

Promoting a patient's right to autonomy: implications for primary healthcare practitioners. Part 1

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Abstract

It is an established legal and ethical principle that healthcare practitioners must respect a patient's right to autonomy. However, clinicians may sometimes find this difficult for various reasons. Patients may be unable or unwilling to contribute to decisions about their care, and practitioners can find it difficult to accept some of the decisions patients make, particularly if they appear unwise or even irrational.

A lack of understanding of the law may contribute to the challenge of balancing an obligation to provide care. This article discusses the legal basis of patient autonomy and considers how this theory can be applied in practice. Part 2, in the next issue of Primary Health Care, will explore a range of situations in which practitioners may find respecting an adult patient's right to autonomy challenging. Opportunities to reflect on practice are presented.

Introduction

THE PRINCIPLE of autonomy is common to law (Re C (adult: refusal of treatment) 1994, Mental Capacity Act (MCA) 2005) and ethical theory (Singleton and McLaren 1995, Burkhardt and Nathaniel 2008). The right to self-determination is not only a concept entrenched in healthcare policy (General Medical Council (GMC) 2008, Department of Health (DH) 2010, 2012), but is also central to the philosophy of person-centred care (Kitwood 1997, Brooker 2007, Butterworth 2012, Cummings and Bennett 2012, Willis Commission 2012). An individual's right to autonomy is regarded as so fundamental that there are circumstances where even the 'sanctity of human life must yield to the principles of self-determination' (Airedale NHS Trust v Bland 1993).

Obtaining a patient's informed consent is generally a fundamental requirement before starting any form of treatment or healthcare intervention, including assistance with personal care needs (Re MB (medical treatment) 1997). For practitioners to have confidence in their ability to comply with their legal obligation to respect a patient's autonomy, they must be aware of the theoretical legal basis and understand what this means in practical terms. Therefore, while the focus of this first article (the second will be published next month)

is the legal rationale for respecting a patient's right to autonomy, the reader will be guided in the application of this theory to their daily practice. This article aims to discuss the legal basis of patient autonomy and consider how this theory can be applied in practice.

After reading the article, you should be able to:

- Critically summarise the law relating to patient autonomy.
- Provide a rationale for obtaining informed consent before commencing any treatment or episode of care.
- Outline the prerequisites of valid consent.
- Identify situations where patients may lack the capacity to consent.
- The need for consent

It is established in common law that, where healthcare providers accept an individual as their patient, they assume a duty to care for that individual (Kent v Griffiths and others 2000). This means that they are obliged to take what has been described as 'reasonable care' of that patient (Watson v British Boxing Board of Control Ltd and another 2000).

What might constitute reasonable care was considered by Stuart-Smith LJ in the case of Capital and Counties Plc v Hampshire County Council (and other appeals) (1997), which found: 'There is no doubt that,

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once the relationship of doctor and patient or hospital authority and admitted patient exists, the doctor or the hospital owes a duty to take reasonable care to effect a cure, not merely to prevent further harm.'

It is important to note that, although case law examples may make specific reference to the medical profession, the legal principles extend to all healthcare professionals, whether registered or not (Halsbury's Laws of England 2011).

Now do time out 1.

Once that duty has been assumed, an action in negligence may arise if it is breached, and there is a failure to provide care of an acceptable standard (Taylor 2013a). The test for breach of duty was set out by McNair in *Bolam v Management Committee* (1957: p122) and is commonly known as the 'Bolam test'; it states that '...a doctor is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular art'.

For a claim to succeed, the claimant (the patient or their estate) must prove negligence and that, on the balance of probabilities, at the time of treatment care was not of a generally accepted standard (Maynard v West Midlands Regional Health Authority 1984). It is not enough for the claimant to prove that care was negligent, they must also demonstrate that they have suffered some harm as a result (*Barnett v Chelsea and Kensington Hospital Management Committee* 1968). Further, the harm must be of a type that the defendant healthcare provider could have reasonably foreseen (*Overseas Tankship (UK) Limited v Morts Dock & Engineering Company Limited (Wagon Mound No.1)* 1961).

Now do time out 2.

1 Definition of 'reasonable care'

Time out

The definition of 'reasonable care' given in the cases of *Watson v British Boxing Board of Control Ltd and another* (2000) and *Capital and Counties Plc v Hampshire County Council (and other appeals)* (1997) refers specifically to 'effecting a cure' and not simply avoiding further harm to the patient.

- Consider what that definition might mean in practical terms and how it might apply in situations where curing the patient is not possible, for example in the terminal phases of caring for a patient with cancer.
- Recall episodes of care that you have delivered to patients and what the goal of such care was. Was it always to secure a cure?
- If a cure is not the goal of care what might then represent 'reasonable care'? Note down indicators of what you believe signal that care was reasonable.

The previous section looked at practitioners' legal obligation to provide treatment for their patients, but did not examine the patient's right to choose. What if Michael (the patient in time out 2) decides that he does not want his dressing changed? Although it could be argued that, by presenting for health care, the patient has indicated his willingness to accept any treatment practitioners consider appropriate, there is no legal obligation for him to do so. Patients have the right to decide whether they wish to accept the offer of treatment or not, and the extent and implications of this principle will now be considered.

Consent to treatment

It is an established principle in law that, subject to some exceptions – for example, where personal contact is necessary in self-defence, to prevent crime, to protect

2 Duty of care

Time out

Consider the scenario: Sarah is a district nurse and makes regular visits to Michael at home. Michael has a leg ulcer, which requires frequent dressing changes due to a high level of wound exudates. He is embarrassed by the odour and frustrated by the limitations his wound imposes on his daily life.

One day Sarah's visits are running late. She is aware that she can schedule another visit the next day, so decides to omit her visit to Michael today. The next day she forgets her missed visit of the previous day, and does not visit him.

When she does visit – the following day – the dressing has adhered to the

wound, and previously granulating tissue is removed along with it. There are also signs of infection.

In this example:

- Did Sarah owe Michael a duty of care?
- Did Sarah breach that duty of care (think about the Bolam test)?
- If so, do you think that Michael has suffered harm as a result?
- If so, is that harm of a type that Sarah could reasonably have foreseen? (Could Sarah have reasonably foreseen that omitting regular dressing changes could have resulted in tissue damage and signs of infection?)

If you have answered yes to all four questions, it is possible that Sarah's care could be considered negligent and Michael could succeed in a claim for damages. Here the overlap between the need to comply with legal obligations and providing best possible care can be seen. Reflect on your own practice.

- Identify a situation where, like Sarah, your day-to-day work pressures might affect practice.
- Identify strategies that might help you to address these challenges and avoid situations where care could be compromised.

a property or to chastise a child (Children Act 2004, s58) – it is unlawful to touch another person without their agreement (Collins v Wilcock 1984). This means that, even in an emergency, practitioners must generally obtain a patient's consent before treating them, and they may incur liability in both civil and criminal law if they do so without permission.

An exception to this will arise in a situation where the patient lacks capacity to make decisions – for example, if the patient is unconscious, and then it is subject to certain conditions (this is considered in more detail in the second article). In such cases, there is legal provision for emergency treatment to be given without the patient's consent (Taylor 2013b).

Consent acts as a legal defence, and makes what would otherwise be unlawful lawful (Taylor 2013a). For this defence to be effective it must first be demonstrated that (Taylor 2013b):

- Consent was available as a defence in that particular situation. For example, is the proposed touching or intervention something that the patient can actually consent to?
- Consent had been given.
- The consent was valid.
- The touching was what the patient had agreed to.

Consent is available as a defence

Individual autonomy is important, but it is not absolute. Sometimes the state has to strike a balance between an individual's right to choose and the need to promote the wider public interest. Article 8 of the Humans

Rights Act 1998, 'Right to respect for private and family life', states: '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... 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.'

Although consent is generally available as a defence to touching or other interventions that would otherwise be unlawful, there are limits, and some forms of touching will be unlawful, even if they have been agreed to. This generally relates to anything more than a minor injury inflicted with the intention of causing harm to another person (R v Brown 1993, Taylor 2013b).

This point may make you reflect on the legality of some procedures routinely performed in health care, such as amputations and the removal of diseased organs, which could properly be regarded as amounting to more than a minor injury. The point to consider here is the intention of the person performing the act; surgical procedures performed with the intention of benefiting the patient will be lawful if performed with the person's consent (Taylor 2013b).

Now do time out 3.

In some circumstances, an individual's right to choose will be limited. This usually relates only to situations where the rights of one individual are restricted to protect those of others, for example arrest by a police officer where there is reasonable suspicion of involvement in criminal activity (Police and Criminal Evidence Act 1984, s24).

Situations where choice is limited may arise in health care where case law has established that, although individuals have a right to refuse treatments offered to them, they usually have no legal right to demand treatment practitioners do not consider to be in their best interests (for example, R (on the application of Burke) v General Medical Council 2005, MCA 2005: ss24-26). In other words, although practitioners generally have a legal obligation to provide treatment, their duty of care does not require them to offer treatment that is not in the patient's best interests – for example, the test referred to in Bolam v Friern Management Committee (1957).

Consent has been given

The law makes clear that for consent to be valid the patient has to have been advised of the full implications of the proposed intervention and its precise nature (Chester v Afshar 2004). The patient must communicate understanding of, and agreement to, receiving a treatment or intervention. The manner of this consent will depend on the circumstances. For example, while it might be sufficient to imply consent for procedures

3 Individual autonomy v public interest

Time out

Reflect on the balance between individual autonomy and the need to protect greater public interest.

A landmark legal judgment came in the case of R v Brown (1993) in which it was held that consent would not provide a valid defence to the mutually inflicted injuries committed by a group of sadomasochistic males.

The defendants argued that their activities were conducted in private, and that they were free to choose what happened to their own bodies.

They appealed their conviction for actual and grievous bodily harm to the European Court of Human Rights (Laskey and Others v the United Kingdom 1997).

Their appeal was disallowed because the acts they performed presented a risk of wider transmission of infections such as HIV and hepatitis, and that justified the restriction to individual autonomy in the public interest.

Further examples include:

- A ban on smoking in public buildings.
- Making specified recreational drugs unlawful.
- Restrictions on the sale of alcohol.

Consider for each of these the impact on individual autonomy, and the perceived public benefit. Identify some additional examples.

such as checking blood pressure by rolling up a sleeve to enable application of the sphygmomanometer cuff, this will not be the case for more complex procedures (Taylor 2013b).

It is important that the practitioner keeps an appropriate record of how consent has been given, such as by making a summary of the conversation in the casenotes. This is good practice to facilitate continuity of care, but may also prove useful evidence of proper conduct in the event that a patient makes an allegation that they have been treated or otherwise touched without having given their consent (R v Donovan 1934).

Now do time out 4.

4 Obtaining consent

Time out Sections 32-35 of the Reference Guide to Consent for Examination or Treatment (Department of Health 2009) provide guidance on how the form of consent will vary according to the proposed intervention.

- Why might the use of a consent form be good practice, even if a signature on a consent form does not, in itself, make consent valid?
- Consider the process of obtaining consent and the opportunities this presents.

Is the consent valid?

For consent to provide an effective defence, it must be valid (Re T (an adult: refusal of treatment) 1993, Re C (adult: refusal of treatment) 1994). This generally means that, providing the three other prerequisites for consent have been satisfied, the patient has:

- Been fully informed about the treatment, including benefits and any associated risks, and was able to understand and retain the information.
- Believed the information.
- Been able to evaluate the information.
- Come to a voluntary decision.

There will be situations where patients are not able to give valid consent, either due to a cognitive function impairment (MCA 2005) or because the patient is a child and has yet to develop the level of intellectual functioning required to make valid decisions (Gillick v West Norfolk and Wisbech AHA 1985. The law relating to capacity to consent is different for adults, young people (16 and 17 year olds) and children.

Adults Since its enactment in April 2007, the MCA 2005 has provided a framework supporting the autonomy of adults who either lack, or have reduced, capacity to make decisions (Herissone-Kelly 2010). It gives a statutory presumption that all adults have the capacity to make decisions unless there is substantive

evidence to the contrary (MCA 2005, s1). Many aspects have been consolidated in existing common law (for example, Re MB (Medical Treatment [1997] at p437 and the definition of 'inability to make decisions' enshrined in the MCA 2005, s3) and best practice principles (Manthorpe *et al* 2009, Wilson *et al* 2010).

The starting point must always be the presumption that an adult patient will have capacity to make decisions, regardless of age, diagnosis, behaviour or appearance, and this can only be set aside if, after an assessment of capacity has been made, it can be shown that the patient is not able to (MCA 2005, s3(1), Taylor 2013a):

- Understand the information relevant to the decision.
- Retain that information.
- Use or weigh that information as part of the process of making the decision.
- Communicate his or her decision, whether by talking, using sign language or any other means.

The law not only makes a presumption of capacity, but makes clear that, even in those situations where decision-making capacity is impaired, 'reasonably practicable' measures are taken to involve the patient in the decision-making process (MCA 2005, s4(4)). While it is important to promote autonomy where the patient's mental capacity is impaired, this will undoubtedly present the practitioner with some challenges (these issues are considered in more depth in the second article).

Young people There is a statutory presumption that young people will have capacity to consent to medical treatment (Family Law Reform Act 1969, DH 2009), subject to the conditions specified for adults. This means that the presumption of capacity may be rebutted if it can be shown that the young person lacks the mental capacity necessary to understand, evaluate and retain the information necessary to make an informed decision. Other than sections relating to making a lasting power of attorney, the making of statutory wills and advance decisions to refuse treatment, much of the MCA (2005) applies to young people (Department for Constitutional Affairs 2007).

However, if the competent young person refuses consent, but the treatment would be in his or her best interests, it may still be performed lawfully if either the court or someone with parental responsibility consents to the treatment. That being said, Lord Donaldson (Re W (a minor) (medical treatment: court's jurisdiction) 1992) made clear the importance of taking the young person's views into consideration when making such decisions, with the significance increasing in proportion to the magnitude of the decision and the age of the young person. Further, even where a young person has consented to treatment, the court (but not the parents)

5 Transplant dilemma

Time out

Consider this scenario: Simon is 16, he is generally fit and active and is a high academic achiever. He is keen to go to university and would like to become an engineer. He suddenly becomes very unwell and is diagnosed with acute cardiac failure.

Both he and his parents are advised that his only prospect of recovery is a heart transplant. Initially, Simon gives his consent, but then becomes upset and tells his care team and parents that he would rather die than live with someone else's heart.

His doctors ask Simon if he understands that without the transplant he will die. He tells them he does.

That evening he asks his parents to bring his maths revision to the ward because he does not want to fall behind. Simon's doctors tell his parents that their consent to the transplant would be sufficient, but they all agree that they would prefer it to go ahead with his co-operation.

With Simon's agreement, a meeting is arranged the next morning between Simon, his parents and the cardiothoracic surgeon.

He is asked why he does not want the transplant, and he shares his fears. Simon's mother then asks him why he had been so keen to have his revision the night before if he had accepted

that he was going to die. The meeting gave Simon the opportunity to regain some control in circumstances that had arisen quickly, and to address matters that had not been given time the previous day. Simon agreed to the transplant.

Although the transplant could potentially have been performed without his consent, what would be the implications of this for Simon's compliance with ongoing treatment, and relationship with his parents and care staff?

What do you think was the barrier to Simon's consent, and how was this resolved?

retains the right to veto this choice (Re R (a minor) (wardship: medical treatment) 1991).

Now do time out 5.

Children There is no statutory presumption of decision-making capacity for children, instead a limited right to consent is provided by common law (Gillick v West Norfolk and Wisbech AHA 1985). A child's capacity to consent must be assessed on a case-by-case basis, and will depend on the complexity of the proposed treatment and the child's stage of intellectual development.

Children must satisfy a test of capacity that correlates with that set out in the MCA (2005: s3(1)), in that they must fully understand the purpose and nature of the proposed treatment and the implications of having or not having it. They must also demonstrate the ability to evaluate and remember the information given to them, and convey their decision effectively (GMC 2007).

Should the competent child refuse consent, either the court or at least one of the child's parents (or a person with parental responsibility) may instead consent to the treatment (Re W a minor) (medical treatment: court's jurisdiction) 1992), providing that the treatment is in the child's best interests.

The ruling in Re W (1992) was relied on in the case of Re M (a child) (medical treatment) (1999), which demonstrates the potential conflict between the desire to preserve a child's right to autonomy and the need to act in what is considered to be their best interests.

In a case similar to the scenario relating to Simon (time out 5), M became ill with a coronary disorder when she was aged 15 and a half. Before then she had regularly participated in sport and other activities. When she suddenly became unwell, M and her parents

were advised that she was unlikely to survive without a heart transplant.

Although her mother consented to the surgery, M did not, and the hospital treating her made an application to the court for authority to perform the surgery and allied lifesaving treatment. As part of the application, M was interviewed on behalf of the judge and said that, although she did not want to die, neither did she wish to take medication for the rest of her life or receive someone else's heart.

The judge felt that because her illness had happened so suddenly she had not had time either to fully appreciate the severity of her condition or the implications of her decision, and made an order that the treatment go ahead. M had the transplant.

Now do time out 6.

6 Reflect on your practice

Time out

Consider the scenario described in Re M (a child) (medical treatment) (1999), and the law relating to consent to treatment for a child.

Has a similar situation arisen in your own practice? If so, reflect on your management of that situation and what you learned from it?

Is the touching what the patient agreed to?

It is important that both the mechanics and the nature of the intervention are what the patient agreed to (R v Tabussum 2000, Taylor 2013b). For example, Ms Smith has a long-standing leg ulcer that has failed to respond to all previous attempts to debride the necrotic tissue.

Practitioners now consider maggot therapy to be the most appropriate intervention, but Ms Smith will not discuss this further, telling her nurse that the idea repels her. However, the nurse believes that, given Ms Smith's poor eyesight and general sensory impairment, it would be possible to administer the treatment without her thinking it was anything other than a standard wound dressing.

Such treatment would be unlawful because, although Ms Smith has agreed to the application of a dressing, she has not agreed to that particular type of dressing and has stated her aversion to such treatment in the past.

Conclusion

This article has focused on the role that valid consent plays in upholding a patient's right to autonomy. However, it might properly be regarded as an overview of an 'ideal world', where patients are willing and able to participate in the decision-making process.

Practitioners will undoubtedly encounter situations in practice where this is not the case. Part 2 (in the next issue of Primary Health Care) will address a range of circumstances where practitioners may find respecting

their patient's right to autonomy challenging. This might be because the patient has a cognitive impairment, such as dementia that affects their ability to make some decisions (Department for Constitutional Affairs 2007, MCA 2005, Re C (adult: refusal of treatment) 1994) or because the patient has made a decision that the practitioner finds difficult to accept or considers to be unwise, for example if they refuse consent to life-sustaining treatment.

Now do time out 7.

7 Practice profile

Now that you have finished the article, you might like to write a practice profile of between 750 and 1,000 words.

Go to the Primary Health Care website at phc.rcnpublishing.com and follow the link to the Continuing professional development pages for information on how to make a submission.

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