View Point

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The right to consent: Is it absolute?

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Abstract

Informed consent is required for all medical investigations and procedures and is considered a corner stone of modern medicine. This review article examines the question whether the right to consent is absolute by looking at the philosophical, ethical and legal principles underlying consent. There are several legal exceptions to the right of consent in the United Kingdom concerning minors, incapacitated patients, patients with mental illness and patients suffering from communicable diseases. Furthermore the practical implications of consent and shortcomings of informed consent are discussed as well as the concept of advanced directives and lasting powers of attorneys. While a patient has a right to refuse treatment (all exceptions are discussed), there is no legal right to demand treatment in the United Kingdom.

The patient's right to autonomy should always be respected and steps shall be taken to make consent truly informed. There is, however, no absolute right to consent on the basis of philosophical, ethical, legal and practical considerations.

Introduction

Consent to investigations and treatment is considered a cornerstone in the doctor-patient relationship.[1] The Oxford Dictionary (1998) defines consent as "permission for something to happen or agreement to do something".[2] This definition does not entail understanding of the action agreed to and for medical purposes the term "informed consent" meaning "permission granted in the knowledge of possible consequences" has been developed.[2] General Medical Council (GMC) guidance requires the ability to comprehend and weigh up information as well the ability to communicate for informed consent.[3]

Most authors describe consent as a principle relatively new to medicine.[4-6] This is however incorrect as even Plato and Hippocrates used consent in their medical practice.[7]

This review addresses the issue whether the right to consent is an absolute right by exploring the ethical and legal framework of consent or more specifically informed consent. Whereas most of the ethical issues are universally applicable, the legal aspects and guidance by the regulatory authorities apply only to the United Kingdom (UK). Where law differs between Scotland and the rest of the UK, I have focused on the laws for the latter.

Ethical principles around consent

The four main principles of medical ethics are justice, non-malificence, autonomy and beneficence.[8] Autonomy is the main ethical consideration underlying informed consent. The patients' right to determine what investigations and treatment to undergo must be respected by all doctors.[3] For consent to be informed patients rely on the information provided by their doctor. Honesty and truthfulness are required to make the process of consent valid.[3] The ethical principle of justice needs to be applied when deciding what treatments are offered to or withheld from patients. This touches the process of informed consent and is further explored when the right to demand certain treatments is discussed.

Philosophical aspects

The debate whether a right or a principle is absolute not only involves ethical and legal aspects. It also touches on the philosophical argument of absoluteness. Freedom as an example can't exist as an absolute principle because granting one individual absolute freedom will infringe the freedom of a second individual considerably. Person A's freedom to take any good will influence the freedom of person B to have property. When applying these principles to autonomy the same problem arises: Total autonomy of one individual has a negative effect on autonomy of other individuals. The modern democratic society has designed rules and laws to create a fair way of living. On the one hand this restricts autonomy, while on the other hand this same restricted autonomy guarantees the same amount of it to all members of this society.

I argue therefore that on a philosophical basis the principle of total autonomy contradicts itself when applied to society. As autonomy is the main ethical principle for informed consent an absolute right to consent cannot exist.

Requirements of informed consent

The basic difference between consent and informed consent is the patients' knowledge behind the consent decision. Informed

consent requires the patient to understand the diagnosis and uncertainties about it as well as the different treatment options (including doing nothing) and their advantages, disadvantages and achievable outcomes.[3] The amount of information required to make consent informed may vary depending on complexity and risks of treatment as well as the patient's wishes.[3] Furthermore individual patients will have different intellectual capabilities and understanding of their illness. It is therefore mandatory to tailor information provided to the individual patient and the current situation. An emergency like acute myocardial infarction for example will allow less time to discuss diagnosis and treatment than an elective endoscopy.

To judge whether a patient has really understood the information provided can be difficult and often little of the information is retained (see practical aspects chapter). This leaves physicians in doubt whether their patient's consent is truly informed. Consent based on partial information may be invalid but this may go unnoticed by patient and treating physician.

The principal of an absolute right to consent could be easily undermined by partial information. It is highly dependant on the willingness to provide full information and the patient's capability to understand it and weigh up the options.

Legal framework

A medical intervention without valid informed consent is a criminal offence and the physician can be charged with battery. Examples of such situations include treatment against the patient's will, different treatment than the one consented for and treatment after consenting deliberately with wrong information.[9]

Guidance for consent has been set up by the regulatory body (GMC). While no one can consent for a competent adult UK laws are regulating consent for minors, patients with acutely or permanent incapacity and patients suffering form severe mental illness.

Minors

At the age of 16 persons are to be considered as adults and can therefore be presumed to have capacity. Children younger than 16 years may have capacity depending on their understanding. When a competent child refuses treatment persons with parental responsibility may authorise this or a court may overrule the child's decision.[3] Incompetent children will be treated with consent from a person with parental responsibility.

Acute and permanent incapacity

The presumption that every adult patient has capacity applies unless the opposite can be clearly demonstrated.[3, 10] Patients lacking capacity due to an acute (i.e loss of consciousness after an accident or patients on mechanical ventilation) or chronic illness (i.e dementia) cannot make decisions about their treatments themselves. In those situations it is the doctor's duty to act in the "best interest of the patient". Views about the patient's preferences may be sourced from a third party (relatives for example). This third party can however not consent or object to treatment.[3] If a patient has clearly given an advance directive while still competent, the treating physician is bound to respect this (see advance directive).

To give informed consent a patient needs to have mental capacity and the ability to communicate.[11] The physician needs to establish the patient's "ability to understand, retain, believe, evaluate, weigh and use information that is relevant to a medical intervention or its withdrawal".[11] This test of capacity has been supported by several court rulings[10, 12, 13] and is embedded in the Mental Capacity Act (2005).[14]

Making an irrational choice does by no means constitute lack of capacity and a competent patient's irrational decision has to be accepted even if this leads to an adverse outcome (including death).[3]

Mentally ill patients

The Mental Health Act (1983) regulates the treatment and hospital admission of mentally ill patients not volunteering to undergo assessment and/or treatment.[15] These patients can only be admitted to hospital if due to their mental illness they pose a threat to themselves or others. Patients can be detained against their wishes to conduct an assessment and if their condition is deemed treatable they can be detained to receive such treatment. While this allows treatment for psychiatric conditions, the treatment of physical conditions not related to mental illness cannot be undertaken against the patient's wishes. If needed, a court can decide on treatment of non-psychiatric illnesses in those patients.

This aspect of the law can leave physicians in difficult situations. If a depressed patient takes an overdose of an anti-inflammatory drug he can be detained in hospital using section 5.2 of the Mental Health Act. A resulting medical complication like severe gastrointestinal bleeding is however not covered by the mental health act. The patient therefore still remains competent to refuse a life-saving endoscopy or blood transfusion.

Protecting the public: infectious diseases, infection control and confidentiality

In order to protect the public form contagious infectious diseases the Public Health (Control of Disease) Act (1984) regulates notification of diseases and mandatory treatment of conditions like tuberculosis (TB).[16] The individual's right to consent is severely restricted in two areas: Firstly information about the patient's diagnosis has to be given to the relevant authorities. The patient should be informed about this step. Section 11 regulates the disclosure of information. It is

mandatory for a medical practitioner to disclose personal details of the patient and the diagnosis to the relevant authorities even if the patient does not agree to this. The list of notify-able diseases ranges from food poisoning and viral hepatitis to tuberculosis.

Secondly patients suffering from communicable diseases can be forced to take their medication by supervised administration or involuntary inpatient treatment. Sections 37 and 38 of the Public Health (Control of Disease) Act have recently been used to detain a man for inpatient treatment of TB against his will at North Manchester General Hospital.[17] The act was used to prevent the spread of TB to the wider public by forcing treatment onto an individual, who was not compliant.

While above regulations are clearly set out by law, a physician might encounter situations in which no clear guidance is given. If a patient confesses a crime or a planned crime to a doctor, it is left to him to decide whether to pass on this information to the police. This decision requires careful weighing up whether the right to consent on passing on information is more important than the right of the public to be protected. GMC guidance (Confidentiality: Protecting and Providing Information, 2004) gives general advice on disclosure, but leaves the ultimate decision with the medical practitioner.[18]

The legislative has given clear laws stating when a right to consent does not apply to a patient. Incompetent minors, adults lacking capacity and some mentally ill patients do not have an absolute right to consent. Furthermore patients suffering from some infectious diseases have limited right to consent and can be detained and treated against their will. Using the principles of capacity and justice towards other individuals the right to autonomy has been cut in a few well-defined circumstances.

Advance directives

When an adult becomes incompetent he loses the right to decide on his medical care. To allow patients to express their ideas and wishes before they become incapacitated the Mental Capacity Act was introduced in 2005.[19] Patients can give an advance directive or "living will" to outline the treatments they wish or wish not to receive. A physician is required to act within this advanced directive unless there is evidence that the patient revoked the will when still competent. A "living will" does not necessarily apply to all situations and it has to be checked whether the patient's current condition is covered by his will.

Practical application of advance directives can be difficult: Unclear wording like "no life-prolonging treatment" leaves room for interpretation and the same intervention might have different outcomes depending on underlying conditions. A healthy patient might set up an advance directive to not receive mechanical ventilation without discussing the merits of this intervention with a health care professional. This generally prohibits any doctor from administering such treatment in any situation. While this might be the patient's wish should he suffer a devastating stroke (very little chance of recovery), it could be argued that his view would be different if the merits of ventilation after major emergency surgery (reasonably good chance of full recovery) would have been explained to him.

Furthermore the act established the lasting power of attorney (LPA) concept. This enables the patient to grant rights of consent and refusal to a LPA while still competent. The LPA then takes over these powers when the patient loses capacity.

Research without consent

While consent should always be sought for including patients in clinical research, there are conditions that do not allow a delay: Unconscious patients, patients in shock and studies with short therapeutic windows. While including those patients without consent infringes their right to autonomy society as a whole benefits from such research. The European Union (EU) allows such studies to recruit patients without their consent under strict regulation.[20]

The right to refuse or demand treatment

British law clearly gives competent patients the right to refuse any treatment (the very few exceptions have been outlined in the chapter legal framework). In contrast, however, no patient has a right to demand certain treatments. GMC regulation (2008) states that if a patient wishes treatment that in the doctor's view is clinically not indicated there is no ethical or legal obligation to provide such treatment.[21]

Burke, who suffers from a chronic and progressing neurological illness, challenged this guidance. He wishes to receive artificial nutrition and hydration (ANH) when he loses his ability to swallow and he does not want doctors to make decisions on his behalf. Arguing that the relevant GMC guidance infringes his human rights he took the case to court achieving a favourable ruling initially. Mr Justice Munby ruled in Burke[22] that the Human Rights Act (1998)[23] entitles a person to demand life-prolonging treatments such as ANH. He based his decision on article 2, 3 and 8 arguing that a competent person's right to life and autonomy constitute an entitlement to ANH.[11]

The Court of Appeal overturned this ruling although the right-based analysis of Munby's decision was acknowledged. Two lines of argument were used to justify the decision. Firstly the case of Bland[24] (Airedale NHS Trust 1993), an advance directive to withdraw treatment in a case of persistent vegetative state must be respected, does not automatically lead to a reverse decision in opposite cases.[11]

Secondly an advanced directive demanding life-prolongueing treatment would not be in consistence with the Mental Capacity Act, which requires the doctor to take the incompetent patient's best interest into consideration.[11]

Another aspect of demanding treatment is the effect on the wider community. Graber and Tansey argue that demanding certain (more expensive, equally effective) treatments leads to injustice.[25] While doctors may feel pressured to please their patient's wishes, financial and organisational constraints in society (and a public health care system) will mean that other patients might not get treatments they require.

Currently there is no legal right in the UK to demand treatment. Furthermore such demands infringe justice by prohibiting resources to be allocated by need.

Practical aspects of consent: understanding and retention of information provided

Informed consent requires the ability to understand and weigh up information. Several studies have addressed the issue of understanding and retention of information provided. Even in a research setting where rigorous measures for consent are applied severe defiencies have been identified: in a randomized drug trial 44% of participants did not know that they were assigned to treatment or placebo by chance.[26] A capsule endoscopy study recruited healthy volunteers, of whom 90% had university education and 60% were medical students. Still vital information (drugs used, potential risks) given during the consent was only completely recalled by around 20%.[27] These examples show that most patients or research participants do not have a good understanding and/or recall of the information provided by standard consent procedures. Despite that treating doctors and researcher had treated or included patients based on this "informed" consent.

Methods like enhanced consent forms and multimedia interventions during informed consent have shown mixed results, while only additional time spent in one-on-one interviews significantly improved understanding and recall of information.[28]

Discussion

Informed consent is required for any investigation or treatment proposed to a patient. Understanding of the nature of procedure, benefits and risks are the cornerstones of informed consent. While autonomy is one of the four main ethical principles, I argue that there is no absolute right to autonomy or consent.

On a philosophical basis an absolute right to autonomy and consent contradicts itself.

Several restrictions in the right to consent are set by the legal framework in the United Kingdom (or England). The main statuary instruments concerned are: Mental Health Act, Mental Capacity Act and Public Health Act. UK Law regulates the right to consent for minors, mentally ill patients, patients with incapacity and patients with communicable diseases. Their rights to consent are restricted and in special circumstances not granted. Disclosure of information without consent is mandatory in infectious diseases cases and legal in cases where the doctor believes that non-disclosure will leave the public in danger. Furthermore patients can be recruited to studies of emergency medical treatment without consent under strict EU regulation. On a legal basis there is no absolute right to consent therefore.

Patients with anticipated incapacity can set advance directives to guide their future treatment while still competent or a LPA can be given the right to decide on treatment on the patient's behalf. While this increases the right of consent and improves patient autonomy to refuse treatment, there is no right to demand treatment if this is considered medically inappropriate (futile for example) by the treating medical practitioner.

Looking at the practical aspects of consent shows that the information provided is often poorly understood and retained. Patients giving consent are doing so without being truly informed. In other words they can't give informed consent due to their lack of understanding. As shown in the chapter practical aspects this will often not be noticed by the treating doctor or researcher. It is difficult to conceive an absolute right to consent in practice, when the effort to supply information required for informed consent fails so often.

In summary the patient's right to autonomy should always be respected and step shall be taken to make consent truly informed. On the basis of philosophical, ethical, legal and practical considerations, however, there is no absolute right to consent.

COMPETING INTERESTS
None Declared

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