Adolescent Patients' Consent and Refusal to Medical Treatment: an Ethical Quandary in English Law

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Abstract: A moral and legal quandary appears to arise from the combination of two intuitively convincing ethical-legal principles for the medical treatment of minors, especially adolescent patients, which have a prominent place in the law of England Wales, and with minor modifications in Scotland too. First that the young patients' wishes and autonomous decisions should be respected and carried out, and second that their wishes should be overridden when they are deemed by a court of law to be harmful to their own best interests. This article argues that the two principles are not necessarily antagonistic when a young patient's wishes are based on his settled beliefs and an adequate maturity of understanding which form core elements of his personality and sense of self-worth. In extreme cases a minor may be in danger of death or serious harm if his refusal to clinically indicated treatment is finally accepted and carried out. In such circumstances the imposition of a courtauthorized intervention may be ethically justified. But the two principles operate in a precarious balance which varies with the circumstances of the case.

An ethical quandary for the doctors of adolescent patients

When a patient anywhere in the United Kingdom refuses clinically indicated medical treatment, doctors' principal duty to "protect and promote the health of patients and the public" seems to clash with their equally important duty to "respect patients' rights to reach decisions with you about their treatment and care" (General Medical Council, 2010). For example, doctors who look after a patient suffering from

gangrene may take the view that his health, even his life, is in grave danger unless his foot is amputated; but the patient may be strongly opposed to such a drastic operation. Doctors are expected to try to reason with the patient and discuss his fears and worries, but such efforts may prove entirely ineffective when the patient responds to medical advice in an uncooperative manner which appears irrational or unwise. What are the doctors to do? Do they respect the patient's wishes, or do they force the operation on him for his own good? Doctors find themselves in an ethical quandary, but the law is the law. What exactly does the law provide with regard to a patient's refusal to clinically indicated treatment?

In relation to *adults* who do not lack mental capacity, as defined in the Mental Capacity Act 2005, the law generally requires the doctor to accept and enact the patient's decision. The law in England and Wales makes quite different provisions for *minors* – as will be seen, it may permit coercive treatment in certain extreme circumstances – so much so that it may appear inconsistent and tending to place doctors in a quandary (Shaw, 2001). In the next section I shall discuss some of the difficulties arising from the requirements of the law concerning adolescent consent to treatment, by contrast to the clearer provisions for adults.

Inconsistent approaches of medical law: an illustrative case study

The differential provisions of English law concerning the requirement of consent by patients to clinically indicated treatment can best be illustrated by means of an imaginary, but not unrealistic case. A school bus carrying students and their teacher has a road accident and overturns, causing serious injury to several passengers. An ambulance takes all injured passengers to the Accident and Emergency Unit of the nearest hospital where a team of doctors stabilise the patients. However, X-rays show that six of the patients suffer from internal haemorrhage and the doctors take the view that unless further investigation and operative treatment are carried out to stop the haemorrhage, it is probable that the patients will suffer cardiac arrest and die. Let us give each of the six patients in the story a name and an age:

- Mr Andrews, the teacher aged 30
- Barbara, aged 17
- Charles, aged 16
- David, aged 15
- Emily, aged 14
- Fred, aged 13

Mr Andrews is an adult, and there is no reason to think that he has suffered an impairment of the mind or brain preventing him from understanding the doctors' diagnosis and the recommended treatment. The doctors know that under the Mental Capacity Act 2005 they can only carry out a form of treatment on this patient if he gives his informed consent voluntarily, that is, without coercion or undue pressure, in light of a broad understanding of the nature of his condition and the recommended treatment. If the doctors explain to Mr Andrews that he has suffered internal bleeding and other injuries which pose a serious danger to his health, warn him that without appropriate operative treatment his health may deteriorate irreversibly, and he shows that he understands what is said to him and gives his consent, the treatment can proceed lawfully (see Chatterton v Gerson (1981)). If on the other hand he refuses to give his consent for any reason at all - for example he does not trust the doctors, he is scared, he is a Jehovah's Witness and opposed to receiving a blood transfusion - then the doctors cannot lawfully proceed with the treatment. Any medical procedure carried out on a nonconsenting adult constitutes, under English law, battery, which is a criminal offence (see R v Brown (1993)). The medical team and other specialist personnel in the hospital will most likely show understanding for Mr Andrews' fears and give him time to digest the information. But if he maintains his refusal to treatment, the medical team will have to accept the patient's decision – for this is the clear implication of the law.

Let us now contrast the doctors' attitude to Mr Andrews' refusal to treatment to their attitude towards his young students:

Barbara and Charles are both under 18, and so technically minors. Section 8 of the Family Law Reform Act 1969 stipulates that minors over 16 are empowered to consent to their own medical treatment, including any associated procedures such as administering anaesthetic and blood transfusion. For 16 and 17-year olds, as for adults, consent is valid if is informed and it is given voluntarily. We can imagine that Barbara

receives from the doctors adequate information about her condition and the recommended treatment, and trusting these doctors she gives her consent. This is sufficient warrant for doctors to carry out the treatment which they consider to be in her best interests – although it should be noted that the medical profession considers it to be good practice for doctors, where possible, to inform the young patient's parents, or other persons with parental responsibility, and obtain their consent too (General Medical Council, 2007).

But now let us suppose that, following proper discussions, Charles refuses the proposed treatment and insists on going home. In that case the doctors, mindful of the serious danger facing Charles, can seek consent from his parents, and if this is obtained, then his refusal can be overruled. If the parents also refuse, then the hospital can apply to a court to make Charles a ward and authorize the intervention against his own wishes, but in his best interests (see *Re W (a Minor) (Medical Treatment: Court's Jurisdiction)* (1992)). However, in an important Department of Health (2009) publication containing guidance to the medical profession, doctors are advised to exercise caution:

13. Where a young person of 16 or 17 who could consent to treatment in accordance with section 8 of the Family Law Reform Act 1969 . . . refuses treatment, it is possible that such a refusal could be overruled if it would in all probability lead to the death of the child/young person or to severe permanent injury.

. . .

15. The courts have, in the past, also found that parents can consent to their competent child being treated even where the child/young person is refusing treatment. However, there is no post-Human Rights Act 1998 authority for this proposition, and it would therefore be prudent to obtain a court declaration or decision if faced with a competent child or young person who is refusing to consent to treatment, to determine whether it is lawful to treat the child.

Doctors don't want to find themselves in a situation where in order to protect a young unconsenting patient's life or health they would have to go to court to seek authorization for a coerced intervention.

Except in cases where there is an immediate need for an emergency operation to save a young patient's life, doctors would much prefer to use persuasion and carry young patients and their parents along. For doctors, appeal to a court is only used when the minor's consent isn't forthcoming. Besides, the courts don't always take the side of medical authorities over young unwilling patients, as will be indicated later.

We now turn to the cases of 15-year-old David and 14-year-old Emily. As they are under 16, Section 8 of the Family Law Reform Act 1969 does not automatically empower them to consent to their own treatment. Children under 16, as was established by the landmark *Gillick* case before the Law Lords, are deemed to have a competence to give their consent to treatment just in case they can demonstrate such level of understanding and maturity as to enable them to appreciate 'fully' the specific information given to them by the doctors (see *Gillick v West Norfolk and Wisbech Area Health Authority* (1986)). This suggests that a child under 16 may be capable of giving *informed* consent to some interventions (e.g. placing a broken limb in plaster) but perhaps not to others (e.g. a complicated and risky operation). The teenager's competence to consent to a given treatment should be assessed carefully, following an effort on the part of the medical team to give him the relevant information, intelligible to him.

Suppose that David and Emily are judged by the medical team to be *Gillick* competent. The doctors will try as a matter of course to get in touch with their respective parents and involve them in discussions. If the parents cannot be contacted quickly, the doctors may try to deal with the teenagers themselves. So, since David shows that he understands the broad nature and implications of the recommended treatment and gives his consent, the consent is deemed valid and the treatment can proceed.

But now let us suppose that 14-year old Emily, like 16-year old Charles earlier, refuses obstinately to give her consent and wants to leave hospital. One thing the doctors *cannot* say in good conscience is, "If she refuses treatment despite what we have told her about her condition, it shows she is not competent to decide." The question of her competence to decide is logically independent from the character and consequences of her decision. The choices facing Emily's doctors are (a) to offer no treatment and resign themselves to her likely death or serious harm, (b) to try to get a court order to authorize the intervention – something that

may not be possible in an emergency – and (c) to overrule her objections and take her to the operating theatre, hoping that if death or permanent harm is averted, she and her parents will be grateful after the event!

Emily's case and the quandary that it raises for doctor bears comparison with reports in the British media of Joshua McAuley, a 15-year old Jehovah's Witness, who in May 2010 was the victim of a car accident. According to media reports, the doctors at Selly Oak Hospital in Birmingham advised treatment involving blood transfusion, which he steadfastly refused on religious grounds, and his parents – themselves members of the same faith – did not oppose his decision. As a result the treatment did not take place and the young patient died soon afterwards. It is particularly interesting to consider the reported statement of the spokesman for the hospital (quoted in The Daily Telegraph (2010)): "There's not one single policy and not one single law regarding transfusions. There's no automatic right to override parental wishes or that of a minor. It is a very complex area that has to be approached on a case by case basis."

Finally, we turn to the case of 13-year old Fred. One might assume that his young age indicates a lack of Gillick competence. This, however, would not relieve doctors and nurses of the responsibility to explain to him his condition in terms he can understand and secure his cooperation. In 2008 the British news media (e.g. The Guardian (2008)) reported the case of 13-year old Hannah Jones who had been diagnosed with a rare form of leukaemia at the age of five, and who after many years in and out of hospitals decided she was not going to have a life-saving heart transplant recommended by her hospital. Her parents supported her decision. The girl, whose statements to the media suggested she possessed a remarkably mature view of her condition, said that she had had "too much trauma in her life" and she wanted "to die with dignity surrounded by family and friends." According to media reports, High Court proceedings were initiated, but abandoned on the evidence of a Child Protection Officer, who had interviewed the young patient. Some time later Hannah changed her mind and agreed to a heart transplant, a development that saved her life.

Irrespective of how English law on adolescent consent and refusal to treatment is interpreted, many doctors are in practice wary of seeking to impose a form of treatment on unwilling minors, especially when such

treatment has an extended duration requiring consistent cooperation from patients. For example, it seems pointless to put a young patient on hospital wires and feeding tubes if he refuses to cooperate and is determined to take them off when the nurse is not looking.

The story of the school bus accident was intended to illustrate the differential position of the law in England and Wales with regard to the right to consent to medical treatment and the right to refuse such treatment of minors of different ages and levels of understanding, by contrast to those of an adult. One can ask in response to these facts why the law and its creators - legislators and judges - consider and treat differently the wishes of adults, adolescents and young children in regard to consent and refusal to medical intervention, and strike different kinds of balance between, on the one hand, the wishes and decisions expressed by individuals in these groups and on the other, doctors' judgments on how their best interests can be protected. Why are adolescents who are deemed competent to say Yes to a clinically indicated treatment not given the indefeasible right to say No to it, especially as an adult who has to capacity to say Yes is considered to have the right to say No? Is the health of adults worth less than that of minors, and so a recalcitrant adult patient will be left to suffer the consequences of his decision against the expert judgment of his doctors who are able to take a firmer stand with younger refusers? Are the wishes, beliefs and feelings of young patients less worthy of respect than those of adults, and as a result the former, unlike the latter, can be overridden by doctors, parents and judges? These questions seem natural and provocative, and the next section will attempt to provide answers. The key notion which will emerge from the discussion is that of the developing autonomy of the young person.

The developing autonomy of the young person

Let us ask why contemporary medical ethics and law accords informed consent a crucial role in medical treatment of adult patients who possess mental capacity. McLean and Maher (1983: 79) offer the following response:

Fundamental to the technical lawfulness of all medical intervention is the requirement that the patient concerned must consent to whatever treatment the doctor decides is appropriate to the particular condition. Consent is required primarily to ensure that no unlawful interference takes place with the person or personality of the individual.

But what is to be understood by the phrase "interference with the person or personality of the individual"? The most natural interpretation is that it refers to any medical action which violates or frustrates the core elements of an individual's distinctive personality. These elements include his settled and fundamental wishes and desires, his ambitions and aspirations, his dignity and values, his plans, his beliefs, his sense of himself and his worth and other states of mind and traits of character which motivate and shape his life and his relations with his fellows. But, it may asked, doesn't the law very often interfere with some of the desires and wishes and plans that people have? Some individuals like to hurt other people, some individuals enjoy driving the cars carelessly and at great speed, some steal other people's property or damage their reputation, s cheat state benefits - the list of desires resulting in harm on other individuals or the public good can be extended indefinitely. In a liberal society, legal limits are placed on personal freedom to express desire and choice in action, and the standard rule for determining such limits is the prevention of harm to others. If a person's wishes, desires, values, choices and plans do not infringe on the liberties and legitimate interests of other people, then, according to the liberal standpoint, he should be able to express and act on them without restriction, even though others may think he is being unwise or egoistic or unrealistic. However, this interpretation of 'personality' as the sum of one's settled wishes, desires, values and plans, when applied to the remark of McLean and Maher quoted above, gives rise to a variant of a question raised at the end of the last section. Are the wishes, desires, values and plans which make up a young patient's personality less worthy of protection if they are deemed inimical to his best interests than those which make up an *adult* patient's personality?

The answer to this last question seems to be a qualified Yes, but it is best developed in a roundabout way, via the concept of personal

autonomy, a concept which lies at the heart of ethical thought, including medical ethics. The concept is given a central place in *Principles of Biomedical Ethics* (Beauchamp & Childress, 1989), an agenda-setting textbook that has exercised great influence on medical ethicists in the past generation. The authors explain (p.68) that

the core idea of personal autonomy is ... personal rule of the self while remaining free from both controlling interferences from others and personal limitations, such as inadequate understanding that prevent meaningful choice. The autonomous person acts in accordance with a freely self-chosen and informed plan... A person of diminished autonomy, by contrast, is in at least some respects controlled by others or incapable of deliberating or acting on the basis of his or her plans. For example, institutionalized persons such as prisoners and the mentally retarded may have diminished autonomy. Psychological incapacitation affects the autonomy of the retarded; a severely restricted social environment limits the autonomy of prisoners.

The authors proceed to analyse autonomous action – the practical expression of autonomy – in terms of persons "who act (1) intentionally, (2) with understanding, and (3) without controlling influences that determine the action" (p.69).

The preceding remark by Beauchamp and Childress provide the key to understanding why medical ethicists place so much importance on patient autonomy. Traditionally the requirement of informed consent to medical treatment is regarded as a way of protecting a person's autonomy; that is, that great moral asset of personhood which crucially includes a person's capacity to determine without external interference and improper influences from others, as well as one's own psychological inadequacies, how he is to live his life, what is good and proper for him, and whether to accept the medical treatment recommended by his doctors, assuming of course that he has the capacity to make decisions which are permeated by knowledge and understanding. In a free society one of the aims of the law is to protect personal freedom and autonomy; and any restrictions to a person's freedom have to be given special justifications. Thus, criminals can be sentenced to imprisonment as

punishment, insane people can be kept in a secure hospital for their own safety and that of the public, sufferers from communicable diseases are kept in medical isolation to prevent contagion, and so on.

The next stage in our discussion is to bring to the fore an uncontroversial point: that a human being is not born already possessed of the knowledge and understanding required to make sense of his own needs, set for himself aims, make decisions, fend for himself and protect his health and his other vital interests. A new-born human being has the potential to gain by degrees knowledge, understanding and practical skills from babyhood through infancy, childhood, adolescence to the various stages of adulthood as a result of his growing brain, his experiences, the various forms of instruction and teaching he undergoes at home, school and the neighbourhood, his relations with his fellows, his immersion in his culture. As a general rule, the more he learns, the better he understands what is best for him, what to do to secure his interests, and by what means to reach his goals, especially his long-term 'staged' goals. As the child gains knowledge and increases his ability to articulate his wishes and beliefs, he commands increasing attention and indulgence among his elders on matters that concern him, and not only in the area of medical care.

The last point is given expression in Article 12 (1) of the United Nations *Convention on the Rights of the Child* (1989) which states:

States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

The second part of this statement expresses an understanding of what was earlier called 'the developing autonomy of the young person', and an appreciation of the implications of this fact of nature for a young person's dealings with his parents, the government, the courts, schools and other institutions, including the medical profession. Doctors are encouraged by professional bodies to involve children in the decision-making process together with their parents, and to seek consensus. The idea is that if a young patient does not see himself as a partner in the decision-making process, he will not be an engaged participant and

probably he will not be cooperative. It is, therefore, very important that doctors see to it that young patients and parents (or guardians) are aware of the participatory decision-making rights of adolescents, even when they are not competent to actually consent to treatment or refuse it. The young patient, if at all possible, should be given time to digest the information and the recommendation given by the doctor and discuss it with those he loves, likes and trusts. In a way it is one of the doctor's or the clinical team's important jobs to maximize the understanding not only of the patient, but also of his family and friends who support him. Some writers (e.g. Mackenzie (2010)) argue that given the close relationship which young patients have, in most cases at least, with their parents, siblings and friends, patient autonomy is best understood as 'relational autonomy', that is decision-making by the patient together with (or with the advice and support of) his close relations.

But a consensual decision, or even passive acquiescence of the patient and his relations to the doctors' recommendations, desirable as it certainly is, may not be possible. The young patient who may have an adequate level of understanding of his condition and the clinically indicated treatment wishes one thing, his parents who may or may not be more mature in their judgments may wish something else (or they may disagree, or worse, they may not be talking to each other), and the doctors may believe that it is imperative that they follow a different course of action to avert death or serious harm. The doctors know that they are duty-bound to act in the patient's best interests. The question is, are these interests necessarily different from the settled point of view and the associated emotional welfare of the young patient? If a young person is absolutely averse to amputation of his leg because playing football or dancing is everything to him, how can the surgeons carry out this drastic intervention against his will? At the very least the medical team will have to think hard whether any less dramatic alternatives are available and what would be their consequences for the patient's future life.

The British Medical Association (BMA) has considered what considerations need to be taken into account when assessing a child's or young person's best interests and offers the following advice to doctors (British Medical Association, 2010):

A 'best interests' judgement is as objective a test as possible of what would be in the child's actual best interests, taking into account all relevant factors. It is customary to assume that a person's interests are usually best served by measures that offer the hope of prolonging life or preventing damage to health, but this is not always the case. A number of factors should be considered, including:

- the patient's own wishes, feelings and values (where these can be ascertained)
- the patient's ability to understand what is proposed and weigh up the alternatives
- the patient's potential to participate more in the decision, if provided with additional support or explanations
 - the patient's physical and emotional needs
- clinical judgment about the effectiveness of the proposed treatment, particularly in relation to other options
- where there is more than one option, which option is least restrictive of the patient's future choices
- the likelihood and extent of any degree of improvement in the patient's condition if treatment is provided
- risks and side effects of the treatment or non-treatment
- the views of parents and others who are close to the patient about what is likely to benefit
- the patient relevant information about the patient's religious or cultural background
- the views of other health care professionals involved in providing care to the child or young person, and of any other professionals who have an interest in their welfare.

It is clear from this text that the medical profession in Great Britain does not see the young patient's best interests as something which is *opposed* to the various elements that make him the person that he is and the degree of autonomy he has attained. These carry considerable weight in any 'best interests' assessment. But doctors must also think about the patient's *long-term* life-and-health prospects and choices which the patient, experiencing the fear of a drastic operation and possibly

insufficiently mature to think about the future, may have closed his eyes to. The BMA states in another publication that "it is unlikely to be ethically justifiable to override a young person's sustained, competent and informed refusal of treatment, unless the treatment is essential to save or significantly enhance life" (British Medical Association, 2001). The idea, here, is that a young patient's best interests include the nonviolation, indeed as far as practicable the prevalence of his wishes, feelings, beliefs and other elements that he recognizes as aspects of himself; but the saving of his life or the restoration of his health are also included in his best interests. The two sets of considerations have to be viewed together and their significance assessed within the wider concatenation of the circumstances of the individual case, if a proper balance is to be attained which can result in a medical decision that is best for the patient. The process of assessment of conflicting elements and the framing of a wise and compassionate decision is not an exact science, and no rule can replace sound medical judgment.

Conclusion

The basic idea that emerges from the preceding discussion is that the notion of a patient's best interests, at least in its contemporary patient-centred interpretation endorsed by the British medical establishment, is not opposed to the patient's complex of wishes and desires, beliefs and values, ambitions and aspirations which constitute his personality. The two notions of a person's best interests on the one hand and on the other his personality whose autonomous expression a free society seeks to protect are not ideas of two different things which operate on the same level and sometimes clash, like individual freedom and public order. It may be suggested that the notion of best interests is an intellectual tool used by health professionals to reach a balance between two elements: (a) an appreciation of a young patient's present wishes, beliefs, aspirations, ideas as they bear on the particular treatment that is clinically indicated and (b) an assessment of his wishes and aspirations regarding the capacities he will want to be able to exercise and the goals he will want to be able to reach in his own future life, if his

life is saved or his health restored. In other words, doctors must make a diagnosis of the patient's sickness now, form a judgment on what the practical options are, and try to form a view of how he would wish to live his life next week or next month or next year, in light of his ideas and values. And then the doctors will have to explain to the patient and his relations at a level which is appropriate to them what needs to be done to treat the sickness or abnormal condition in order that he should get well, or better. There is, in extreme cases, an unavoidable element of speculation in the doctors' judgment of what kind of life the patient desires for himself, but in general terms they would be safe to assume that the patient wishes to be healthy, active, alert, pain-free and happy in his chosen way of life. The adolescent patient, however, given his youth and his not yet fully mature understanding, and the not unnatural fear of a drastic or painful treatment, may not be able to appreciate the point that if he undergoes the treatment he will be in the long term better off and be able to do more of the things he wants. This extreme kind of case may provide the circumstance which could justify the doctors' or the judges' decision to override the present wishes of the young patient.

Acknowledgment

This work was supported by the Nuffield Foundation which funded the 'Medical Practitioners, Adolescents and Informed Consent' project. The Nuffield Foundation is a charitable trust with the aim of advancing social wellbeing. It funds research and provides expertise, predominantly in social policy and education. It has supported this project, but the views expressed are those of the authors and not necessarily those of the Foundation. More information is available at www.nuffieldfoundation.org.

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