Dilemmas in the medical treatment of patients facing inevitable death

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Paediatricians feel that they are now compelled to treat a patient against their wishes and may be liable to civil or criminal action if they withdraw treatment

The judgment of Mr Justice Holman in the case of *MB* [2006] EWHC 507 (Fam) has raised concerns amongst paediatricians that they are now compelled to treat a child against their conscience. MB was a child who had the most severe form of spinal muscular atrophy. An NHS Trust sought a declaration that the child MB lacked the capacity to make decisions with regard to his future treatment and that it shall be lawful, notwithstanding his parents' refusal to consent, and in MB's best interests, for the medical staff to (a) withdraw all forms of ventilation and (b) provide palliative care. The judge refused to grant the declaration. This paper explores the concern of paediatricians that they are now compelled to treat a patient against their wishes and may be liable to civil or criminal action if they withdraw treatment.

MB was a child who suffered from the most severe form of congenital spinal muscular atrophy (SMA), which is degenerative and progressive. He was admitted to hospital at the age of 7 weeks when his condition was diagnosed. SMA affects the voluntary muscles which become progressively weaker and ultimately cease to function at all. Because the respiratory muscles are affected, death is inevitable in the most severe cases. At birth MB could use many of his muscles in an age normal way and could cry, smile, breath and move his limbs. At the time of the hearing in March 2006, he could no longer open his eyes fully but could follow movement with his eyes, although his eyes movements were irregular. Other movement was limited to a slight frown and perhaps slight movement in his thumbs or feet. He could probably feel stroking and touch. It was already impossible to assess his cognition or whether he had suffered brain damage. He had been unable to breath unaided since July 2005 and required positive pressure ventilation through an endotracheal tube. He was unable to swallow and was fed via a tube through his stomach

wall into his stomach. He was conscious during the day and slept at night. He was assumed by the judge to have the normal thoughts and thought processes of an 18-month-old subject to the limitations of his life within hospital.

In deciding the case the judge stated that so far as he was aware the courts had not yet been asked to approve the withdrawal of treatment against the will of the child's parents with the predictable, inevitable and immediate death of a conscious child with sensory awareness, normal cognition and no reliable evidence of brain damage. He considered the decisions of Sir Stephen Brown President in *Re C (a baby)* [1996] 2 FLR 43 and *Re C (a minor) (Medical treatment)* [1998] Lloyds Law Reports Medical 1.

In the first case, Sir Stephen Brown made an order allowing artificial ventilation in an 18-month-old child to be withdrawn, which would result in immediate death. The child had suffered from serious brain damage and had a very low awareness of anything, if at all. In the second case, the child suffered from severe SMA, as did MB. She was on intermittent positive pressure ventilation which the parents and doctors agreed should be withdrawn before she became dependent, but they could not agree on whether such ventilation should be reintroduced if the child suffered respiratory failure. The parents sought an order that it should be reintroduced, but Sir Stephen Brown declined to grant one in part because of the well-established principle that a court will not order a doctor to undertake a course of treatment which the doctor is unwilling to do. He also held it was not in the best interests of the child. Mr Justice Holman found that the facts of the case were very close to those of MB but did not involve or contemplate the immediate death of the conscious child.

Mr Justice Holman considered the legal and ethical framework. He held that in the widest sense the case concerned the upbringing of a child and accordingly s.1

of the Children Act 1989 sets out the statutory test that must be applied, which is "the child's welfare shall be the court's paramount consideration". The way in which that test should be applied was set out in the judgment of the Court of Appeal in *Wyatt v Portsmouth Hospital NHS Trust* [2005] EWCA Civ 1181, which states that where parents and doctors cannot agree on a course of treatment for a child who lacks the capacity to decide for himself, it is the duty of the court to make an independent and objective decision. The test to be applied is the best interests of the patient and best interests means every kind of consideration including medical, emotional, sensory (pleasure, pain and suffering) and the instinctive will to survive.

The judge considered the correct approach to the factual distinction between withholding and withdrawing life support. He relied on the opinion of Lord Goff in *Airedale NHS Trust v Bland* [1993] AC 789 in which Lord Goff agreed with Professor Glanville Williams that the doctor's conduct in discontinuing life support can properly be categorised as an omission. In each case the doctor is simply allowing his patient to die in the sense that he is desisting from taking a step which might prevent his patient from dying as a result of his pre-existing condition. Mr Justice Holman concludes that there is no legal distinction between withholding or withdrawing life support and the best interests test applies equally in both situations. He went on to consider the ethics of withholding and withdrawing life support and sought guidance from *A framework for practice* (2nd edn, 2004) published by the Royal College for Paediatrics and Child Health, which states that there is no ethical difference between withdrawing (stopping) and withholding treatments given the same ethical objective although emotionally they are sometimes poles apart. The judge, however, stressed that he was not concerned with the ethical issues. His task was only to decide where the objective balance of the best interests of the child lay. He stated,

The ethical decision whether to actually withdraw or withhold treatment must be made by the doctors concerned, judges are neither qualified to make, nor required, nor entitled to make ethical judgments or decisions.

In respect of medical evidence, the judge heard the oral evidence of two key consultants under whose care MB had been since his admission: a paediatric intensivist and a paediatric neurologist. Eight other consultants involved in the

child's care gave evidence by written statement. Four further consultants were instructed as expert witnesses by the parties and provided written reports. The medical witnesses were unanimous in their opinion that it was in MB's best interests to withdraw treatment and give palliative care. The independent experts provided a joint report in which they stated that it was very difficult to assess how much discomfort or distress MB suffered. It was inevitable that blood sampling, deep endotracheal suction, physiotherapy and bagging were uncomfortable for him. It was clear that his condition would continue to deteriorate, although he would remain fully sensate. The consultant intensivist said that the main issue was that it was so difficult to know how he felt, it was very hard to know whether he was comfortable or in distress or pain. The consultant neurologist stressed that for a considerable time he had felt he had been acting unethically in continuing to subject MB to discomfort and pain and that he would personally find it very difficult to continue doing so much longer.

The parents opposed the application of the Trust and sought artificial ventilation to continue. At a late stage they sought a declaration that it shall be lawful and in the child's best interests for a tracheostomy to be performed to enable long-term ventilation to be carried out. The mother believed that if her son were kept alive long enough a cure might be found. The father did not want resuscitation in the event of heart failure, although the mother did.

The options for treatment were considered in the joint expert report. Although five options were listed, only two were considered as realistic by the judge: the first to continue treatment as at present with artificial ventilation, the second to withdraw treatment with the inevitable result of immediate death but with palliative care to relieve pain and suffering.

The judge followed the guidance of the Court of Appeal in asking each advocate to draw up a list of benefits and burdens of continuing or discontinuing the treatment as at present. A composite schedule was drawn up by the Guardian's counsel. The list of burdens was very much longer than the list of benefits. The Guardian supported the application of the Trust to withdraw treatment.

The judge accepted the burdens upon MB of discomfort, distress and short episodes of pain from deep suctioning, but he found that they were outweighed by the benefits of the relationship with his family and the pleasure he continued to gain from touch, sight and sound. He

found that it was impossible to put a mathematical or any other value on the benefits but that they are precious and real and the only benefits that MB was ever destined to gain from life. Mr Justice Holman refused the declaration sought by the Trust (to withdraw ventilation and provide only palliative care). He stated that he was not persuaded, even taking into account predicted future deterioration, that it was currently in the best interests of MB to discontinue ventilation with the inevitable result that he would immediately die. He went further to state that he considered it positively in MB's best interests to continue with continuous pressure ventilation and the nursing and medical care that properly go with it, including suctioning and deep suctioning when required. The judge stated that although that was his opinion, he could not and did not make an order or declaration to that effect, he merely stated his opinion. The judge did agree to grant a declaration that it was lawful and in MB's best interests that procedures which went beyond maintaining ventilation requiring the positive infliction of pain (which would mean that MB had naturally moved towards his death) need not be given; these treatments were cardiac resuscitation, ECG monitoring, intravenous antibiotics and blood sampling.

Did the refusal to grant the declaration that the trust sought have the effect of compelling doctors to continue to administer treatment contrary to their conscience?

The relationship between doctor, parent and court was helpfully explained by Lord Donaldson in *Re J (A Minor)(Wardship: Medical Treatment)* [1991] 1 FLR 366 thus:

No one can dictate the treatment to be given to the child - neither the court, parents nor doctors. There are checks and balances. The doctors can recommend treatment A in preference to B. They can also refuse to adopt treatment C, on the grounds that it is medically contraindicated or for some other reason is a treatment which they could not conscientiously administer. The court or parents, for their part, can refuse to consent treatment A or B or both, but cannot insist upon treatment C. The inevitable and desirable result is that choice of treatment is, in some measure, a joint decision of the doctors and the court or parents.

A similar approach is taken in the fourth judgment of Mr Justice Sedley in the case of *Charlotte Wyatt* [2005] EWHC

2293 (Fam) in which he states that the clinician's duty is to act in the best interests of his patient where the patient is not competent to make his own decision. Where the patient is a child, the doctor has a responsibility to work in partnership with the parents. If the parents and doctors differ as to their perception of the child's best interests, the court may be called upon to rule upon the best interests of the child. Sedley J identified four possible categories of disagreement:

- (a) Where a doctor advocated treatment which the parents resisted and a failure to treat would be an affront to the doctor's conscience;
- (b) Where a doctor advocated treatment which the parents resisted on reasonable grounds but which were contrary to the doctors view;
- (c) Where the parents wanted treatment which the doctor could not advise but the giving of which would not amount to an affront to conscience;
- (d) Where treatment requested by parents would be an affront to conscience.

Sedley J considered that the vast majority of disagreements fall into categories (b) and (c) and that doctors would usually accommodate the views of the parents in the last resort, a result of which Sedley J approved. However, Sedley J made it clear that a doctor could not be required to act contrary to his conscience and turned to another judgment of Lord Donaldson in *Re J (A Minor)(Child in Care: Medical Treatment)* (1993) Fam 15 where Lord Donaldson MR said at pp 26H-27B:

The... issue... is whether the court in the exercise of its inherent power to protect the interests of minors would ever require a medical practitioner or health authority acting by a medical practitioner to adopt a course of treatment which in the bona fide clinical judgment of the practitioner concerned is contra-indicated as not being in the best interests of the patient. I have to say that I cannot at present conceive of any circumstances in which [it] would be other than an abuse of power as directly or indirectly requiring the practitioner to act contrary to the fundamental duty which he owes to his patient. This... is to treat the patient in accordance with his own best clinical judgment, notwithstanding that other practitioners who are not called upon to

treat the patient may have formed a quite different judgment or that the court acting on expert evidence may disagree with him.

Sedley J went on to say that in coming to the decision as to whether or not a particular treatment is an affront to his conscience, the doctor does not have to be sure that he is 100% right, conscience is not so rigid a concept, but he must take account of all the circumstances. He must take account of guidance offered by the Royal College, he must consider whether the treatment is futile or the patient's condition hopeless. He must take a second opinion (or more if necessary). Through an intellectual process he must arrive at a conclusion about what is in his patient's best interests.

It should be noted that the mere fact that a doctor believes he has acted in accordance with the best interests of his patient does not give him immunity from disciplinary, civil or criminal proceedings. If he follows the path to a decision described by Sedley J above, he is unlikely to be the subject of disciplinary proceedings and may have a strong defence to civil or criminal proceedings.

If, as in *MB*, having carried out the intellectual exercise required, he comes to the conclusion that it is contrary to his conscience and not in the best interests of his minor patient to continue treatment but the parents do not agree, he should refer the matter to the court to decide. This is a matter of good practice rather than legal obligation (see *Burke v GMC* [2005] EWCA Civ 1003). Referring the matter to the court has the potential benefit of the court endorsing the opinion of the doctor as to the best interests of the patient. It also carries the risk that the court will not agree with the doctor, a risk realised in *MB*. Who, then, is to prevail where the doctor and court differ as to their opinion of the best interests of the patient? It is clear that the court's decision as to best interests will prevail when the question is not whether to withdraw or withhold treatment but which treatment out of a number which all meet the Bolam test is to be selected see in *Re S (Adult patient: Sterilisation)* [2001] Fam 15, 30–31 per Thorpe LJ, save that the court will not make a declaration requiring a doctor to act contrary to his conscience.

What then is the effect of the "opinion" of Holman J that the best interests of *MB* were that the current treatment should be continued contrary to the doctor's conscience? It cannot be that the doctor in question must treat against his conscience since that would have the same effect as making a declaration which would be an abuse of power. The usual course of action for a doctor in these

circumstances would be to withdraw so that another doctor took over. What, however, if no other doctor was willing to treat according to the views of the court? If the doctor withdrew in these circumstances, could he be the subject of civil or criminal action for the inevitable death of the child, not for breaching a court order but for breach of his common law duty to treat his patient in the patient's best interests? Certainly Holman J did not appear to contemplate this possibility. He was at pains in his judgment to stress that the actual decision whether to withdraw treatment was an ethical decision to be taken by the doctors and one in which he had neither the jurisdiction nor training.

However, notwithstanding that Holman J did not consider the prospect of civil or criminal action, is it possible to contemplate such a course being taken? At first glance it may be difficult to imagine a prosecution even being brought let alone a jury convicting when a doctor, as in *MB*, is supported by unanimous and overwhelming professional opinion, but the decision of the Court of Appeal in the case of *Burke v GMC* [2005] EWCA Civ 1003 is authority which, by implication at least, might suggest that fear of prosecution or civil action is well founded. The issue in *Burke* was the lawfulness of the GMC guidelines for the withdrawal or withholding of treatment, specifically the withdrawal of artificial nutrition and hydration (ANH) of the sentient but incompetent patient. In considering and contrasting the position of the incompetent patient whose wishes are not known with the position of Mr Burke, Lord Phillips MR said at paragraph 34:

No... difficulty arises... in the situation... of the competent patient who, regardless of the pain, suffering or indignity of his condition, makes it plain that he wishes to be kept alive. No authority lends the slightest countenance to the suggestion that the duty on the doctors to take reasonable steps to keep the patient alive in such circumstances may not persist. Indeed, it seems to us that for a doctor deliberately to interrupt life-prolonging treatment in the face of a competent patient's expressed wish to be kept alive, with the intention of thereby terminating the patient's life, would leave the doctor with no answer to a charge of murder.

In an earlier part of his judgment at paragraph 32, Lord Phillips was careful to point out that the obligation to treat Mr Burke arose not from Mr Burke's own

wishes but from the doctor's duty at common law to treat in the best interests of his patient, Mr Burke's wishes happened to be coincident and merely underscored that duty.

What then of the child patient who cannot express his views as to the withdrawal of treatment and the court is asked to make a decision on his behalf? If the court comes to the conclusion that it is in the child's best interests not to withdraw or withhold treatment, it may be argued that the child is in the same position as Mr Burke. It may be that in *Burke*, as in *MB*, the court would not make a declaration compelling the doctor to treat if he stated it to be contrary to his conscience, but would this be sufficient to protect him from a charge of murder if he withdrew in the light of the strong words of Lord Phillips?

The answer, it is suggested, lies in the use of the words "deliberate" and "intention" in the concluding passage quoted above of Lord Phillips. If the doctor continued to treat and deliberately ended ANH with the intention of ending the patient's life, he would clearly be in jeopardy. But a doctor who carried out the intellectual exercise described by Sedley J in the case of *Wyatt* and then declared his wish to withdraw is surely in a very different position.

Lord Phillips was careful in the use of the words "deliberate" and "intention". Murder is defined in statute and common law as "where a person of sound mind and discretion unlawfully kills any reasonable creature... with intent to kill or cause grievous bodily harm". Clearly the act of withdrawing is deliberate, but it is not made with the intention to kill or cause grievous bodily harm where a doctor has made a decision in good faith and according to his conscience. Neither can the act of withdrawal for reasons of conscience be unlawful since otherwise a doctor would be compelled to treat against his conscience, a proposition for which there is no authority in support and the strong authority of Lord Donaldson against.

Alternative offences are involuntary manslaughter and manslaughter by gross negligence, which have all the elements of the offence of murder save for the requirement of intent. Involuntary manslaughter still requires that the act causing death must be unlawful and the above comment applies. Further, in respect of involuntary manslaughter, the unlawful act in question cannot be an omission (see *R v Lowe* [1973] 1 Q.B 703, 709B-D). An act of withdrawal is an act of omission (see *Bland* per Lord Goff above). Finally, an act of omission may give rise to manslaughter by gross negligence. What constitutes gross negligence has

been described as “a reckless disregard of danger to the health and welfare of the infirm person” (see *Andrews v DPP* [1937] A.C. 576 H.L. per Lord Atkins). The intellectual exercise required to justify withdrawal on the grounds of conscience is clearly a world away from recklessness and any indictment on such a charge would be quashed as an abuse of process.

Fittingly, a doctor will tend to be protected by the opinion of his colleagues. If there is divergent opinion as to the treatment options, then he may withdraw

knowing there are other doctors who will give treatment which his conscience cannot contemplate. If there is unanimity, it shows that he has almost certainly carried out the intellectual exercise in good faith.

Ultimately a doctor is safeguarded by the strength of his conviction and his intellectual honesty. It is very well established in law that he cannot be compelled to treat against his conscience. If that opinion is truly held, he must make it clear to the court. It will not bind the

court, but it is right that the judge should understand clearly that the treating clinician will not act against his conscience whatever the decision.

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IMAGES IN PAEDIATRICS.....

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Sinovenous thrombosis due to mastoiditis

A 9-year-old child presented with a 4-week history of headache, diplopia and mastoid pain. She was diagnosed with mastoiditis, received intravenous antibiotics and underwent mastoidectomy. Headache and diplopia persisted and the neurology service was consulted. Examination revealed right sixth nerve palsy and bilateral papilloedema. MRI demonstrated mastoid opacification and inflammation, and ipsilateral jugular and sigmoid venous sinus thrombosis (fig 1). The patient received low-molecular-weight heparin and acetazolamide, with prompt resolution of headache, diplopia and papilloedema.

Sinovenous thrombosis (SVT) is a known complication of acute mastoiditis,¹ and although the incidence of SVT has declined in the antibiotic era, it remains an important diagnostic consideration.^{2–4} In most cases, treatment of SVT includes aggressive hydration and anticoagulation, which has been associated with improved cognitive outcome and a trend to lower mortality³ without an increase in intracranial haemorrhage.^{3,4} The clinical improvement may occur long before the thrombosis improves on imaging and may be related to improved microcirculatory venous drainage. Delay in diagnosis and initiation of treatment with anticoagulation

may increase morbidity, including permanent visual deficits.

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Figure 1 (A, B) MR venography demonstrates signal void in the right sigmoid sinus and jugular vein (arrow). (C) T1 weighted MRI demonstrates opacification of the right mastoid (arrow) and the venous hyperintensity (dotted arrow) indicates that absent flow-related signal on venography is due to acute clot, not sinus hypoplasia.