

Special Workshop 94

Title of Workshop	Bioethics and Biolaw and the question of human dignity
Abstract	<p>Dignity is a malleable concept that needs re-definition to be adapted to the context in which it is deployed. This is especially the case when the concept is used in bioethical and biolegal debates. Indeed, in this context, the concept of human dignity has gained a central role in defining institutional strategies and policies. As testified by the first all-embracing Convention on bioethical issues of the Council of Europe, <i>the Convention on Human Rights and Biomedicine</i> (Oviedo Convention), dignity of the human being is strictly related to protection of fundamental rights. And in fact, one of the objectives of the Council of Europe is to protect the individual's dignity and fundamental rights with regard to the applications of biology and medicine. Since the Oviedo Convention has been promulgated, the bioethical and biolegal reflection has widened from traditional issues (end-of-life issues, beginning of life issues etc.) to include frontier issues like robotics, artificial intelligence, human enhancement.</p> <p>This workshop investigates the 2019 IVR topics by focusing on the bioethical and biolegal discussion of both traditional and frontier issues at the European and national level. We welcome contributions on both traditional and frontier issues in Bioethics and Biolaw that address the question of human dignity in relation to other fundamental rights and principles like the principles of self-determination and equality. Following this integrated vision, according to which dignity is related to, albeit not completely exhausted in, other fundamental rights as it constitutes the real basis for their protection, we particularly focus on end-of-life issues and on human enhancement, but do not exclude contributions about other bioethical issues.</p> <p>Languages: English, German, French, Italian</p> <p>CONVENORS: Patrizia Borsellino, Silvia Salardi</p> <p>PARTICIPANTS AND ABSTRACTS:</p> <p>Prof. Dr. Patrizia Borsellino- School of law, University of Milano-Bicocca (Italy)</p> <p>Title: <i>Dying with dignity: what are the conditions and what can the Law do to protect this right?</i></p> <p>In the last decades, end-of-life has become a crucial topic in philosophical-legal and bioethical research, which has focused and still does on questions regarding meaning of dying with dignity and conditions, to be granted to all individuals, for ending life in a dignified way. The debate has however highlighted relevant disagreements with regard to the notion of 'dignity of dying'. In order to overcome these different opinions, the best way is to propose a clear redefinition with the intent to initiate the discussion and possibly reach agreement on choices and courses of action useful to offer the best care to terminally ill patients. But how can we identify the conditions needed to properly discuss about dignity at the end-of-life and dignified dying?</p> <p>The analysis realised in the presentation will argue in favor of the thesis that dying with dignity requires first of all that the suffering patient is never subject to others' interests, including family, who often wants to prolong life at any cost. In the second place, it requires that we really understand how devastating is the impact of lies on the patient's overall</p>

condition. Finally, it requires that efforts be made to overcome prejudices in order to preserve the patient from mortification caused by not been considered any longer a person with full rights: This occurs anytime the patient is denied the right to choose and possibly adopt nonconformist lifestyles. Conclusions of the paper focus on some considerations concerning values at stake and foreseeable impacts on health policies and legal regulations regarding the vision of dying with dignity in the shape of the proposed definition.

Prof. Margareth Vetis Zaganelli - Università Federale di Spirito Santo (Brasil)

Title: *Accesso Alle Cure Palliative: Un Diritto Fondamentale Del Paziente Del Sistema Pubblico Sanitario In Brasile*

L'integrazione delle cure palliative (CP) è un fattore importante della qualità delle cure in salute, ma l'implementazione è ancora limitata in Brasile. Seconda relazione di The Economist Intelligence Unit del 2015, Brasile è a 42 ° posto nella promozione delle cure palliative (CP), un approccio che secondo l'Organizzazione Mondiale della Sanità (OMS) migliora la qualità della vita dei pazienti e le loro famiglie ad affrontare problemi connessi con le malattie pericolose per la vita, previene ed allevia la sofferenza per mezzo di ricerca iniziale, corretta valutazione e trattamento del dolore e altri problemi fisici, psicosociali o spirituali. Nel paese, l'aumento del numero di persone anziane e con cronica malattia solleva nuove sfide per i sistemi sanitari. Di fronte a questo fatto, l'articolo ha lo scopo l'accesso alle cure palliative nel sistema sanitario pubblico in Brasile. Inizialmente, traccia una breve una breve retrospettiva storica e descrive le attuali metodologie di medicina palliativa; presenta quindi le disposizioni di legge e le misure per la promozione di tale diritto nell'ordinamento giuridico brasiliano. Con l'uso della metodologia esplorativa di natura qualitativa, attraverso la ricerca bibliografica e documentaria, lo studio sottolinea che i trattamenti di cure palliative sono inerenti i diritti umani, pertanto, devono essere rafforzati e ampliati il tuo accesso nel Sistema Unico Sanitario (SUS) del Brasile, per conto della qualità della vita del paziente, la tutela della vostra dignità e supporto per la tua famiglia. Considerando che la politica nazionale di attenzione basica alla salute ha come obiettivo di sviluppare una cura completa che hanno un impatto sullo stato di salute e autonomia delle persone, evidenzia la forte dipendenza delle politiche pubbliche per l'efficacia delle cure di fine vita, alla luce dei principi della dignità umana e la completezza dell'assistenza nell'ambito del Sistema Unico Sanitario (SUS).

Prof. Juana María González Moreno, Departamento de Derecho Financiero y Filosofía del Derecho, Universidad de Málaga (Spain)

Title: *Les stratégies pour légaliser la “gestation pour autrui”. Une remise en question à partir de la dignité et l'autonomie reproductive des femmes.*

Cette communication analyse deux des stratégies qui sont utilisées dans les lois et les propositions de loi, dans la doctrine et dans la jurisprudence, aussi bien en Espagne que dans d'autres pays européens, à fin de légaliser et/ou légitimer la “gestation pour autrui”: d'une part, sa configuration contractuelle et d'autre part, son classement ou son lien avec certains droits déjà juridiquement reconnus. Et ce que les résultats de l'analyse mettent en évidence, surtout au travers de ces deux stratégies et de l'ambiguïté et du caractère contradictoire des termes, des concepts et des arguments qui supportent ces stratégies, c'est que la dignité et l'autonomie reproductive des femmes ne sont pas vraiment prises en compte.

Prof. Aránzazu Novales Alquézar, Philosophy of law, University of Zaragoza (Spain)

Title: *When Does Life Begin In Europe? Dignity And Techniques Of Assisted Reproduction.*

At the European level, the question of the nature and status of the embryo and / or the fetus is not subject to consensus, even if they appear elements of protection of fetuses and embryos, in view of the scientific progresses and the future consequences of the research about genetic manipulations, medically assisted procreation or experiments in embryos. All

the most can be found as a common denominator of the States the belonging of the embryos to the human species; it is the potentiality of this being and its ability to become a person protected by civil law in a large number of States, which must be protected in the name of human dignity without thereby making him or her a "person" who would have a "right to life" within the meaning of Article 2 of the ECHR.

But a principle of legal logic requires the right to life to be absolutely protected or not protected, because the intermediate positions have no consistency and neither do they make sense, from a philosophical point of view, if we speak about human dignity. Thus, the Oviedo Convention does not give a definition of the human being, whose dignity, identity, primacy and interest consecrates. Also it does not speak about the beginning of life. As one of the main objectives of the Council of Europe is to protect the individual's dignity and fundamental rights, this article aims to clarify and discuss the position of the European Union on the beginning of human life and the level of protection of the embryo and its dignity, specially in the ECHR Jurisprudence on assisted reproduction.

Prof. Dr. Silvia Salardi, School of law, University of Milano-Bicocca (Italy)

Title: *Human rights and dignity: the challenge of robots and AI*

Advances in robotics and Artificial Intelligence pose new challenges to legal categories and institutions. The paper will focus on the proposal of attributing e-personality to robots with autonomous, self-learning abilities and will examine the interrelationship between the category of personhood and the concept of person with other legal categories and concepts, namely dignity, autonomy, freedom, responsibility, and equality.

PHD Mariana Karadjova, Independent Researcher

Title: *Oviedo Convention and the right of donor conceived children to know their origins*

The Oviedo Convention doesn't directly give to donor conceived children a right to know their biological origins. However, art. 10 grants to everyone the right to respect for private life in relation to information about his or her health. How to benefit from this right if donor conceived children don't know anything about their biological donors? The European Court of Human Rights had already approached the right of anonymously adopted children to know their origins. There are also several similar cases pending before the Court filed by donor conceived people. There were communicated to their States and the judgments would be of importance for further evolution of private life and health information rules related to gamete donation.

Would it be an opportunity to revisit the Oviedo Convention and include not only the protection of embryos created for research, but also of embryos donated to future parents different than the biological ones (embryo adoption) What rules for this kind of donation? How Oviedo Convention and the ECHR could remediate to ART practices and provide respect of human dignity?

Art. 21 of the Oviedo Convention prohibits financial gain from parts of the human body. Is there a relation between financial motivation of donors and anonymity of gamete and embryo donation?

The purpose of my participation will be to explore protection of beginning of life of donor conceived children in the light of human dignity provided or not yet provided by the Council of Europe Human Rights instruments

Prof. Dr. Igor Milinkovic, Faculty of Law, University of Banja Luka (Bosnia and Herzegovina)

Title: *Right to refuse medical treatment and the value of human dignity (a view from Bosnia and Herzegovina)*

The right to refuse medical treatment is universally recognized as one of the basic patients' rights. This right has been justified by reference to values of autonomy and self-

	<p>determination, which makes it closely related to the value of human dignity. However, dignity cannot be reduced on autonomy. Every autonomous act of an individual will not necessarily be in accordance with the value of human dignity. One of the issues that arouse ethical dilemmas is the right to refuse life-saving treatment.</p> <p>In the first part of the paper, ethical bases of the patient's right to refuse medical treatment will be analyzed. Special attention will be given to the relation of the right to refuse medical treatment and the value of human dignity. The right to refuse treatment will be analyzed in the light of different concepts of human dignity defined in the literature (and the usefulness of some of these forms of dignity in the analysis of ethical dilemmas surrounding the right to refuse treatment will be examined). In the second part, the case law of the European Court of Human Rights related to refusal of medical treatment will be analyzed, as well as the relevant legal provisions adopted in national legislations of different countries. The legal framework of the right to refuse medical treatment in Bosnia and Herzegovina (its entities) will be explored, and the differences between entity laws will be pointed out. In Federation Bosnia and Herzegovina, patients do not have the right to refuse a life-saving treatment. In Republic Srpska, this right is established by the Health Protection Act. In conclusion, possible modifications of current entity legislations in Bosnia and Herzegovina will be suggested.</p> <p>Prof. Kamil Zyzik, Jagiellonian University in Kraków (Poland)</p> <p>Title: <i>Ethical dilemmas of the tort of 'wrongful life' and its possible model of application</i></p> <p>The technological advancements in prenatal diagnostics seen in recent years provide parents with opportunities to make decisions regarding their offspring. Thanks to detailed medical examinations, parents are now faced with opportunities to track the development of the foetus or even decide on its fate. The aforementioned medical achievements have contributed towards emergence of laws that protect the rights to decide about the shape of the family, such as the torts of 'wrongful birth' (brought by parents of a child against a medical professional whose negligence has contributed towards a birth of an unwanted child) and 'wrongful life' (made on behalf of a disabled child, whose living is claimed to cause them more harm than they can endure). While both torts cause substantial ethical dilemmas, the tort of 'wrongful birth' happens to be widely accepted by courts as a form of pursuing compensation for lost opportunities to decide about one's offspring. Contrarily, the tort of 'wrongful life' faces an almost unilateral rejection, which may be connected with an obligation of the plaintiff to demonstrate in the process that their parents would have inevitably terminated the pregnancy in view of the diagnosis. Assessing, if not being born may cause less harm for an individual than living, causes major moral dilemmas. In the paper I will discuss the telos of the two torts and assess the similarities and differences of the conditions in which they may apply in European legal systems. Most importantly, I will analyze the legal and axiological conditions of applying the tort of 'wrongful life' in states that allow it (such as the Netherlands). Finally, I will propose hypothetical conditions of applicability of the mentioned tort in Polish legal system, where it is now rejected.</p> <p>Prof. Michele Saporiti, School of law, University of Milano-Bicocca (Italy)</p> <p>Title: <i>Human dignity and the migrants issue: a right to health based approach</i></p> <p>The arrival of migrants is increasingly becoming a pressing issue in the political agenda, stimulating huge debate on the very concept and significance of human rights protection. Nevertheless, little attention has been paid on the guarantee of their human dignity as a reflection of the effective protection to their fundamental right to health. This paper addresses the issue from a legal philosophical perspective, questioning the relationship between the migrant status, the right to health, and the resulting concept of dignity as a variable notion depending on the political status of people.</p>
<p>Organiser(s) (Name / Affiliation)</p>	<p>Patrizia Borsellino, Full Professor of Philosophy of Law and Bioethics, School of law, University of Milano-Bicocca, Italy Silvia Salardi, Assistant Professor of Philosophy of Law and Bioethics, School of law, University of Milano-Bicocca, Italy</p>