Conference Abstract

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Title: How to best justify exposing children to risks of "non-beneficial" biomedical research

Biomedical research without potential to produce results of direct clinical benefit to subject who are unable to give informed consent, especially children, creates serious ethical conflict between interests of the subjects and interests of science and society. There is an ethical and regulatory consensus that such research projects are needed for developing safe and effective treatments for childhood diseases, and as such justified. But there is still a controversy about the best way to reconcile the principle of the primacy of the individual, being a fundamental requirement of research ethics, with the fact that participation in "non-beneficial" biomedical research exposes incompetent subjects to risks and burdens solely for the sake of others.

In this paper, I will critically analyze different moral justifications for allowing children to participate in "non-beneficial" research presented in bioethical literature, in particular different interpretations of the "best interests of the child" standard and the principle of the primacy of the individual (Kopelman 1997[2], 2002, 2007; Litton 2008; Wendler 2012, Spriggs 2012; Litton 2012; Kopelman 2012; Johansson & Brostrom 2013; Shah 2013; Wendler 2014; Piasecki et al. 2015). I will discuss how those different interpretations translate into different approaches to setting minimal risk threshold adopted by international and European regulations as well as scholars (Ackerman 1980; Barnbaum 2002; Freedman et al. 1993; Kopelman 2000, 2004; Resnik 2005; Wendler 2005; Wendler & Glantz 2007; Westra et al. 2011; Binik 2014).

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