

Conference Abstract

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Title: **Who gets to decide when we are gone? - On limitations of proxy decision makers in transplantations.**

Abstract text: Increasing pressure on global scale requires us to procure more transplantation organs and tissues for the ever increasing number of patients who urgently need organ replacements and other procedures involving human tissues. The existing shortage is an ever more important factor for the societal disease burden in the developed countries. This situation puts medical professionals in a position where they have both moral and professional obligation to obtain such organs or tissues. Depending on donation system in a particular jurisdiction consent maybe be available from proxy decision maker to procure tissues or organs of dead or dying (in some cases just incapacitated) patients for the benefit of others, or it may be only a family's objection that even if not legally binding might be an ethical issue. When proxy decision is required a family member, a lawyer, a judge must make the decision. He or she has to take into account various laws that may regulate the situation, but also the ethical aspect of the situation. Weighing the various normative concerns he or she should arrive at a decision. That is the ideal. In an actual situation the proxy decision maker is an acting human agent with all limitations characteristic of any person making decisions about his or her own body. There are cognitive biases involved, mental disturbances, trauma, limited intellectual capabilities, various ideological backgrounds and many other factors that will influence this process.

The purpose of my presentation is to provide an outline of limitations of decision makers in tissue or organ donation processes and their various types: the ones resulting from simply being human, from mental strain, from pathological processes of mind and body, limited bodily function etc., but also from normative limitations as expressed in ethical principles such as best interests, beneficence and justice. The obvious and most common example of obstacles to proxy consent in jurisdictions with opt-in donation system will be the ability of proxy decision makers to conceptualise and accept the notion of brain death and its implications that is far less obvious than some bioethicists would like. The resulting framework will show which types of decisions are even possible to conceptualise as autonomous and which are possibly beyond the capacities of at least some agents.

This presentation is a part of a project to create new standard of competence assessment and here I would like to show how it extends to healthy subjects who act as proxies. It also aims at showing the ethical boundaries and limitations of proxy decision making in general, that among other things is based on incomplete and biased knowledge and biased thinking.

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