

The need for a Liaison and Mediation Service to assist doctors and their young patients who refuse treatment

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ABSTRACT: This paper attempts four things:

- (1) to identify uncertainties and ambiguities in English law and medical guidance concerning the circumstances in which a competent adolescent patient who *refuses* a clinically indicated treatment can be overruled by a court of law in their own best interests;
- (2) to clarify the nature and sources of two opposing attitudes towards the matter of the extent and limits of an adolescent patient's right to refuse clinically indicated treatment;
- (3) to argue for the need to set up in hospitals a Liaison and Mediation Service to facilitate communication between an adolescent who refuses treatment and their doctors with a view to developing, if possible, an agreed decision; and
- (4) to outline a widened conception of an adolescent's best interests which includes, besides the restoration of their health, respect for their personality and autonomy, acknowledgement of their right to be informed about the treatment proposed to them, recognition of their capacity to gain considerable understanding of the nature and consequences of the treatment and any alternatives, and also acceptance by doctors and judges of their ability to make their own decisions which is commensurate to the degree of intellectual and emotional maturity they have attained.

1. The background to a problem that needs a solution: an adolescent patient's refusal to a treatment that is clinically indicated

In the past twenty years or so, several academic writers and commentators on medical ethics and law have discussed the uncertainties, ambiguities and internal tensions of English law in relation to the question of how far an adolescent patient who is deemed competent to consent to medical treatment can *refuse* such treatment, specifically in circumstances when their doctors judge that they suffer from an acute condition and the treatment is imperative for saving their life or preventing serious harm from occurring.¹ The Family Reform Act 1969, section 8, provides that a young patient aged

16 or 17 is presumed to have the competence to consent to treatment recommended by their doctors. Further, according to common law a younger patient under 16 who can show their doctors that they have the necessary understanding of what a certain treatment involves, and are thus deemed to be ‘Gillick competent’, can also give their consent and their consent will be accepted. But can a competent minor refuse consent? In a famous case of *Re W (A Minor) (Medical Treatment: Court’s Jurisdiction)*, tried before the High Court in London in 1992, Lord Donaldson made a decision which still provides authority on the subject. The judge stated:

It will normally be in the best interests of a child of sufficient age and understanding to make an informed decision that the court should respect its integrity as a human being and not lightly override its decision on such a personal matter as medical treatment, all the more so if that treatment is invasive.... Nevertheless, if the court’s powers are to be meaningful, there must come a point at which the court, while not disregarding the child’s wishes, can override them in the child’s own best interests, objectively considered. Clearly such a point will have come if the child is seeking to refuse treatment in circumstances which will in all probability lead to the death of the child or to severe permanent injury.²

The views of academic writers and commentators on the matter of adolescent consent and refusal of treatment fall on different points in a spectrum of positions. At one end of the spectrum there are writers whose thinking is similar with that of Lord Donaldson in that they consider a minor as someone who has not yet attained ‘the age of reason’, and although their wishes should always be heard and considered seriously, when they cannot judge their healthcare needs properly and make the correct decision, they have to be placed under the benevolent protection of their parents, legal guardians or courts of law who can in principle override their wishes in their own best interests.³ At the opposite end of the spectrum, there is a very different view which sees the child as a full person whose wishes and opinions should carry increasing weight as they grow in age and maturity, and when they are able to *fully understand* the treatment proposed to them they should be recognized as having full rights to autonomy in personal matters,

including the right to consent to or refuse this treatment without undue influence from others.⁴

Both lines of thinking have their supporters who base their opposing claims on serious ethical and practical grounds. It may be that within the medical profession and scholarly community the broad balance between considerations of adolescent patient autonomy and those of best interests as assessed by doctors and other adults is shifting in favour of adolescent autonomy; but still the *legal* position appears to be influenced by both lines of thinking, and so it remains ambiguous in some respects. The United Nations Convention of the Rights of the Child, ratified by the UK as well as almost all other members of the UN, requires state parties to “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.”⁵ Plainly, a medical treatment proposed for a child is a matter affecting that child. However, a *specific* reference to the context of healthcare occurs in a document by the UN Committee on the Rights of the Child, which states:

Children, including young children, should be included in decision-making processes, in a manner consistent with their evolving capacities. They should be provided with information about proposed treatments and their effects and outcomes, including in formats appropriate and accessible to children with disabilities (para.100).

The document proceeds to state:

The Committee welcomes the introduction in some countries of a fixed age at which the right to consent transfers to the child, and encourages states parties to give consideration to the introduction of such legislation. Thus, children above that age have an entitlement to give consent without the requirement for any individual professional assessment of capacity after consultation with an independent and competent expert (para. 102).⁶

The Committee shies away from actually indicating what the age of *consent* to medical treatment should be, and whether any specific age set by a particular state party is necessarily the age of valid *refusal* to treatment that is medically indicated. This leaves the situation in considerable uncertainty, and obliges doctors and judges to exercise their personal judgment in line with their subjective intuitions. The UK Department of Health and medical bodies advise doctors to approach the courts in cases of doubt, and as things are at present the courts retain inherent powers to overrule a competent refusal of life-saving treatment in accordance with the Children Act 1989 which places paramount importance on the welfare of the child.⁷

Later in this paper I shall develop the following proposal: that in cases where an adolescent, over or under 16 looks reluctant or unwilling to give their consent to any treatment that is clinically indicated, it is important for hospitals to be prepared and able to make intelligent and sympathetic efforts to understand the young patient's attitude, improve their grasp of their treatment options, clear up any difficulties in their communication with the doctors, and to mediate between them and their families on the one hand and their doctors on the other with a view to developing an agreed decision. Every hospital which takes young patients is well advised to set up what I shall call a *Young Patient/Doctor Liaison and Mediation Service* (or LMS for short), staffed by healthcare professionals and other experts drawn from the hospital personnel or from outside it who have special experience and skills in dealing with opinionated, worried, frightened or obstinate adolescents and their families. This service needs to be ready to take action and seize the opportunity to prevent a crisis *before* the young patient's doctors feel obliged to apply to a court of law to authorize what would be a coerced medical intervention. Whatever decision a court may finally make in a given case of adolescent refusal, the very fact that a patient-doctor dispute is brought before a court and the young patient's condition and much of their personal and family life becomes the subject of testimony by witnesses and arguments by lawyers, with all the attending hassle, anxieties, unwanted publicity and bad feelings, to say nothing of the legal costs, tends to aggravate the worries of the patient and their families. An actual decision by the court to authorize a coerced intervention on a young patient can cause a

lasting psychological trauma on them and their families. The use of a Liaison and Mediation Service (LMS) to remove or reduce the disagreements between the two sides wherever they exist, and to reconcile as far as possible the professional duty of the doctors with the wishes of the young patient before attitudes get hardened can obviate the need for a court hearing with all its attendant aggravation. I shall claim that in some hospitals in the UK, including general and specialist hospitals, this service is lacking or it is badly inadequate.

2. The sources of the opposing attitudes of young patients and their doctors

Any attempt at reconciling the opposing points of view of (1) the young patients who refuse to give their consent to medical interventions despite their acute condition, and (2) their doctors who insist that such interventions are necessary for saving their lives or preventing serious harm must begin by appreciating that both points of view have as one of their sources a *moral* conviction. What is meant by ‘moral conviction’ is a fundamental belief held by each side on who has the moral right and authority to make the *final* decision on whether the treatment takes place. I shall try to indicate the nature of the contrast between the two opposing convictions by describing each in artificially sharp terms:

(1) The young patients, at least in certain clear cases, hold the belief (which they may not be able to state clearly, but the general idea is potent in their minds) that if for any reason they do not wish to put themselves in the hands of their doctors for the purpose that has been explained to them, they are simply not obliged to submit, and that is that. They are the masters of their fates and the captains of their souls; and so the final decision and responsibility in this matter rests with them and them alone.

(2) Doctors believe that their long medical training and their experience with patients have equipped them to carry out a diagnosis on the young patients, to determine the cause of their illnesses or conditions and to decide on the most appropriate treatments for protecting their best interests. This is, after all, the

doctors' professional duty, supported by time-honoured public attitudes of trust in their profession. They are the experts in matters of sickness and treatments, and their expertise endows them in the particular circumstances of the case with *final* decision-making authority.

Let this schematic explanation suffice. One can see immediately that such clear-cut cases of patient-centred thinking and doctor-centred thinking rarely occur in real life. The young patients are not isolated, entirely independent individuals, but they are often flanked, comforted and influenced by their families on whose support they count when they are in trouble. Doctors do know that both the law and General Medical Council (GMC) guidelines require them to show great respect and sensitivity in their communications with young patients or children. The GMC pamphlet entitled *0-18 Years: Guidance for all doctors* says that in assessing the young patient's best interests, doctors should consider not only what is clinically indicated in the particular case, but also

- a) the views of the child or young person, so far as they can express them, including any previously expressed preferences,
- b) the views of parents,
- c) the views of others close to the child or young person,
- d) the cultural, religious or other beliefs and values of the child or parents,
- e) the views of other healthcare professionals involved in providing care to the child or young person, and of any other professionals who have an interest in their welfare,
- f) which choice, if there is more than one, will least restrict the child's or young person's future options.⁸

These points of guidance discourage any indifference on the part of doctors to the young patient's wishes and opinions, but they do not rule out that doctors can apply to a court for authorization of an intervention if they decide that this is necessary for preventing death or serious harm. Whenever courts consider cases of children, they are required by the Children Act 1989, Part I, Section 1, to accord paramount

consideration to “the child’s welfare” and also to have regard to “the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding)”.⁹ The Children Act 1989 is not specifically concerned with children’s rights to consent to, or refuse, medical treatment; however, medical practitioners, medical lawyers and ethicists, and judges accept the relevance of the Act to medical treatment.

The idea of forcing adolescents, in cases of extreme medical emergency, to receive medical treatment against their wishes in their own best interests attracts both support and opposition among lawyers, ethicists, health professionals and academic writers. One group argues that however desirable the adolescent’s consent to the treatment may be, if such consent is not forthcoming, the treatment should proceed, on condition that it receives court authorization on the basis that this is required by the young patient’s best interests. The other group argues for the need to allow maximum autonomy to the young patient (if they are sufficiently competent to understand the option before them), whatever the consequences.

Let us call the two groups of lawyers, ethicists, healthcare professionals etc (each group defined in terms that are artificially sharp, given that in both groups there are many variations and combinations of ideas) respectively ‘benevolent protectionists’ and ‘competent autonomists’. The two terms may be explained as follows:

- *Benevolent protectionists*: This group takes the view that that adolescent patients should be heard, even encouraged to express their concerns and questions, but they should not be allowed to have the final say if they refuse treatment deemed by doctors to be essential for saving their lives or preventing serious harm or more generally protecting their health and welfare interests.
- *Competent autonomists*: This group argues that adolescents and younger minors should be given as accurate information about the proposed treatment, its risks and anticipated benefits as they can understand and appreciate, and then they should be permitted as much freedom to participate in decision-

making as is warranted by their actual intellectual competence and emotional maturity.

Benevolent protectionists and competent autonomists do appreciate both the authority and duty of the medical expert and the claims or rights of the adolescent patients, but they tend to place different degrees of importance to the judgements of the doctor and adolescent patient respectively. The differences between the two groups may be in part philosophical. Some thinkers are attracted to utilitarian ethics which conceive of the right course of action to be that which has the best, the most beneficial, even the ‘happiest’ consequences than any other practicable alternative course. Other thinkers are inclined towards a Kantian (or ‘deontological’) kind of ethics, which ascribes paramount importance to according respect to the autonomous decision-making of rational agents.¹⁰

However, I want to suggest that the differences between benevolent protectionists and competent autonomists reflect to a considerable extent their different beliefs and appraisals regarding the adolescents’ capabilities to understand health issues, process complex bodies of information and make competent decisions for their own good, and consequently the role of the state in ensuring the health and welfare interests of young patients. It is impossible to give anything like a comprehensive list of characteristic beliefs held by the two groups, but I will attempt to sketch a few illustrative examples.

I begin with a number of beliefs underpinning the attitude which I have called benevolent protectionism.

- Children themselves, by and large, prefer to leave decisions on serious matters to their parents as they do not think they have to knowledge and experience necessary for a good decision. In the circumstances, to ask children to decide whether to give their consent to medical treatment is to trivialise the process of obtaining consent – it would be a kind of empty gesture – since the children would turn the question to their parents who ‘know best’.

- Jehovah's Witnesses from time to time refuse blood transfusion for themselves and their children – even when this procedure is deemed by doctors to be necessary for their survival – on the grounds that their faith teaches them that the procedure is sinful and if they go through with it they will be damned for all eternity. Supporters of benevolent protectionism argue that young members of this faith are unduly influenced by their parents' religious dogmas, and if they were forced to receive blood transfusion and their lives are saved, they will soon be grateful to their doctors for saving their lives.
- Children and adolescents have an inadequate understanding of death or permanent injury, as these ideas fall outside their knowledge and experience. They believe they are invincible.
- Children may refuse an intervention in fear and horror of the pain of the procedure, or alternatively in the belief that they will be 'all right' at the end *without* the dreaded procedure. Fear and self-delusion are bad counsels for making decisions against the doctors' recommendations.
- Sufferers of certain kinds of illnesses with a psychological dimension, like *anorexia nervosa*, are by the very nature of their condition incapable of recognizing it for what it is, even though they are not in any general way lacking in competence.¹¹

Benevolent protectionists can also argue that the court of law – the judicial arm of the state – enjoys a traditional and widely accepted position as *parens patriae* which represents the power of the state to protect those who are too weak and vulnerable to protect themselves. The court's duty includes intervening against an abusive or negligent parent, guardian, informal carer, and further, assuming the role of the protector of any child or older individual who is in need of protection. The British parliament and society have never seriously questioned the legitimate role of the state to protect those who are incapable of protecting themselves.

These traditional ideas about children and childhood are opposed by the competent autonomists who hold that adolescents and older children, or most of them in any case, have to varying degrees useful abilities and experiences to enable them to form a good

grasp of their health situation and make responsible choices, once they are given information and explanation that is appropriate to their intellectual level.

Priscilla Alderson has written extensively on the variety and extent of abilities which older children can be seen to possess, and she casts doubts on simplistic paternalistic claims that children are incapable of understanding treatment choices. She has argued that there is growing research evidence that many young children are capable of understanding complex information about their conditions, including distressing information. Children do want to be informed, and many do wish to share in making decisions about their health treatment. Further, the medical profession expects decisions about clinical treatment to be based on evidence rather than personal opinion. Should not the same standard apply to decisions about the social and ethical treatment of patients?

In her paper ‘In the genes or in the stars? Children’s competence to consent’¹² Priscilla Alderson argues persuasively that there is ample evidence of all kinds, recognized by respondents to the questionnaires used in her surveys, that children can have a sophisticated understanding of health and sickness, and sick children can often use their imagination to grasp what it would be like for their health to deteriorate or improve. Piaget’s theories about the stages in mental and intellectual development, which claim that certain ethical concepts cannot be grasped by children until they reach a certain age, need to be questioned in view of children’s complex response to episodes of soap operas such as *Eastenders* and also to TV appeals to help sick children which raise complicated issues about relationships and moral obligation. Children, according to Alderson, are not isolated individuals whose development follows a predetermined ‘natural’ course, quite apart from the problem-raising situations to which they have been exposed and their relationships to their peers, families, their environment, their health.

Priscilla Alderson has co-authored with Jonathan Montgomery a report entitled *Health care choices: Making decisions with children*¹³ which recommends a code of practice that embodies fundamental principles of children’s rights. It is important for children

- that they should receive clear and detailed relevant information
- that they have the right to share in making decisions by expressing views if they have them
- that they may grant or withhold consent to proposed treatment if they are competent to do so, subject to the supervisory role of the court
- that their privacy, dignity and confidentiality should be respected.

The authors make the point that most adults tend to underestimate the maturity of children and the law needs to change so as to counteract this tendency. The assessment of competence would be based on the child's functional ability, not on age or outcome of the decision. Competence should be defined as when a child understands the type, purpose, and broad nature and effect of treatment, and possesses the capacity to choose whether to accept it or not. Parental consent would continue to be valid if it was not opposed to the ascertained wishes of the child. A competent child's refusal of a treatment plan should be respected, and if a child is assessed to be incompetent, the basis of an assessment should be properly documented.¹⁴

Research by Alderson and other like-minded child specialists has increased support for the competent autonomist attitude, which grants considerably more scope and expression to personal autonomy to competent children than was deemed wise in previous generations, and currently among traditionalists.

But the nagging problem remains: if adolescents refuse a course of treatment which their doctors consider crucial for saving their lives or preventing serious injury, and if the doctors feel they have done all they can to maximize their patients' understanding and assuage their fears without effect, do they just give up and leave the patients to their own devices, or do they put their collective foot down and say that society has given them, as medical professionals, the final say in determining whether the young patients have to have the indicated treatment for their own good? Alderson and Montgomery accept that special provision is needed in law for cases in which a refusal of treatment would result in serious irrevocable harm or death. There *is*, indeed, a role for the courts in such extreme cases which healthcare professionals before them. The authors write:

The court would first assess whether the child is competent. For non-competent children the court would make the order that it believes to be in their best interests. For competent children, there would be a presumption that their wishes be followed. The refusals of care by children would only be overridden in cases involving serious irreparable harm. It would not be automatic that their refusals would be overridden in such cases, as the alternative to the serious irreparable harm to the non-treatment may be an equally unsatisfactory situation if treatment is attempted. However, such harm is the minimum threshold for disregarding the child's view.¹⁵

Our authors' competent autonomism is not opposed to the inherent powers of the court to examine and when it considers it appropriate to override a young patient's refusal to treatment. However, they argue that the court should only authorize treatment against a minor's declared wishes either (a) in case the patient is non-competent, or (b) in case a competent patient refuses treatment aimed at preventing irreparable harm in circumstances when non-treatment is judged to more harmful than treatment.

3. The involvement of a multi-disciplinary team when an adolescent refuses treatment – a useful idea that needs careful and effective implementation

The GMC pamphlet to which I have referred earlier offers the following advice to doctors in the kind of cases when a young person refuses treatment:

You must carefully weigh up the harm to the rights of children and young people of overriding their refusal against the benefits of treatment, so that decisions can be taken in their best interests. In these circumstances, *you should consider involving other members of the multi-disciplinary team, an independent advocate, or a named or designated doctor for child protection.* Legal advice may be helpful in deciding whether you should apply to the court to resolve disputes about best interests which cannot be resolved informally. You should

also consider involving these same colleagues before seeking legal advice if parents refuse treatment that is clearly in the best interests of a child or young person who lacks capacity, or if both a young person with capacity and their parents refuse treatment.¹⁶

This advice makes practical sense only if doctors have in their hospital or medical centre, or within easy reach, a “multi-disciplinary team” which is readily available or can be put together and brought into the case quickly. As I have already indicated, it will be my contention that in some UK hospitals such a multi-disciplinary resource is unavailable or inadequate. But there is another issue here: even when doctors do have prompt access to such a team, what kind of role can they ask it to perform? The GMC guidance provides no clear advice on this matter, but the wording of the guidance implies that the primary purpose of the multi-disciplinary team and the legal advisers is to advise doctors on how best to carry out – and if necessary to *enforce* – the clinically indicated treatment. There is a presumption that the *main* job of the team is to assist the doctors in carrying out the decision they have already made. This probably means that the team will hear the doctors’ diagnosis and recommendation, obtain clarifications which are demanded by the patient and their family, convey the clarifications to the latter, and look for some way to end their resistance, perhaps pointing to the prospect of a recourse to a court. There is no suggestion here that the team could seek to overturn or modify the doctors’ recommendation, or indeed ask for a second opinion regarding the patient’s case. Yet it is the common experience of people who come to hospitals as patients or healthcare professionals that refusal of treatment may have a variety of sources and causes – including the patient’s true or false beliefs about the recommended treatment, or their justified or unjustified fears about the pain and the consequences of this treatment. These beliefs and fears need to be taken seriously, and dealt with sympathetically by professionals with appropriate knowledge and skills. Thus, a multidisciplinary team can play an important role when an adolescent (or indeed, an adult) patient resists the recommendation of an intervention, especially in a situation where they need a lot more information and time to digest it than they are usually given by busy doctors.

The GMC pamphlet lays great store on the duty of doctors to *communicate effectively* with both the patient and their family. The advice to doctors includes the following text which deserves to be quoted at some length:

Effective communication between doctors and children and young people is essential to the provision of good care. You should find out what children, young people and their parents want and need to know, what issues are important to them, and what opinions or fears they have about their health or treatment. In particular you should:

- a) involve children and young people in discussions about their care,
- b) be honest and open with them and their parents, while respecting confidentiality,
- c) listen to and respect their views about their health, and respond to their concerns and preferences,
- d) explain things using language or other forms of communication they can understand,
- e) consider how you and they use non-verbal communication, and the surroundings in which you meet them,
- f) give them opportunities to ask questions, and answer these honestly,
- g) and to the best of your ability do all you can to make open and truthful discussion possible, taking into account that this can be helped or hindered by the involvement of parents or other people,
- h) give them the same time and respect that you would give to adult patients.¹⁷

It should be noted that several of the things that, according to the preceding text, doctors have a duty to do in the context of their relationships with their patients require skills and abilities which even highly qualified general practitioners, medical scientists, clinicians, surgeons etc may actually lack. There may be many talented doctors who are not nearly as good in communicating with children and young people or their parents as some run-of-the-mill doctors who have the knack of talking comfortably on

TV chat shows and explain in simple and clear terms to a lay audience the nature and treatment of various diseases or conditions. (There are parallels in other professions. An erudite and wise lawyer may not be such a good communicator as a BBC legal affairs correspondent.) Again, there may be gifted doctors who lack the degree of patience and empathy necessary for communicating simply and effectively with young patients and their families. If children sometimes try the patience of their parents and teachers, they can also try the patience of their doctors. Another notable point is that busy doctors will not ordinarily have much time to devote to listening to their patients' concerns and answer a long series of queries (and some queries arise in the patient's mind *after* the doctors are gone).

These considerations suggest that it is desirable to create a service within hospitals and clinics to provide assistance in cases where doctors recommend a certain treatment to a patient and they refuse or are reluctant to give their consent, especially when there are indications that the patient's attitude is due to (a) their confusion about the nature of the treatment, misconceptions about its consequences, fears about the risks, doubts about the benefits etc, or (b) the doctors' technical explanations, insufficient reassurance, poor bedside manner or short temper. This service could put together a specialist multidisciplinary team composed of personnel from the hospital itself or outside whose special talents, expertise and personalities suit them to the task of carrying prompt and effective investigation into what, if anything, may have gone wrong in the contacts between patients (and their families) and their original doctors; help each side to clarify its beliefs, fears, anxieties, motives and ideas, and mediate between the two sides so as to increase their understanding of each other. A team whose purpose is to facilitate communication and mutual understanding between the point of view of the patient and that of the doctors has to approach both sides with equal respect and in a determined effort to understand what lies at the bottom of the disagreement, for that is a prerequisite for successful mediation and the development of a joint decision.

The creation of what I have called a Young Patient/Doctor Liaison and Mediation Service (LMS) will aim to organize the healthcare professional personnel in hospitals and clinics into a special facility which gets to work when a disagreement arises

between adolescent patients (typically supported by their families) and their doctors on a course of treatment recommended by the latter. The function of LMS is to set up a team to interpose itself between the two sides with their express permission, to prevent the possible deterioration in communication and to create a cooperative attitude between the two sides. Among other things, an LMS team tries to ascertain the nature of the disagreement and the sources of any bad feelings between them, open better channels of communication, liaise between the two sides to ensure that each of them understands precisely what the other believes and wants, and try, by encouraging each side to trust the other, to develop a clearer view of why the doctors recommend a certain treatment and why the patient refuses it.

The sources of a young patient's unwillingness to have an intervention may be one or more of a considerable variety of conditions. Below I give, by way of illustration, a few possible examples.

1. As mentioned earlier, the young patient may be afraid of the risks and consequences involved in the treatment – maybe the treatment will leave indelible scars on their body or maybe permanent disabilities, and it may even cause their death. In such cases they may need a lot more reassurance that they have been given by their original doctors. The LMS team may spend more time with them than the doctors have given them to explain the nature of the risks of the intervention set against the risks of alternative treatments or of no treatment. It would be a bad tactic for the LMS team to allow itself to appear to the patient as the agent of the doctors, but it can indicate its wish to understand the patient's concerns and even help them to articulate them better, since they may have failed to explain them properly to the hospital staff. It can secure for them a second opinion, talk with their family and friends, give them and their family some time to consider the matter among themselves, put them in touch with other adolescents who have also had that particular kind of intervention to explain their own experiences and any benefits they may have derived, and so on. Providing additional information and explanation and support may require time and patience from a dedicated team of professionals – including child and adolescent psychologists – who are skilled in communicating with children and

young people, and then take their views to the doctors. The doctors may not have realized during their own earlier contacts what has been bothering the adolescent patient. They may be willing to modify the treatment to some extent – for example, to use general anaesthesia than the administration of local anaesthetic, if that is going to help – though they cannot be expected to do anything they consider to be clinically unwise.

2. The young patient may have a psychological or moral aversion to the proposed treatment. Maybe the young patient is a Jehovah's Witness who has suffered from internal bleeding due to an accident and they object to an emergency treatment which involves blood transfusion on grounds derived from their religious convictions. Doctors who are not Jehovah's Witnesses – as most will not be – will be unlikely to agree with the patient's objections, and many of the doctors are probably out of sympathy with their patient's beliefs. Again, it may be imagined that the patient is an adolescent woman who has an ectopic pregnancy, and on being told by doctors that this is a medical emergency and unless she has an abortion she may die, she refuses this intervention on moral and religious principles. Doctors will recognize their duty to give clear explanation of the reasons for their proposed intervention to the patient, but they may not have the patience to listen sympathetically to objections based on principles they do not share themselves, and in any case they will not have the time to engage, day after day, in an exercise in persuasion. What can an LMS team do in cases like these? One thing they must *not* do is to deride the young patient's religious convictions. A skilled family counsellor will listen to the patient's and the family's point of view and deal sympathetically with their concerns. If appropriate, the LMS team may argue that if the only alternative to the proposed treatment is death, would that be consistent with their religious faith? Will God see their chosen path to death as being justified? It may be pointed out that some Jehovah's Witnesses now do accept in extreme cases transfusion of plasma, platelets and other blood products, and therefore these cannot be denounced as having turned against their faith.¹⁸ Again, some Catholics are willing to concede that abortion of a seriously defective foetus is

ethically permissible, especially if that is the only way of saving the life of the woman. Through a carefully paced dialogue with the patient which is informed with respect and sympathy, the LMS team may be able to persuade the patient to consent to the clinically indicated treatment.

3. The young patient may dislike or distrust their doctors for any of a number of reasons that have no bearing, on any impartial assessment, on the merits of their diagnosis and recommendations, and they refuse treatment on such irrational grounds. Such bad reasons may include the fact that the doctors who see them belong to particular racial or religious groups, they speak with foreign accents, they are female, their looks and demeanour do not inspire confidence in the patient and so on. How can a LMS team deal with such irrational reactions on the part of the patient? Again, if the aim is to persuade the patient to consent, it would be a bad tactic to mock, ridicule or scoff their prejudices, especially as in all likelihood they share them with their family and friends. It will take great tact and forbearance on the part of the LMS team – which may include members of ‘objectionable’ groups – to bring the young patient to see that they suffer from a disease or condition which requires expert care if they are to recover their health, and that expertise is not the exclusive gift of any one racial or religious or gender group. The team is unlikely to ask any of the doctors to remove themselves from the case, but perhaps the team can ask health professionals belonging to a group ‘favoured’ by the patient to examine them and offer them their own opinion.

4. A young patient may suffer from a physical or learning disability, and they and their family believe (perhaps because they have had bad experiences in the past) that the doctors are not taking their worries seriously or respecting their wishes and sensitivities, or that they consider them a pushover, or they are not attending to their needs and comforts with the kind of care they show towards ‘normal’ people. The LMS multi-disciplinary will need to examine sympathetically, but fairly, the complaints, even if their first impulse is to

assume that the patient has a chip on their shoulder. This may be a suitable case for bringing into the team an experienced advocate for children.

It may be asked at this point: aren't there in hospitals up and down the UK already in existence multi-disciplinary teams which provide what is in effect a service in liaison and mediation between patients and doctors? After all, many of the large hospitals, perhaps the majority, have in place a Patient Advice and Liaison Service (PALS) whose declared purpose is "to ensure that the NHS listens to patients, their relatives, carers and friends, and answers their questions and resolves their concerns as quickly as possible."¹⁹ The PALS web site says, among other things, that a patient who feels that treatment options have not been properly explained to them can receive help from the Service. The web site goes on to say: "An important part of PALS is to help people to talk through their concerns so that they can identify the nature of the problem and work out options to resolve it. Concerns may be resolved by listening, providing relevant information, or be liaising on your [i.e. the patient's] behalf with relevant colleagues." The last point at least suggests that a hospital's PALS can use the services of staff who can conduct communication between a patient and their doctors on a matter about which they are unhappy. However, PALS is mostly concerned with providing information and advice to patients, families and carers, it gives support to NHS staff, and it receives and handles patients' complaints with a view to improve the quality of NHS service and environment. This service is neither intended nor equipped to respond to any difficulties between a patient and their doctors, when the former refuses to go along with the recommendations of the latter and there is a threat of breakdown of trust and, communication between the two sides.

The fact of the matter is that in cases where a young patient refuses the clinically indicated treatment, different hospitals deal with the matter in different ways, depending on the particulars of the case, the available human and other resources, the existence of Ethics Committees, the policies of the management team, the disposition of the healthcare staff, and many other factors.²⁰

As a result, across the country there is a considerable variety of arrangements, some of which appear to serve well the needs of the young patients for sympathetic

understanding, patient discussion of their concerns and reassurance, and some others are much less satisfactory for the patients and capable of considerable improvement. On the better 'resourced' end of the spectrum, there are hospitals which actually have the capability to set up promptly a LMS team composed of a number of health professionals, including (where necessary) other doctors and nurses, child psychologists, family counsellors, play therapists, medical ethicists and other specialists, as well as trained mediators. In response to a crisis occasioned by a young patient's refusal to go along with the doctors' recommendation, the team will engage with the patient and their family if they are with them (and we have to remember that this is a big *if*, given that some adolescents leave home early, sometimes before they complete their compulsory education), in the hope that they will help them understand and appreciate medical necessities and persuade him to accept them. It is not always recognized that there are cases where the parents themselves may add to the patient's diffidence and mistrust of medical procedures.

On the less well 'resourced' end of the spectrum, hospitals react to the crisis by getting the doctors and nurses to spend some more time with the patient explaining what's what, even though the patient's recalcitrance may have something to do with their bad chemistry with their own doctors. If young patients are under misconceptions about their conditions or have fears that need to be addressed, they could get more help from other specialists, including a child or adolescent psychologist and pastoral nurses; but not all hospitals have such additional resources readily available, and the chances of a successful mediation leading to a jointly agreed decision are remote.

4. Concluding remarks: a widened conception of the patient's best interests

In this final section I want to emphasize a number of points that are implicit in the preceding discussion and look briefly at a decision of the Canadian Supreme Court which bears directly on one of my suggestions.

It is generally understood that doctors looking after an adolescent patient – indeed any patient – are required by law, guidance by professional bodies, and society at large to act in the patient’s best interests, and this includes in a very fundamental way to save their life, prevent serious harm, restore or improve their physical or mental health, alleviate their pain or whatever else is the matter. If doctors decide that the young patient needs to have a life-saving operation, and they are deemed competent to decide but they refuse, the doctors are duty-bound to talk to them and their family and hear what they have to say, and try to understand and take account of their wishes and opinions. It may or it may not be possible for doctors to accommodate their wishes. If it is not, the doctors may apply to a court of law, in the spirit of benevolent protectionism, and make a case for an authorization for the intervention against the young patient’s wishes. As the law is currently taken to be, the court has the powers to grant such an authorization in the patient’s best interests. But this is not necessarily a happy outcome, even if the intervention is, in strictly clinical terms, successful. An objection may be raised in the spirit of competent autonomism which points out that the young patient’s settled wishes and considered opinions have been ignored, their personality has been violated, their private life has been discussed in court and possibly found its way into the press, and they now have to live with the trauma and mental stress which may affect their attitude towards doctors and medicine for ever.

All this cannot be a good development for the young patient. It is not good for them to be in ill health, but equally it is not good for them to suffer a violation of their personality with detrimental effects on their state of mind, to say nothing about any permanent or long-term consequences of the intervention – e.g. having a part of the body removed or walking with a pronounced limp – to which they may not be able to adjust. Competent autonomism, no less than benevolent protectionism, is committed to placing the system of healthcare in the service of the patient’s best interests, in a wide sense which includes both their physical health and their emotional balance and moral welfare. However, one difference between competent autonomism and benevolent protectionism is that the former attitude attributes much greater importance than does the latter in respecting the wishes, the sense of dignity and the claims to decision-making of the young patient. For competent autonomism, the integrity of a patient’s

personality and wishes, and their emotional balance and moral welfare *are* constituent elements of their best interests. Competent autonomism maintains that when healthcare professionals form a judgment what is in a patient's best interests, they must consider their personality, wishes, dignity and other aspects of their sense of self, independence, freedom and respect for their rights, as these elements are just as important as the health of their vital organs. So if an intervention is clinically indicated which means that some of the elements of their best interests need to be sacrificed to preserve other elements, the medical practitioners do not have an *a priori* authority to decide on their own, apart from the patient and their family and trusted friends, how the choice is to be determined.

This is the dramatic context in which the LMS team has an important role to perform, always in the best interests of young patients, conceived in a widened sense which includes the protection of their autonomy and all that it implies. The team gets to work when the young patients (with or without the support of their families) obstinately refuse the treatment considered by their doctors to be vital for saving their lives or preventing serious harm. The LMS team is composed for the most part by healthcare professionals bound by the same ethos as the patients' original doctors, and its principal task is to spend time with the patients and exercise its skills in understanding troubled, worried, frightened and sometimes inarticulate young people with health and psychological issues. The team will also want to talk to the doctors to find out what the patients' clinical profiles are and whether the recommended treatments are the only available options. Through its mediation efforts, the team will try to ascertain if there is any way in which the patients can be persuaded without undue pressure and within an appropriate period of time to accept the original decision of the doctors, or a variant of that decision which is also medically sound, in order to obviate the need for a court-authorized medical intervention, which may save the young patients' limbs or internal organs, but traumatize their mental lives. If the team is able, through sustained and tactful contacts, to improve communication between patients and doctors and, through gentle and reasoned persuasion, to shift the attitude of each side sufficiently to secure the patients' informed consent to an intervention recommended by, or in any case acceptable to, the doctors, there will be no need for the case to come before a court of law raising the prospects of a coerced intervention.

It has to be emphasized that although as the law stands, the coercive powers of the court are available for doctors to resort to, it should not be a foregone conclusion that judges will automatically agree to grant the authorization applied for. There are trends in judicial thinking which suggest that a widened conception of the patient's best interests, which includes physical, intellectual and emotional health, is increasingly being accepted.

In an important case of *A.C. v Manitoba (Director of Child and Family Service)*²¹ which came before the Supreme Court of Canada in 2009, the judges had to consider a number of difficult issues concerning the life-sustaining treatment recommended by doctors for A.C., a minor female patient:

- What is the nature, purpose and utility of the recommended medical treatment? What are the risks and benefits?
- Does the [minor] demonstrate the intellectual capacity and sophistication to understand the information relevant to making the decision and to appreciate the potential consequences?
- Is there reason to believe that the [minor's] views are stable and a true reflection of his or her core values and beliefs?
- What is the potential impact of the [minor's] lifestyle, family relationships and broader social affiliations on his or her ability to exercise independent judgment?
- Are there any existing emotional or psychiatric vulnerabilities?
- Does the [minor's] illness or condition impact on his or her decision-making ability?
- Is there any relevant information from adults who know the [minor], like teachers or doctors?

These questions illustrate very sharply the Canadian judges' view of how an adolescent patient's best interests are to be assessed.

Justice Rosalie Silberman Abella who delivered the main judgment took the view that

There comes a time when it is in the child's best interests to exercise autonomy, whatever consequences the exercise of that autonomy might result in; her best interests are the exercise of autonomy. When the young person's best interests are interpreted in a way that sufficiently respects his or her capacity for mature, independent judgment in a particular medical decision-making context, the constitutionality of the legislation is preserved. Properly construed to take an adolescent's maturity into account, the statutory scheme strikes a constitutional balance between what the law has consistently seen as an individual's fundamental right to autonomous decision making in connection with his or her body, and the law's equally persistent attempts to protect vulnerable children from harm.

Giving the dissenting opinion Justice Ian Binnie said that

Forced medical procedures must be one of the most egregious violations of a person's physical and psychological integrity. The state's interest in judicial control over the medical treatment of "immature" minors ceases to exist where a "mature" minor under 16 demonstrates the lack of need for any such overriding state control. In the present case, three psychiatrists and the judge at first instance accepted that C. had capacity... Whether judges, doctors and hospital authorities agree or disagree with C.'s objection, the decision belongs to her, as the Charter [i.e. Canada's Charter of Fundamental Rights and Freedoms] is not just about the freedom to make the wise and correct choice; it also gives her the individual autonomy and the religious freedom to refuse forced medical treatment, even where her life or death hangs in the balance, regardless of what the judge thinks is in her best interest.²²

This decision appears to represent a trend in judicial thinking about adolescent patient's rights which may not leave unaffected British courts in the wake of the Human Rights Act 1998, and more especially Article 8.²³

By incorporating the idea of autonomy in the best interests test, the court is enabled to set the autonomy interests of adolescent patients side by side with their physical welfare interests. An approach of this kind would be compliant with Article 12 of the UN Convention on the Rights of the Child²⁴ and Article 8 of the Human Rights Act 1998. A number of academic studies have considered how to respond to children's evolving autonomy rights in *court*,²⁵ but I have tried to show that the practical implications of this change in emphasis also need to be accommodated. Hospitals employ a variety of means to avoid the necessity for coercive treatment in the welfare interests of the child, including the involvement of play therapists, child and adolescent psychologists, and family therapists are some of the methods used to ensure that children participate in decisions about them, and their refusals are not brushed aside but they are discussed with them seriously and tactfully.

However, two aspects might need to change. First, a subtle change in emphasis from benevolent protectionism to competent autonomism requires a corresponding change in the ethos of the medical team and the criteria they use in assessing competence. Doctors who espouse benevolent protectionism may seek to persuade or induce adolescent patients to accept their view, indicating that recourse to the courts is a distinct possibility. On the other hand, doctors who act in the spirit of competent autonomism seek to maximize the patients' understanding of their treatment options and encourage them to look at the doctors' recommendations with a clear mind and reduced fear. In some cases, it may be in the adolescent patients' best interests, broadly conceived, that their competent decision should be respected and complied with, even if their lives are shortened as a result. Second, if it is accepted that doctors have a role in maximising competence as well as assessing autonomy,²⁶ then the recent practices recommended by autonomist writers and practised in some of the better resourced hospitals need to be extended to the length and breadth of the healthcare system. I have suggested one means by which this might be achieved – the creation and use of properly suitably qualified LMS teams in all hospitals.

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- ¹ See for example Mike Shaw, Competence and consent to treatment in children and adolescents. In: *Advances in Psychiatric Treatment*, 2001, 7:150-9.
- ² All ER 627 [1992] 4.
- ³ Among such writers are Brooks, W.G. Jr., Bahar-Posey L., Weathers L.S. Pardue W. Children's consent to treatment, *British Medical Journal*, 1994;309:807
- ⁴ See Priscilla Alderson and Jonathan Montgomery, *Health care choices: making decisions with children*. London: Institute for Public Policy Research, 1996, Chapter 5 and *passim*.
- ⁵ United Nations General Assembly Resolution 44/25, 1989, Art. 12 (1).
- ⁶ Committee on the Rights of the Child, *The right of the child to be heard* (2009).
- ⁷ The Department of Health in its pamphlet *Reference guide to consent for examination on treatment*, 2nd ed. (2009) advises that a case be brought before a court to test the validity of the Children Act 1989 following the enactment of the Human Rights Act 1998, Art. 8, which recognizes for everyone respect for private and family life.
- ⁸ General Medical Council, *0-18 Years: Guidance for all doctors*, (2007) para. 12.
- ⁹ The text of the Children Act can be found in <http://www.legislation.gov.uk/ukpga/1989/41/contents>.
- ¹⁰ Both benevolent protectionism and competent autonomism, as well as other tendencies in medical thinking such as involving the young patient's parents and other healthcare professionals, are given expression in General Medical Council guidance. *Ibid.*, paras. 29-33.
- ¹¹ See note 3 above.
- ¹² *Journal of Medical Ethics*, 1992;Vol. 18, No. 3
- ¹³ See note 4, above.
- ¹⁴ For the report's summary of conclusions and recommendations see pp. 85-93.
- ¹⁵ *Op. cit.* p. 92
- ¹⁶ *Op. cit.* paras. 32-33. Emphasis added.
- ¹⁷ *Ibid.*, para. 14
- ¹⁸ See <http://www.ajwrb.org/>
- ¹⁹ PALS web site is <http://www.pals.nhs.uk/cmsContentView.aspx?ItemID=932>
- ²⁰ The remarks that follow are based on a small-scale study into the practices of some twenty large hospitals in the UK, conducted by the author in January-March 2012.
- ²¹ 2009 Supreme Court of Canada 30.
- ²² 2009 Supreme Court of Canada 87.
- ²³ Article 8 of the Human Rights Act 1998 states: "(1) Everyone has the right to his private and family life, his home and his correspondence. (2) There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others."
- ²⁴ See note 4 above.
- ²⁵ See, Taylor, R., 'Reversing the retreat from Gillick?: R (Axon) v Secretary of State for Health.' *Child and Family Law Quarterly*, 19 (1) (2007), 81; Choudhry, S., Fenwick, H. 'Taking the rights of parents and children seriously: Confronting the welfare principle under the Human Rights Act' in *Oxford Journal of Legal Studies* 25

(2005), 253; Hall, A., 'Children's rights, parents' wishes and the state: The medical treatment of children.' *Family Law* 36 (2006), 317.

²⁶ On the doctors' duty to maximize a patient's autonomy see Cave E., 'Maximising minors' capacity.' *Child and Family Law Quarterly*, (2001) 3, 429-450.