A critical appraisal of GMC Guidelines on withholding and withdrawing medical treatment in light of the recent challenge by Leslie Burke.

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The practice of medicine has entered an era where technological advances are quantitatively prolonging life, however the quality is not always preserved with it, and increasingly members of the public such as Leslie Burke are legally challenging doctors. The guidelines produced by the General Medical Council (GMC) provided a long awaited legal and ethical framework for the justifiable withholding and withdrawing of treatments that were no longer desired by the patient, clinically indicated or provided any comfort. This essay delineates the vast scope of case law, human rights, advanced directives, autonomy, beneficence, non-maleficence and justice incorporated in the guidelines and identifies their marked deficiency in addressing certain theological and social issues. [1] The ability to infinitely prolong life by administering treatments such as mechanical ventilation, artificial nutrition and hydration, and renal dialysis may be hailed as a miracle of modern medicine however such an extension has occluded the recognition of a natural end of life. It is imperative that when the treatment process reaches the stage whereby certain interventions and therapies are considered to be ‘futile’ or burdensome the introduction or continued use of them is reviewed. A recent study indicated that over 90% of deaths reported in the Intensive Care Unit (ICU) occur after the withdrawal of life support. [1]
reducing life support before death is commonplace in ICUs, the decision and variety of approach in doing so represents a colossal challenge to the practice of modern medicine in an increasingly litigious society. The fundamental entitlement to the best standard of care afforded to patients treated in the NHS should also be applied as that treatment is omitted or discontinued. Such clinical governance can only be delivered when a doctor demonstrates professional competence, good relationships with colleagues and observes the codes of medical ethics.

Prior to the GMC publication, withholding and withdrawing treatment decisions remained one of medicine’s ill-defined, grey areas. Doctors widely reported the need to develop realistic, ethical guidelines to ensure the primacy of the patient’s best interests, protect the integrity of the doctor-patient relationship and fortify the duties of a doctor [2]. In 1993, the case of Anthony Bland brought to the fore the key issues of withholding and withdrawing treatment from patients who lacked capacity, such as those in a Persistent Vegetative State (PVS). Formal identification of the doctor as the autonomous adult responsible for making the decision in the patient’s best interests in such cases left doctors feeling uncomfortable at the lack of guidance for doing so [3]. The much scrutinised guidance on withholding and withdrawing treatment produced by the BMA, in 1999, contained several inadequacies and therefore was superseded by the publication of the GMC guidelines in August 2002. These guidelines provided a well delineated legal and ethical framework to guide end of life treatment decisions and won the approval of many doctors.

This essay will examine how the legal, ethical, theological and social principles are reflected in the guidelines and discuss the special issues regarding children, artificial nutrition and hydration, respiratory assistance and emergency medicine for which the ethical principles and clinical applications are more complex. Let’s care for those we treat!
The case of Leslie Burke, the first public challenge of the GMC guidelines, highlighted three principal legal aspects of withholding and withdrawing treatment; case law, basic human rights and the importance of advanced directives. Public fears that allowing patients to die constitutes euthanasia via the back door [4] are displaced by citing legal opinion within the guidelines. The guidelines clearly state that withholding and withdrawing is an omission not an act and that for a doctor to bring about death by primary intention is unlawful. In those cases whereby court proceedings are instigated the GMC guidelines will be especially useful in providing a benchmark against which a judge can attest a doctor’s compliance [5].

Whilst the legal stance on withholding and withdrawing treatment is ever changing on a case-to-case basis, it is widely accepted that hard cases make bad laws! The GMC guidelines adequately outline the clinical indications such incapacity, PVS and futility, where it is legally justifiable to withhold and withdraw. Doctors feared that the application of the UK Human Rights Act 1998 (see Appendix A) [6], incorporating the European Convention on Rights and Freedoms, to medical practice would lower the threshold for human rights litigation and increase the profile of the individual case in the public scrutiny of medical practice [7]. These fears were borne into practice by Leslie Burke! Reflecting these rights in the published framework for decision making imposes a duty on doctors to consider their actions in relation to the multitude of interpretations and implications of the three relevant articles. Article two, the legal right to life [8], creates a paradox for withholding and withdrawing treatment when considered in conjunction with non-maleficence; should a doctor act to save life at all costs yet if in doing so may actually prolong suffering? The GMC’s declares that a doctor will protect the life and further health of a patient but has no obligation to provide treatment where deemed futile or burdensome. Article three, prohibition of inhumane or degrading treatment [8], is also addressed by these declarations and on the basis of acting in the patient’s best interests. The GMC upholds article 8, respect
for private and family life \[8\], by reminding doctors to maintain a patient's dignity and be considerate towards the sensitive and emotional nature of the dying process. Burke used these three articles to challenge the GMC on the basis that he had the right to live and receive care rather than deny it, and that when he did die it should be in a dignified manner.

Another human right indicated in the guidelines is that of the patient's right to refuse both current and future treatments. The optimal declaration of such a refusal is in the form of an advanced directive. Advanced directives have proven to be a useful addition to end of life care plans as they provide assistance to both doctors and family members, reduce psychological stress on the care provider and improve provider-patient-family communication \[9\]. In accordance with the GMC guidelines, directives set out by individuals whilst fully competent and informed are legally binding. In contrast, recent evidence shows that the vast majority of patients would want their decision overridden if it varied greatly from that of the doctor and their family \[10\]. Therefore I believe a certain degree of flexibility should be afforded to allow a nominated decision maker to use their up to date judgement of the situation to reach the final decision in accordance with perceived patient wishes. However the legal debacle of advanced directives is far from solved by the guidelines. The new Mental Capacity Act (see Appendix B) \[11\], which the government is introducing, will create much controversy by making doctors liable if they do not adhere to advanced directives. Not only does this undermine the integrity of the medical profession but it will create further family conflict and will require the GMC to respond and update their framework when this law comes into full force this October.

The legal recognition of autonomy afforded to individuals who produce advanced directives reflects one of the four key ethical considerations enshrined in the GMC guidelines. The guidelines provide an extensive ethical framework outlining the key issues regarding autonomy, beneficence, non-maleficence and justice and their clinical applications.
In recent years ethical practice has rarely been governed by the paternalistic role of the doctor [12] due to a profound shift in societal consensus that promotes enhanced recognition and mutual respect of autonomy between patient and doctor. It is therefore acceptable that the GMC guidelines have focused much of their ethical framework around this principle and its applicable clinical scenarios. For a doctor to respect and adhere to a patient’s wishes they must be satisfied that the patient’s decision meets the four pre-requisites of autonomy; competence, disclosure, voluntary and understanding [9]. The guidelines clearly state that it is the role of a competent individual, be it patient (paragraph 13) or doctor (paragraphs 14, 15, 54 and 55), to follow the expected assessment criteria encompassing potential risks, benefits, burdens and intolerability when considering administering new or continued treatment. Regardless of a patient’s current state of capacity if they had previously written or verbally disclosed their wish to refuse certain treatments the guidelines indicate that a doctor is legally bound to adhere to them. Formal disclosure of wishes to withhold and withdraw treatment is best represented in living wills however in many instances these are either not available, inaccurate or non-existent [2]. Whilst the guidelines fail to recognise the possibility of coercion they aptly address the duty of a doctor to ensure their clinical knowledge is up to date and therefore the patient is well informed when making a decision. The senior clinician gains a more paternalistic role in decision making only in situations where an individual has lost consciousness or become incompetent and in both instances the patient’s wishes are unknown and there are no previously agreed advanced directives. In these cases the guidelines emphasise that the doctor will assimilate the best available clinical knowledge and liaise with those close to the patient in effort to act in the patient’s best interests.

The interlinked principles of beneficence and non-maleficence have been the forerunning principles of medical ethics since the days of Hippocrates. The complex and time-consuming process of deciding to
withhold or withdraw should focus upon the patient's preferences and best interests, as fortified in the GMC guidelines. Access to a second opinion, other members of the healthcare team and appropriate length of contact time with relatives, will provide a beneficial forum for the patient to discuss the perceived benefits, risks and burdens of treatment in effort to reach a satisfying decision. Burke argued that subjective assessment quality of life would take precedence in those instances where a doctor has the absolute decision to withhold and withdraw treatment. However, the guidelines suggest that the decision will be based upon determining a treatment as burdensome or intolerable, a less crude subjective measure than the impossible determination of another person's quality of life. The GMC guidelines aim to ensure minimal distress to the patient by encouraging comprehensive analysis of whether administering or omitting treatment causes the least harm. This vital backing of the principle of non-maleficence is further endorsed by assuring patients that their basic care and support will continue once treatment has been withdrawn or withheld.

Provision of healthcare in the NHS was morally founded on the principle of justice; to provide equal access on a basis of equal need. Resource management is a vital component of clinical practice in a budget-strained health service. The GMC accredits the allocation of treatment to the discretion of the managerial doctor and decisions must reflect appropriate quantitative examination of clinical evidence regarding the potential risk/benefit ratio\[13\]. The initial court ruling in Burke’s challenge "may be interpreted as giving patients the right to demand certain treatments, contrary to the judgement of their medical team, that would lead to patients obtaining access to treatment that is not appropriate for them, and to unfairly skewed use of resources" [14]. Had this ruling not been overturned the financial strain of providing intensive care beds, costing £1500 a day to run [14], would greatly exacerbate the NHS’s current debt!
An aspect of medical ethics that is poorly reflected in the GMC guidelines is that of rule ethics; the moral codes dictated by a theological perspective [15]. Religious values often influence decision making by both doctors and patients, particularly at the end of life, and respecting these values is pivotal to providing a holistic approach to medical care. Whilst there are differences both within and between different religious beliefs the vast majority accept that there are circumstances in which withholding and withdrawing treatment is lawful and morally acceptable. The extensive nature of the guidelines, and their acknowledgement of making best use of resources, indicates that there are few absolutes in withholding and withdrawing treatment and therefore is an ideal hybrid of deontological and utilitarian ideas.

A common humanitarian respect for life is endorsed in paragraph 9 of the guidelines however to have respect for life one has to regard it of value. This worth or sanctity of life is determined by the belief that we are created in God’s image and therefore each life carries intrinsic heavenly worth [16]. Some may view withholding and withdrawing treatment as morally wrong as omission leads to death yet others may argue that life in heaven is the natural residing place of the soul and that to act in prolonging life on earth would be unjust. The guidelines merely recognise that this principle is not well respected from a legal perspective and provides no further explanation of its relevance to medical practice. Despite such shortcomings there is wide acceptance of the GMC guidelines across religious groups [17] and Christian medical groups such as the Christian Medical Fellowship (CMF) [18]. As a member of the CMF I believe that it is important to recognise the religious issues in medical practice yet I am aware that society today is becoming increasingly secular and Christian morals and attitudes are not applicable to all. However it remains both a Christian teaching and a societal preference not to judge others. The GMC deems it for doctors to act professionally in not allowing factors such as age, disability or lifestyle or their own views to prejudice the choice of treatment. Paragraph 26 of the guidelines
adequately endorses the importance of non-discrimination and practicing in both a religious and culturally sensitive manner.

In a multi-cultural society provision of equitable care regardless of race, colour, beliefs or sexuality has never been of such paramount importance. Language barriers and diverse viewpoints on the dying process [16], [19] are two of the main social problems apparent in the practice of multicultural medicine. One only has to look to countries such as Switzerland to realise that cultural opinion of dying and our ability to exert control over its time and place is changing. As the decision making process is both crucial and emotional it is essential that the doctor maintains social communicational skills when liaising with the patient, those close to them and allied professionals. Unrealistic requests for treatment are often made as a result of misunderstanding information [2] and even where doctors have relayed the relevant information efficiently conflict may result such as in parental/spouse feud of the Terri Schiavo case. The guidelines endorse provision of adequate time for a doctor led, multidisciplinary family conference that openly assesses the benefits, burdens and risks of treatments as a proven solution to minimise the incidence of both scenarios [20]. In the event that such a mediation strategy does not achieve a societal consensus the guidelines also indicate the relevant legal protocols the doctor should follow.

Whilst the guidelines indicate the necessity to maintain an open, transparent and justifiable decision making process, media coverage of court proceedings in the controversial cases of Anthony Bland, Leslie Burke and Charlotte Wyatt, generated a highly emotive response from society, not all of which has been favourable to the health service. On the one hand individuals may view open discussion of such issues as a necessity to create a better informed society and provides increased recognition of the agonising process for doctors, patients and family alike. However it creates unjust public scrutiny of medical practice and vilifies doctors for wishing to withhold or withdraw futile treatments, a
practice which the guidelines maintain is managerially, legally and ethically justifiable.

The treatment of children, especially neonates and the terminally ill, is a highly emotive aspect of medical practice. The physiological resilience of an infant, such as Charlotte Wyatt, often astounds even the medical profession and creates conflict between doctors and parents [21]. Therefore it is extremely difficult to place legal and ethical absolutes into a code of practice for paediatrics. It is inevitable that in the majority of cases patient confidentiality is overridden and consent is mainly from those with parental responsibility. Much of the GMC guidelines regarding paediatric treatment decisions address previously discussed factors of autonomy, beneficence and non-maleficence. A particular strength of the guidelines is their upholding autonomy by encouraging participation of a child in the treatment decision process where, at the discretion of the doctor, the child is fully informed and competent to do so.

Provision of artificial nutrition and hydration (ANH) to patients, especially those for whom death is not imminent, is enshrouded in ethical complications. The court ruling in the Bland case declared that artificial nutrition and hydration were indeed medical treatments and could reasonably be withdrawn in the best interest of the patient [3]. Previous BMA guidance condoned withholding ANH from the critically ill [22], which caused uproar from those who believed it, gave physicians the licence to starve or dehydrate brain-damaged patients to death. The guidelines provide welcomed clarity in that withdrawal of ANH in patients, such as Bland, is only permitted where the patient is so critically ill and prognosis is extremely poor. In Burke's case however he will remain competent, though not able to communicate, during the final stages of his illness. Despite the fact the GMC guidelines maintain that in these circumstances treatment will be provided, Burke reasoned that he would be aware of the pain and suffering during prolonged starvation and
dehydration and challenged the guidelines on the basis that it would not only contravene beneficence and non-maleficence but directly act against article three of the HRA.

Mechanical ventilation and cardiopulmonary resuscitation (CPR) are the two main forms of respiratory assistance common in ICU. Prior to the publication of the GMC guidelines the case of Miss B, a quadriplegic woman, won the right to refuse the mechanical ventilation maintaining her life came to public attention\textsuperscript{23}. Her lengthy court battle could have been a lot shorter had there been official guidelines in place \textsuperscript{13}. The guidelines give special consideration to the application of cardiopulmonary resuscitation (CPR), which some view to be a heroic measure. This method of restarting heart and lungs can lead to complications and prolong the pain and suffering of the dying process. The GMC provides vital backing for and encouragement of well-communicated Do Not Attempt Resuscitation (DNAR) orders serves to greatly benefit the patient.

**Emergency medical care** requires rapid decision-making and often results in the initiation of various interventions and therapies prior to a definitive diagnosis \textsuperscript{13}. In treating both children and adults in the accident and emergency situations formal recognition of a doctor's legal and ethical allowance to override autonomy is clearly identified in the guidelines.

In conclusion the GMC guidelines have inevitably improved medical practice by clearly establishing an inclusive, standardised framework in which doctors of all levels can use as useful reference point when faced with the tough ‘life or death’ decisions so frequently made in medicine. A particular strength of the guidelines is their formal consideration of controversial cases involving children, administering ANH and resuscitation. It is undoubtedly difficult to include all relevant legal,
ethical, theological and social considerations in withholding and withdrawing treatment and the GMC recognises some of its inherent shortcomings by referencing more extensive literature. I envisage that with future developments in medical treatment, case based law and the introduction of the Mental Capacity Act the guidelines will suitably evolve.

Rebecca undertook the 2nd Year Student Selected Component “Murder or Mercy: the Euthanasia Debate” co-ordinated by Dr David Bell and Dr Vivienne Crawford, School of Medicine and Dentistry, in autumn 2006 and was the winner of the Forum’s 2007 Essay Competition.

References

[18] Saunders P. GMC Guidance: A big improvement on the first draft. Triple Helix 2002; Autumn: 3
[20] Breen CM, Abernethy AP, Abbott KH and Tulsky JA. Conflict associated with decisions to limit life-sustaining treatment in