
VIII Annual Symposium on Biomedicine, Ethics and Society: "Rethinking Informed Consent: The limits of autonomy"

Dafna Feinholz Klip, Ph D (i) and Miguel Moreno Muñoz, Ph D (ii)

i National Commission of Bioethics, Mexico
FLACEIS (Latin American Forum for Health Research Committees)
ii University of Granada, Spain
E-mail: dafna@fliceis.org

Critical review of informed consent and autonomy in the context of biomedical research in developing countries

There is an urgent need to rethink autonomy, informed consent and vulnerability in biomedical research in developing countries, particularly linked to international research. Most of the participants in research in developing countries are disempowered and have restricted access to health; for many, research means the only access to treatment. Living in poverty is associated with less agency capacity (as defined by Amartya Sen), and a core element to question the accepted meaning of autonomy; It forces to take into consideration the concrete situations in which people make decisions, and to stress the need to think about autonomy as the recognition of rational agents making autonomous decisions, which for researches mean an obligation to create the circumstances for people to give free not only informed consent. In many developing countries, there is a great socio-cultural-ethnic heterogeneity. There is a big debate over the need to consider culture when conducting informed consent ("ethical imperialism" vs. "double standard"). Differences in culture often mean differences in access to power. Many idiosyncratic issues are ignored by standard international parameters for informed consent such as: the different meanings of the signature, most of the participants are analphabets and asked to signed a 8 pages document, often rated as understandable according to existing scales, which do not consider cultural meaning of concepts and technologies; the psychological defense mechanisms and impact of illness, hope and fear which produce therapeutic misconception, the asymmetry in the researcher-participant encounter (participants lack experience of being heard). Some alternatives for improvement are included.