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

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The role of informed consent and the principle of autonomy: developments and perspectives

In the second half of the twentieth century, the doctor-patient relationship underwent a radical change in terms of the status accorded to individual patient autonomy. The reasons are various but some broad trends need to be understood when we re-evaluate the pre-eminence given to informed consent in healthcare today. Not least, recognition of the ethical duty to seek informed consent in medicine has echoed the similar emphasis on individual rights in international human rights law and national legislation. This paper provides a brief overview of how the notion of informed consent developed when modern ethics guidance began to be formulated to some more recent developments and perspectives.

Medical research took the lead in developing the notion of informed consent but up until the mid-twentieth century, researchers generally lacked guidance about patient autonomy. From the 1720s to the 1950s, the frequent use of marginalised populations such as prisoners or orphans in research projects appeared antithetical to the very idea of autonomy. The exposure of the shocking scale of lethal human experimentation in the second world war sparked the first modern wave of international standards on informed consent, including the Nuremberg Code and Declaration of Helsinki, as well as generating national agencies such as the US National Institute of Health and the UK 's Medical Research Council. In the 1960s, however, Pappworth and Beecher were among those exposing the continuing lack of adherence to the agreed standards. Among the sad landmarks of the 1970s, disclosure of the Tuskegee and Willowbrook studies launched a further wave of international and national guidelines, focussing on informed subject consent. Retrospective information about past abusive research continued to leak out until the end of the twentieth century. Then, as guidance tightened up the requirements for research conducted in developed societies, the focus of anxiety shifted to the standards of consent required for research conducted in developing countries.

In many jurisdictions, the law has played a significant role in achieving recognition of patients' rights to self determination in medical treatment. In 1767, for example, a British judge ruled that patients must be properly informed so that they can take courage and prepare themselves. In 1792, however, Thomas Percival published his classic text on "Medical Ethics" arguing that informing patients would frighten them and that secrecy should be strictly observed. His code became the basis of much subsequent ethical guidance and influenced attitudes until the 1970s. This period saw the influence of theorists rather than doctors alone shaping ethical codes and the growing emphasis on individual autonomy, often supported by the law. When we look back now, modern norms and standards bear little relationship to the contexts in which the idea of informed consent was first suggested. But there is still some utility in recalling those contexts when debating whether autonomy is perhaps over-emphasised now.