ABSTRACT – Personal autonomy and the right of self-determination are the basis of the right to refuse treatment. They do not grant the right to demand treatment that the responsible doctor regards as not clinically indicated. ‘Best interests’ operates as a test in relation to patients who are incompetent. The doctor–patient relationship is a joint enterprise with the aim of improving patient welfare as clinically judged, but only to the extent permitted by the patient. The decision of the Court of Appeal in the case of R v General Medical Council (GMC) ex parte Burke (2005) is explored.

KEY WORDS: artificial nutrition and hydration, best interests, patient autonomy, patient welfare, professional autonomy

The Court of Appeal decision in R v General Medical Council (GMC) ex parte Burke clarified the legal force of a direct request by a competent patient for a treatment that the responsible medical professional felt was not clinically indicated.1 As a general proposition, the principle of personal autonomy and its close relation the right of self-determination, do not entitle a patient to insist on a treatment, irrespective of the nature of the treatment.

The case

Mr Burke suffered from spinocerebellar ataxia which had resulted in progressive disability. Sadly his prognosis was limited. The condition, however, did not affect his cognitive function. The evidence was that in the final stages of the disease process he would initially lose the ability to communicate but retain his sentience. He would soon thereafter lapse into a coma. During those final stages artificial nutrition and hydration (ANH) would no longer be capable of prolonging his life. Mr Burke desired that ANH should be provided during the final stages of his illness. His concern was that the then current GMC guidance would place the final power of decision over his course of treatment in the hands of the doctors looking after him. Amongst other parts of the guidance he challenged paragraphs 32 and 81:

32: If you are the consultant or general practitioner in charge of a patient’s care, it is your responsibility to make the decision about whether to withhold or withdraw a life-prolonging treatment, taking account of the views of the patient or those close to the patient as set out in paragraphs 41–48 and 53–57.

81: Where death is not imminent, it usually will be appropriate to provide artificial nutrition or hydration. However, circumstances may arise where you judge that a patient’s condition is so severe, the prognosis so poor, that providing artificial nutrition or hydration may cause suffering or to be too burdensome in relation to the possible benefit.1

In a controversial judgement,2 Munby J declared these parts (inter alia) of the GMC guidance to be unlawful. The GMC appealed. The Court of Appeal reversed this first instance decision, finding no grounds upon which it could declare any part of the GMC guidance unlawful in relation to the facts of the case. Although it felt that the guidance was not defective, it did read into it the inference that ANH could be withheld contrary to the wishes of a competent patient.

It drew a clear distinction between life-prolonging ANH and ANH that does not prolong life. There is a rebuttable presumption in law in favour of respecting the sanctity of life.4 Thus, the duty of care will normally require the provision of life-prolonging ANH. This duty is not absolute. Exceptions exist for

Key Points

A patient cannot require the delivery of a treatment that the responsible doctor determines not to be clinically indicated

Personal autonomy and the right of self-determination ground the right to refuse treatment. These principles do not ground a right to demand treatment that is not clinically indicated

Patient wishes, welfare and best interests are separate concepts

Best interests are most usefully considered in relation to incompetent patients
Determining the course of medical treatment

The process to arrive at a final treatment plan starts with a doctor exercising his/her clinical skills and judgement to determine which treatment options are clinically indicated. This obligation arises out of the doctor-patient relationship which imposes a duty of care upon the doctor to promote the welfare of the patient. The doctor then offers those clinically indicated treatment options to the patient who can then choose which, if any, of them to accept. The power rests with a competent patient to refuse any or all of these for any reason, however irrational, or even no reason at all. This is where the shield of personal autonomy, patient consent, operates.

Once the patient has accepted an offered treatment option the doctor is obliged to provide it in accordance with his/her duty of care to the patient. If the patient refuses the treatment it is unlawful for that treatment to be delivered. What if the patient demands a treatment option that the doctor has not offered him/her? In Burke, Lord Phillips, Master of the Rolls, approved the following statement:

the doctor will, no doubt, discuss that form of treatment with him (assuming that it is a form of treatment known to him) but if the doctor concludes that this treatment is not clinically indicated he is not required (ie he is under no legal obligation) to provide it to the patient although he should offer to arrange a second opinion. This is an important result. It delimits the balance of obligations and responsibilities that arise between doctors and patients in modern clinical practice. The consequence is that the doctor-patient interaction should only operate to improve patient welfare as clinically assessed but only to the extent permitted by the patient. The practice of clinical medicine is therefore a partnership with the goal of improving patient welfare.

The weight of the obligation imposed upon a doctor to deliver a clinically indicated treatment that accords with the wishes of a competent patient remains powerful. The failure to provide life-prolonging ANH whilst Mr Burke was competent and desired the treatment would amount to a breach of duty. Indeed, if this breach of duty were intentional and resulted in the premature death of the patient, a charge of murder could result.

Best interests

It is possible to argue that the best interests of a competent patient are best defined by the patient. Since a doctor is bound to pursue the best interests of their patient, the final choice of medical treatment should therefore be determined by the patient. This was the route taken by Munby J in the first instance decision of Burke. However, the Court of Appeal in Burke disagreed. It felt that the test of best interests should be confined to an objective test that is used in relation to incompetent patients when considering medical matters. The wishes of a competent patient and the tool of best interests should not be conflated. This is a helpful clarification of when to use the best interests test.

On these facts, the best interests test would come into play once the disease process had advanced to the stage where Mr Burke had become incompetent. This would arise once he was unable to communicate, although he would be likely to remain sentient for some period of this phase. The test of competence is not purely about the ability to make a decision. A patient who cannot communicate their decision is not competent. Sentience without the ability to communicate wishes cannot help those who are caring for the patient to make better decisions. This was confirmed as the position in common law and it accords with the recently passed Mental Capacity Act 2005, which is due to come into force in April 2007.

Advance directives and artificial nutrition and hydration

If Mr Burke were to become incompetent, how would his previously expressed wishes be dealt with in the context of determining whether or not it would be in his best interests to receive ANH? The key problem here was that the issue had not yet arisen. Mr Burke was competent and likely to remain so for some time to come. The Court felt unable to reach a clear conclusion in advance of the event about whether or not ANH would be in the best interests of Mr Burke at that stage. Despite this, it was able to make some useful statements.

Reflecting on the judgements of the House of Lords in the Bland case, the Court of Appeal concluded that an advance directive requiring ANH should be respected, but that it would not require that ANH be given solely because it was in place. This view of the common law once again accorded with the provisions of the Mental Capacity Act 2005. The decision of whether or not ANH should be given to an incompetent patient requires that an advance directive be taken into account, but that an advance directive alone is not determinative of the outcome of the decision.

Conclusion

The result is that patient’s wishes are important. They remain so even when made in anticipation of a loss of competence and they do affect the decisions made after the loss of competence. However, patient’s wishes are not determinative of treatment decisions either in competent or incompetent adults – even if the expression of those wishes is separated in time from the actual decision to be made.

From the perspective of the doctor the question in relation to competent patients is, ‘What treatment is clinically indicated here?’ In relation to incompetent patients the question is, ‘What treatment option is in the best interests of this patient?’

The future is made more interesting by the prospect of the Mental Capacity Act 2005 coming into force. This Act confers on

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patients the ability to create lasting powers of attorney which extend to decisions over the patient's personal welfare. This will no doubt affect a sea change in how such decisions will be made in the future.

References

5. Barnett v Chelsea & Kensington Hospital Management Committee (1968) 1 All ER 1068, QBD.
11. s.3(d) Mental Capacity Act 2005 www.opsi.gov.uk/acts/acts2005/20050009.htm
13. ss.4 and 26.