

Assessing capacity and obtaining consent for thrombolysis for acute stroke

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ABSTRACT – When offering treatment to a patient with capacity they should be informed of the risks and benefits of therapy and consent should be obtained. For patients without capacity, treatment is given in their ‘best interests’. Achieving and assessing capacity to consent for treatment in the presence of acute illness can be difficult and especially so in patients suffering with acute stroke. This article presents patients’ and doctors’ perspectives on assessing capacity to consent to thrombolytic therapy for stroke.

KEY WORDS: acute illness, capacity, consent, thrombolysis for acute stroke

A 47-year-old, right-handed, barrister (JA) arrived in accident and emergency at 13:45 having collapsed, without loss of consciousness, at 12.40 while playing golf. He had no speech difficulty but could not get up because of weakness. At 12.53 London Ambulance Service recorded ‘slight asymmetry towards right side of mouth’ and a Glasgow Coma Score of 15/15. He was able to stand and walk to the ambulance trolley. His previous medical history was arthroscopic knee surgery and he was taking no medication. He felt unwell, with intermittent headache but noticed no weakness or speech defect. During triage, at 13:55, he became dysphasic with right facial weakness.

Diagnosis at 14:23 was stroke with mild expressive dysphasia and right hemiplegia, with a National Institute of Health Stroke Score (NIHSS) of six.¹ His wife was told of his condition by telephone. Computed tomography, at 14.45, was normal with maintenance of grey/white matter differentiation and no evidence of intracranial haemorrhage.

On route to the scanner the patient deteriorated neurologically. By 14.50 he had right face, arm and leg weakness with right sensory inattention, right hemianopia, mild expressive dysphasia without receptive component and a NIHSS score of 17.

Considered a candidate for thrombolysis, the nature, risks and benefits were discussed with him. It was explained treatment was intravenous therapy to dissolve the clot that was blocking an artery in his brain. He was quoted an approximately one in eight chance of significant benefit and a one in 18 chance of harm. He was strongly advised to accept thrombolytic therapy. He became distressed and withheld consent, wishing to wait for his family’s

arrival, fearing that he might die and not see them again. His wife was on her way to hospital (arriving at 15.35) and not available by telephone. After further discussion JA consented to thrombolysis and was given thrombolytic therapy at 15:15 with rapid improvement in hemiplegia, visual disturbance and speech symptoms. His NIHSS score improved to four at 17.00 and one at 22.00.

Ethical and legal aspects

The principle of autonomy, professional duty and the common law require doctors to obtain consent before giving treatment.² Consent provides a ‘flak jacket’ that protects the doctor from the fire of litigation.³ English law does not recognise the doctrine of ‘informed consent’, where all risks and benefits are explained, and in the tort of battery (assault) consent must confer understanding only of the nature and purpose of the procedure.⁴ In the civil tort of negligence it must also cover possible outcomes and complications.⁵ A procedure must be adequately explained and the patient must have capacity to consent. If a patient does not have capacity, treatment is given in their ‘best interests’.

The law on capacity is governed by the Mental Capacity Act 2005. There is a rebuttable presumption that everyone has capacity until proved otherwise.⁶ A person is deemed to lack capacity:

if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.⁷

It does not matter whether the impairment or disturbance is permanent or temporary.⁸ To determine whether a person lacks capacity or not the following must be established:

Is the person able to:

- (a) understand the information relevant to the decision
- (b) retain that information
- (c) use or weigh that information as part of the process of making the decision
- (d) communicate their decision (whether by talking, using sign language or any other means).⁹

In relation to (c) this includes information about the reasonably foreseeable consequences of deciding one way or another, or failing to make the decision.¹⁰

Medical perspective

Despite mild expressive dysphasia JA appeared to understand, retain and weigh information given to him and communicate

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his wishes. Given the likely devastating effect of middle cerebral artery occlusion on JA and conscious of the maxim 'time is brain', we were eager to give thrombolysis without delay and did so the instant he consented verbally. We appreciated JA's wish to see his wife before consenting. However the advantages of treatment without delay, the uncertain interval until her arrival and his reluctance to accept thrombolysis until his wife arrived made us question his capacity; nevertheless we believed he possessed it. To us it seemed likely that JA's wife would probably wish him to have early treatment to obtain maximum potential benefit from therapy and we used this probability as one of our arguments to persuade him to accept thrombolysis. It can be frustrating for doctors when a patient refuses treatment of large potential benefit for what seem poorly considered or irrational reasons. Though consent is only valid when given without coercion,¹¹ doctors arguably have a duty to do their best to persuade a patient to accept a remedy likely to benefit them and exerting pressure to accept treatment may be justified.¹²

Patient perspective

I have a clear recollection of all the events from collapsing on the golf course till after receiving thrombolysis. I understood I had had a stroke and that the doctors wanted to give me a treatment to give the best possible chance of full or partial recovery. I recall being given some statistics on the effectiveness of treatment but was not able to understand their meaning. I understood the importance of immediate rather than delayed treatment. However I was very frightened and in emotional turmoil with all sorts of thoughts going through my head, from my family to my career, death or serious disability and I was not concentrating on everything being said to me. I wanted to ask questions but could not get the words out properly. For example I was concerned that my clerks be informed of what had happened to me as I was due to start a trial three days later. Though I know it well, I could not give my clerks' correct phone number although I managed to bring it up on my mobile phone and give the doctors their names. Frustration added to my fears. For some reason, I cannot really explain why, I thought the treatment was some form of brain surgery and I believed if I consented that I would never see my loved ones again. I therefore initially refused consent and kept asking for my wife. In terms of the Mental Capacity Act 2005 I do not believe that I understood the information relevant to the decision, neither did I retain the information, nor use or weigh the information as part of the process of making the decision. I did not have capacity to consent.

It is my view that it is difficult to see how a patient in my situation could be expected to have the capacity to consent to treatment when going through such emotional turmoil. It is extremely difficult to take in all the information that is being given to you and in my case this was made even harder because of the difficulty expressing myself clearly. Furthermore because of the thoughts that are going through your mind as a patient in

these particular circumstances, such as the prospect of serious disability which will have a major impact on your family, career, personal independence or indeed death, one clearly misses important information being imparted under the requirements of the act.

Capacity and consent

Consent requires capacity and JA's case is an example of how sudden serious illness, requiring rapid treatment, makes understanding complex medical issues almost impossible for a patient and assessing capacity complicated for the doctor. The amount of information as to risks and benefits that a patient can understand will depend upon many factors including their education and intelligence, the time available and the psychological impact of the situation on the patient. Acute illness can impair understanding of disease and especially the concepts of proportionality and risk, even when simple tests of cognitive function are normal.¹³ The courts understand this and Lord Woolf (MR) in an Appeal Court judgement wrote:

*the doctor, in determining what to tell a patient, has to take into account all the relevant considerations, which include the ability of the patient to comprehend what he has to say to him or her and the state of the patient at the particular time both from the physical point of view and an emotional point of view.*¹⁴

Judging a patient's ability to weigh information is usually the most difficult aspect of consent. Stroke is sudden, life threatening, much feared and likely to affect capacity even in the absence of dysphasia. With thrombolysis for acute stroke, capacity requires understanding the nature and seriousness of stroke, the risks and benefits of treatment and how the benefit, but not risk, rapidly falls with time.¹⁵ Diagrams or pie charts may not help in a patient's understanding of the options because benefit may be large or small and is time dependent, whereas the likely harm is severe and less related to time.¹⁵ Many emergency medical treatments (such as anti-arrhythmics) are given immediately, or almost immediately after only a brief (and sometimes without) explanation of what is proposed rather than after formal assessment of capacity and obtaining consent. The courts judge that patients with capacity may refuse treatment 'for any reason, rational or irrational or for no reason at all' but also recognise that capacity is commensurate with the gravity of the decision and may be affected by fear, pain and drugs.¹⁶ They also may accept withholding of information on the basis of therapeutic privilege if it might cause distress and/or result in a patient refusing treatment that is in their 'best interests'.⁵

Our society sets great store by bodily integrity and autonomy has become the paramount principle in medical practice. A competent patient may choose which treatment to accept and which to reject and the medical profession is not the arbiter of the patient's 'best interests'.¹⁷ The courts and society recognise that even the sanctity of life principle does not trump autonomy and that the patient's 'best interests' may not necessarily be their

'best medical interests'.^{17,18} Lord Donaldson (MR) in a case of a Jehovah's witness and a transfusion stated, 'A patient's right of choice is not limited to decisions which others might regard as sensible' and went on to say, 'That the patient's choice is contrary to what is to be expected of the vast majority of adults is only relevant if there are other reasons for doubting his capacity to decide'.¹¹ Sudden critical illness, requiring immediate treatment decision, are an example where the level of understanding of the issues required for capacity is likely to be impossible for a patient to achieve. A patient may have decided in advance that they would not wish for a specific treatment, such as transfusion, whatever the circumstances; but refusal of a treatment with the potential to rescue a patient from death and/or serious disability without a long-held or strong logical reason is grounds for doubting 'capacity to decide'.

JA's recollections of the discussion after the event may be incomplete but his belief that the proposed treatment involved brain surgery showed he had not understood even the 'nature and purpose' of thrombolysis. This highlights the difficulties in understanding therapeutic options that even a highly educated and intelligent person experiences when suffering acute life-threatening illness. Patients are assumed to have capacity but this case also illustrates the problems assessing it. Our discussion never mentioned surgery so we could not know that he believed a neurosurgical treatment was proposed. In retrospect our assessment of capacity was wrong and JA should have been given thrombolysis earlier, in his 'best interest', with expiation in terms of his being given treatment designed to dissolve a clot in his brain. This approach would have given opportunity to refuse a treatment to which he had especial or prior considered objection or to ask for further information and yet have avoided delay.

JA made an excellent recovery but had we given thrombolysis without consent and had he died without seeing his wife, it could be argued we paternalistically confused his 'best medical interests' with his 'best interests'. Conversely had he continued to refuse treatment and we to withhold it, he would probably have been left with right hemiplegia and unable to work. This would not have been in his 'best interests' and he might have had

grounds to seek legal redress for lost opportunity to benefit from thrombolysis based upon an incorrect assessment of capacity.¹⁹

That we obtain consent to treatment is essential if patients are to make autonomous decisions regarding their care; but the key to autonomy is capacity. A patient with acute stroke may easily understand that they have had a stroke but many will not have capacity to decide complex treatment options and a refusal of treatment in such circumstances may be more a reflection of anxiety and confusion than considered rejection of therapy.

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