

Bioethics and Informed Consent



Professor Lucy Allais

Informed consent is a central notion in bioethics.

The emphasis on informed consent in medical practice is relatively recent (20th century).



Bioethics is a relatively young field, beginning, in the USA, in the 50s and 60s, maturing in the 80s and 90s.

This is different to both medical ethics, and ethics generally.



Medical ethics

Reflections by doctors and societies on the ethics of medical practice is probably as old as doctoring (Hippocratic oath; the Code of Hammurabi, written in Babylon in 1750 BC).

Traditionally focused on the doctor-patient relationship and the virtues possessed by the good doctor. (Kuhse and Singer *A Companion to Bioethics* 2001:4).

Ethics in philosophy:

Morality: how should we live? what is right? what is wrong?

Ethics: the academic study of morality.

Are there objective values?

Are there truths about right and wrong?

What makes actions wrong?

How do we resolve moral disputes?

What is the basis of human rights?

When (if ever) is euthanasia permissible?

Is it morally justifiable to incarcerate MDR TB patients?

“in 1972, no American medical school thought medical ethics important enough to be taught to all future physicians.... A decade later, in 1984—after the advent of bioethics—84 percent of medical schools required students to take a course in medical ethics or bioethics during their first two years of instruction.” (Baker 2013)

The four core values of **autonomy**, **justice**, **beneficence** and **non-maleficence**.

Autonomy often dominates discussions of bioethics.

Informed consent is linked to autonomy. Autonomy means being self-governing.

Autonomy is often thought to be at the basis of human rights: human rights protect the capacities of each individual to live their life for themselves. It is also at the basis of democracy: government with the consent of the governed.

Consent gets its significance against a background of rights to be self-governing.

The emphasis on autonomy represents a huge shift in medical practice, from paternalistic doctors making decisions, to giving central place to patients choosing.

The emphasis on autonomy in relation to informed consent is exaggerated and sometimes confused, leading to exaggerated understandings of informed consent practices, which can do harm, and can result in less actual consent.

Rethinking Informed Consent in Bioethics

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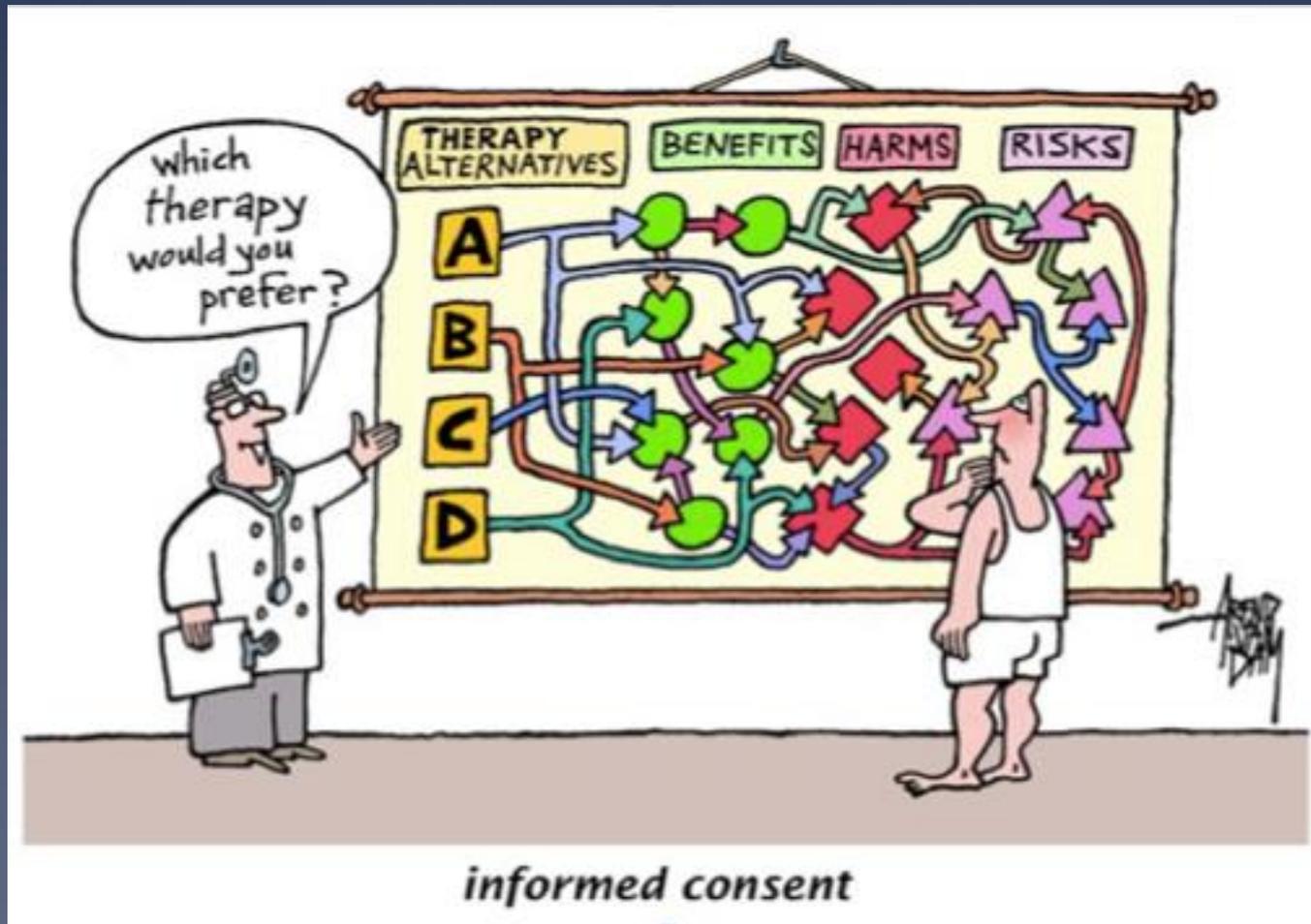
The link between informed consent and autonomy is sometimes understood in terms of promoting choice.

Consumer model

Promoting choice or the capacity to choose is not the role of health care practitioners (just like promoting health is not the role of plumbers or accountants).

Medical treatment typically involves limited options; in many cases the health care worker who is trying to help a patient understand the point and possible consequences of a test or procedure aims to help the patient understand their situation, not to promote their having more choices.

It is intrinsic to the practice of medicine that it involves expertise.



Our current informed consent practices developed in the context of **medical research**, in response to the abuses of Nazi doctors.

What makes sense in the context of research does not necessarily translate without change into the context of clinical practice.

That no one participates in medical research without their explicit consent is at least a coherent goal. Patients are frequently not in a position to give consent, and this is intrinsic to the medical context.

“ [i]ncompetence and impaired competence to consent are more common in medical practice than elsewhere, since impaired cognitive capacities are a common effect of illness and injury. Very many patients are unconscious or too ill, cognitively impaired or mentally confused, too young or too frail to grasp the relevant information, so cannot give informed consent to their medical treatment. Few of them are likely to (re)gain competence in time to consent. Even those ‘in the maturity of their faculties’ find it hard to grasp information about complex diagnoses or treatments, or severe outcomes.” Mansen and O’Neill

There is a point at which the attempt to make patients more informed will result in giving them more information than anyone could realistically process, which is likely to result in their being less informed than they would have been, had you tried to give them less information.

Exaggerated ideas about informed consent give health care practitioners an impossible goal, which may discourage them from taking informed consent seriously.

Thinking informed consent is covered by signing a form may allow health care practitioners to avoid responsibility to communicate with the patient.

We cannot give patients full and complete information.

Patients frequently aren't in a position to give consent.

We cannot solve the problems by always appealing to proxies or hypothetical choice. Proxies aren't always present. Hypothetical choice often involves imagining what someone who is not this person would choose.

Consent is not a self-standing source of moral justification; it matters in the context of things which would be wrong if I did not consent to them; things to which I have a right.

There are things which would be wrong, even if we consent to them.

Health is a very intimate, personal matter, and making decisions about your health and your body for yourself are regarded as most fundamental rights.

Health care is not just like good and services we purchase. We need health care when we are unwell. We are frequently vulnerable when we are unwell.

Many health care treatments involve doing things to people which, outside of the context of medicine, would constitute assault (making someone unconscious, cutting them up, poisoning them)

Basic rights to autonomy and bodily integrity mean that people have a right to refuse medical treatment, even if it is in their own interest.

We need systems that protect against abuse and paternalism (against the patient being in the practitioner's power).

We need a legal framework governing good practice (this protects both patients and health care practitioners).

Where a medical intervention involves doing something that would be a serious wrong or harm outside of the medical context, we need to waive the right not to be harmed in this way.

In this case, informed consent does not exist to promote choice, but to protect patients from wrongful harm.

Where patients are unable to provide this consent, practitioners must act on the patients' behalf, within the constraints of best practice as described by the legal and regulatory system.

We shouldn't assume that written consent for every test or treatment is an ideal of good care which only practicalities get in the way of.



Having signed legal forms is not the same as having informed the patient.

Communicating properly with a patient is an important part of developing trust, as is treating the patient respectfully.

We should re-examine the regulatory frameworks.

HIV tests

A prominent HIV doctor in Massachusetts writes: 'I saw a 35-year-old woman with a large brain abscess late last year who was comatose. An HIV test would have been invaluable to help distinguish bacterial brain abscess from possible toxoplasmosis—conditions which obviously require different therapies—but she couldn't give consent and, as is very common in younger patients, she had no health care proxy.'

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