



The 5<sup>th</sup> International and Interdisciplinary Conference on  
**Health, Culture and the Human Body**

Principles of Biomedical Ethics,  
Genetics and Human Enhancement

4–6 October 2018 • Istanbul • Turkey

## ABSTRACTS



## COMMITTEE OF ORGANIZATION

### Presidency

**Hakan Ertin, PhD**, Istanbul University

**İlhan İlkılıç, PhD**, Istanbul University

**Rainer Brömer, PhD**, Istanbul University

### Secretary

**Tayyibe Bardakçı, PhD**, Istanbul University

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The 5<sup>th</sup> International and Interdisciplinary Conference on  
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The frontlines of biomedical developments are expanding at an increasing speed. Novel technologies such as genome editing or repairing tissues in the human body or changing behavior through drugs are promoted with great emphasis on how they might improve human life. At the same time, they raise profound concerns and fears. Since medical ethics began to professionalize in the 1970s, there has been demand on ethicists to increase their efforts to help society come to terms with the new possibilities and risks of biotechnologies. For almost four decades, Beauchamp and Childress's foundational *Principles of Biomedical Ethics* has provided a widely used framework for the analysis of questions arising in healthcare and biomedical research. Now in its 7<sup>th</sup> English edition (2012), which has recently been translated into Turkish by Dr. M. Kemal Temel (2017), the book of the highly recognized principles of the diverse field of medical ethics is still being subject to a lively debate, increasingly beyond the limits of Anglo-Saxon and general Western discourses. The cultural adaptability of any given set of ethical principles is controversial yet growing in importance in an interconnected world of health tourism and strategic choices of convenient research locations, especially by the industry.

This year's conference will focus on the rapidly changing areas of genetic and genomic science and other forms of enhancement. We want to discuss principlist and other innovative ethical approaches to these biotechnologies, consider the historical formation of contemporary bioethics, and examine the history of reading and rewriting human nature with the aim to restore, enhance, or innovate bodily and mental functions.

We particularly welcome interdisciplinary perspectives from areas such as medical history and ethics as well as human and social sciences in healthcare (medicine studies, epidemiology, social anthropology). Our four earlier conferences under the theme "Health, Culture and the Human Body" (Mainz 2010, Istanbul 2012 & 2014, Bremen 2016) established a dynamic platform for a collaborative discourse on medical interventions and organ transplantation as well as palliative care and the topic of migration and health. Such international and interdisciplinary discussion from ethical, historical and epidemiological perspectives has been the "trademark" of our congress series.



## PROGRAM

### 4 October 2018, Thursday

#### Venue

Istanbul University Rectorate Building, Doctorate Hall Beyazıt, Istanbul

12.00 – 13.00

#### Registration

13.00 – 13.40

#### Welcome

13.00 – 13.10

#### **Assoc. Prof. Hakan Ertin**

Istanbul Faculty of Medicine, Istanbul University  
Director of Beşikçizade Center for Medical Humanities  
(BETIM)

13.10 – 13.20

#### **Dr. Ahmet Özdemir**

President of Hayat Foundation for Health and Social  
Services

13.20 – 13.30

#### **Murat Aydın**

Mayor of Zeytinburnu

13.30 – 13.40

#### **Prof. Dr. Mahmut Ak**

President of Istanbul University

13.40 – 14.15

#### Keynote Address

#### **Christine Hauskeller** (Exeter, UK)

The role of philosophy in shaping biomedical science

14.15 – 14.25

#### Break

14.25 – 15.35

#### Genetics and Ethics

**Chair:** Aasim I. Padelá (Chicago, US)

14.25 – 14.45

#### **Khalid Al-Ali** (Doha, QA)

The duty to know in the genomic era

14.45 – 15.05

#### **Clara Hick** (Exeter, UK)

Genetics and identity

15.05 – 15.25 **Achim Rosemann, Christine Hauskeller** (Exeter, UK)  
Heritable gene editing in humans: discussing the opportunities and limitations of international guidelines

15.25 – 15.35 **Questions & Answers**

15.35 – 15.45 **Break**

15.45 – 16.55 **Human Enhancement**

**Chair:** Christine Hauskeller (Exeter, UK)

15.45 – 16.05 **Jennifer Schmid, Ralf J. Jox** (Munich, DE)  
Ethics and brain-computer-interfaces: a mixed-methods study with healthy users

16.05 – 16.25 **Tayyibe Bardakçı, Hakan Ertin** (Istanbul, TR)  
A discussion of the emerging ethical problems in implantable chip technology as inspired by the series *Black Mirror*

16.25 – 16.45 **Melike Şahinol** (Istanbul, TR)  
Unless they do not build cyborgs: ethics missing the point of cyborg constitution in neuroscientific trials?

16.45 – 16.55 **Questions & Answers**

16.55 – 17.05 **Break**

17.05 – 17.55 **Human Nature, Human Dignity**

**Chair:** Murteza Bedir (Istanbul, TR)

17.05 – 17.25 **Ismail Lala** (Oxford, UK)  
Immutable or alterable? Human nature and the immutable essences in the metaphysical/ethical weltanschauung of Ibn ‘Arabi

17.25 – 17.45 **Şaban Ali Düzgün** (Ankara, TR)  
Philosophical and theological roots of the conceptualization of human dignity

17.45 – 17.55 **Questions & Answers**

## 5 October 2018, Friday

### Venue

Istanbul University Rectorate Building, Doctorate Hall Beyazıt, Istanbul

09.30 – 10.05

### Keynote Address

**Dieter Birnbacher** (Düsseldorf, DE)  
The ethical ambivalence of enhancement

10.05 – 11.40

### Human Enhancement Transhumanism & Posthumanism

**Chair:** M. İhsan Karaman (Istanbul, TR)

10.05 – 10.25

**Hakan Ertin, Tayyibe Bardakçı** (Istanbul, TR)  
A normative approach to the human enhancement debate

10.25 – 10.45

**Cenk Özdağ** (Ankara, TR)  
Humanist reactions to human enhancement and transhumanism

10.45 – 11.05

**Jiwon Shim** (Seoul, KR)  
Human enhancement and Heaven Project: the definition of the boundaries of my body in posthuman

11.05 – 11.25

**Hakan Darıcı, Erdal Karaöz** (Istanbul, TR)  
Transhumanism and human enhancement: the role of stem cells and exosomes

11.25 – 11.40

### Questions & Answers

11.40 – 11.50

### Break

11.50 – 12.40

### Principles of Biomedical Ethics

**Chair:** Fuat Oduncu (Munich, DE)

11.50 – 12.10

**İlhan İlkılıç** (Istanbul, TR)  
Can principlism be used as a universal concept for solving clinical ethical problems?

12.10 – 12.30

**Melike Konuk, M. Murat Civaner** (Bursa, TR)  
Does principlism provide enough guidance on ethical problems? The example of genetic diagnosis and therapy

12.30 – 12.40 **Questions & Answers**

12.40 – 14.20 **Lunch Break**

14.20 – 14.55 **Keynote Address**

**Aasim I. Padelá** (Chicago, US)  
Genetics and human reproduction: what can religious values offer?

14.55 – 16.05 **Genetics, Ethics, Human Research**

**Chair:** M. Alpertunga Kara (Istanbul, TR)

14.55 – 15.15 **John D. Lantos** (Kansas City, US)  
The promise and the perils of whole genome sequencing of newborns

15.15 – 15.35 **Cemal Hüseyin Güvercin, Serap Kaya** (Izmir, TR)  
Designer babies through gene editing: utopia or dystopia?

15.35 – 15.55 **İbrahim Topçu, Nadir Koçak** (Istanbul, TR)  
Ethical boundaries of genomic editing applications

15.55 – 16.15 **Mukadder Gün** (Ankara, TR)  
International standards of human research (2018) and the example of Turkey (a critical approach)

16.15 – 16.30 **Questions & Answers**

16.30 – 16.40 **Break**

16.40 – 18.10 **Genetics and Ethics**

**Chair:** İlhan İlkılıç (Istanbul, TR)

16.40 – 17.00 **Selvi Çopur** (Münster, DE)  
Ethical assessment of genetic prevention measures in consanguineous marriages in Muslim societies

17.00 – 17.20 **Ülkücan Kaplan** (Ankara, TR)  
Genetic counseling in Turkey and bioethics

17.20 – 17.40 **Başak Işıl Çetin** (Istanbul, TR)  
Discrimination based on genetic information in the working life



17.40 – 18.00 **Hatice Keskin** (Ankara, TR)  
Genetics in service of a better life

18.00 – 18.10 **Questions & Answers**

19.00 – 22.00 **Gala Dinner**

Zeytinburnu Belgradkapı Social Facilities

## 6 October 2018, Saturday

### Venue

Beşikçizade Center for Medical Humanities (BETIM)

09.30 – 10.05 **Keynote Address**

**Fuat Oduncu** (Munich, DE)  
The role of ethical principles (principlism) in end-of-life medicine

10.05 – 11.15 **The Beginning and the End of Life / Hall 1**

**Chair:** Achim Rosemann (Exeter, UK)

10.05 – 10.25 **Ayşenur Günaydın** (Istanbul, TR)  
The ongoing ethical debate: mitochondrial donation

10.25 – 10.45 **Sarah Jafri** (London, UK)  
Ethical implications of mitochondrial donation

10.45 – 11.05 **Betül Kılıç, M. Murat Civaner** (Bursa, TR)  
Aborting the fetuses with Down syndrome: is it ethically justifiable?

11.05 – 11.15 **Questions & Answers**

11.15 – 11.25 **Break**

10.05 – 11.15 **The Beginning and the End of Life / Hall 2**

**Chair:** Mukadder Gün (Ankara, TR)

10.05 – 10.25 **Tutku Özdoğan, İlhan İlkılıç** (Istanbul, TR)  
How do Turkish parents decide for their children at the end of life?

- 10.25 – 10.45 **Selda Okuyaz, Meltem Direk, Oya Ögenler, Didem Derici Yıldırım** (Mersin, TR)  
A pilot study on empathy skills of pediatricians
- 10.45 – 11.05 **Annette Kurrle** (Mainz, DE)  
Medical ethical questions at the end of life in geriatrics and the intercultural aspect
- 11.05 – 11.15 **Questions & Answers**
- 11.15 – 11.25 **Break**
- 11.25 – 12.40 **Genetics and Ethics**
- Chair:** Khalid Al-Ali (Doha, QA)
- 11.25 – 11.45 **Cihan Taştan** (Istanbul, TR)  
Hope and cure for treatment of genetic/rare diseases with CRISPR Genome Repair Technology
- 11.45 – 12.05 **Davide Battisti** (Milano, IT)  
CRISPR/CAS9 and CRISPR/EvoCas9. Ethical issues in Germline Gene Editing
- 12.05 – 12.25 **Maide Barış** (Istanbul, TR)  
Moral issues regarding non-therapeutic genome editing and parental expectations
- 12.25 – 12.40 **Questions & Answers**
- 12.40 – 13.40 **Lunch Break**
- 13.40 – 15.35 **New Technologies, Ethics, Privacy**
- Chair:** İnanç Özekmekçi (Kayseri, TR)
- 13.40 – 14.00 **M. Murat Civaner, Filiz Bulut** (Bursa, TR)  
Can artificial intelligence practice medicine? A critical appraisal with reference to present-day medicine
- 14.00 – 14.20 **Gülten Özkan, M. Murat Civaner** (Bursa, TR)  
The evolution of the nursing profession at the dawn of humanoids: adaptation or assimilation?

- 14.20 – 14.40 **Yusuf İhsan Özdilek, Enes Pay, Ahmet Ali Çelik**  
(Istanbul, TR)  
Using Google glass in medicine and potential ethical issues
- 14.40 – 15.00 **Zeynep Aybikem Sağlam, Mehmet Göktuğ Günel, Hakan Ertin, Mehmet Ali Sungur, Şükrü Öksüz**  
(Düzce, TR)  
Privacy perception of health professionals and recent debates in Turkey
- 15.00 – 15.20 **Rabia Yücel, Merve Karaca, Muhammed Cihan Işık, Çağrı Emin Şahin** (Ankara, TR)  
Evaluating social media usage in disasters from an ethical perspective
- 15.20 – 15.35 **Questions & Answers**
- 15.35 – 15.45 **Break**
- 15.45 – 16.55 **Historical Approach**  
**Chair:** M. Murat Civaner (Bursa, TR)
- 15.45 – 16.05 **Mustafa H. Sayar** (Istanbul, TR)  
Asking gods for healing
- 16.05 – 16.25 **Arın Namal, Hakan Kızıltan** (Istanbul, TR)  
The scientist and painter Akil Muhtar Özden (1877–1949) from the virtue ethics perspective and his work entitled “Ethics in Terms of Science”
- 16.25 – 16.45 **Alexandra Bettag** (Munich, DE)  
Contemporary ethics seen in a historical perspective: early modern thought as the beginning of the questioning of values
- 16.45 – 16.55 **Questions & Answers**
- 16.55 – 17.05 **Break**
- 17.05 – 18.15 **Workshop: Interculturality at the End of Life / Hall 1**  
**Moderators:** Fuat Oduncu (Munich, DE)  
İlhan İlkılıç (Istanbul, TR)

17.05 – 18.15

**Workshop: ILEM Special Session / Hall 2**

**Moderator:** Lütfi Sunar (Istanbul, TR)

17.05 – 17.25

**Lütfi Sunar** (Istanbul, TR)

“Reputable doctor”: subjective and objective dimensions of social prestige

17.25 – 17.45

**İhsan Kutlu** (Sakarya, TR)

Evaluation of healthy lifestyle behaviors (physical activity and nutrition) according to some sociodemographic variables

17.45 – 18.05

**Ömer Ataç** (Istanbul, TR)

The so-called importance given to health

18.15 – 18.30

**Closing Remarks**

**İlhan İnkılıç**

Istanbul University, Istanbul Faculty of Medicine

## COMMITTEE OF ORGANIZATION

### Presidency

**Hakan Ertin, İlhan İlkılıç, Rainer Brömer**  
Istanbul University, Istanbul Faculty of Medicine

### Secretary

**Tayyibe Bardakçı**  
Istanbul University, Istanbul Faculty of Medicine

### Ahmet Karakaya

University of Exeter, Center for the Study of Life Sciences (EGENIS)

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## CONGRESS VENUE

**4-5 October 2018** Istanbul University Rectorate Building, Doctorate Hall Beyazıt, Istanbul

**6 October 2018** Beşikçizade Center for Medical Humanities (BETİM)  
Kızılelma St., Topçu Emin Bey Dr. 4, Fındıkzade, Istanbul

## LANGUAGES

Conference language is English.

## ACCOMMODATION – Recommended Hotels

### Hotel Linda, Beyazıt

www.istanbulhotellinda.com - Phone: +90 212 517 28 50  
Room price (single) € 25

### Wyndham Istanbul Old City, Laleli

www.wyndhamhotels.com - Phone: +90 212 514 90 00  
Room price (single) € 70

## PATRONAGE

The conference will be held under the auspices of Prof. Dr. Mahmut Ak, president of Istanbul University, and Dr. Ahmet Özdemir, president of Hayat Foundation for Health and Social Services.



# ABSTRACTS

## Health, Culture and the Human Body

4-6 October 2018 · Istanbul · Turkey

## The 5<sup>th</sup> International and Interdisciplinary Conference on **Health, Culture and the Human Body**

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4 October 2018, Thursday

13.00 – 17.45 Istanbul University Rectorate Building, Doctorate Hall

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### **The role of philosophy in shaping biomedical science**

**Christine Hauskeller** (Exeter, UK)

Philosophy has contributed directly to research agendas as well influenced clinical research and the practice of biomedicine. In some rough clustering, bioethics may be styled as the application of normative principles to address risks of interfering with biological processes and objects. Philosophy in medical ethics discusses good practice in doctor-patient-interactions and principle concepts that should guide it. Philosophy of science claims an epistemological role, reflecting on the inherent logic and validity criteria for methods, object choices and foci in biomedical research. All three often work closely with science and in effect shape research designs and narratives about aims as well as risks and problems in biomedicine.

Biomedical science and its advancement is highly politicized. Governments and industries have stakes in what is researched, how, who and where. Biomedicine is suffused with - often conflicting - political and economic interests. I will report briefly on some of these.

If philosophy aims to contribute critical reasoning to this field intent on fostering science and medicine to be as good as they could be, it should therefore take more notice of these powerful interests. Contemporary social political philosophy and political economy provide concepts and methods of thinking to analyse such power dynamics in biomedicine. Opening-up this political perspective would give bio- and medical ethics more bite in controversies about biomedicine and ongoing developments in research and clinical practice.



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## The duty to know in the genomic era

**Khalid Al-Ali** (Doha, QA)

The completion of the sequencing of the human genome has been faced with both excitement and skepticism, and several countries in the region showed a keen interest to join this genomic revolution. This interest was tied to the potential that new genome-based technologies and medicine would have in advancing public health. However, this has been tempered by ethical concerns regarding protection of the human subject. This paper will explore ethical issues arising in human genome research and its application in the field of health. Although certain ethical principles are universal, their application varies in different countries and is influenced by the respective religion and culture. Genomic research raises a number of ethical and governance issues such as sample collections, export and ownership, consent, and privacy. The use of archived data and data sharing and how to handle incidental findings will also be discussed. Finally, an attempt will be made to identify some of the basic principles for ethical standards related to genomic research as it pertains to cultural and religious norms in the region. These ethical issues can best be identified and addressed where ethics is embedded in the design and implementation of such research projects.

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## Genetics and identity

**Clara Hick** (Exeter, UK)

With the genomics revolution, interesting questions about the genetic component of identity have arisen in the philosophical discussion. The access to ever more precise genetic information that gives insight into one's ancestry, the risk of certain diseases, or even speculation about one's character development, have shifted the way in which we think about the self. In the context of this conference, I want to discuss how identity is shaped through access to new technologies of genetic information, how one's place within society is established in a different light and how through new mechanisms of establishing disease risks, a new form of pathologization of personality traits has arisen. I will analyze the literature on the current development of genetics, and combine this scientific insight with philosophical literature on pathologization, in a Foucauldian sense, and identity theory. I will particularly focus on identities that have socially been established for a long time, such as race and disability, but have now become analyzable in a new way. I will discuss literature from critical race theory and disability studies to guide me through this analysis. Through this discussion, I wish to highlight the importance of an informed, cautious handling of the insights that the technologies surrounding genetics supposedly give us about ourselves and our position in society as compared to others.

## **Heritable gene editing in humans: discussing the opportunities and limitations of international guidelines**

**Achim Rosemann** (Exeter, UK), **Christine Hauskeller**

Ethical governance strongly builds on international regulatory guidelines. This paper discusses the opportunities and limitations of such approaches based on theoretical and empirical research with regulators conducted in the past three years. While support for heritable human gene editing (HHGE) for the prevention of severe monogenetic disorders has grown, there are widespread concerns that the technology will be used for non-medical purposes, including human genetic enhancement. Some commentators argue that the adoption of international guidelines will prevent problematic applications; others that a concerted control of human germline gene editing is illusionary and that non-medical applications will be inevitable if the technology progresses. We draw on insights from a multi-stakeholder study in the UK that has addressed the challenges and options for the governance of HHGE. Involved were scientists, regulators, IVF clinicians and representatives of patient groups, learned societies and NGOs. Project participants recognized the importance of international guidelines but pointed out a range of limitations of such a regulatory approach. Instead, a variety of complementary national and international regulatory instruments seemed a better way forward. The paper introduces the regulatory measures discussed and their likely benefits and problems in light of the global experience with how international guidelines work and how they organize research and clinical practice.

## **Ethics and Brain-Computer-Interfaces: a mixed-methods study with healthy users**

**Jennifer Schmid** (Munich, DE), **Ralf J. Jox**

Research on Brain-Computer Interfaces (BCIs) has rapidly increased in the last decades. BCIs record and use brain activity in order to control external devices such as personal computers or neuro-prostheses. Thus, persons can act by the power of their thoughts.

Based on maximum variation sampling, 24 qualitative interviews were conducted and analyzed using Qualitative Content Analysis (Mayring). Furthermore, an online survey of the German public is currently in preparation.

The results indicate that BCIs as a unique neurotechnology influence subjective perception of human-machine interaction in a novel way. Successful BCI use was highly dependent on training and individual motivation. Discomfort was mainly expressed due to the use of gel and the time-consuming procedure of EEG application. Almost all of the interviewees expressed being fascinated and puzzled by this new technology, often

using the word weird. This ambivalence regarding BCI technology is representative for almost all users. BCI experts considered the future potential of this neurotechnology as extremely high based on a rapid technological progress and individualization of mental strategies.

Furthermore, a wide range of ethical issues arise. Questions of agency and responsibility in the context of BCIs are still important topics which require further attention. Additionally, most users report privacy issues and increased concern about the loss of causal relations for their actions. Above all, unrealistic expectations regarding BCIs could easily lead to frustration. Our findings can be the basis for a broad discussion in public and policy trying to support a responsible and legally secure future use of BCIs.

### **A discussion of the emerging ethical problems in implantable chip technology as inspired by the series *Black Mirror***

**Tayyibe Bardakçı** (Istanbul, TR), **Hakan Ertin**

Although implantable chip technology is primarily utilized for medical necessities, it can also be used occasionally for enhancing normal human functionality and, in some cases, for transcending people's capacities beyond their biological limits. This shows us that the human-machine interaction is not only a matter of science fiction, but also becoming a reality of life. According to the reports in the media and literature, people are likely to choose to have these chips implanted in their bodies for practical reasons, such as being able to open doors automatically or use certain devices without using external equipment. The episode entitled "The entire history of you" of the series *Black Mirror* includes another good example of a type of chip technology that records every moment of people's lives and may provide unauthorized access to them.

This study aims to develop reflections on the morality of the implantable chip technology in reference to the fictitious episode as well as today's similar existing applications, like smart glasses, which can be considered the predecessors of such technology. Of the relevant perils, the possible complications during the implantation are trivial, compared to the risks of privacy violation and autonomy-breaching perceptual and preferential manipulation based mostly on commercially or politically purposeful use of personal data obtained unethically. Most importantly, implantable chips combining human and nonhuman elements in the human body also obscure the frontier between the human and machine. Collaboration of medical ethicists, philosophers, and scientists is the first crucial phase in the formulation of a proper policy of reaction toward these stunning medical developments, which are in close association with the meaning of being human.

## Unless they do not build cyborgs: ethics missing the point of cyborg constitution in neuroscientific trials?

Melike Şahinol (Istanbul, TR)

Neuroethics discusses a number of ethical implications of neuroscience and neurotechnology, including Brain Computer/Machine Interfaces (BCI/BMI), as their usage in the medical field raises philosophical and ethical questions. These questions focus on neuroscientific trials or treatment that may concern ethical concepts like informed consent, free will, autonomy, patient rights, privacy, and mind-reading (Clausen, 2010; Clausen & Levy, 2014; Müller, Clausen, & Maio, 2009). Broadly discussed is the anthropological figure of the cyborg (Haraway, 1991), linked to futuristic visions of human enhancement, transhumanism, etc. (Chatterjee & Farah, 2012; Downey & Dumit, 1997; Heikkilä, 2015; Illes & Sahakian, 2011; Müller, 2010; Pickering, 1995; Schmitz, 2010). What these neuroethical studies often have in common is that ethical arguments are less based on ethnographical fieldwork, looking at distributed interactions of human and machine, even at the practices of Neuroscientists in trials with BCI. So, what would it mean for neuroethics if the usage of BMI marked the constitution of an acting cyborg?

This paper examines how the constitution of a cyborg emerges within neuroscientific trials with BMI in chronic stroke patients, looking at the micro level and describing how human and machine act in an adaptive way. It does so through a description and an analysis of cyborgical actions within the BMI system. Based on a laboratory study and interviews with several neuro scientists/surgeons, patient care givers, neuroethicists, and patients who worked with BMI, I argue that if something or someone can be understood as a cyborg, his or her actions – within which these organic and inorganic parts interact – should be performed in a circular manner. Since circularity is the first principle and central concept of cybernetics and actions are based on the circularity of biological and technical aspects, one can also speak of an *acting cyborg* (Şahinol, 2016).

As one result of this work, we could rethink ethical concerns underlying neuroethics with regard to the constitution of acting cyborgs.

### References

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## Immutable or alterable? Human nature and the immutable essences in the metaphysical/ethical weltanschauung of Ibn ‘Arabi

Ismail Lala (Oxford, UK)

What is human nature? Is it definable? And if it is definable, is it alterable? This study considers these questions from the perspective of the ubiquitous Sufi theorist, Muhyi al-Din ibn ‘Arabi (d. 634/1240). Far beyond our sensible representation, and way before it, it is our immutable essences (*a‘yan thabita*), says Ibn ‘Arabi, that make us what we are. These essences are our true realities. They are our selves in the presence of, and considered from, the plane of divinity (*al-hadra al-ilahiyya*). The physical self—the subject of genetic alteration—is only a parochial, three-dimensional representation of a four-dimensional entity. Editing somatic or germ line genes, then, is not alteration, much less enhancement. Our nature, our *‘ayn thabit*, is fixed in the divine consciousness. And if it precedes our phenomenal existence, it endures after it. All the changes we perceive, the flux of palpable reality, are merely sequential temporal points of a reality that abides, forever unchanging. Gene editing, birth, adolescence, senescence, even death, are not changes, when considered four-dimensionally from the divine perspective. But we would be hasty if we thought gene editing posed no moral challenges for the Muslim community. For an ineluctable corollary of Ibn ‘Arabi’s strident determinism would be flagrant antinomianism. Yet this is not the case. Quite the contrary. So how does the metaphysical become the ethical? And can gene editing, though not changing our immutable nature, still change us?

## Philosophical and theological roots of the conceptualization of human dignity

**Şaban Ali Düzgün** (Ankara, TR)

One of the questions regarding ‘human dignity’ is what makes a human dignified and what makes it possible for others to take this dignity into account. Another question is whether ‘dignity’ is a quality shared by all human beings. Yet another one is under what circumstances a person who has innate dignity guards or loses it. The existentialists consider human beings as a part of events in nature; thus, in their understanding human dignity is not innate but formed at the end of a process; another part of the discussion about human dignity includes the arguments of those trying to attribute the human being a metaphysical origin, thereby making humans more significant. When discussed in the light of these questions and arguments, it could be seen human that dignity or value also carries the meaning of honour, glory, virtue, pride, self-respect, and being respected. The value of human being lies in (1) the whole of their qualities that distinguish them from other living things and (2) their purpose of creating ‘the common good and benefit’. This honour allows one to develop consciousness and behaviour in accordance with one’s own imagination and to expect such behaviour from others. The discourse of religion claiming that the human species as a whole is dignified, but at the same time its statement that some human beings have lost their dignity and have fallen lower than animals is striking and makes the discussion more significant.

5 October 2018, Thursday

09.30 – 18.10 Istanbul University Rectorate Building, Doctorate Hall

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## The ethical ambivalence of enhancement

**Dieter Birnbacher** (Düsseldorf, DE)

“Enhancement” is one of the key concepts of modern biomedicine. Biomedical means procedures and techniques are no longer used only for the traditional aims of medicine: healing illnesses, prolonging life, alleviating symptoms and disease prevention, but also, and increasingly, for the purpose of enhancing capacities, improving the quality of life, and serving the lifestyles of the healthy. This has had important repercussions on the image and the self-image of the medical profession. The *raison d’être* of medicine and its subsidiary professions is no longer the need to treat diseases and other health problems, but also to provide the means to enhance physical fitness (sports medicine), to compensate natural degeneration (anti-aging), to enhance physical attractiveness (aesthetic surgery) or to raise psychic well-being (psychopharmacology, psychotherapy). In particular, modern methods in genetic engineering such as gene editing hold the promise to vastly increase the range of control over the physical and mental properties of human individuals, living and yet to be born.

In my talk, I argue that many of the arguments against enhancement in the public discussion are philosophically unconvincing and neglect important distinctions such as that between compensatory and non-compensatory enhancement. On the other hand, there are good reasons to be concerned about enhancement: It is a symptom of a problematic proliferation of the spirit of competition in all areas of social and private life and of an ultimately unhealthy increase in mutual expectations of fitness and achievement.

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## A normative approach to the human enhancement debate

**Hakan Ertin** (Istanbul, TR), **Tayyibe Bardakçı**

Conventional medicine already made great progress in fighting diseases and extending average life expectancy; but now, previously unimaginable developments have been achieved in biotechnology, including preimplantation genetic diagnosis, genome editing techniques, prostheses, implants, cosmetic surgery, and medication designed to enhance intelligence or specific characteristics of the human body or personality. These novel tools and modalities do not function merely therapeutically, but they also serve to transcend people’s capacities beyond their biological limits, provoking concurrent debate on the possibility of even further or radical enhancements, such

as designer babies. According to some contemporary philosophers, who describe themselves as “transhumanists,” use of such technology should be allowed and discussed in the context of respect for autonomy, while their opponents, mostly known as “bioconservatives,” agree in that the very same procedures have a potential to change the human nature in a nonhuman way.

Accordingly, this paper adopts a normative approach discussing both transhumanist and bioconservative philosophers’ arguments based on notions as such as consistency, human nature, human dignity, and pursuit of perfection as well as referring to the four main principles of biomedical ethics developed by Beauchamp and Childress.

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## **Humanist reactions to human enhancement and transhumanism**

**Cenk Özdağ** (Ankara, TR)

Human intervention in the human body actually goes back to the first human attempts of civilization. Yet the term ‘human intervention in the human body’ and more specifically the term ‘human enhancement’ gained peculiar attention with the advance of technology. In this presentation, I will try to draw attention to the continuity of human attempts for human enhancement throughout the civilized ages and to the relation between humanism and transhumanism with respect to the ethical debates on human enhancement.

Agriculture, breeding animals, urbanization, schooling, and engineering in general are all human attempts to create better life conditions for the human race. However, what is at stake is that there are emerging areas, such as genetics and biomedical engineering, which open up a new realm for engineering humans to create a ‘better version’ of ourselves. The emergence of these technologies results in deep ethical debates on human nature. In this context, I will problematize the humanist position against these attempts and propose a particular understanding of transhumanism, which provides a legitimate ground for human intervention in the human body. The problem with the humanist reaction against transhumanism, concerned especially with preserving a genuine human existence, is that this reaction undermines its own ethical and political grounds. The main conclusion of this presentation is that there is a possible way to construct a version of transhumanism that is compatible with the ethical concerns of humanism.



## Human enhancement and Heaven Project: the definition of the boundaries of my body in posthuman

**Jiwon Shim** (Seoul, KR)

Due to the development of technology, the human body has been deformed, mechanized, and expanded. There are two ways in which the human body could be expanded to complement the normal functions of humans or to strengthen human capacities. First, mechanical devices or artificial organs can be combined with the body. For example, when someone has stolen a prosthetic limb, it can be asked whether this act constitutes personal injury or theft. In this case, the question is: are body implants part of my body? Second, the human body (or our brain) is connected to a computer network. And when the human brain is connected to the computer net, the boundary between the individual and the body becomes unclear. In this case, it is to be asked to what extent the body can be called my body?

In the Heaven project, a functioning brain of A, whose body was paralyzed, was implanted in B's body, who was in brain-dead state. In this case, who is the result of the body transplant? Is it A, B, or a completely new person? In the context of the preceding two discussions, to whom does the transplanted body belong? (brain of A + B's body, who was in brain-dead state = whose body?) I would like to refer to Daniel C. Dennett, Merleau-Ponty, and Gilbert Simondon's discussion of the boundaries of one's body in the post-human era.

## Transhumanism and human enhancement: the role of stem cells and exosomes

**Hakan Darıcı** (Istanbul, TR), **Erdal Karaöz**

Designer babies and robot rights are among today's ethical discussions while technologies like smartphones and smartwatches are bringing us closer to being transhuman, without notice. Human genetic enhancement on the other hand is not as easy a task as has been thought. Gene therapies have been tried since 1990 with less efficiency than expected. Following the discovery of the CRISPR/Cas9 method, treatment of several deadly genetic conditions of children and embryos has already been accomplished. Currently, the working gene therapy strategy for adults is to isolate the patient's own cells like keratinocytes or leukocytes and modify them *ex vivo*. Although this strategy is sufficient for various diseases, it is not applicable to patients whose defective cells have already been established within the body, like muscle cells in muscular dystrophy patients.

We have applied stem cell therapies to patients in various conditions from cerebral palsy to muscular dystrophies and observed significant improvements in their conditions.

One interesting finding was the demonstration of an intact dystrophin gene within the patient's own cells, indicating that transferred stem cells replaced the mutated gene with the healthy one using the body's own gene transfer method, i.e., exosomes. Exosomes are small vesicles secreted from cells which allow the transfer of proteins, mRNA, miRNA, and even DNA to other cells as signals. Due to their ability to transfer multiple molecules at once, exosomes attracted interest from medical experts for drug delivery and cellular therapies. We believe that treating diseases with stem cells or exosomes may be the first step towards human genetic enhancement, which will be followed by parents or patients asking for new features like a stronger build or higher intelligence for their babies or themselves. Considering enthusiastic people who are already experimenting with CRISPR technology on their own, scientists and regulatory bodies should embrace the inevitable and prepare the relevant regulations before any unwanted consequences occur in order to use the technology for the benefit of humankind.

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### Can principlism be used as a universal concept for solving clinical ethical problems?

**İlhan İlkılıç** (Istanbul, TR)

Since the publication of Tom L. Beauchamp and James F. Childress' book *Principles of Biomedical Ethics* in 1979, the work very quickly achieved fame and today enjoys worldwide reputation. This reputation seems to have – amongst others – two main reasons, one being the simplistic character of their concept (principlism) and the other one the fact that the included principles are well known in many cultures and countries. Some authors argue that principlism is culture-invariant and has a universalistic character. According to these authors, principlism can be applied within every culture and is able to solve clinical ethical problems in the relevant countries. In my presentation, I will challenge this position. At first, I will illustrate that having the same principles does not mean that these principles or moral terms have the same moral implications in various cultural groups. The second problematic point is the implicit hierarchy underlying the concept. Even if the authors of principlism relativize this hierarchy, it is clear that in their concept, patient autonomy is given an exceptional importance in comparison with the other three principles: beneficence, non-maleficence, and justice. I will also argue that the verification of a universal character of this concept depends mainly on proving that patient autonomy has the same function and power in other cultural groups.

## Does principlism provide enough guidance on ethical problems? The example of genetic diagnosis and therapy

**Melike Konuk** (Bursa, TR), **M. Murat Civaner**

The “principlism” approach is a practical methodology, rather than a theory, which is used for finding a justifiable solution to bioethical problems. It was first introduced in 1979 by Beauchamp and Childress, who claim that the four principles of ‘beneficence’, “non-maleficence”, “autonomy” and “justice” could be applied to every situation in all cultures, asserting that those principles are universal. It has been widely used among healthcare workers and bioethicists since then, mainly because it provides a practical tool for decision making.

However, principlism has been criticized extensively in the literature. Examples include “putting the principle of autonomy in the highest place”, or, maybe paradoxically, “to be too indeterminate to give an account of ethical decision making when the principles conflict,” or “to be analogous to a checklist or a chapter heading while containing no moral substance,” so that their content – especially the principle of “justice” – would be hugely varied; theoretical difficulties of determining “autonomy” and problems related to misinterpreting the difference between ‘non-maleficence’ and ‘beneficence’ might be mentioned as other common critiques.

Recent technologies in genetics have made diagnosis and therapy possible for many diseases, while they confront us with new ethical questions, such as the limits of eugenics, problems related to informed consent, breach of confidentiality, or maybe most importantly, devaluing the very existence of the human being. In this presentation, the level of guidance of principlism is evaluated in the context of ethical dilemmas regarding genetic diagnosis and therapy, by considering the justifications of mainstream critiques.

## Genetics and human reproduction: what can religious values offer?

**Aasim I. Padela** (Chicago, US)

The success of the human genome project and the development of genomics research programs globally have spurred bioethicists and law makers to analyze the ethical implications of genetic and genomic technologies and information (ggT/I). The significant, growing application of ggT/I to human reproduction raises questions about the value placed on being human, as offspring, parents, society, and human species. A robust and plural ethical analysis must account for ggT/I’s ability to affect directly, immediately, noticeably, and irreversibly at least the biological constitution of human individuals, and indirectly societies and the human species, and can benefit from the perspectives of

religious traditions. Through a systematic literature review, we highlight the dominant ethical issues relating to the application of ggT/I to human reproduction and then offer a framework to point out where and how religious constructs may contribute to this contemporary debate.

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## **The promise and the perils of whole genome sequencing of newborns**

**John D. Lantos** (Kansas City, US)

The cost of genome sequencing has plummeted over the last ten years. Many scientists and doctors hope that affordable genome sequencing will lead to more personalized medical care and improve public health in ways that will benefit children, families, and society more broadly. Francis Collins, the current director of the U.S. National Institutes of Health, has argued that all newborns could be sequenced at birth and that doing so will improve their medical care throughout their lives. I will present data from early forays into genomic sequencing for newborns that shows that, while sequencing is technically possible and may soon be affordable, it will far more complex to analyze the data that is generated by sequencing and to make good medical decisions based on that data. In this analysis, I will discuss genome sequencing in three different contexts; 1) as population screening of all newborns; 2) as targeted sequencing of newborns who are suspected of having a genetic disease; and 3) as a direct-to-consumer commodity. In each context, I will discuss to potential benefits and potential harms. The benefits are straightforward: treatment of a rare disease that would otherwise not have been diagnosed. There are also possible benefits to family members in learning of their own genetic risks. The harms are more difficult to define. False positive tests may cause increased parental anxiety and unnecessary testing. True positives may lead to treatments that are more risky than the disease. Furthermore, it is not always easy to differentiate “true” from “false” positives in genomics, due to phenomena like expressivity and penetrance. Thus, the predictive value of a genomic variant may vary widely.

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## **Designer babies through gene editing: utopia or dystopia?**

**Cemal Hüseyin Güvercin** (Izmir, TR), **Serap Kaya**

Gene editing therapies, having been described as the greatest biotech discovery of the century, reveal the potential of genes. It allows for a loss or gain of genome function by making precise additions, deletions, and alterations. Genome editing technologies such as CRISPR/Cas9 promise great hopes for the treatment of hereditary diseases, cancer, and HIV, as well as bringing to the agenda important ethical problems such as efficiency, risks, and cost.

First and foremost, genome editing must be safe before use. Some studies suggested that therapies could trigger an immune response in a majority of patients, which could render potential treatments either ineffective or dangerous.

Another concern is that it could allow us to change our outward appearance or physical abilities as we wish. We even might be able to design a baby. But we could not predict which kinds of genetic side effects could occur in a designer baby. Additionally, this genetic makeup might increase eugenic tendencies.

Another concern is that only a few rich people might get the benefit: thus, genome editing technologies could increase existing disparities in access to health care.

Although it is a debatable topic, there is a wide consensus in the international area that gene editing for reproductive purposes is not appropriate at this time and that there is a need for studies to make gene therapy safe and effective. In 2014, there were about 40 countries that discouraged or banned research in germline editing because of ethical and safety concerns.

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## Ethical boundaries of genomic editing applications

**İbrahim Topçu** (Istanbul, TR), **Nadir Koçak**

Genomic editing is a technology that allows scientists to change an organism's DNA. These technologies allow genetic material to be added, removed, or altered in certain places in the genome. Several approaches to genome regulation have been developed. In particular, the development of the CRISPR-Cas9 system has been a milestone in genomic editing. The CRISPR-Cas9 system has accelerated scientific work in this area because it is faster, cheaper, and more efficient than previous methods.

CRISPR-Cas9 is adapted from a naturally occurring genomic editing system in bacteria. Bacteria catch DNA particles of attacking viruses and use them to generate DNA segments known as CRISPR sequences. If the viruses attack again, the bacteria produce RNA segments from the CRISPR sequences to target the DNA of the viruses. The bacteria then use their own Cas9 or similar enzyme to cleave the DNA, thus disabling the virus.

Genome regulation has attracted much attention in the prevention and treatment of human diseases. This new method promises to cure and prevent many diseases such as cystic fibrosis, hemophilia, sickle cell anemia, cancer, heart disease, diabetes, and HIV infections.

Changes made with genomic regulation are now allowed only in somatic tissues, and thus the produced changes are not transferred from one generation to another. However, changes made in germline cells or in the genes of an embryo can be transferred to future generations. This technology therefore brings with it a series of moral questions, including whether or not to allow normal human traits to be developed for other

purposes. The manipulation of germline cell and embryo genomes is already illegal in many countries, especially when done for the purpose of eugenics, out of ethical and legal concerns. However, how a harmonization with the current bans will be achieved is an ongoing debate.

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## **International standards of human research (2018) and the example of Turkey (a critical approach)**

**Mukadder Gün** (Ankara, TR)

In the historical process, the damage that people suffered and the exploitation they were subjected to have caused tragic results in the case of experiments and research performed on people. The human trials performed in Nazi Germany are the best-known examples. Similarly, the Tuskegee syphilis study and the Thalidomide disaster after the Guatemala CYBA research are some serious problems that show us the damage that people suffer. Firstly, the Nuremberg Code was created for the purpose of addressing ethical issues such as participant approval and information, which was ratified by many countries. Due to problems between benefits of achievement for science and humanity and the loss of volunteers in experiments on human beings that have been or will be done, many regulations were required, such as the Declaration of Helsinki. However, this declaration is insufficient and has undergone many changes to regulate research on human beings.

Nowadays, many research projects that include human beings (embryonic stem cell, genetic research, drug research in various phases) are approached in a complex way. In order to prevent ethical problems in such research, it is necessary to renew the regulations according to the requirements and to prepare new regulations.

In this study (International Compilation of Human Research Standards 2018 Edition), assessments will be made within the International Standards of Human Studies (2018) and the case of Turkey. Published in late 2017, this Standard text contains over 1000 research laws, regulations, guidelines, and standards from more than 130 countries.

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## **Ethical assessment of genetic prevention measures in consanguineous marriages in Muslim societies**

**Selvi Çopur** (Münster, DE)

Consanguineous marriage (CM) is a worldwide phenomenon with traditional and religious roots. A marriage is considered consanguineous if it is contracted between persons who are biologically second-degree cousins or even more closely related partners. The most common and medically most important form is first-cousin marriage. From a medical

perspective, because of the increased risk of autosomal recessive hereditary diseases, CM almost doubles the genetic mortality and morbidity. Therefore, this type of marriage is faced with major medical and socio-cultural challenges to the family and health policies in the relevant countries.

The talk focuses on the question of how genetic preventive measures (PM) in consanguineous marriages in Muslim societies should be evaluated from the perspective of a secular medical ethics according to Beauchamp and Childress. The ethical problem of consanguinity is concretized by two case studies ( $\beta$ -Thalassemia screening program from Cyprus and a Turkish family from Germany).

It is attempted to provide answers to the following questions: Which genetic PMs can be imagined? Which of the possible PMs are suitable for the Muslim population? How should we rate these PMs from the perspective of secular medical ethics after Beauchamp and Childress? Why is this type of marriage among the Muslim population still preferred despite the now known risks?

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### Genetic counseling in Turkey and bioethics\*

**Ülkücan Kaplan** (Ankara, TR)

Genetic counseling (GC) is a service including the review of the patient's family story, the application of genetic tests and genetic diagnosis. It can be considered relatively new in many health care applications. GC is also characterized by a comprehensive communication process in which significant and profound decisions can be made affecting human life, including not only medical but also economic, social, and psychological aspects. Completion of the process in the most beneficial way on behalf of both individual and society will be possible if genetic counselors maintain the stages of the GC process within a bioethical framework. In the scope of the "Genetic Counseling in Turkey and Bioethics" study, the applications of the GC process in Turkey were presented and possible problems were evaluated from the viewpoint of bioethics. Research data which have been given or made to serve in the GC area in Turkey were gathered in in-depth interviews with physicians in various branches of medicine. According to the data, the lack of post-graduate training programs for GC, the lack of trained human resources, and the lack of legal and ethical regulations in this area have been identified as some of the problems that are rooted in different dimensions in Turkey. Consequently, the definition of the GC process in general, the principles of professional genetic counselor, the current state of practice in GC in Turkey, and identification of issues relating to the area assessed in terms of bioethics and possible solutions have been developed.

\* This abstract is based on the "Genetic Counseling in Turkey and Bioethics" doctoral dissertation, which was scheduled to be defended in June, 2018.

## **Discrimination based on genetic information in the working life**

**Başak Işıl Çetin** (Istanbul, TR)

Developments in biotechnology have brought up certain problems concerning the identification, storage and sharing of individuals' genetic information. In fact, this information, which prima facie is related to the health sector, has other dimensions, such as affecting the working life of currently employed persons or job seekers. It is unclear what purpose genetic requirements can serve in the working life. In this context, it is important to evaluate the opportunities and threats that genetic information may have to establish an appropriate point of view on human rights and freedoms and to take appropriate actions accordingly. With the widespread use of genetic testing, it is highly probable that such opportunities and threats will become more visible. As a matter of fact, the assumption that "knowledge is power" brought the important, and problematic, ethical question of where this power should be used.

## **Genetics in service of a better life**

**Hatice Keskin** (Ankara, TR)

This presentation will be examining the services of a private genetics clinic in Turkey which claims to be giving the first and only predictive and preventive health service in Turkey. They basically claim that genes make each individual unique – even the personal physiology and bodily needs are determined by this unique arrangement of genetic code.

Our critique will be based on two dimensions: one regards the causal relationship between health and the genetic code, while the second considers the probable oppressive implications of medical genetics, especially in the context of psychiatry in public health, which is dealing with human behavior.

Lastly, we will include a case report of an adult male from three years back. His present impressions of the service and its perceived contribution to his life quality after three years from his test will be presented as an exemplary case.



6 October 2018, Thursday

09.30 – 18.30 Beşikçizade Center for Medical Humanities (BETIM)

## The role of ethical principles (principlism) in end-of-life medicine

**Fuat Oduncu** (Munich, DE)

Medical doctors in developed countries are increasingly faced with decisions about end-of-life issues. This is a consequence of an ageing population and considerable advances in medical technology in the fields of life-sustaining and life-prolonging treatments where the process of dying has already begun and the prognosis is poor. In this vulnerable phase of life, the principles of biomedical ethics – *principlism* – may provide a guiding frame for doctors for end-of-life medical practices. Due medical care is primarily based on the fundamental principle of *beneficence* (intrinsically including the principle of non-maleficence), which as such is incumbent upon all physicians. Without this principle, medicine would lose its *modus operandi* and cease to have any clear direction or basis. Ideally, the doctor's beneficence-based perspective is fully compatible with the *patient's autonomy*-based perspective. In this line, the German Medical Association's Principles of Terminal Medical Care define the duty of the physician in accord with Cicely Saunders' concept of "total care" as "to relieve suffering and be there for the dying until death, while respecting the patient's right-to-self-determination is paramount." The underlying principle of beneficence can be traced back to the Aramaic term of "RAHME" of ancient Mesopotamia (in Arabic 'rahim', in Hebrew 'hesset') which according to Warren Reich means both *taking care of* the sick person by the delivery of professional care and *taking care for* the patient by the virtue of devotion to or concern for the other as an autonomous person, i.e. 'the patient as person' (P. Ramsey).

Thus, the principle of beneficence arises from an anthropology of solidarity, responsibility and attentiveness due to a Levinasian facing the vulnerable and dependent human individual patient who does not lose his/her dignity despite all infirmity and frailness.

## The ongoing ethical debate: mitochondrial donation

**Ayşenur Günaydın** (Istanbul, TR)

Mitochondria are energy-producing organelles in the cytoplasm of human cells that have their own separate DNA. Cells cannot function in a normal manner if their mitochondria are unhealthy, causing severe disorders known as mitochondrial diseases. The majority of these diseases are caused by mutations in the mitochondrial DNA (hereafter: mtDNA). mtDNA is inherited by the child on a maternal route, in contrast with nuclear genes that

are inherited from both mother and father. Mothers are at risk of passing on serious diseases, even in cases where they themselves do not show any symptoms. Since the nature of these diseases is quite complex, the therapy is very difficult and it can be said that there is no effective verified treatment yet. However, new assisted reproduction methods having the potential to prevent the transmission of serious mtDNA diseases are said to result in unaffected pregnancies. The latest technique “mitochondrial replacement therapy” or “mitochondrial donation” is based on an in vitro fertilization method using mitochondrially healthy oocytes. The baby is considered to have two mothers and one father genetically, thus being called a “three-parent baby”.

After the UK legalized mitochondrial donation (2015), the first three-parent baby was born in Mexico (2016), and in the same year, the US Food and Drug Administration declared mitochondrial replacement therapy research to be ethically acceptable (2016). While there is a broad support from patients with mitochondrial diseases, the “three-parent baby” story raises ethical concerns. This review will focus on main ethical issues raised by mitochondrial donation which have been carefully scrutinized since 2015.

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## Ethical implications of mitochondrial donation

**Sarah Jafri** (London, UK)

Mitochondrial donation is a new form of IVF approved by the UK parliament in February 2015. The aim is to remove mitochondrial disease caused by pathogenic maternal mitochondria to prevent a disorder and its transmission at the level of fertilization. The regulations came into effect on October 29, 2015. The two methods proposed are pronuclear transfer (PNT) and maternal spindle transfer (MST). In PNT, fertilization with a donor egg and the intended mother’s egg takes place. Then two pronuclei from the donor are replaced with two pronuclei from the intended mother. In MST, the intended mother’s spindle is placed into an enucleated donor egg and then fertilization takes place. After these respective techniques have been applied, the zygote is implanted in the uterus of the intended mother. In monotheistic faiths, maintaining a family is fundamental. Both techniques pose their own specific ethical dilemmas. However, within the ambit of monotheistic faiths, MST is more likely to be acceptable because fertilization does not take place between the donor egg and the father’s sperm. This article aims to explore the legal and ethical repercussions of these procedures.

## Aborting the fetuses with Down syndrome: is it ethically justifiable?

**Betül Kılıç** (Bursa, TR), **M. Murat Civaner**

Down Syndrome (DS), or Trisomy 21, is a chromosome abnormality causing physical and mental developmental delays and disabilities. Together with the development of new technologies, including screening tests and diagnostic tests such as chorionic villus sampling and amniocentesis, it is now possible to diagnose DS accurately. Accordingly, the question “Is aborting fetuses with DS ethically justifiable?” arises, requiring answersto guide policy-makers, clinicians, and potential parents.

Some experts argue that DS is a condition not a disease, since people with DS might have an optimal quality of life through parental and community support together with medical guidance. In addition, people with DS may reach an IQ level of 80, although the chances are slight, the average IQ being between 50 and 60. Therefore, they would argue that fetuses with DS should not be treated differently from those not carrying DS. By contrast, some people argue that it would be immoral to carry on with a pregnancy if the mother knew the fetus had DS.

We think that both arguments have their own fallacies and potential pitfalls, such as violating couples’ right to self-determination, creating a slippery slope towards paternalism and eugenic policies aiming ‘perfect’ individuals. Instead, we propose a decision-making model that includes a “soft version” of genetic-counselling, measures for evaluating the couples’ preferences, and an advisory board that would consider the justification of termination request thoroughly. We also propose a regulation regarding genetic counselling and aborting fetuses with DS.

## How do Turkish parents decide for their children at the end of life?

**Tutku Özdoğan** (Istanbul, TR), **İlhan İlkılıç**

**Introduction:** There are 1,310,000 births/ year in Turkey and the infant mortality rate is 10/1000. Most Turkish citizens are Muslim, with varying degrees of religiosity.

In most Western countries, medical treatment can be withdrawn when it is not in the patient’s best interest to continue, while in Turkey withdrawing treatment is disallowed both legally and ethically.

We propose that termination of treatment be legalized, giving the parents the right to decide on end-of-life issues in neonatal intensive care (NICU), based on an understanding of the process of shared decision-making in Turkish NICUs as a contribution to the literature from a Muslim country’s viewpoint.

**Methods:** Parents of 9 newborns (3 healthy, 3 disabled, 3 deceased) who had been confronted with an end-of-life situation including resuscitation in the NICU were interviewed after the NICU period and 25 open-ended questions were asked. The answers were audio-recorded. A qualitative analysis is being done.

**Results:** There are various important themes in the study: Lack of communication, hope, suffering, attachment to life, helplessness, quality of life, God's will.

**Conclusion:** The parents felt that only God takes life, but sometimes they prayed to God to let their diseased child die, which may show a reluctance to take responsibility for the decision as an effect of religious and social dynamics. The parents interviewed are aware of the complexity of end-of-life decisions and might have accepted to withdraw treatments if it had been explained properly. With a strong public opinion the laws can be changed in Turkey.

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### A pilot study on empathy skills of pediatricians

Selda Okuyaz (Mersin, TR), Meltem Direk, Oya Ögenter, Didem Deric Yıldırım

**Introduction:** Pediatricians are in direct contact not only with the patient but also with the relatives of the patient, requiring empathy skills which make this area different from other disciplines.

**Aim:** In this pilot study, it is aimed to determine empathy skills and the factors affecting it of pediatricians at a hospital in Mersin.

**Materials and methods:** This study was conducted with 55 physicians working at the Department of Pediatric Diseases in Mersin University Faculty of Medicine on a voluntary basis. The data collection form consists of two parts; in the first part there are questions about the demographic characteristics of the physicians and the second part administers the "Jefferson empathy scale".

**Results:** The average age of 55 (26 male and 29 female) physicians was  $34.11 \pm 6.99$  years. 6 (10.9%) of the participants were professors, 2 (3.6%) associate professors, 5 (9.1%) assistant professors, 1 (1.8%) sub-branch expert, 10 (18.2%) sub-branch assistant physicians, 31 (56.4%) assistant physicians. The number of physicians with children was 28 (50.9%), the ones who were exposed to violence by patient relatives was 8 (14.8%). The average of the total score of the participants was  $98.42 \pm 12.71$ .

**Conclusion:** Although the participants' average score on the Jefferson Empathy Scale was slightly above the mean, it was lower than the suggested scores in the literature for physicians. According to the data obtained in this pilot study, it is suggested to increase the number of studies to improve the positive aspects, which will reveal the factors affecting empathy skill.

## Medical ethical questions at the end of life in geriatrics and the intercultural aspect

**Annette Kurrle** (Mainz, DE)

**Introduction:** In the consequence of demographic change, people grow older and older. While in 2015, according to statistical information, 13 percent of people were older than 65 years, it is estimated that in 2050 this number will be 21 percent. At the same time, migration has led to multicultural structures of society in most countries. And even the group of old people has become a heterogeneous one. The coincidence of intercultural factors for old, mostly multimorbid patients is discussed in the context of medical-ethical aspects.

**Discussion:** Old age and illness are not synonymous, but growing older for most people's daily lives means becoming patients with the necessity of medical treatment, suffering from an increasing loss of cognitive, affective, motoric, sensory, and social functions. In spite of these limitations, old people have to deal with numerous intercultural factors, even in the case of in-patient treatment in special geriatric departments. Besides the medical treatment at the end of life, medical-ethical questions concerning death, limitation of medical treatment, dignity, patient autonomy in the case of dementia – to name but a few – play an important role. The special factors and competencies necessary to cope these difficult situations for old people was the subject of our study.

**Conclusion:** The consideration of medical-ethical questions at the end of life for geriatric multimorbid patients in their special intercultural situation is a great challenge and needs special intercultural, medical, and medical-ethical competence.

## Hope and cure for treatment of genetic/rare diseases with CRISPR Genome Repair Technology

**Cihan Taştan** (Istanbul, TR)

Approximately 7000 mostly genetics-based rare diseases have been identified globally. Most of these rare diseases affect the quality of life considerably. In this respect, studies on the development of trustable and efficient genetically-based treatment methods are critical. Newly designed nuclease-targeted genomic regulation techniques are exciting for the biomedical research field, providing a hope for clinical applications as never before.

The CRISPR/Cas system paved the way for the manipulation of gene expression or regulation and led to the examination of gene functions in mammalian cell lines in vitro and in many different organisms in vivo, including insects, plants, animals and now, humans. This genetic engineering approach is a highly efficient and scalable biotechnological tool that generates genome-wide mutations through sequence-

specific target guide RNAs to induce double-stranded DNA breaks. These human-made mutations allow fixing or repairing the site of disease-related genetic disorders with the help of a homology-directed repair approach. Thousands of scientific publications have been recently published on CRISPR/Cas technology, demonstrating successfully repaired or altered DNA sequence in cells. Here, I will illustrate through examples how tens of genetically-based diseases are treated in the laboratory or in animal models using CRISPR/Cas genome repair technology, which induces biotechnology and therapeutic companies to work on genetic therapies.

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## **CRISPR/CAS9 and CRISPR/EvoCas9. Ethical issues in Germline Gene Editing**

**Davide Battisti** (Milano, IT)

In this paper, I will study the issue of germline manipulation in an ethical perspective. More specifically, I will consider the ethical issues concerning the CRISPR gene editing system. I will analyse some deontological arguments about (a) playing God and vexing Nature, (b) consent, (c) autonomy, (d) identity, (e) discrimination; and I will consider other consequentialist issues about (f) security, and (g) cost-benefit issues in a socioeconomic perspective.

Assuming a distinction between moral value and moral status, I intend to solve the relevant deontological problems, justifying the moral acceptability of germline manipulation in the embryo. However, consequentialist problems still need further academic debate to be solved, especially after January 2018, when a paper was published in Nature Biotechnology, concerning the discovery of a new system for gene editing that improves the CRISPR technology. Using a protein called Evocas9, the system allows for a more precise, efficient editing than the CRISPR/Cas9; thus the possibility of safe germline editing seems closer than ever. As a result, the security issue for the new system CRISPR/EvoCas9 is less problematic, but it remains unsolved.

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## **Moral issues regarding non-therapeutic genome editing and parental expectations**

**Maide Barış** (Istanbul, TR)

Recent scientific developments and breakthroughs, namely CRISPR-Cas9 genome editing technology, raise tremendous hope for the treatment of the genetic diseases, cancer, and deadly viral infections. It is claimed to be a cheaper and easier solution operating by extraction of the affected genes and insertion of normally functioning equivalents. This

technology uses a modified version of an ancient bacterial immune response formed against phages: they detect the unwanted DNA region, cut it off and repair the damage either by ligation of the broken ends of the DNA or by addition of new pairs of the nucleotides to reconstitute the wild type of the genes. In a single-celled organism like bacteria, it is relatively straightforward to accomplish the desired action. However, in a multibillion-celled organism such as a human being, it is challenging to single out the target cells, such as cancer or virally infected cells. So, what if this technology were applied at the single-cell stage of the human beings, the fertilized ovum? It would be easier to detect and remove the genes responsible for devastating diseases such as sickle-cell anemia, cystic fibrosis, or Huntington's disease and replace them with the normal ones. Although expectations are high, research is going on and the long-term effects of genome editing with CRISPR are not yet known or foreseeable.

In addition to the therapeutic use of intervention into the genome, non-therapeutic purposes such as enhancement, ending the aging process, or choosing particular features for the offspring might arise. Besides, if the alterations are made in the germline, they will be passed on to the next generations and might thus affect the future of the human species. Although clinical use of CRISPR for genome editing in the embryo is not allowed in many countries, trials on animal models are continuing. It is anticipated that this intervention will be available for clinical use within a decade. Debates are unending, and concerns are multidisciplinary. The purpose of this research is to scrutinize the possible moral issues regarding non-therapeutic genome editing at the embryonic level and question the nature of parenthood and parental expectations, as well as limitations of parental authority.

## Can artificial intelligence practice medicine? A critical appraisal with reference to present-day medicine

**M. Murat Civaner** (Bursa, TR), **Filiz Bulut**

Cloning bodies, hibernating people, enhancing human beings, and CRISPR are new techniques which are promising, yet remain ethically controversial. Artificial intelligence (AI) is another technology which develops faster than ever, finding new application areas in medicine day by day. From the first computers to humanoid robots, it has already affected a vast area of our daily life irreversibly. This phenomenon creates various kinds of ethical problems. Inaccessibility, inequalities, unemployment, breach of confidentiality, or even threats to the very existence of humankind are the most concerning issues on a general level. Together with the ability of processing data, which has the potential of developing some kind of 'thinking', the old question of 'personhood' is being asked for AI this time.

In the context of medicine, there is a wide spectrum of application areas of AI from data processing systems to surgical interventions. The questions “Can a robot practice medicine?” and “Is it possible for a robot to be a physician?” are hot topics in bioethics in this sense. Some futurists claim that it will be possible inevitably, while dystopic projections argue that it would be the end of humanistic medicine. In this presentation, these questions will be explored by considering the nature of medicine as a profession and a societal institution, the aphorism “there is no disease, but the patient,” and professional values with reference to present-day medicine.

### **The evolution of the nursing profession at the dawn of humanoids: adaptation or assimilation?**

**Gülten Özkan** (Bursa, TR), **M. Murat Civaner**

Today, the nursing profession is under pressure from various dynamics that challenge its care-based nature. Commercialization of healthcare, beginning from the last quarter of the twentieth century, together with its policies of competition, cost-effectivity, and performance-based payment, is increasing the number of hospital admissions, workload and occupational stress unnecessarily while decreasing income levels and motivation for work, thus putting the profession, which is traditionally patient-centered and communication-based, into a dire situation.

In addition, the emergence of new technologies such as artificial intelligence force the nursing profession to be dismantled into pieces that could then be delegated to electronic means and media. Breach of confidentiality, diminished trust – which is a vital part of healing process – in nurse-patient relationships, or even alienation of patients might be experienced by using applications like tele-nursing. Another development in the foreseeable future is the substitution of nurses by humanoid robots. According to current projections, they will be able to take over elderly care and 30% of all nursing services by the year of 2030.

All of the developments mentioned above create new ethical dilemmas and force the profession’s very nature to evolve. However, the profession – together with its members, policy-makers, organizations, educational institutions, and regulations – does not seem to be prepared to lead that evolution in a more humanistic manner. In this presentation, conditions and possibilities are explored in order to adapt to new technologies, while keeping the essence of the profession and its core values, and preventing assimilation in the stream of external dynamics that could harm patients.



## Using Google Glass in medicine and potential ethical issues

**Yusuf İhsan Özdilek** (Istanbul, TR), **Enes Pay, Ahmet Ali Çelik**

Google Glass is a technological device which was invented in 2013, allowing users to view messages, texts and images via the eye projector, taking pictures, recording sound and sharing video in real time through the camera as well as providing communication with others through voice (1). Since Google Glass does not restrict the user while working and enables them to use it without needing any help, researchers are hopeful about its potential uses in various areas such as education, travel, journalism, and medicine. In medicine, Google Glass has many areas of application from surgery to education of medical trainees. It offers remarkable advantages to health professionals and reduces the time for transferring and saving patient data, as well as allowing medical staff to see the patient status during an operation and pre-post operation. It allows the surgeon to communicate with his or her colleagues in order to ask for help during an operation. Google Glass also is of considerable significance in medical training. Medical trainers can watch operations first hand and can develop the ability to demonstrate medical techniques and maneuvers. There is no doubt that Google Glass will create many advantages and novelties in the health sector. However, alongside its benefits, there are some ethical issues that need to be addressed. When patients are asked to give permission to their doctors to use Google Glass for their treatment, they focus on four topics. These are anonymity, confidentiality, data protection, and privacy (2) which will be discussed in our presentation.

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## Privacy perception of health professionals and recent debates in Turkey

**Zeynep Aybikem Sağlam** (Düzce, TR), **Mehmet Gökтуğ Günel, Hakan Ertin, Mehmet Ali Sungur, Şükrü Öksüz**

Lately, there have been debates in Turkey arguing that privacy is not regarded highly enough in the medical field. Some find these critiques justified while others consider them to be unwarranted or mention them as results of organizational problems in medicine. This study assesses how physicians and other health professionals perceive

privacy in medicine. Their behavior and level of knowledge is investigated through a face-to-face interview technique with a prepared questionnaire. Considering the results of this study, ongoing debates in our country about privacy in medicine are evaluated.

## Evaluating social media usage in disasters from an ethical perspective

**Rabia Yücel** (Ankara, TR), **Merve Karaca**, **Muhammed Cihan Işık**,  
**Çağrı Emin Şahin**

**Introduction:** Disaster bioethics deals with the ethical issues and dilemmas in all types of disasters including natural and human-made ones. While dealing with these situations, it focuses on macro-ethics, which is about collective topics rather than individual matters. One of the ethical issues in disaster medicine is social media usage and invasion of privacy. The aim of our study is to evaluate social media usage in disasters from an ethical perspective.

**Methodology:** A search was made using an advanced method for all titles including “disaster”, “ethics” and “social media” in PUBMED. Of the 24 articles identified, 7 articles were categorized for the aim of study.

**Results:** Sharing disaster photographs can be addressed from three ethical points of view. Patient confidentiality is the main component of medical ethics. While journalism ethics imposes transparency of the disaster situation, representing people, situations or photos risk to affect people’s psychology adversely.

The use of social media in crisis situations has negative effects such as spreading false news, increasing terrorist attacks, or undermining authority, as well as positive effects such as strengthening communication, increasing donations, and providing global attention.

In a case presentation, Ebola cases shared in the media in Nigeria caused stigmatization of people in society. Also, this is a violation of personality rights. Postings can cause new traumatic responses for patients or relatives.

**Conclusion:** Social media usage in disasters is important and it improves solidarity and cooperation but bioethical principles such as privacy, confidentiality, and non-stigmatization should not be violated. There is a need to develop guidelines and professional codes for social media usage in disasters.

## Asking gods for healing

**Mustafa H. Sayar** (Istanbul, TR)

Stelai containing reliefs of certain diseased organs were found in ancient times in the Eastern Mediterranean and especially in temples around the Aegean World. With the reliefs on these stelai and through inscriptions on these objects, it is possible to determine in which regions more organs are diseased and from which God treatment is expected. These findings, usually dating back to the period between the 1st century BC and the 3rd century AC, show that not only Asclepios and his daughter Hygieia, but also other ancient gods and goddesses were expected to have healing capacities. In this paper, some examples from Western and Southern Anatolia will be presented to give information about local and supraregional health centers.

## The scientist and painter Akil Muhtar Özden (1877–1949) from the virtue ethics perspective and his work entitled “Ethics in Terms of Science”

**Arin Namal** (Istanbul, TR), **Hakan Kızıltan**

Akil Muhtar’s biography portrays a life decked by virtues. His life is also meaningful when examined from a virtue ethics point of view which takes being and behaving virtuously as a basis. There are many aspects in his life story from which training and practicing physicians will be enlightened. Born in Istanbul in 1877, Akil Muhtar Ozden discontinued military medicine school due to oppression in the period of Abdulhamid (1842-1918) and received medical education in Switzerland, where he graduated with a doctoral degree. He completed his specialization in clinical pharmacology at Geneva School of Medicine and was awarded the right to lecture. In 1908 he returned to his country. He laid the foundations of the discipline of Clinical Pharmacology at Darülfünun Faculty of Medicine and started experimental treatments. He was elected as Dean twice in 1917 and 1919. Akil Muhtar published books and articles on internal diseases and treatment, and on drug development. Between 1941 and 1943, he published an article in the *Revue de Thérapeutique et Expérimentale*, where French abstracts of the articles were also included. In this journal, he also made room for articles about the history of medicine. Thanks to him, the *Medical Faculty Journal* was regularly published from 1916 to 1928, with six issues each year. He had a very effective role in the preparation of the Turkish Codex of 1930. Ozden, who supported the University Reform in 1933, retired in 1943, was elected as a deputy in the Republican People’s Party in 1946 and became a member of parliament for one term. He died in 1949 after being diagnosed with mediastinum tumor. Akil Muhtar was a painter at the same time. There are 755 colored and monochrome pictures bearing his signature. He also issued publications containing comparisons and

interpretations in paramedical matters. His published aphorisms are very famous. “İlim Bakımından Ahlak [Ethics in terms of Science]”, which went through three editions, is one of his works that attracted much attention. In this work, Ozden tried to explain that, under the influence of Herbert Spencer (1820-1903) and especially Charles Darwin (1809-1882), morality has a scientific base in biology and that moral rules were established in order to let people live fruitfully and happily within an order and be able to develop continuously.

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### Contemporary ethics seen in a historical perspective: early modern thought as the beginning of the questioning of values

**Alexandra Bettag** (Munich, DE)

The work of the contemporary philosopher Peter Singer provoked intense controversies, severe hostilities and criticism. Especially in his book “Practical Ethics,” he touches upon fundamental questions about the value of life and possible reasons, circumstances and subjective legitimations to put an end to it. Whereas its connection to the tradition of Utilitarianism is generally underlined, Singer’s work could also be read as a result and further development of Early Modern thinking emerging in different cultural areas during the so-called European Renaissance. Pico della Mirandola’s programmatic discourse “De hominis dignitate” from 1486 can be seen as representative for some of the new phenomena of its time and context: the seeking of emancipation from traditional authorities and the gear for human autonomy. In his work, Pico della Mirandola attributes a central role to human free will: according to him, it is this capacity that distinguishes the human being and is the prerequisite to achieve the highest forms of human life or to fall back to the level of non-humans. Only by the capacity of making decisions, the human being can gain his or her highest dignity.

About 500 years later, Singer also insists on the importance of free will and decision making for human dignity, especially in questions about life and death.

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### Workshop: ILEM Special Session

Moderator: **Lütfi Sunar** (Istanbul, TR)

This session will include presentations that assess health in a social context. The session will focus on health and social inequality from three different perspectives. In this context, changing occupational prestige of the medical doctor, the attitudes of different social groups toward being healthy, and the changing meanings of illness and health will be discussed.

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## **“Reputable doctor”: Subjective and objective dimensions of social prestige**

**Lütfi Sunar** (Istanbul, TR)

Measuring occupational prestige is important in terms of understanding the structure of society, given that occupational prestige is one of the basic parameters of many areas such as stratification, mobility, working life, and education. For this reason, the examination of professions and the measurement of their prestige is an important field of study in contemporary sociology. There are many different approaches to measuring occupational prestige in the world. Although these approaches measure occupational prestige with different components, one of the common aspects is that being a medical doctor is always the most prestigious occupation. In studies conducted in different countries, the medical doctor is always at the top of the rankings. The factors that determine this are as follows: (i) the medical profession can be entered on the basis of a long and difficult education that not everyone can access, and the profession is also dependent on having the requisite diploma; (ii) the social benefit of the profession is clear and concrete; (iii) the level of earning achieved is quite high; (iv) the level of the professional autonomy is high, and (v) the professional hierarchy and special occupational ethics originate from the special way of execution of the profession and the spatial structure of the health buildings. The prestige of the occupation is also related to the fact that the medical doctors are well-organized, have a high level of occupational solidarity, and their numbers are low. However, these conditions may change depending on social and economic conditions. For example, the increase in the number of medical doctors, the widespread access to medical education, and the emergence of different channels of access to medical information have changed medical doctors' reception towards their profession. The social perspective towards medical doctors is also changing. In this presentation, the changing objective and subjective social prestige of medical doctors in Turkey will be discussed based on changing factors in the health system.

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## **Evaluation of healthy lifestyle behaviors (physical activity and nutrition) according to some sociodemographic variables**

**ihsan Kutlu** (Sakarya, TR)

There are many factors that affect being healthy. Some of these factors may be biological, medical, genetic, and also affect the health of individuals in their own way of life. Thus, the adoption of healthy lifestyle behaviors has an important place in being healthy. A healthy lifestyle has different subdimensions, including health responsibility, physical activity, nutrition, spiritual development, stress management,

and interpersonal relationships. The study at hand is a field survey focusing on physical activity and nutrition. This study aimed to measure the physical activity and nutritional status of university students and graduates through a scale and evaluate them in terms of various sociodemographic variables. In this way, we wanted to show which factors are particularly decisive and effective in healthy lifestyle behavior. A total of 463 participants who graduated from or were studying at the University were reached. The level of participants' healthy lifestyle behaviors related to physical activity and eating habits and a range of sociodemographic information were collected. The collected data were analyzed and interpreted using statistical software.

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### **The so-called importance given to health**

**Ömer Ataç** (Istanbul, TR)

The importance that is given to health as a notion is inversely proportional to its frequent usage in daily parlance. Although it is agreed upon by all that “health comes first,” it tends to be pushed into the background when balancing our preferences in life. When we buy products such as clothes, houses, or cars, we do not necessarily consider whether they are healthy. We only know about physical and psychological wellbeing to the degree that the medical world discovers. The process of finding answers for questions such as how and to what extent the social determinants of health affect our health continues. While invariable risk factors such as age, sex, and genetic factors influence our health, it has also been known that variables such as region, area of residence, social status, education level, and jobs can affect our health as well. However, to what extent are we sure about the idea that those variables can really be changeable? Although we might want to change all of them, can we actually do this? Most people who have a lower socioeconomic status desire to upgrade this status, but the reasons behind it do not necessarily include health as an initial motivation. However, even our zip codes may have much more impact on our health than our genetic factors. Nevertheless, we tend to focus on the perfection of our bodies rather than optimizing our social factors.

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