

Conference Abstracts

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SESSION

[Organizer: the Polish Unit of the UNESCO Chair in Bioethics (Haifa)]

Topic: **BIOETHICS AND DEMOCRATIC CULTURE**

Introduction: Although many scholars still conceptualize bioethics as a part of (applied) normative ethics or practical philosophy, there is a growing consensus that bioethics is a form of public discourse deeply embedded in democratic values. Bioethical theory (especially principlism) and regulations (based upon human dignity and human rights discourse) as well as different forms of bioethical practice – in particular various forms of bioethical consultations and bioethical education – they are all based on goals, values and ideals that are foundational for liberal and democratic societies. This session will provide forum for an in-depth discussion of the historical, axiological and practical relationships between bioethics and democracy.

Session speakers:

- Prof. Pawel Lukow, PhD (University of Warsaw), *Democratic culture, informed consent, and the social role of bioethics.*
- Joanna Rozynska, PhD (University of Warsaw), *Healthcare Ethics Committees in young democracies.*
- Marek Czarkowski, PhD MD (Warsaw Medical University), *Challenges for the patient-centered mission of Hospital Ethics Committees.*
- Jakub Zawila-Niedzwiecki, MA, PhD Candidate (University of Warsaw), *Clinical Ethics Consultations, democratic inclusion, and the best interests standard.*
- Emilia Kaczmarek, MA, PhD Candidate (University of Warsaw), *The role and the limits of democracy in bioethical education.*

Chair-person:

Joanna Rozynska, PhD – Head of the Polish Unit of the UNESCO Chair in Bioethics (Haifa)

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Democratic culture, informed consent, and the social role of bioethics

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It is no accident that modern democracies, informed consent to medical intervention, and bioethics are essentially contemporaries. Informed consent and bioethics, it will be argued, are indispensable instruments of respect for the values and ideals of democratic societies.

The ethical and legal institution of informed consent emerged in response to citizens' endorsement of democratic values and ideals (in particular, those of individual liberty and equality) and their expectations, motivated by those values and ideals, in their encounters with healthcare professionals. The practice of seeking and respecting patient's or research subject's informed consent itself strengthens the democratic culture to the extent to which democratic values and ideals inform decisions and actions of patients, research subjects, and healthcare professionals. These values and ideals constitute the normative framework for discussions of ethical matters in medicine, including informed consent. The forum for such deliberations in a democratic society is provided by bioethics understood as a field of academic study and social practice, which engages both specialists and lay citizens. Bioethicists, therefore, assume part of responsibility for continued existence of the democratic culture. In particular, they need to make sure that bioethical debates and medical practice are not misused as a tool of promotion of a worldview, ideology, or religion but offer hospitable environment for participation of diverse moral outlooks which respect democratic ideals and values.

Healthcare Ethics Committees in young democracies

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Healthcare Ethics Committees (HECs) developed in response to complex medical, ethical and legal changes in health care delivery in the last two decades of 20th century. They provide a multidisciplinary forum for discussion of difficult clinical issues where the voices – goals, interests, values, and preferences – of all of the involved parties, especially patient or patient's surrogate and health professionals, can be heard and respected. Therefore, it is often said that HECs “introduce local democracy into clinical practice” (Beyleveld et al. 2002, p. 20).

HECs have already become a vital element of health care delivery in the United States, Western Europe, and many other well-developed democratic societies. However, they are still a relatively novel phenomenon in many young democracies (transitional societies), for example in Poland and other CEE countries.

In this talk I will present result of literature review and empirical studies on HECs in CEE countries that have been conducted under the auspices of the Center for Bioethics and Biolaw, University of Warsaw. The result will be discussed against research hypothesis that organization and functioning of HECs in CEE countries are highly influenced by two groups of factors, namely: socio-cultural factors and economic factors. The first group contains: weak tradition of democratic discourse; low awareness and respect of the patient's rights, in particular the patient's right to information and her right to autonomy; strong tradition of medical paternalism and an authoritarian style of medical decision-making. The second group contains factors stemming from the weaknesses of health care systems in low- and middle-income countries. In such systems HECs are often considered to be an unnecessary luxury as they are time-consuming and costly.

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Challenges for the patient-centered mission of Hospital Ethics Committees

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Hospital Ethics Committees (HECs) are an integral part of the organisational infrastructure of many health care institutions (hospitals, nursing homes and hospices) in the USA, Canada, Australia and numerous European countries. They perform a variety of roles out of which the following three seem to be the most important: (i) providing ethical consultations in tough clinical cases, (ii) developing or revising institutional policies on controversial clinical matters, for example, on continuation of life-sustaining treatment, and (iii) providing ethical education for health care professionals as well as for patients and their families. All these activities must serve the HECs' principal mission which is to promote patients' rights and interests by facilitating shared decision-making being a key component of patient-centered healthcare defined as "care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (IOM 2001: 40).

The HECs' mission is embedded in values and ideals shared by all democratic societies. Thus, HECs' ability to fulfill this mission depends on the political context and intuitional environment. HECs seem to be useless or impotent in societies where ethical and legal perplexities in health care delivery are ignored or unseen. Patients cannot seek HECs' support when the most morally controversial procedures are prohibited or decisions in such cases (i.e. withholding or withdrawing life-sustaining treatment) are left entirely to physicians. Moreover, HECs are not able to fulfill their principal role if there is no understanding that they "should be designed primarily to assist the patient rather than the health care team of institution" (Belton & Meyer, 1992: 205). Finally, HECs cannot function properly, if they have no access to necessary funds and resources. In this talk, I will analyze these problems, using – as an example – the current situation of HECs in Poland (Czarkowski et al. 2015).

Clinical Ethics Consultations, democratic inclusion, and the best interests standard

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The phenomenon of persons unable to make choices (incompetent persons) presents unique set of challenges for clinical ethics consultations (CECs). Such persons, while being right-holders, need other persons' judgements to benefit from their rights. In a sense, substitute decision-makers hold some part of the autonomy of incompetent persons and take up their role in relevant situations. They are the voice of the incompetent – the children, the senile, the persons with mental disability.

In this presentation I will analyze the best interests standard as a unique mechanism of inclusion and protection of the incompetent person's interests within the context of CECs understood as a forum for democratic discourse. First, I will discuss how best interests standard is relevant to all of substituted decision making in modern biomedicine. Second, I will propose a typology of interests as employed in the best interest standard. I will show that incompetent patient's interests differ in terms of their epistemic status, their relation to the patient's primary goods, their temporal connection to the patient's present, past, or future goals and preferences, and in terms of their potential to enter into conflict with the interests of the substitute decision-maker. I will argue that these differences should influence the standards for substitute-decision making in biomedicine, if we want the best interests standard to be a genuine inclusion mechanism, not just a useful normative fiction. Finally, I will show how my analyses of the best interest standard serve to elucidate the possible conflicts and faults within usually employed substitute-decision making frameworks, and the rules of selecting of the substitutes.

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The role and the limits of democracy in bioethical education

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Bioethics as a discipline has been deeply involved in democratic values since its beginnings - this fact is also reflected in bioethical education. In this presentation three challenging aspects of the role of democracy in bioethical education will be briefly analyzed. The first one concerns the role and the limits of democracy during the process of bioethical education. The next two refer to the goals of that education - both in academic and broader social dimension.

The first problematic aspect of the role of democracy in bioethical education can be observed during academic classes. How democratic education should look like? What is the role of a teacher in bioethics? Shouldn't we assess students beliefs? Is there a place for relativism in bioethical education? In this part of presentation the dual goals of bioethical education - formative and philosophical – will be analyzed.

The second aspect discussed concerns the future of the students who receive bioethical education. Who do we want to “make bioethicist”? What role should they play in a democratic societies? Are we, bioethicists entitled to act as moral experts?

The last problem discussed during the presentation refers to the broader impact of bioethical discourse and education on society. It can be argued that bioethics – while contributing to the democratization of medicine – increase also medicalization of society. There is a need of bioethical education that would be aware of both opportunities and threats of further democratization in the world of medicine.