

New Considerations on Informed Consent

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Informed consent is an extremely delicate theme that -though entering with legitimacy the sphere of medical ethics after the horrors of the Second World War as a response to unethical medical experiments and trials- it has recently come under scrutiny as a too fixed notion that risks to remain an empty concept unable to help individuals truly preserving their autonomy and, more important still, act in their best interest in an appropriately conscious way.

To improve the guidelines of informed consent, the European Union has financed the Horizon 2020 project "I-CONSENT" (grant agreement No 741856), bringing together partners from different countries and professional expertise to collaborate in the analysis of the state of affairs and propose possible improvements: www.i-consentproject.eu

Hence, in order to investigate more in depth the multilayer dimensions of informed consent, in December 2017 and February 2018, the UNESCO Chair in Bioethics and Human Rights organized two separated workshops in Rome where national and international experts where invited so to share and discuss two themes strongly connected with informed consent: neuroscience and multiculturalism. The papers here collected are the result of these meetings and aim at providing the readers with new material for discussion.

The specific objective of the neurobioethical perspective of informed consent was to implement procedures to assess patients' or participants' capacity to consent while assessing the interconnection between neural activity, autonomy and informed consent.

Informed consent presupposes a level of individual autonomy that can be challenged by development in neuroscience. Should we -as some scholar suggest while interpreting some of the findings that neuroscience have produced in the last decade- accept that free will does not exist? If so, what would be the consequences that such an acceptance would entail for our currently widely accepted notion of autonomy? In order to enter the specificity of the debates related to the application of the notion of autonomy and informed consent in current neurobioethical contexts, it was first needed to be constructed a more general framework within which we can move, and both the authors concerned with this theme did that before moving towards a more specific analysis.

The multicultural and interreligious perspective had a different specific objective. Namely, that to frame questions for a multi-layered informed consent review: multicultural and interreligious variables for patient's understanding and communication, cross-cultural vision of vulnerability, knowledge, communication and empathy, adopting individualized approaches to promote health protective behaviors and an analysis of the East/West – North/South perspectives.

The notion of informed consent relies on a set value of individual autonomy that not all cultures and approaches to life share. A patient's cultural disposition and past experiences

with medical health care professionals will have an impact on the amount of trust that the can have in a vaccines' efficacy for example. Although local culture may shape people's perception over time, people are more likely to trust experts that share a similar background, tradition, religion and culture with them. When working with ethnic minority patients, it is important to note that comprehension may also transcend simply linguistic barriers. The conceptualization of illness and cultural bias both play a role in the ways that information is presented and understood. Thus, it is important to understand the role that culture plays in obtaining informed consent. In this respect all the contributions from the authors here included have provided valuable inputs for further the understanding of the "other", increase the doctor-patient dialogue and reduce the gap and barriers among different groups of our global society.



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