

## Ethics of (Palliative) Care and the Question of Euthanasia

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### Introduction

From an anthropocentric perspective, every human being is entitled to his or her life as a basic human right – the right to live! But in the contemporary era, human life often becomes a “subject” of manipulation<sup>3</sup>, especially at the end of its duration, life’s *finale*. This is so because the basic human experience is that life is running on unstopably, revealing how much we are in love with life, even though we may be reluctant or not at all prepared to think about life’s fragility, temporality and transience. And the reality is that hour by hour, every person’s life is getting closer to its final stages, relentlessly rushing towards its end – towards death.

Until recently, the process of dying usually took place within the family, where both young and old were gathering to bid farewell to the dearest member of the family, creating a kind of school of dying<sup>4</sup>. To-

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3 Not least because of the distinction creature-person and an ambiguous concept which comes out from it: biological life-life of the person, as well as biological death-death of the person.

4 For further reading see Kaluđerović and Jašić 2012, 155-161.

day, at least in countries of within the Western civilization, around 60% of people die alone, left to the fatal course of biological disaster (Salas 1994, 11-20). In such conditions, very often the burden of mortal fear and pain stays exclusively with the one who dies. This neglect results in a not-so-reassuring situation where the human being is reduced to the smallest of all his or her vital dimensions – to the level of a merely bodily existence, already in the abyss of the so-called spiritual death, abandoned by all – helplessly watching the end approaching (Pozaić 1995, 49-54), in illness, suffering, pain, and sometimes agony.

Hence, in today's modern society the question of the right to dignity in dying and death, and the right to a painless death are increasingly at odds. Frequently discussed "exceptions" from the legal protection of human life, e.g. in the areas of abortion, death penalty, and especially euthanasia, raise one crucial question: Should we be allowed to decide when and how we can terminate our life and can a human make the inevitable death "beautiful" and "sweet"?

In this context, issues of death and dying, considered as the most certain happening in everyone's life, as well as the question of the beginning of life, are always the leading concerns in the academic debate, not only from the point of view of religion, philosophy, medicine..., but also from a general perspective. Moreover, euthanasia is often discussed and has been studied in a number of ways: scientific, theological, ethical, medico-empirical..., that is, generally speaking, culturally, so now we have more confusion in its determination, especially when it comes to the actual meaning of the term euthanasia. Finally, the emphasis on the present – which is expressed and understood through the maxim "*Carpe Diem*" – further complicates the understanding of euthanasia by imposing a dilemma: euthanasia – necessity or a fashion?! So, the question of the basic human right to live vs. human dignity in suffering and dying has equally practical and theoretical aspects beyond a mere academic question.

### **Debate and arguments FOR and AGAINST euthanasia**

Since the second half of the 20th century, there has been a growing concern regarding the role of medicine in our lives. As technology progresses and medical knowledge and expertise advance, the technological ability to sustain and prolong life has improved tremendously. This

advancement of technology has evoked new ethical questions regarding the end of life: Should life be sustained no matter what, notwithstanding the condition of the patient, his/her wishes and his/her quality of life? Who should decide when to stop treatment? Can a patient decide the point in time when his/her life comes to an end? What is the role of autonomy, self-determination, and informed consent in the decision-making process? What is the role of the physician?

These and other questions occupy the thought of philosophers, bio-ethicists, lawyers, as well as of decision-makers: legislators, government officials, and judges. Although the general public in many democracies, including the United States (Carroll 2006; Taylor 2005), England (Ward and Carvel 2007, 9), Australia (ERGO News List 2007), Canada (The Ottawa Citizen 2001), and even Croatia (Groenhuijsen and van Laanen 2006) believe that life should not be prolonged at all costs, and that the law should satisfy patients' wishes at the end of life, most countries in the world have refrained from passing legislation that would permit mercy killing and physician-assisted suicide.

The first decisive step in the attempts to answer these questions, at least on European soil<sup>5</sup>, was taken by the Netherlands, through the process of decriminalization of euthanasia in 1971, after a doctor had killed its severely ill mother by injection. Already at the beginning of the 80's of the last century, surveys of public opinion in the Netherlands showed that 75% of citizens are willing to accept a law that would permit doctors to finish the life of the terminally ill as a token of mercy upon their own request (Geversn 1996, 26-33). Since January 2001, euthanasia has been decriminalized in the Netherlands based on criteria supported by the Dutch Royal Medical Chamber since 1984, which defined the application of euthanasia and its different versions (Zurak 2001, 39-46):

- the request for euthanasia or assisted suicide must come from the ill person, based on his or her free will;
- the request should be repeated by the patient after 7 days;
- the suffering of the patient should be unbearable and with no hope

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5 The Nederland is the first European country, and second in the world after Australia (North Australia, which even for a brief while, in 1995, legalized euthanasia when the State passed the Bill for rights of terminal ill patients), which together with Belgium and Luxemburg legalized euthanasia through the Bill for shortening life on request and assisting in suicide in 2001.

- without of any possible improvement;
- the active termination of life must be the last resort and it should only be enacted when no alternative solutions to the situation of the patient exist;
  - the physician must consult another independent colleague who must confirm the opinion of futility and the unbearable nature of suffering, i.e. the lack of alternatives;
  - there must be a written notice (referring to the diagnosis, prognosis, therapy, healing perspective, data from another independent medical practitioner, the request of the patient, as well as the way the life of the patient is to be terminated).

But despite these safeguards, research and numerous indicators concerning the application of euthanasia in the Netherlands show that in 1995 alone, 25,656 patients were killed by euthanasia in one or another of its forms, which is 19% of the annual total number of deaths in that country. Dominant among the reasons for such requirements are the feeling of loss of dignity, dependence on others, life fatigue – while unbearable pain as the only reason to perform euthanasia is stated only in 6% of the requests, which is typically three times larger than the number of performed euthanasia (Gevers 1996, 26-33; van der Mass et al. 1996, 699-705; Schepens, 2000, 63-85). That is to say that the decision for applying euthanasia to the terminally ill person does not arise from the biological area of unbearable pain, but at the core of the problem there is its psychological and social character.

This observation further fuels the debate on acceptance or rejection of euthanasia, because the human component of the same cannot be ruled out, so the public cannot guarantee a certified social viability of its application. This is why in the attempts to create a positive climate *in favor of* euthanasia the following arguments are commonly cited:

- *the right to choose for one's own life and death*, which is an essential prerogative of liberal democracies;
- *it is humane to shorten the sufferings of the person "sentenced" to death*;
- *the quality of life*, because due to the disease it comes to a change in the quality of life that leads to physical pain and suffering and mental pain due to the loss of independence in the performance of life functions, hence the preservation of dignity in death is required;

- *economic reasons*, i.e. hospital equipments, the pharmaceuticals and engagement of clinicians should be used for those patients whose lives can be saved, instead of continuing the life of those who want to die;
- *by legalization various types of abuse and gray areas of euthanasia will be avoided ...*

...while as an argument *against* euthanasia the following points are commonly proposed:

- *the question of right and its scope in relation to the physical integrity of every individual;*
- *the professional role of doctors*, who entering their duty, are bound by the Hippocratic Oath which excludes euthanasia;
- *the relative nature of medical skills* that is best reflected in the unanticipated possibility of recovery, particularly in the contemporary conditions of constant development of the medical sciences;
- *moral reasons* - the understanding of euthanasia as murder, because the right of life is an inalienable human right that cannot be violated under any condition, nor can the holder of the right relinquish it, especially in cases where consent has been given under the influence of heavy pain they suffer (Pozaić 1985, 98-108);
- *the ability of people to freely express their will and give consent to euthanasia* assumes a questionable power of judgment for a patient who is in a state of impaired consciousness;
- *the consent that patients give* is mostly expressed under psychological and financial pressure;
- *possible abuses of a decriminalization of euthanasia* known as “pin argument” or “argument of the slippery slope” (Cavalier 2002);
- *the legalizing of euthanasia as diametrically opposed to the universal principle of life support ...*

The debate is still taking place and with increased intensity, especially when one of the strongest, socially and humanly accepted motives is introduced in the game – the value of human dignity. While there is still a battle ground around the fact that severe disease conditions and dying are in an irreconcilable opposition to a human right to dignity in dying, the definition of Guenther Duerig is generally accepted, according to which

the human dignity is violated if a person is reduced to a pure object, only a means, an interchangeable quantity. Examples of the worst violations of human dignity are: torturing, enslavement, mass expulsion, genocide, deprivation of opportunity for equal access, forced labor, terror, mass killing, abusive experiments on people (Schmoller 2000, 171-211).

This leads to the necessity in bioethical considerations of euthanasia and the context in which it is carried out, to take into account the considerations of L.M. Martin (Martin 2004, 202-210).

### **Palliative medicine and care as an opposite response to the requests for euthanasia**

In this sense, euthanasia imposed on the decision over someone's life and death does not resolve the quandary of human dignity but opens up a new very emotional and distressful dilemma in the search for a possibly effective and tenable answer compatible with the human right to live and our dignity in dying, which is dealt with in the *ethics of (palliative) care*.

In other words, regardless of culture, civilization and time, dying is always difficult, irrespective of the speed with which human life relentlessly rushes to its end – death. Sometimes it ends up as a long-term process of dying in sickness, suffering, pain and agony, which inevitably and with great importance to the individual and the society, raises the question of the meaning, way, and living of this last phase of life. This is so because illness and death today, as always, are and will be an inevitable and integral part of human experience. The way through which we try to determine and respond to the unique and individual needs of those who are dying and their families, as they struggle with illness and loss of the appreciated person, is actually an indicator of the maturity of a society in which medicine has its own part.

Hence, there are several viewpoints apart from its role and importance in the process of dying. Looking at the possibilities of modern medicine, which through costly efforts can prolong life, for various number of authors this becomes meaningless, because it means continuing death and suffering (Šeparović 1990, 297-307). They consider euthanasia as a way to help the individual to be saved from suffering.

On the other hand, burdened with compulsory identification with

the achievements of Western civilization, we failed to separate the positive from the negative, and even thoughtlessly accept the consequent products of modern society and spiritual alienation, as well as moral crisis. Impoverished generational emotional solidarity leads us to loss of ourselves, the faith in helping, the empathy, the support of loved ones in moments of illness or aging, in the destruction of the basic nucleus – the family and its values. Thus, according to the thesis of the opponents of euthanasia, one complete and quality solution related to the question of the sick and elderly can be the hospice, where palliative medicine is conducted, i.e. the access to palliative care and carefulness.

The hospice is based on a philosophy of carefulness as a modern health institution, with a number of levels of offering help to people who are at the end of life, through its caregivers, and even after the death, for the bereaved in mourning. In the Middle Ages, the term “hospice” was used to describe the place where sick travelers and pilgrims were taken care of. In Europe, the relationship between hospice and care offered to those who were dying makes its appearance in 1842, associated with the name and work of Jeanne Garnier who founded *L'Association des Dames du Calvaire* in Lyon, France, in 1842 (Clark 2000, 50–55). This work was later continued by the Irish Sisters of Charity with the opening of Our Lady's Hospice in Dublin in 1879, and with the opening of St. Joseph's Hackney, London in 1905.

As regards the establishment of the first modern hospice, the same is associated with the name of Cicely Saunders, who opened the hospice St. Christopher in London in 1967, and linked the compassion for the suffering of the terminally ill and the dying with the highest medical advances, creating the basis for the development of the hospice movement and palliative medicine, in whose center is the autonomy of the person of the ill patient who alone has the right to decide where to die, or whether to take the drugs or not, whether wanting to follow cultural customs etc.

For this type of activity (in the hospice), nowadays there prevails the term “palliative care” or “palliative medicine”. Palliative medicine is a type of medicine that deals not only with the disease, but turns also to the sufferer, i.e. to patients. It is able to understand that at some moment the priority is no longer fighting a disease, but alleviating pain and

suffering instead, favoring the natural process of end of life, i.e. trying to complete the life in the least painful way possible. Hence, palliative medicine aims to control pain and suffering of the dying, providing relief in dying and death. This shows that palliative medicine is not used for monitoring the process of dying, but the recovery of the patient's remaining life skills. Its center of gravity is focused on raising the quality of life before death, regardless of its length, which indicates that the main goal of palliative medicine is emotionally and spiritually stabilizing the physically and mentally decompensating sick persons, thus enabling their normal functioning with the family and the attending staff.

The advancement of drug therapy in the second half of the 20<sup>th</sup> century, combined with a growing understanding of the psychosocial and spiritual needs of dying patients, paved the way for the development of palliative care which indicates the approach to improve the quality of life of the patients facing terminal illness and their families. It is about an active and comprehensive, complete care of patients whose disease no longer responds to curative treatment, so it is necessary to control pain and other symptoms, as well as psychological, social and spiritual problems in its focus (World Health Organization 1990, 11). Therefore, palliative care includes all treatments that are designed to ease the suffering: psychological, mental and physical, which is done through prevention and relief of symptoms through early detection, assessment and treatment of pain, as well as through the easing of other socio-psychological problems.

The term "palliative" comes from the Latin word *pallium*, which means a mask or a cape; etymologically, "palliative care" indicates "masking results" of incurable disease, or one that provides a warm cover for those left out in the cold, because they cannot be helped further by curative medicine.

Given the fact that palliative care is an active, comprehensive care of patients whose disease no longer responds to treatment, it includes the medical, ethical and social aspects, as well as psychological help, because its aim is a better quality of life of the patient and its family. In this sense, palliative care accepts death as a normal process, as the last phase in life, as a special time for integration and reconciliation, hence accepts the need of those who are dying to live completely satisfied and

comfortable until they die, which means that it neither hastens nor postpones death, but provides support for the grieving family and friends (Jušić et al. 1995).

What we have just seen suggests that on the issue of euthanasia there is an alternative available today. Although euthanasia attempts to regulate itself legally, the best solution seems to be an ethical alternative - palliative medicine, or care, which seeks to be an integral part of any health system and an integral element of the right of the citizen's health care. It is undeniable that palliative medicine is trying to promote a culture of life at the end of life, and connects the highest medical advances with the empathic carefulness for the patient and its family, with an emotional and spiritual support, which significantly reduces the demand for euthanasia, rendering it unnecessary. Moreover, according to the proponents of this idea, it is because the practice of euthanasia destroys the foundation of the value system, and thus the entire human community. Euthanasia, as violence towards human life, regardless of the motive for it, is contrary to human dignity. Dignity in dying, which the hospice provides through palliative care for those who die, and an emotional warmth that relieves pain and removes symptoms of dying, are the only human and humane solutions at the end of life. It is a need for those who die not to feel abandoned, undesirable and worthless. The example of Mother Teresa supports this perspective (Хироми Џозефа Кудо, 2006).

The hospice and the hospice movement are not considered as an alternative to euthanasia, but as some followers love to say, they are the only proper humane care measures for those who are at the end of their lives. As stated, it must not be allowed for the public to easily accept the fashion of euthanasia, but we must be ready to offer the right solution - the hospice! (Jušić 1997, 119: 214-215) This is even more so because of today's so-called justification of euthanasia, which for the proponents of palliative care is neither ethical nor medical, but a social fashion, and according to which terminal suffering is an excessive financial burden for the society.

Finally, euthanasia is not a solution. Its only ethical alternative is palliative medicine that helps the terminally ill to enjoy the last moments of life with the help of state-of-the-art medical achievements, and most

importantly with sincere human compassion and love towards close ones, with human dignity emphasized until death. In this context, such as the pain becomes a significant factor in the decision of the patient to die, palliative care should become an imperative.

### **Conclusion**

Euthanasia, be it unfortunately or fortunately, is still a criminal act in most countries in the world. This is not just a legal issue, but also a human and ethical one. It comes out as a result of still lacking a single general acceptable view for it, which in turn is understandable if we take into account the large number of cultural, civilizational and historical burdens, as well as the influence of the dominant philosophical, religious, ethical and moral beliefs related to attitudes towards life and death, human dignity, fundamental duties of a physician and medical deontology, the progress of medicine...

According to prevailing trends, alongside the growing demand for legalization or decriminalization of euthanasia, the contrary response increases as well, expressed through the hospices, which are considered as more humane places, retaining the dependability and authenticity of human existence, while treating euthanasia as violence against human life that regardless of motive is at variance with human dignity. That is why many insist on palliative care as a contrary response, a counter reaction to the increased demands for decriminalization of euthanasia. In this context, as opposed to the promotion of the right to a dignified "mild" death, there is more and more insistence on teaching the younger generations about a dignified death and the return of emotional warmth, as Mother Teresa was doing.

This means that every life, in all its stages, is worth living and needs all the medical care and human attention. In this context, the Declaration of the World Association of Physicians (WMA - World Medical Association) made at the General Assembly in Madrid in 1987 in relation to this question, says that: "Euthanasia, that is the act of deliberately ending the life of a patient, even at the patient's own request or at the request of close relatives, is unethical. This does not prevent the physician from respecting the desire of a patient to allow the natural process

of death to follow its course in the terminal phase of sickness.”<sup>6</sup> In these words, the World Association of Physicians expressly indicates that it is aware of all developments on the issue of euthanasia, which is a medical-ethical problem.

Hence, whatever the modern period will accept for the future, as an appropriate response and practice, in the meantime, we are dealing with a bioethical problem to which bioethics seeks an interdisciplinary and pluri-perspectival way of approaching and offering a possible solution. In this context, a clear terminology is the first step towards trying to offer an ethically “right” solution because people are social beings. We communicate with one another, converse, exchange ideas and different points of view via language/s and signs. Language constructs affects and changes reality, facilitating communication, promoting understanding, helping to erect bridges between cultures. That is why in the field of bioethics, concepts and categories should convey a clear meaning, and should not be open for interpretation. This is so because phenomenology is important – language does play a critical role in the shaping and reshaping of our existence – it is important to reflect on the language people use to describe their experiences, especially those concerning life and death (Cohen-Almagor 2000, 267-278).

This is so, because we are talking about one relation between euthanasia and palliative care which is very confused: the first being about ending life, the second about improving the quality of life; and the experience across countries shows that these two concepts tend to converge and mix when it comes to end-of-life decision-making.

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İlhan İlkılıç, Hakan Ertin, Rainer Brömer, Hajo Zeeb (Eds.)



BETİM CENTER PRESS

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BETİM CENTER PRESS

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Betim Center Press

# Health, Culture and the Human Body

Istanbul 2014

## Editors

İlhan İlkılıç, Hakan Ertin, Rainer Brömer, Hajo Zeeb

## Publisher

Hayat Foundation for Health and Social Services

## Contact

Kızılelma Cad. Topçu Eminbey Çıkması Sk. No. 30  
Fındıkzade, Fatih / İstanbul  
0212 588 2545 Fax. 0212 632 8579  
www.betimcenter.org

## Production

Selika

## Design Application

Ahmet Yumbul

## Printing and Binding

Pınarbaş Matbaacılık Ltd. Şti.

## ISBN

978-605-86957-1-9

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## TABLE OF CONTENTS

<b>Preface</b> .....	08
<b>MIGRATION AND HEALTH</b>	
<b>History</b>	
Medical selection in the recruitment of migrant workers (“Gastarbeiter”) <b>Sascha Topp</b> .....	19
The Historical Development of Health-Conditions Among Female Immigrants from Turkey in the Federal Republic of Germany <b>Asli Topal-Cevahir</b> .....	39
The Political Making of Care Worker Migration: The Austrian Example <b>Lukas Kaelin</b> .....	63
<b>Epidemiology</b>	
The Role of Illness Perceptions in The Health Care Provision of Turkish Migrants <b>Patrick Brzoska, Yüce Yılmaz-Aslan, Oliver Razum</b> .....	79
Storytelling for and Along with Turkish Caregivers in Germany: the <i>saba</i> Study <b>Susanne Glodny, Yüce Yılmaz-Aslan, Oliver Razum</b> .....	99
Contested Medical Identities, Migration of Health Care Providers and Middle Eastern Students at Western Universities <b>Frank Kressing</b> .....	113
Health Policies and Cultural Sensitivity in the Care for Elder Turkish Migrants in Austria and Germany and the Role of Turkish Migrants <b>Nevin Altıntop</b> .....	127
Medically Unexplained Physical Symptoms Among Turkish Migrant <b>Merlijn van Schayk, Karen Hosper</b> .....	137

## Ethics

- Medical Care for Migrants Without Health Insurance in Germany and the Role of Civil Society  
**Fiene Wolf, Christa Blum, Jakov Gather, Hannah Windeln, Eva-Maria Schwienhorst** ..... 167

## INFECTIOUS DISEASES

### History

- European Physicians/Specialists During the 1893–95 Cholera Epidemic in Istanbul  
**Nuran Yıldırım, Hakan Ertin** ..... 189

- “Ethnology and Dermatology”. Lorenz Rigler and Alfred Marchionini in Turkey (1842-56 and 1938-48 respectively)  
**Werner Friedrich Kümmel** ..... 217

- Syphilis Control in the Age of Abdülhamid II  
**Nil Sarı** ..... 231

- “Afflicted by God.” Ernst v. Düring and Endemic Syphilis in Anatolia Around the Year 1900  
**Werner Friedrich Kümmel** ..... 257

- Düring Pasha’s Services for the Ottoman Empire  
**Nuran Yıldırım** ..... 269

- The Impact of Syphilis on the Military Capacity of the Ottoman Army During the First World War  
**Murat Yolun** ..... 291

- A Sanitary Journal for Common People: *Yaşamak Yolu*  
**Ceren Gülser İlikan Rasimoğlu** ..... 299

### Epidemiology

- Awareness of Sexually Transmitted Diseases Among Adolescents with and Without Migrant Backgrounds in Bremen, Germany  
**Florence Samkange-Zeeb, Saskia Pöttgen, Beate Schütte, Hajo Zeeb** ..... 313

- Current viral hepatitis B status and policy in Turkey and the relevance to major immigration countries  
**Mehlika Toy** ..... 327

Doctors' and Parents' Perspectives on Communication Regarding HPV Vaccination in Bulgaria <b>Elitsa Dimitrova, Yulia Panayotova, Irina Todorova, Anna Alexandrova-Karamanova</b> .....	341
<b>Ethics</b>	
Integration of People With HIV/AIDS to Social Life: AIDS in Turkey and Socio-ethical Reflections <b>M. Kemal Temel, Hakan Ertin</b> .....	365
<b>BEGINNING OF LIFE/REPRODUCTIVE MEDICINE</b>	
<b>History</b>	
The Stone Tekija as a Cultic Place for the Cure of Infertility and the Prevention of Various Diseases: Exploring Macedonian Folk Medicine <b>Dragica Popovska</b> .....	379
<b>Epidemiology</b>	
Advances in Perinatal and Neonatal Care for High-Risk Newborns: Ethical Implications - a German Perspective <b>Herwig Stopfkuchen</b> .....	393
<b>Ethics</b>	
The Dignity of the beginnings of Human Life <b>Hans-Martin Sass</b> .....	403
End-of-life decisions at the beginning of life <b>İlhan İlkılıç</b> .....	433
Contemporary Cultural and Clinical Conflicts at the End-of-Life in Neonatology Ethics <b>Ayesha Ahmad</b> .....	447
The prohibition of egg donation as an issue of medical ethics <b>Clemens Heyder</b> .....	463
Abortion According to the Turkish Law <b>Hakan Hakeri</b> .....	483

## **END OF LIFE**

### **History**

- Concepts About Death Throughout Turkish History. A Historical Perspective of Religious Ethics in Connection with a Dying Patient  
**Nil Sarı** ..... 497

### **Epidemiology**

- Psychological, Religious, Legal and Folkloric Dimensions of Death  
**Tuğba Gencer, İbrahim Başağaoğlu** ..... 525

### **Ethics**

- End-of-Life-Decisions in Germany: Crucial Aspects of the Medico-Ethical Debate and Clinical Practice  
**Monika Bobbert** ..... 547

- Ethical Evaluation of the Pharmacy Services for Geriatric Patients  
**Sözen Şahne, Sevgi Şar** ..... 567

- Be Healthy to Live – Live to be Healthy? Bioethics, Biopolitics in Aging Society  
**Petra Kutscheid** ..... 577

- Advisory Ethics Committees for Artificial Nutrition and Hydration in Patients  
**Hanzade Doğan** ..... 589

- Ethics of (Palliative) Care and the Question of Euthanasia  
**Dejan Donev, Željko Kaluđerović** ..... 603

- Demise and Death from the Perspective of Philosophy of Law; Especially Violations of Dignity  
**Altan Heper** ..... 617

- Legal Situation of Organ and Tissue Transplantation in Turkey  
**Yener Ünver** ..... 631

## **HUMAN BODY**

### **History**

Representations of the Female Body in Feminist Zines <b>Melanie Boeckmann</b> .....	659
--	-----

### **Epidemiology**

Exploring the Role of Narrative Therapy in Obesity: Overcoming Body Image Disturbances <b>Somayeh Sadat McKian</b> .....	667
---	-----

## **INTERCULTURALITY AND ETHICS**

### **Epidemiology**

The Need for Cultural Competence in Health Care: The Case of Roma Population in Poland <b>Agata Strzadała</b> .....	683
---	-----

### **Ethics**

Interculturality and Ethics in Health Care <b>İlhan İlkılıç</b> .....	697
Cross-Cultural Ethical Conflicts in Health Care. Developing Cultural Competence in Health Care Personnel and Ethics Consultants <b>Tatjana Grützmänn</b> .....	711