newer than the first are argued with context of Picoult's novel *For My Sister* and other ethical problems mentioned in the novel are dealt with.

Anna, the hero of the novel, had been given birth as a specially produced child whose genes were chosen privately. The only reason for her birth was contributing the treatment of her big sister who had a fatal illness and saving her life somewhat. However at the beginning of her puberty period, Anna made a decision that a great deal of adults can't dare upon her own life which she had begun to interrogate with the effects of her situation. At the end of the legal process of this decision that concerning her sister's life which had intersected with her own life, a legal judgement in the direction of supporting Anna's decision about processes being applied on her own life and body betray the importance of "consent" notion. Consequently when a human being experience something out of account, untoward situations may arise and he/she may not exist as an ethical subject possibly, just like the ending of Anna's life unexpectedly and series of events developing after that.

This novel, which reflects that the human being's life may form excluding choices as well as in the direction of choices, is a noteworthy work of art in terms of ethics as well as literature through the ethical problems it harbours and commits, it is my belief.

Key Words: Keeper sister, consent, preference

PATIENT RIGHTS AND PROFESSIONALS: KNOWLEDGE OF HEALTH CARE WORKERS IN ISTANBUL ON PATIENT RIGHTS

Nuran Akyurt¹, Gurkan Sert², Tolga Güven², Murat Balıkcıl¹, Hakan Albayrak¹

¹ Marmara University Vocational School of Health Related Professions, Radiology Department, Üsküdar-İstanbul, E-mail: nakyurt@marmara.edu.tr

² Marmara University Faculty of Medicine Department of Medical Ethics and History of Medicine, E-mail: gsert@marmara.edu.tr

Presented at the Conference by: Nuran Akyurt

Abstract:

This study was planned as a part of the research that aimed to investigate the knowledge and opinions of health care workers in İstanbul on patient rights. The data presented here is based on the questionnaire investigating their knowledge. The questionnaire was answered by 1762 health care professionals from 255 health care institutions (ranging from private outpatient clinics to university hospitals) were interviewed between October 2010 – January 2011. The data were collected by using questionnaires filled out during face to face interviews. The largest group of participants consisted of health care technicians (%44.7), followed by nurses (14.6%). 52.0% were females and 41.2% were between the ages 18-25 years of age. The majority (70%) were employed in state institutions.

The knowledge about patient rights was evaluated with 6 different statements derived from the text of Turkey's Regulation on Patient Rights and the participants were asked to answer with the terms "true" or "false". The first item was based on the patient's right to demand both written and oral information on the course and consequences of their disease and 91.1% found responded as "true". Similar responses were also given for the patient's right to demand all available records regarding their medical conditions (% 87.8), the right to forbid disclosure to oneself and to her family ("the right not to know") (85.0%) and the right to demand the completion of missing data on patient files (88.3%).

However, an interesting difference was observed on 2 other items. The first of these asserted that "the patient does *not* have the right to choose the health care professionals, to change their physicians and to demand consultation". 38.4% of the participants responded with the term "true" to this claim and this was the largest group of incorrect response in the study. While the negative phrasing of the claim may have been confusing for some of the participants, we think this could be reflecting a negative reaction to this universally recognized patient right, which also has been addressed in the Regulation on Patient Rights. The second item asserted that "physicians and other health care professionals, who are providing or who will provide health care service to a patient, have to provide information regarding their titles and their duties when demanded so by the patient." 16.4% of the participants thought this was true, forming the second largest incorrect response group in the study. These findings suggest that some health care professionals may have a tendency to react negatively to some patient rights and they may also be perceiving

some of the obligations imposed on them through the implementation of patient rights as a threat to their professional authority. We believe these possibilities should be taken into consideration during the formulation of patient rights implementation policies in the country.

Key Words: Patient rights, patient autonomy, patient rights regulation

VIEWS OF A GROUP OF PHYSICIAN IN RESIDENCY TRAINING ON INFORMED CONSENT

Oya Öğenler¹, Nursel Bilgin², Selim Kadioğlu³, Tamer Akça¹

¹ Mersin University Faculty of Medicine Department of History of Medicine and Medical Ethics, E-mail: oyaogenler@gmail.com, tamerakca@gmail.com

² Mersin University Faculty of Medicine Department of Forensic Medicine E-mail: nurselbilgin@yahoo.com

³ Çukurova University Faculty of Medicine Department of History of Medicine and Medical Ethics, E-mail: selimkad@cu.edu.tr

Presented at the Conference by: Oya Öğenler

Abstract:

Adopting the informed consent approach is both legal and ethical obligation in the context of modern medicine. Informed consent is on one hand a theoretical principle that should be adopted, on the other hand a practical skill that should be developed. Therefore, this approach is a critical subject of medical education, especially in residency training.

The aim of our study is to find out the views of a group of physician in residency training on informed consent and to determine how much these views are compatible with regulations.

Our research was conducted in the Training Hospital of Mersin University in January-March 2011. Participants were 118 of 228 physicians in residency training from different clinical branches.

In the data collection tool prepared by authors; there are four questions to detect socio-demographic features of participants, eight questions to detect their relations to informed consent and 37 statements in order to detect their view about the issue. "Informed Consent Regulations Draft" prepared recently by Turkish Health Ministry was utilized in the preparation of statements. To declare their views, participants gave points in the range of 0-10; being "10" for most adoption, "0" for least adoption.

In the analysis of data, frequency and mean scores; in group comparisons, student t, one way ANOVA and correlation methods were used. $p < 0.05$ was accepted statistically significant.

The sample consisted of 40 female, 75 male (and 3 unanswered) participants with mean age 30.45 years. Average duration of occupation is 7.17 years. 61% of the participants are resident in the branches of internal medicine, 57% of them are resident in the branches of surgery. Average of the points given for all statements by all participants is 8.22.

"Informing patients and obtaining their consent is very important for major surgical operations" is the highest statement with average points of 9.19. The statement with lowest point is "informing the patient should be done with visual materials such as

detailed pictures and video records” with 5.04 average points.

There is no statistically significant difference between the gender sub-groups and also among the sub-groups concerning their relations to informed consent.

Sub-groups between which there is a statistically significant difference for most statement are residents of the internal medicine branches and residents of the surgical branches. In this context; 12 of the statements were given highest adoption points by residents of surgical branches.

A statistically significant association was found between the mean age of participants and the average of adoption point given for one of the statements. Weak but statistically significant, negative correlations were found between the occupation duration and adoption points given for two statements.

Participants strongly adopt the informed consent and their views comply with the regulations draft of Health Ministry. Participants who are in residency training in the branches of surgery are more sensitive to informed consent.

Key Words: Informed consent, residency training, medical ethics

THE SENIOR NURSING STUDENTS IN WEST BLACK SEA UNIVERSITIES ASSOCIATION ATTITUDES TO PATIENT RIGHTS

Rahime Aydın Er¹, Nermin Ersoy², Sevim Çelik³

¹ Lecturer Phd. Kocaeli University, Kocaeli Health School, Kocaeli, Turkey
E-mail: raay@kocaeli.edu.tr

² Professor Phd. Kocaeli University Faculty of Medicine, Department of History of Medicine and Medical Ethics, Kocaeli, Turkey, E-mail: nersoy@kocaeli.edu.tr

³ Associate Professor Phd. Zonguldak Karaelmas University, Zonguldak Health School, Zonguldak, Turkey, E-mail: sevimakcel@yahoo.com

Presented at the Conference by: Rahime Aydın Er

Abstract:

Introduction and objective: Patient rights by taking the source of human rights consist of positive and negative rights has a different content from health right.^{1,2} The health right is caused by the individual-state relationship, patient rights are due to patient-medical relationship.¹ In this regard, the health team members have an important role in the implementation and the protection of patient rights.³ Role of the patient rights advocacy which especially is installed to nurse in health team members requires the patient must have been used his rights, also when the patient can not use to advocacy of the rights on his behalf.⁴ Because the nurse's obligations caused by patient rights is essential.⁵ Therefore, nursing students should have taken ethics education to get ready for this contemporary role. Based on these grounds, in this study we wanted to see how nurses of the future get ready to this role and to bring into sharp relief ethics education in nursing education at the universities cooperated in Black Sea Universities Association where it is considered as our country industrial area.

Material and Method: This descriptive study was carried out between October 2010 and February 2011 at 5 of the existing 7 health school in Black Sea Universities Association (Kocaeli University, Sakarya University, Zonguldak Karaelmas University, Abant İzzet Baysal University, Düzce University, Karabük University, Bartın University). Because one of the universities does not have nursing education and other does not have appropriate class.

The population of the study consisted of last year student in the academic year 2010-2011 which is 322 student nurses. After giving information to students about the study, the questionnaire which configured about attitudes regarding rights including patient rights regulation and pre-tested by us was distributed to students to answer, students were left alone. After the percentage distribution of the data obtained, the socio-demographic characteristics were used as independent variables and statistical analysis was conducted using chi-square test.

Findings: There are 303 students participated in this study where there are 322 students in final year (%94,1). The students' mean age is 22.0 ± 1.2 where ages ranging between 17 and 28. The students of 85.3% were female and 55.5% stated that

lived in the province.

Students' attitudes related to patient rights evaluated; even the vast majority (97%) think the patient should be informed that they are being given the role of patients' rights advocacy is sing of hope; less more than half (59.7%) preferred to say the truth to the patient, around half of students think that patient that right to refuse treatment (49.2%) with believe that children should not participate in decisions related to treatment (48.5%) and nearly one quarter (23.8%) students to report that person has right to die cause doubt to effect this contemporary role. The use of organs after the death of the patient has high participation rate (92.1%), the use of their organs fall to half (52.1%). Students' opinions about to be the criterion of patient's quality of life for continued treatment (62%) with to be allowed to die for newborns whose quality of life will never well (13.2%) concern about observing the best benefit of the patient.

Result: The results of this study concern about the nurse students are ready to contemporary duties such as role of the patient rights advocacy. Therefore, we think that the restructuring of nursing education (ethics education) related to patient rights and obligations imposed to nurse of these rights would be beneficial.

Key Words: Nursing ethics, ethics education, role of the patient rights advocacy

INFORMED CONSENT IN VETERINARY PRACTICE

R. Tamay Başağaç Gül, Özgül Küçükaslan

Department of Veterinary History & Deontology, Veterinary Faculty, Ankara University, Ankara-Turkey, E-mail: basagac@veterinary.ankara.edu.tr
E-mail: patella80@hotmail.com

Presented at the Conference by: R. Tamay Başağaç Gül

Abstract:

As it is known informed consent is an extremely important concept both in routine medical practices and in scientific researches. It originates from the legal and ethical rights the patient has to direct what happens to his/her body and from the ethical duty of the physician to involve the patient in his/her health care. Informed consent was brought to a universal dimension with the Nuremberg Code, has become an essential part of the patients' rights, and has been protected by laws. It is one of the most important ways to show respect for autonomy of the patient whose body is a sacrosanct matter, something not to be trifled with lightly by a physician or by anyone else.

In last decades informed consent has also taken place in veterinary medicine and begun to be discussed within ethical issues related to this profession. However, because of as animals' lack of autonomy and competence to make decisions and various approaches to their moral status, it is quite problematic process in veterinary practice. Different from human medicine, informed consent was founded predominantly in preserving the owner's economic value of the animal undergoing diagnosis and treatment by the veterinarian. Accordingly, the principle interest of the animal owner was to protect his/her investment in a business asset, and the main concern of the veterinarian was to provide a reasonable estimate of the cost for medical services with a mind to minimizing expense and maintaining profitability for the client. The animal's interests in this business transaction were moot, and the relationship between animal and owner were overwhelmingly utilitarian. While this pragmatic relationship continues to be valid for especially farm animals and their owners today, the growing populations of companion animals and the shift in veterinary-client relationships to one founded in the human-animal bond have effectively altered the paradigm of informed consent, even if the profession has not yet fully acclimated to this important change. In this instance the economic foundation of informed consent has largely been replaced by an emotional and moral one, wherein risk and benefit are judged in terms of quality of life, empathy, anthropomorphism, and considerations for informed consent not unlike those for parent, child and pediatrician.

This presentation aims at providing a general overview and insight into informed consent in veterinary practice and bringing out the differences of this process between human and veterinary medicine.

Key Words: Ethics, informed consent, veterinary practice

PATIENT RIGHTS AND PROFESSIONALS: OPINIONS OF HEALTH CARE WORKERS IN ISTANBUL ON PATIENT RIGHTS

Tolga Güven¹, Nuran Akyurt², Gurkan Sert¹, Murat Balıkçı², Hakan Albayrak²

¹Marmara University Faculty of Medicine Department of Medical Ethics and History of Medicine, Üsküdar-Istanbul, E-mail: tolgaguen@hotmail.com

² Marmara University Vocational School of Health Related Professions, Radiology Department, E-mail: nakyurt@marmara.edu.tr

Presented at the Conference by: Tolga Güven

Abstract:

This study was planned as a part of the research that aimed to investigate the knowledge and opinions of health care workers in Istanbul on patient rights. The data presented here is based on the questionnaire investigating their opinions. The questionnaire was answered by 1703 health care professionals from 255 health care institutions (ranging from private outpatient clinics to university hospitals) were interviewed between October 2010 – January 2011. The data were collected by using questionnaires filled out during face to face interviews. The largest group of participants consisted of health care technicians (%46.1), followed by nurses (15%). 52.0% were females and 41.2% were between the ages 18-25 years of age. The majority (70%) were employed in state institutions.

The opinions about patient rights were evaluated with 5 different statements derived from the text of Turkey's Regulation on Patient Rights and the participants' answers were grouped by using a 5-point Likert scale. In the first item, it was stated that patients had the right to receive diagnosis, treatment and care in accordance with medical requirements and the right to refuse these services; the percentages of those who strongly agreed (34.2%) and agreed (48.4%) with this statement suggested that the right to receive and refuse health care service was supported by the majority of the participants. This support was also observed for the second statement which asserted that the patient may demand all kinds of information in verbal or written form; frequencies for those who totally agreed and agreed with the statement were observed as 34.6% and 51.9%, respectively. The third statement, "the patient must be aware of all kinds of interventions related with herself" and the fourth statement, "the patient can refuse and stop treatment" were similarly supported by participants: 48.2% agreed with the third statement and 45.5% agreed with the fourth statement, whereas 35.7% strongly agreed with the third statement and 45.5% strongly agreed with the fourth statement. Findings from these first four items suggested a significant support for a patient autonomy-centered health care among the participants. However, this situation was reversed for the fifth item, which asserted that "if a medical condition that may worsen the patient's situation by demoralizing the patient is present, then the diagnosis may be hidden from the patient". 38.2 % agreed, whereas 21.9% totally agreed with this statement; thus, the total support reached 60.1 %, suggesting a possible influence of the paternalist tradition and the so-called doctrine of "therapeutic privilege" among the professionals. However,

since this statement is also contained in the provisions of the Patient Rights Regulation, these findings may also be reflecting the influence of the Regulation on health care professionals' opinions. For this reason, we recommend the relevant provisions to be amended and updated if patient autonomy is to be respected in Turkey's medical practice.

Key Words: Patient rights, patient autonomy, patient rights regulation

**LIST OF PARTICIPANTS OF
EACME 2011
ANNUAL CONFERENCE
ISTANBUL**

Abma, Tineke A.

VU Medical Centre Dept
Medical Humanities Amsterdam
NETHERLANDS
t.abma@vumc.nl

Aboud, Ann

Shared Service Agency
AUSTRALIA
ann.aboud@ssa.qld.gov.au

Ahteensuu, Marko

Public Choice Research Centre (PCRC)
Assistentinkatu 7, 20014
University of Turku
FINLAND
mataah@utu.fi

Akpınar, Aslihan

Kocaeli University, Medical School
Department of History of Medicine and
Ethics,
TURKEY
aslyakcay@yahoo.com

Aksu, Murat

Adnan Menderes University School of
Medicine, Department of Medical Ethics and
the History of Medicine
TURKEY
murataksumd@gmail.com

Akyurt, Nuran

Marmara University Vocational School of
Health Related Professions
Radiology Department
TURKEY
nakuyurt@marmara.edu.tr

Albayrak, Neris San

Acibadem University School of Medicine
Istanbul -TURKEY
neris.albayrak@acibadem.edu.tr

Alpinar, Zumrut

Institute of Biomedical Ethics, University of
Zürich Pestalozzistrasse 24 CH-8032 Zürich
SWITZERLAND
zumrut.alpinar@ethik.uzh.ch

Ashcroft, Richard E.

School of Law, Queen Mary, University of
London
ENGLAND
r.ashcroft@qmul.ac.uk

Aslim, Gokhan

Department of History of Veterinary
Medicine and Deontology, Veterinary
Faculty, University of Selçuk, Konya
TURKEY

Aydin Er, Rahime

Lecturer Phd. Kocaeli University
Kocaeli Health School, Kocaeli
TURKEY
raay@kocaeli.edu.tr

Baccarini, Elvio

University of Rijeka Faculty of Humanities
and Social Sciences Slavka Krautzeka bb
51000 Rijeka
CROATIA
ebaccarini@ffri.hr

Bahus, Marianne K.

Center for Medical Ethics Institute of
General Practice and Community Medicine
Faculty of Medicine University of Oslo
NORWAY
marbahus@online.no

Bakirci, Nadi

Acibadem University School of Medicine,
Department of Public Health
TURKEY
nadiba@gmail.com

Balein, Gemma N.

University of the East Ramon
Magsaysay Memorial Medical Center, Inc.
Aurora Boulevard Quezon City
PHILIPPINES
gemmaalein@yahoo.com

Basagac Gul, R. Tamay

Department of Veterinary History &
Deontology, Veterinary Faculty, Ankara
University, 06110 Ankara
TURKEY
basagac@veterinary.ankara.edu.tr

Benaroyo, Lazare

Interdisciplinary Ethics Unit (Ethos),
Sciences-Society Interface,
University of Lausanne,
SWITZERLAND
lazare.benaroyo@unil.ch

Berkiten Ergin, Ayla

University Kocaeli Health High School
TURKEY
ayla.ergin@kocaeli.edu.tr

Biller-Andorno, Nikola

Ethicist for the Ethics and Health Unit in
the Director General's Office of
the World Health Organization, Geneva
SWITZERLAND
biller-andorno@ethik.uzh.ch

Borgoño, Cristián

School of Bioethics Pontifical Athenaeum
Regina Apostolorum Via degli
Aldobrandeschi 190 00163 Rome
ITALY
bioethicsresearch@upra.org

Bosisio, Francesca

Interdisciplinary Ethics Unit (Ethos)
Sciences-Society Interface
Health Psychology Research Centre
(CerPSa) Institute of Psychology, University
of Lausanne
SWITZERLAND
francesca.bosisio@unil.ch

Caenazzo, Luciana

Department of Environmental Medicine and
Public Health
Legal Medicine Unit, University of Padova,
Via Falloppio 50
35121, Padua – Fondazione Lanza
ITALY
luciana.caenazzo@unipd.it

Chakarova, Lyudmila

Medical University – Sofia
Chair Medical ethics and law
luchak@abv.bg

Chamova Stoycheva, Galya

Medical Faculty/ Trakia University
BULGARIA
galia.chamova@gmail.com

Chenik, Marie

Karolinska University Hospital
Quality and Patient Safety.
SWEDEN
marie.chenik@karolinska.se

Chukova, Yu.P.

Krasnopresnenskiy Ecological Fund.
Moscow
RUSSIA
y.Chukova@mtu-net.ru

Civaner, Murat

Uludag University School of Medicine
Dept. of Medical Ethics, Bursa
TURKEY
mcivaner@gmail.com

Cokar, Muhtar

Acıbadem University School of Medicine,
Department of History of Medicine and
Ethics
Gülsuyu, Fevzi Çakmak Cad. Divan Sok.
No. 1, Maltepe-Istanbul
TURKEY
mcokar@ikgv.org

Couccke, Trees

West Vlaanderen
BELGIUM
trees.couccke@stimul.be

Deans, Zuzana

University Of Bristol Canynge Hall 39
Whately Road
ENGLAND
Zuzana.Deans@bristol.ac.uk

Denemy, Eniko

Central European University
HUNGARY
demenye@ceu.hu

Denier, Yvonne

Catholic University of Leuven (KULeuven)
Faculty of Medicine
Centre for Biomedical Ethics and Law
Kapucijnenvoer 35 box 7001,
3000 Leuven
BELGIUM
Yvonne.Denier@med.kuleuven.be

Dierickx, Kris

Centre for Biomedical Ethics and Law
Katholieke Universiteit Leuven
Kapucijnenvoer 35 Blok D – box 7001
3000 Leuven
BELGIUM
kris.dierickx@med.kuleuven.be

Doppelfeld, Elmar

Nuclear Medicine at the University of Bonn
GERMANY
med.ethik.komm@netcologne.de

Doskocil, Ondrej

University of South Bohemia
Faculty of Health and Social Studies
J. Boreckeho 27, 370 11, Ceske Budejovice
CZECH REPUBLIC
doskon@centrum.cz

Durante, Chris

Faculty of Religious Studies
McGill University, Montreal
CANADA
C.Durante@hotmail.com

Edisan, Zehra

Cukurova University Faculty of
Medicine Department of Medical Ethics
TURKEY
zedisan@hotmail.com

Elisabeth, Gjerberg

Centre For Medical Ethics
NORWAY
elisabeth.gjerberg@medisin.uio.no

Elveris, Aysegul

Bioethics Division Health and Bioethics
Department, Directorate General III- Social
Cohesion Council of Europe
FRANCE
aysegul.elveris@coe.int

Engstrom, Karin

Orebro University
SWEEDEN
karin.engstrom@oru.se

Engström, Ingemar

Swedish Medical Society
Delegation for Medical Ethics
PO Box 738, SE-101 35 Stockholm
SWEDEN
ingemar.engstrom@orebroll.se

Eriksson, Stefan

Centre for Research Ethics
Bioethics, Box 564, 751 22 Uppsala
SWEDEN
stefan.eriksson@crb.uu.se

Ersoy, Nermin

Kocaeli University Faculty of Medicine,
Department of History of Medicine and
Medical Ethics, Kocaeli
TURKEY
nersoy@kocaeli.edu.tr

Falkenström, Erica

Department of Education,
Stockholm University, SE-106 91 Stockholm
SWEDEN
erica.falkenstrom@edu.su.se

Famenka, Andrei

Legal Medicine State Service Minsk
BELARUS
info@sudmed.by

Faneye, Benedict

West African Bioethics Training
Program University of Ibadan
Oyo State Nigeria, West Africa
NIGERIA
Bfaneye1@yahoo.com

Fernando, Anoja

Sri Lanka Medical Association
6, Wijerama Mawatha Colo,mo 7
SRI LANKA
anojaf@yahoo.com

Ferrari, Arianna

KIT/ITAS (Karlsruhe Institute of Technology)
Institute for Technology Assessment and
Systems Analysis, Hermann-von-Helmholtz-
Platz 1
76344 Eggenstein-Leopoldshafen
GERMANY
arianna.ferrari@kit.edu

Feuillet, Brigitte

University of Rennes
Membre of Institut Universitaire de
France Faculté de droit 9
rue Jean Macé 35700 RENNES
FRANCE
brigitte.le-mintier@univ-rennes1.fr

Fieldsend, David

CARE for Europe/Centre for Bioethics
Public Policy
57 Rue Archimède, 1000-Brussels
BELGIUM
david.fieldsend@careforeurope.org

Findik, Sinan

Instructor, Acibadem University
Vocational School of Health Services,
Gülsuyu Mah. Fevzi ÇakmakCad.
Divan Sok. No:1 34848 Maltepe,
İSTANBUL
TURKEY
sinan.findik@acibadem.edu.tr

Florea, Teddy

Center for Ethics and Law in Biomedicine
(CELAB)
Central European University, Budapest
HUNGARY
florea_george@ceu-budapest.edu

Forde, Reidun

Center for Medical Ethics
Institute of General Practice and Community
Medicine Faculty of Medicine University of
Oslo
NORWAY
reidun.forde@medisin.uio.no

Fuchs, Michael

Institut Für Wissenschaft Und Ethik
GERMANY
iwe@iwe.uni-bonn.de

Friedo Zölzer

Faculty of Health and Social Studies
Southbohemian University in České
Budějovice
CZECH REPUBLIC
zoelzer@zsf.jcu.cz

Gastmans, Chris

Catholic University Leuven
Centre for Biomedical ethics and Law
Kapucijnenvoer 35, 300 Leuven
BELGIUM
Chris.Gastmans@med.kuleuven.be

Genc, Volkan Savas

Mehmet Akif Ersoy University
Faculty of Veterinary Department of
Veterinary History and Deontology
TURKEY
svgenc@yahoo.com

Geneviève, Pinsart Marie

Chairman of the Belgian Advisory
Committee on Bioethics 4, Rue de
l'Autonomie B-1070 Brussels
BELGIUM
gpinsart@ulb.ac.be

Gordijn, Bert

Ethics Institute at Dublin City University
Dublin 9,
IRELAND
b.gordijn@gmail.com

Gorkey, Sefik

Marmara University, Faculty of Medicine,
Department of Medical Ethics and History of
Medicine
TURKEY
sgorkey@marmara.edu.tr / gorkey@super-
online.com

Gun, Mukadder

GATA Eğitim Hast.
Spor Hekimliği AD, Ankara
TURKEY
mukadder200@yahoo.com

Güven, Tolga

Marmara University Faculty of
Medicine Department of Medical Ethics and
History of Medicine
TURKEY
tolgagüven@hotmail.com

Haines, Erica

Policy, Ethics and Life Sciences Research
Centre, Newcastle University
UNITED KINGDOM
erica.haines@newcastle.ac.uk

Hamiti, Mentor

South East European University
MACEDONIA
m.hamiti@seeu.edu.mk

Hammond Browning, Natasha

University Of Bristol Canynge
Hall 39 Whatley Road
ENGLAND
N.Browning@bristol.ac.uk

Hambro Alnæs, Anne

Center of Medical Ethics,
Faculty of Medicine, Oslo University
NORWAY
ahambro@online.no

Hattori, Kenji

Department of Medical Philosophy and
Ethics Gunma University Graduate School
of Medicine
3-39-22 Showa-machi
Maebashi, Gunma 371-8511
JAPAN
hattorik@med.gunma-u.ac.jp

Helgesson, Gert

Stockholm Centre for Healthcare Ethics
Dept. of Learning, Informatics, Management
and Ethics (LIME)
Karolinska Institutet, Stockholm
SWEDEN
gert.helgesson@ki.se

Heijnen, Angelique

Hofmann, Bjørn

Center for medical ethics,
University of Oslo Section for Health,
Technology, and society,
University College of Gjøvik
NORWAY
bjoern.hofmann@hig.no /
b.m.hofmann@medisin.uio.no

Horak, Hana

Faculty of business and economics,
University of Zagreb,
Trg J.F. Kennedyja 6, 10000 Zagreb
CROATIA
hhorak@efzg.hr

Horn, Ruth

Centre for Ethics in Medicine University of
Bristol Canynge Hall 39 Whatley Road,
Bristol, BS8 2PS
UNITED KINGDOM
Ruth.Horn@bristol.ac.uk

Ispas, Ioana

Center for Applied Ethics
University of Bucharest
204 Splaiul Independentei Blvd, Bucharest
ROMANIA
ioana_isp@yahoo.com

Izmirli, Serdar

Department of History of Veterinary
Medicine and Deontology, Veterinary
Faculty University of Selcuk, Konya
TURKEY
sizmirli@selcuk.edu.tr

Ilbars, Hilal

Turkish Ministry of Health,
General Directorate of Drug and Pharmac
Sogutozu Mah. 2176 Sok. No:5 Çankaya-
ANKARA
TURKEY
hilbars1970@yahoo.com

Jensen, Karsten Klint

University of Copenhagen
DENMARK
kkje@life.ku.dk

Jivkova, Christina

Department of Social medicine and Health
Management
section "Medical ethics and History
of Medicine", Medical Faculty, Medical
University, Sofia
BULGARIA
hr_jiv@yahoo.com

Jox, Ralf

Institute for Ethics, History and
Theory of Medicine Ludwig-Maximilians
University Munich Lessingstrasse 2 D-
80336 Munich
GERMANY
Ralf.jox@med.lmu.de

Kaboglu, Ibrahim O.

Marmara Üniversitesi, Hukuk Fakültesi,
34766 Haydarpaşa, İstanbul,
Professor of Constitutional Law
Chair of the Department of Constitutional
Law Faculty of Law Marmara University
(İstanbul)
TURKEY
ikaboglu@marmara.edu.tr

Kadioglu, Funda

Cukurova University, Faculty of
Medicine Department of Medical Ethics
TURKEY
fgkadioglu@cu.edu.tr

Kakuk, Péter

Department of Behavioural Sciences
Medical and Health Sciences Center
School of Public Health University of
Debrecen, Nagyerdei krt. 98. P.O.Box 45.
4032 Debrecen
HUNGARY
kakukp@med.unideb.hu

Karatas, Mehmet

Inonu University Faculty of Medicine
History of Medicine and Ethics Dept.
TURKEY
drkaratas@hotmail.com /
m.karatas@inonu.edu.tr

Kato, Shuichi

Meiji Gakuin University
JAPAN
katos@soc.meijigakuin.ac.jp

Kavas, M. Volkan

Ankara Üniversitesi Tıp Fakültesi Tıp Tarihi
ve Etik AD Sıhhiye/Ankara
TURKEY
volkankavas@yahoo.com

Kerasidou, Angeliki

The Ethox Centre, Department of Public
Health, University of Oxford, Badenoch
Building,
Old Road Campus, Oxford, OX3 7LF
ENGLAND
angeliki@well.ox.ac.uk

Kind, Christian

Central Ethics Commission of the Swiss
Academy of Medical Sciences
Ostschweizer Kinderspital
CH-9006 St. Gallen
SWITZERLAND
christian.kind@kispisg.ch

Kirklin, Deborah

University College London
ENGLAND
d.kirklin@ucl.ac.uk

Kobert, Klaus

Im Pferdebrook 8b 33619
Bielefeld
GERMANY
klaus.kobert@evkb.de

Kovacs, Laszlo

Moral Deliberation Group VUmc & GGNet
Secretary
P.O. Box 2003 - 7230 GC Warnsveld – the
Netherlands

Kucukaslan, Ozgul

Ankara Üniversitesi Veteriner Fakültesi
TURKEY
ozgulkucukaslan@hotmail.com

Marinova J. Krumova

Department of Social
Medicine and Healthcare Management
Medical Faculty at Trakia University – Stara
Zagora Bulgaria 11 Armeiska Street, 6000
Stara Zagora
BULGARIA
marinova@mf.uni-sz.bg

Kusterer, Liliane Elze Falcão Lins

Biomorphology Bioethics Pos-graduation in
Medicine and Human Health Escola
Bahiana de Medicina e Saúde Pública
EBMSP (School of Medicine and Public
Health from Bahia)
Rua Frei Henrique, n 8. Nazaré, CEP
40050420.Salvador,Bahia
BRAZIL
lilianelinskusterer@bahiana.edu.br

Lichterman, Boleslav L.

The Burdenko Neurosurgery
Institute, Moscow
RUSSIA
lichterman@hotmail.com

Lee, Hsiao-Lu

Department of Nursing, Chung Hwa
University of Medical Technology, Tainan
County
TAIWAN
thmoas.suen@msa.hinet.net

Liu, Hung-En

Law National ChengChi University, Taipei
116
TAIWAN
markliu@nccu.edu.tw

Lillemoen, Lillian

Centre for Medical Ethics, University of Oslo
NORWAY
Lillian.lillemoen@medisin.uio.no

Madanamoothoo, Allane

ESC Business School of Troyes, France
allane51100@gmail.com

McKeown, Alexander

University of Bristol Centre for Ethics in
Medicine School of Social Medicine
Canynge Hall
39 Whatley Road Bristol BS8 2BS
UNITED KINGDOM
alex.mckeown@bristol.ac.uk

Mertz, Marcel

CELLS – Centre for Ethics and Law in
the Life Sciences Institute for History,
Ethics and Philosophy of Medicine
Hannover Medical School
Carl-Neuberg-Str. 1, D-30625 Hannover
GERMANY
Mertz.Marcel@mh-hannover.de

Metodieva, Dimitrova Svetlana

Department of Social Medicine and
Healthcare Management Medical Faculty at
Trakia University – Stara Zagora, 11
Armeiska Street, 6000 Stara Zagora
BULGARIA
svdimitr@mf.uni-sz.bg

Michailov, Michael Ch.

Inst. Umweltmedizin c/o Int. Council Sci.
Dev. Int. Acad. Sci., Austria, Bulgaria,
Germany, Slovakia
Univ. Erl.-Nürnberg & Univ. Innsbruck. ICSD
e.V. Postfach
(POB) 340316, D-80100 München
GERMANY
m.michailov@hotmail.de

Miyagi, Akiko

Gunma University
JAPAN
akiko-m@med.gunma-u.ac.jp

Mladenova, Sylvia

Medical University – Sofia
sylvia_m@abv.bg

Neitzke, Gerald

Institute for History, Ethics and Philosophy
of Medicine Hannover Medical University
Carl-Neuberg-Str. 1 D – 30625 Hannover
GERMANY
Neitzke.gerald@mh-hannover.de

Nicholson, Richard

6 Gallia Road, London N5 1LA No institutional
affiliation;
former editor, Bulletin of Medical Ethics
ENGLAND
bullmedeth@hotmail.co.uk

Niekerk, Anton A van

Centre for Applied Ethics Philosophy
Department
Stellenbosch University
Privage Bag X1, Matieland, 7602,
SOUTH AFRICA
aavn@sun.ac.za

Ospanova, Tetyana

Kharkiv National Medical University,
4, Lenina pr, 61022, Kharkiv,
UKRAINE
t.ospanova@mail.ru

Ogenler, Oya

Mersin University Faculty of Medicine
Department of History of Medicine and
Medical Ethics
TURKEY
oyaogenler@gmail.com

Okuyan, Zuhâl

Dokuz Eylul University, School of Medicine,
İzmir
TURKEY
zuhâl.okuyan@gmail.com

Ors, Yaman

Ankara University Medical Faculty
Dept. of Deontology
TURKEY
bilimselfelsefeci@tr.net

Ozcan Senses, Muesser

Kocaeli University
TURKEY
muesser@kocaeli.edu.tr

Ozden, Dilek

Cumhuriyet University,
Faculty of Health Sciences, Nursing
Department.
TURKEY
dozden2002@yahoo.com

Ozdogan, Tutku

Marmara University Neonatology
Department
TURKEY
tutkuozdogan@yahoo.com

Ozguc, Meral

Hacettepe University, Faculty of Medicine
Department of Medical Biology and
DNA/Cell Bank
Ankara, Turkey
mozguc@hacettepe.edu.tr

Ozgur, Atilla

Ankara University, Faculty of Veterinary,
Department of Veterinary History and
Deontology
TURKEY
ozgur@veterinary.ankara.edu.tr

Ozsunay, Ergun

Council of Europe
CDBI Delegate of Turkey
Strasbourg, FRANCE
ergunozsunay@yahoo.com

Parashkevova, Boryana

Medical Faculty/ Trakia University
BULGARIA
b_par@abv.bg

Pegoraro, Renzo

Fondazione Lanza, Via Dante 55, 35139
Padua
ITALY
renzo.pegoraro@fondazioneanza.it

Peker, Gonul

Ege University Faculty of Medicine
Dept. of Physiology, Izmir
TURKEY
gonul.peker@ege.edu.tr

Perkins, Henry S.

The University of Texas Health Science
Center at San Antonio, Texas
U.S.A.
perkins@uthscsa.edu

Peters, Tim

Institute for Medical Ethics and History of
Medicine Ruhr University Bochum
Malakowturm-Markstr 258a, 44799 Bochum
GERMANY
tim.peters@rub.de

Petrova, Galina

Medical Faculty/ Trakia University
BULGARIA
gpetrova@mf.uni-sz.bg

Pisu, Salvatore

Department of Forensic Medicine,
University of Cagliari, Cagliari,
ITALY
salvatore.pisu@libero.it

Plana Borrás, Juliana

Institut Borja De Bioètica
SPAIN
bioetica@ibb.hsjdbcn.org

Porz, Rouven

Head, Ethics Unit, University Hospital Bern
Murtenstr.10, Fachstellen DP
Bern University Hospital "Inselspital"
CH - 3010 Bern
SWITZERLAND
Rouven.Porz@insel.ch

Räikkä, Juha

Department of Behavioural Sciences and
Philosophy University of Turku
Assistentinkatu 7, 20014 University of Turku
FINLAND
jraikka@utu.fi

Rakić, Vojin

Institute for Philosophy and
Social Theory University of Belgrade
Kraljice Natalije 45 11000 Beograd
SERBIA
vojinrakic@hotmail.com

Refolo, Pietro

Institute of Bioethics (Director: Prof. Antonio
G. Spagnolo)
"Agostino Gemelli" School of Medicine
Università Cattolica del Sacro Cuore
L.go Francesco Vito, 1 - 00168 Rome
ITALY
pietro.refolo@rm.unicatt.it

Rodriguez, Daniele

University Of Padova
ITALY
daniele.rodriguez@unipd.it

Rozynska, Joanna

University of Warsaw, Institute of
Philosophy, Department of Ethics
3 Krakowskie Przedmiescie
Street, 00-927 Warsaw
POLAND
jrozynska@gmail.com,
j.rozynska@uw.edu.pl

S.Aljarallah, Jamal

Department of Family and Community
Medicine,
College of Medicine, King Saud University,
Riyadh,
SAUDI ARABIA
jaljarallah@ksu.edu.sa
jaljarallah@gmail.com

Şahinoğlu, Serap

Ankara Üniversitesi Tıp Fakültesi
Deontoloji Anabilim Dalı Öğretim Üyesi
TURKEY
serapsahinoglu@yahoo.co.uk

Salloch, Sabine

Institute for Medical Ethics and
History of Medicine, Ruhr University
Bochum
GERMANY
Sabine.Salloch-s52@Rub.de

Sehiralti, Mine

Kocaeli University, Medical School,
Department of History of Medicine and
Ethics
KOCAELI
msehir@gmail.com

Schildmann, Jan

Institute for Medical Ethics and History of
Medicine Ruhr University Bochum
Malakowturm-Markstr 258a, 44799 Bochum
GERMANY
jan.schildmann@rub.de

Schofield, Behnaz

Centre for Ethics in Medicine School of
Social and Community Medicine University
of Bristol Canynge Hall 39 Whately Road
Bristol BS8 2PS
ENGLAND
Behnaz.Schofield@bristol.ac.uk

Sert, Gurkan

Marmara University, Faculty of Medicine
Department of Medical Ethics and History of
Medicine
TURKEY
ozgurgurkan@yahoo.com

Sevimli, Sukran

100. Year University Medical Faculty
Medical History and Ethics Dept. Van
TURKEY
sukransevimli@gmail.com & mhistory.deon-
tology.ssevimli@gmail.com

Shevchenko, Alexander

SI "Institute of Pediatrics
Obstetrics and Gynecology National
Academy of medical sciences of Ukraine",
Kiev-04050, 8, P. Mayborodi str.
UKRAINE
aashevchenko@mail.ru

Siminoff, Laura

Virginia Commonwealth University, Mcv
USA
lasiminoff@vcu.edu

Siipi, Helena

Department of Behavioural Sciences and
Philosophy,
20014 University of Turku
FINLAND
helena.siipi@utu.fi

Sjöstrand, Manne

Karolinska Institutet, Centre for
Healthcare Ethics, Berzelius väg 3,
11771 Stockholm
SWEDEN
manne.sjostrand@ki.se

Slatman, Jenny

CAPHRI School for Public Health and pri-
mary Care Department Health, Ethics and
Society,
Maastricht University Medical Center
PO Box 616 6200 MD Maastricht
NETHERLANDS
Jenny.slatman@maastrichtuniversity.nl

Sofaer, Neema

Centre of Medical Law and Ethics
School of Law King's College London
ENGLAND
neema.sofaer@kcl.ac.uk

Somer, Pervin

Kadir Has Üniversitesi Hukuk Fakültesi,
Kadir Has Cad. D-Blok-Cibali-
Eminönü/İSTANBUL
TURKEY
pervins61@hotmail.com

Sorokina, Iryna

Kharkiv National Medical University
UKRAINE
soririna1@mail.ru

Sozen, Bilge

Ankara University Faculty of Pharmacy
Department of Management
TURKEY
bilgesozen@yahoo.com

Spagnolo, Antonio G.

Università Cattolica S. Cuore
Largo Francesco Vito
00168 Rome
ITALY
agsoagnolo@rm.unicatt.it

Spranzi, Marta

Medical ethics University of
Versailles CERSES (University of Paris
Descartes)
FRANCE
marta.spranzi@club.fr

Simek, Jiri

University of South Bohemia,
Faculty of Health and Social Studies.
Adress
J. Boreckeho 27, 370 11, Ceske Budejovice,
CZECH REPUBLIC
jr.simek@volny.cz

Sultan, Raji

Brocher Foundation Route
d'Hermance 471, CH-1248
Hermance Geneva
SWITZERLAND
r.sultan@brocher.ch

Stålhandske, Maria Liljas

Uppsala Religion and Society Research
Centre, Uppsala University,
Box 511, SE 751 20 Uppsala,
SWEDEN
marla.liljas@crs.uu.se

Strech, Daniel

Hannover Medical School
Centre of Public Health and Healthcare
Institute of History, Ethics and Philosophy
Carl Neuberg Str. 1, 30625 Hannover
GERMANY
Strech.Daniel@mh-hannover.de

Stutzki, Ralf

Dept. Medical and Health Ethics,
Medical Faculty, University Hospital Basel,
Switzerland, Missionsstrasse 21, CH-4055
Basel
SWITZERLAND
ralf.stutzki@unibas.ch; <http://medethik.unibas.ch>

Taylor, Kenneth

4th Floor Claremont Bridge
Newcastle University
ENGLAND
kenneth.taylor@ncl.ac.uk

Tekin, Demet

İstanbul Bilgi University, School of Health
Sciences
Physiotherapy and Rehabilitation
TURKEY
tekindemett@gmail.com

ter Meulen, Ruud

Centre for Ethics in Medicine
University of Bristol
ENGLAND
r.termeulen@bristol.ac.uk

Tozun, Nurdan

Acibadem University School of Medicine
Vice-Rector.
Gulsuyu, Fevzi Cakmak cad. Divan sok
No.1 Maltepe- Istanbul TR-34848
TURKEY
nurdantozun@hotmail.com

Tozzo, Pamela

Fellow at Legal Medicine of University of
Padua Fondazione Lanza Padova
ITALY
pamela.tozzo@unipd.it

Turkmendag, ilke

Policy, Ethics and Life Sciences Research
Centre, Newcastle University,
UNITED KINGDOM
ilke.turkmendag@ncl.ac.uk

Ulman, Yesim Isil

Acıbadem University School of Medicine,
Department of History of Medicine and
Ethics
Gülsuyu, Fevzi Çakmak Cad.
Divan sok. No. 1
Maltepe-Istanbul
TURKEY
yesimul@yahoo.com

Unalan, Pemra

Department of Family Medicine,
Marmara University Medical Faculty,
Istanbul, Turkey
pcunalan@gmail.com

Vanderhaegen, Bert

University Hospital Ghent
De Pintelaan 185, 9000 Gent
BELGIUM
bert.vanderhaegen@uzgent.be

Vanlaere, Linus

Centre for Biomedical Ethics and Law
KULeuven, Kapucijnenvoer 35, 3000
Leuven
BELGIUM
Linus.Vanlaere@med.kuleuven.be

Verbitskiy, A.N.

Institute of Neurosurgery National
Medical Academy of Ukraine, Kiev-04050,
32, P. Mayborodi str.
UKRAINE
pitulik@mail.ru

Widdershoven, Guy

VU medisch centrum
Afdeling Metamedica
Van der Boechorststraat 7
1081 BT Amsterdam
NETHERLANDS
g.widdershoven@vumc.nl

Wu, Chuan-Feng

Institutum Iurisprudentiae
Academia Sinica 128 Academia Road
Section 2, Taipei City 11529
TAIWAN
cfw@gate.sinica.edu.tw

Yeates, James

Centre for Ethics in Medicine
University of Bristol
ENGLAND
James.Yeates@bristol.ac.uk

Yildirim, Gulay

Cumhuriyet University, Faculty of Medicine
Department of Deontology and History of
Medicine-Sivas
TURKEY
gyildirim@gmail.com

Yusof, Aimi

The Ethox Centre, Department of Public
Health
University of Oxford, Badenoch Building
Old Road Campus, Oxford, OX3 7LF.
ENGLAND
aimi.yusof@st-hildas.ox.ac.uk

Yucel, Ozge

Atılım University Faculty of Law
Department of Civil Law, Kızılcaşar Mah.
İncek/Gölbaşı/Ankara
TURKEY
oyucel@atilim.edu.tr

Yurur, Kizilca

Istanbul University School of Medicine
Dept. of Medical Ethics, Istanbul
TURKEY
kizilca2002@yahoo.com

Yuzbasioglu, Ayse

Hacettepe University, Faculty of Medicine
Department of Medical Biology and
DNA/Cell Bank, Ankara
TURKEY
ayuzbasi@hacettepe.edu.tr

Zillen, Kavot

Uppsala University
SWEDEN
kavot.zillen@jur.uu.se

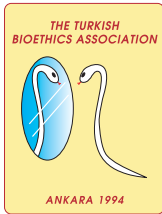
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