A reappraisal of the guidance and legal protection for medical practitioners in cases of medical futility

Sarah Cheetham

1. Introduction
Rapid advances in medical technology have now allowed patients to be kept alive when they would not have otherwise survived. Yet these have sometimes given rise to concerns that such efforts could be futile. The task of defining ‘medical futility’ has, however, proved to be a difficult one and this can present many problems. For instance, should the doctor’s role be based on whether a life can no longer be preserved or, alternatively, when there is an unacceptable quality of life? (Mason and McCall Smith 2006). The concept therefore needs to be approached with caution as it is something which could lead to the ‘inescapable duty to let some patients die’ (Slater 1973; Schneiderman and Jecker 1993). Four definitions have been offered by Jecker and Pearlman (1992). These are: treatment which is useless or ineffective; treatment that fails to offer a minimum quality of life; treatment that cannot possibly achieve the patient’s goal; or treatment that does not possibly offer a reasonable chance of survival. These definitions are nevertheless far too wide and leave too much scope for subjective viewpoints. For example, what is a ‘minimum quality of life’ and what is ‘a reasonable chance of survival’? It is because of the ambiguities inherent in defining medical futility that a number of professional governing bodies have responded by setting out guidelines. This has been done with the aim of preventing any potential misuse of the discretion conferred on doctors by the concept of medical futility. Courts have also observed that until a body of experience and practice has been built up, it is desirable that court approval be sought before a decision is made to remove life-sustaining measures from such patients (Airedale NHS Trust v Bland 1993; Practice Direction 2002).

The adequacy of such professional and legal guidelines has nevertheless been questioned. Views have been expressed, for instance, about ‘the unsatisfactory nature of the legal framework in which they were operating’ (per Mustill, L. J. in Bland) and how the matter needed to be legislated on (Morris 2008). This paper seeks to show that the current system, although not perfect, is adequate and satisfactory in providing guidance and legal protection for medical practitioners. In order to do this, this paper will firstly set out what the current professional and legal guidelines are in respect of adults and infants. It will be demonstrated here that the current system allows for flexibility, and enables doctors and judges to come to
morally defensible decisions. It will then, through a reappraisal of the current law and professional guidelines, contend that the current system is preferable to any possible changes that could be made by legislation.

2. Medical Futility and Guidelines for Medical Practitioners

Medical practitioners who have to make decisions in respect of medical futility are currently guided by a variety of sources. These include guidelines issued by different professional governing bodies, the main one being the General Medical Council’s Guidelines on Withdrawing and Withholding Medical Treatment: Good Practice on Decision Making. These guidelines are not legally binding, and in some instances they require the medical practitioner to look at other guidelines set by governing bodies, such as the Royal College of Physicians’ guidelines on PVS (The Vegetative State: Guidance on Diagnosis and Management). Another source of guidance is the case law that has built up in this area. Their application will be looked at below in the context of adult and child patients.

2.1. Adults

The seminal case with regard to adults is that of Airedale NHS Trust v Bland (1993). In this case, Anthony Bland, who was involved in the Hillsborough football disaster in 1989, suffered severe chest injuries, which in turn caused catastrophic and irreversible damage to the higher functions of his brain. Due to this brain damage, he was left in a Permanent Vegetative State (PVS). PVS is defined by the Royal College of Physicians (The Vegetative State: Guidance on Diagnosis and Management) as a state where there is no sign of awareness of a functional mind, although there may be times of wakefulness similar to sleeping and waking that has occurred for twelve months (after any head injury) or six months (following other causes of brain damage). After three years in this condition, where his life was sustained by artificial nutrition and hydration, both his parents and doctors agreed that the care had become futile. The hospital therefore applied to the court to find out whether they could lawfully discontinue all life-sustaining treatment and medical support.

The House of Lords took the view that it was not in the best interest of patients in such a condition, who had not clarified their intentions on such matters beforehand, to be given further treatment when no affirmative benefit could be derived from such treatment. The management of such cases should also be in accordance with the ‘Bolam test’, namely whether ‘a reasonable and competent body of opinion believe [the doctor’s actions] to be in
the patients best interests’ (F v West Berkshire Health Authority, 1989; Bolam v Friern Hospital Management Committee, 1957). The Bland judgment also made a distinction between feeding through a tube, which is classed as medical treatment, and an incompetent patient being spoon fed by their carer, which is classed as care. The judgment in Bland set out the following criteria, comprising four stages, which must be satisfied before artificial nutrition and hydration (ANH) can be withdrawn. Firstly, before treatment can be withdrawn, there must be evidence that every effort has been made to rehabilitate for at least six months. Secondly, diagnosis of PVS should not be given until twelve months after the injury. Thirdly, a diagnosis must be confirmed by two independent doctors. Finally, the view of the patient’s family must be given great weight.

It is further clarified that the cessation of ANH is an omission rather than an action. The judgment also stressed that although the medical profession may deem the withdrawal and/or withholding of treatment to be in the patient’s best interest, it is desirable that the court’s approval be sought beforehand in such cases (Airedale NHS Trust v Bland, 1993; upheld by the Practice Direction, 2002).

Bland illustrates the flexibility of the current system. It allows doctors and judges to look at the case individually and apply the guidelines to the specific facts. It is submitted, however, that the case would almost certainly have had a different outcome if it had been governed by legislation, not least because of the rigid nature of the latter. This is an issue that will be returned to later.

Complex issues have also arisen where a patient has not fulfilled the full PVS criteria. In Re D (1997), for example, a twenty-one year old woman was involved in a serious road traffic accident and sustained severe head injuries. Although one of the paragraphs from the guidelines issued by the Royal College of Physicians was not fulfilled, she was described as the ‘living dead’ as there was ‘no evidence of any meaningful life whatsoever’ (per Sir Stephen Brown). Thus when her gastrostomy tube became detached, it was held that it would be lawful for this not to be replaced and for ANH to be withdrawn. In Re H (adult: incompetent) (1997), the patient was also in a road traffic accident and suffered severe brain damage. Her condition also did not fully satisfy the Royal College of Physicians Guidelines, but as she was believed to be in a ‘vegetative state that is permanent’, it was decided that it was in her best interests for ‘treatment…to be brought to a conclusion’ (per Sir Stephen
Brown). Importantly, though, it must be noted that in cases involving patients who are not in PVS and who ‘have some level of awareness’ (Mason and McCall Smith 2006), the courts will not allow ANH to be withdrawn as it would ‘provide no benefit… and would be less dignified than the death faced at some time in the distant future’ (W Healthcare NHS Trust v H and Another, 2005). ANH was allowed to be withdrawn in both Re D and Re H, only because the doctors and the court were convinced that the patients no longer had any awareness of themselves and their environment. As a different conclusion was reached in the cases where the patient was conscious and sentient (as in the case of W Healthcare NHS Trust v H and Another 2005), this again illustrates the flexibility of the current system.

Another issue with regard to PVS and medical futility, which has been brought to the attention of the courts, concerned alleged breaches of human rights. It was explored in NHS Trust A v Mrs M, NHS Trust B v Mrs H (2001) whether the withdrawal of ANH could amount to a breach of Article 2 (‘The Right to Life’), Article 3 (‘The Prohibition of Inhumane or Degrading Treatment’) and Article 8 (‘The Right to Respect for Family Life’) of the Human Rights Act 1998. Lady Justice Butler-Sloss nevertheless stated that if the withdrawal of ANH was in the ‘patient’s best interest…in accordance with the respected body of medical opinion’, then the ‘obligation under Art. 2 is…discharged’. It was also held that ‘Art. 3 does not apply’, because ‘it requires the victim to be aware of … inhuman and degrading treatment’ and ‘a patient suffering from PVS has no feelings’ or awareness of the treatment. Moreover, Art. 8 could not have been breached as the patient did not have autonomy and could not have consented in a PVS. This case accordingly sends out a strong, unequivocal message of reassurance to medical practitioners carrying out such procedures that their actions will not subsequently be found to have breached the Human Rights Act 1998.

If medical treatment is futile and the patient is competent, they themselves can decide that the treatment should cease. To carry out medical treatment on a competent patient who has refused such treatment is a civil wrong, and also potentially a criminal wrong (Sidaway v Bethlem Royal Hospital Governors, 1985; Re T (adult refusal of medical treatment), 1992). A much more complicated scenario arises where a competent patient wishes treatment to continue when the doctor believes that such treatment is futile. Under the law of negligence, the decision not to carry out treatment on a patient may be regarded as a breach of the duty to care if it satisfies the Bolam test (Bolam v Friern HMC, 1957). Yet if a doctor believes that the ‘treatment is not clinically indicated then he is not required to provide it’, although it is
clear that a ‘second opinion should be sought’ (Gurnham 2006). Nonetheless, a situation may arise, as in the case of *R (on the application of Burke) v General Medical Council* (2004), where a competent patient has given his wishes in respect of what is to be done when he becomes incompetent (as defined in section 2(1) Mental Capacity Act 2005). In this case, the claimant, Mr. Burke, suffered from the long-term illness of spino-cerebellar ataxia. This progressively degenerative disease was going to render him incompetent as his illness progressed and thus cause him to become entirely dependant on others to survive. In the latter stages of his illness, he would not be able to swallow and would become reliant on artificial nutrition and hydration. Mr. Burke was concerned that a doctor following the *GMC Guidelines on Withdrawing and Withholding Medical Treatment* (2002) would be able to decide whether or not he lived. He accordingly sought judicial review – a process whereby the High Court has the power to determine whether a public body has acted unlawfully or acted in a way that is incompatible with the European Convention on Human Rights – on the current ‘law’ in this area.

Lord Phillips MR, sitting in the Court of Appeal, stated that the guidelines are in fact lawful. He further stated that if conflict arises between a member of the medical profession and patients, or any of their family members, legal advice should be sought on whether it is necessary to go to court. This case is therefore reassuring for medical professionals. In a similar fashion to the *Mrs M* case, it is apparent that they can now follow the GMC Guidelines safe in the knowledge that they are compatible with the ECHR.

The professional guidance and legal protection with regard to adults is therefore a flexible system, which allows for each case to be looked at individually and based upon its own facts. Moreover, the operation of the system has now been tested in the courts and they have found it to be lawful. In this respect, the guidelines offer more legal protection than they did prior to the cases of *Mrs M* and *Burke*. The guidelines are now entrenched in the common law, and they therefore confer guidance and protection on medical professionals in a manner analogous to that afforded by legislation.

2.2. Infants

Similarly, in relation to very young patients, the situation is now relatively clear. In *Re J (A minor) (Wardship medical treatment)* (1999), it was stated that, although there was a strong presumption to prolong life, the assumed view of the patient must also be looked at. This assumed view should be formed from co-operation between the doctor and parents, and from
any suffering that has taken place. In the end, though, the decision will always be solely based on the patient’s best interests. If a patient who is an infant is a ward of the court, the decision to withdraw medical treatment will be decided in the best interest of that patient (Re B (a minor), 1990; Re J (a minor), 1990). In addition, as stated in Glass v UK (2004), any conflict between the parents and the doctors concerning the best interests of an infant should be taken to the court to be resolved.

Case law regarding infants has allowed for treatment to be withheld on infants who would have otherwise have had an ‘intolerable life which would be inhumane to enforce’, whether their disability was physical or mental (Mason and McCall Smith 2006). The law was summed up in the case of Charlotte Wyatt (Portsmouth NHS Trust v Wyatt, 2005). Charlotte was born prematurely, and she never left hospital during her short life due to a complex medical background. The judgment in this case set out the following criteria. It was held that if there was any disagreement between parents and doctors, the judge should decide on the patient’s best interests. Thus, the ‘best interest’ test will be used, and an ‘intolerable life’ can be used as a guide to the patient’s best interests. Significantly, however, an ‘intolerable life’ per se is not to be used as a sole test for best interests. Finally, the view of the parent(s) should also be taken into account, though this view is not determinate.

The Royal College of Paediatrics and Child Health have also laid down guidelines akin to those of the General Medical Council as to when treatment should be withheld or withdrawn. The document Withholding or Withdrawing Life Sustaining Treatment: A Framework for Practice (2004) sets out five situations when treatment can be discontinued. These situations are when a child: is in a state of PVS; is brain dead; has no chance of survival; is in a situation of no purpose; or is in an unbearable situation. As Campbell et al. suggest, however, the last three situations ‘are by no means self-evident and depend on subjective assessment.’ (Campbell, Gillett and Jones 2005) Therefore, it will always be the child’s best interests and the tests set out by the case law that will determine the final outcome.

Although the law is now clearer, it has taken a considerable amount of time for it to evolve to its present status. Consequently, there are many cases which precede those mentioned above. Mason and McCall Smith (2006) suggest that R v Arthur was the first case to bring the subject before the public conscience. In this case, a baby named John Pearson was rejected by
his parents due to him having uncomplicated Downs syndrome. The defendant, Dr. Arthur, who was indicted for the attempted murder of John Pearson, ordered nursing care only, and the baby died sixty-nine hours later. Dr. Arthur was acquitted, but this case served to illustrate the dangers of futility, particularly in instances where doctors are put under parental pressure. The cases leading up to the present law also allowed for a distinction to be made between physical and mental illnesses. In Re B (1981), a child suffering from Downs Syndrome required a simple operation to remove a blockage of the intestine. Failure to have this operation would have led to the child’s death. Despite this, the parents did not consent to the operation. B became a ward of the court, and Lord Templeman concluded that the court

must decide whether the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die, or whether the life of this child is still so imponderable that it would be wrong for her to be condemned to die.

In Re C (1989), however, the court allowed the hospital to treat the child so as to bring about its death based on the child’s best interests and well-being. Yet notwithstanding the inconsistencies apparent in this earlier case law, which will doubtless have led to confusion amongst medical professionals, the law has now been clarified by subsequent cases and guidelines, as illustrated above.

The way in which the law relating to infants has evolved to its present state illustrates the adaptable nature of the case law and guidelines. This system of legal rules has essentially allowed cases to be decided on the basis of what is morally correct. Although at one stage the law with regard to infants became incredibly complicated and inconsistent – especially in respect of the physical-mental distinction – it is now much simpler and has similar legal rules to those concerning adults. Furthermore, the legal rules relating to infants are in one respect much more flexible than those pertaining to adults, given that the relevant guidelines allow for consideration of the ‘quality of life’ that an infant has or will have.

3. The Current Legal Protection for Doctors – A Reappraisal

It is clear from the above discussion that there are legal guidelines and rules in place for medical professionals to use when dealing with issues of medical futility. McCall Smith (1997) suggests that the legal position at present is ‘just right’, ‘should be left undisturbed’ and that Parliament does not need to ‘legislate on the subject.’ He then goes on to say that the
courts have made it very clear that the patients have a ‘right to reject treatment…and make advanced decisions’, and that the doctors have a right to withhold treatment that is prolonging the life of a suffering patient. As has been highlighted above, though, some have criticised the existing legal and professional guidelines as being inadequate and in need of reform. In particular, a call was made for the area to be legislated on. However, is legislation the correct route to follow in cases of medical futility? Would it be right for life-and-death decisions to be made by following rigid legislation passed by Members of Parliament who do not encounter the reality of the decisions made on a day-to-day basis?

In answering this, it is important to firstly concede that the current professional and legal guidelines are by no means perfect. With regard to incompetent patients who have not left any advance decision (Mental Capacity Act 2005, ss24-26), the law states that the doctor must act in the patient’s ‘best interest’ and that the best interests are decided by a ‘reasonable body of medical opinion’ (Bolam v Friern Hospital Trust 1957). But as the term is an objective test that is easiest to apply when confined to medical interests (R (on the application of Burke) v General Medical Council 2005), it leaves little scope for any consideration of the patient’s own ethical viewpoints. It is therefore rather narrow and could be improved by taking into account other viewpoints, such as those of the patient’s family.

This point also leads on to the very contentious ethical issue of whether a person’s life has sanctity, or whether it merely has a price. In other words, should somebody be kept alive in a state of PVS (or similar) when it could cost the lives of others, not only in the financial sense of resources spent on that patient but also in terms of valuable hospital resources and medical practitioners’ time? These scarce resources may be ‘utilised upon people with a greater capacity to benefit from them’ (Kennedy and Grub 2000). The issues of cost and resources have been raised in numerous cases, including Bland, where Lord Mustill stated that ‘the large resources of skills, labour and money…may be fruitfully employed in improving the conditions of other patients’, before adding that this ‘cost-benefit analysis…must be for Parliament alone’ to decide, and until it is, it is the court’s role to ‘struggle on with the existing law, imperfect as it is’. However, is it just for Parliament to carry out a generic cost-benefit analysis on human lives? I believe not; rather, such an analysis is best carried out on an individual patient basis. Even then, it must be determined when medicine has become futile in order to prevent extended and prolonged suffering, both to the patient and their families. Unfortunately, this is an extremely difficult determination to make. But surely such
individual determinations must be preferred to the generic cost-benefit determinations that would take place if this matter were left in the hands of the legislature?

A majority of decisions as to whether treatment should be withdrawn are made in hospitals in emergency situations. In fact, it is estimated that thirty per cent of patients die due to a withdrawal of treatment that was deemed to be prolonging the process of dying (R (on the application of Burke) v General Medical Council 2005). If every case on the withdrawal of treatment had to go to court, hospitals would be making ten applications each day (R (on the application of Burke) v General Medical Council 2005). These figures illustrate the life-and-death decisions that doctors are making on a daily basis and that the majority do not have to get authority from the court. The authority that the doctor uses comes not from legislation but from the guidelines set out by their peers who may have been put in similar situations.

If Parliament did legislate on this matter, approval by the courts may not actually be necessary. In one respect, this could be beneficial for two reasons, as acknowledged by Samuels (2005; see also Lewis 2007). Firstly, cases that have to go to court can often be distressing for the patient’s family. Secondly, ‘time and resources are used [during the court procedure] that could be better spent on patient care’. However, Parliament has previously tried to legislate on this matter in the form of the Medical Treatment (Prevention of Euthanasia) Bill (2000). Morris (2000) described this Bill as confusing, unhelpful and a failure in its aim to develop the law that would reassure vulnerable patients. Due to the complex nature of medical futility and the way that it has developed over the years, it would be extremely difficult for Parliament to legislate thereon. The legislation would have to be clear and unambiguous, leaving no room for misuse and also be able to cover all possible situations that may arise in the future. Yet due to the very nature of legislation, this is unlikely to happen, as demonstrated by the above Bill and the comments made by Morris. Moreover, with the developmental nature of medical futility, the law would have to be flexible in order to be able to accommodate any future advances – but flexibility is something that legislation lacks. Such a move may also pave the way for Parliament to legislate on euthanasia, although it has been made clear by a number of judges that euthanasia and medical futility are two separate issues (see Bland 1993, for example). Some academic commentators have contended, however, that the ‘distinction between lawful withdrawal and euthanasia’ is ‘wholly a matter of policy’, (see, for example, McGee 2005), and so it is no surprise that Parliament appears to be in no rush to legislate.
The judiciary has a clearer insight into the dilemmas faced by doctors and patients than the elected representatives (Morris 2001), allowing the law to be a lot more flexible. As seen with the Medical Treatment Bill, legislation may even be more confusing than the present law, and if patients such as Mr Burke get the correct and clear advice, they will at least understand that the law is clear in protecting both patients and doctors (per Lord Phillips in R (on the application of Burke) v General Medical Council 2004) Also, since the case of Burke, the General Medical Council guidelines are entrenched in the common law as being lawful and they therefore provide adequate protection. The fact that some decisions in the cases appear to stretch the law in order for the correct decision to be made – or at least what the judges believe to be morally correct – illustrates the adaptability the current guidelines available to doctors. Thus, although some of the judgments in the cases may ‘appear irrational’ and illustrate the ‘distortion of the legal system’ (Airedale NHS Trust v Bland, 1993 per Browne-Wilkinson L.J.), this is necessary because it allows for the much-needed manoeuvrability in this area. This is because the law ‘is much more certain now than ten years ago’ (Mason and McCall Smith 2006), and it allows for each case to be decided on its own merits, instead of having to be uniformly applied to legislation.

4. Conclusion
Medical futility is an area that many people probably believe will never affect them. Yet there is no way of predicting whether it will affect us, or our loved ones, in the future. After all, Anthony Bland was an ordinary seventeen year old who only went to a football match; and the patients in Re D and Re H were merely going about their normal daily lives when they were unexpectedly involved in road traffic accidents. The question we need to ask ourselves is: who would we like to decide our fates if we were unfortunate enough to find ourselves in that situation? By medical professionals bound by rigid and stringent legislation or by medical professionals governed by adaptable guidelines, combined with the court’s oversight where possible? This paper has sought to demonstrate that the latter is much more adequate in dealing with the ever-changing area of medical futility. They not only give medical practitioners adequate legal guidance and protection, but also enable each case to be evaluated on its individual merits.
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