ETHICS

Drafting guidelines for the withholding or withdrawing of life sustaining treatment in critically ill children and neonates

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In 1997, the Royal College of Paediatrics and Child Health (RCPCH) published a framework for practice on the withholding or withdrawing of life sustaining treatment. Based on sound ethical and legal principles, the purpose of the document was to offer guidance for those faced with difficult treatment decisions that could not be resolved by appeal to scientific fact alone.[1]

Unsurprisingly, the RCPCH document has attracted both acclaim and some criticism for its general objectives and specific conclusions.[2 3] Any attempt to provide such guidance might be interpreted as applying unnecessary constraints to clinical practice. Furthermore, such documents can be criticised as being too general to be useful, stigmatising to some individuals or groups, and striking the wrong balance between law and morality. Although these criticisms have some validity, questions such as those dealt with by the RCPCH document and others cannot simply be left to the moral values of individual clinicians or their (possibly mistaken) interpretation of the law.[4] Some considered advice—informed by appropriate collective multidisciplinary deliberation—is imperative. It seems likely, therefore, that other groups will wish to provide guidance or advice on ethico-legal matters. Here, we examine some of the problems they may face by considering the kind of guidance that is required, the appropriateness of standards set, the role of the law, and the relation between guidelines and the law.

Determining the kind of guidance that is required

Many professionals want reasonably specific but not prescriptive guidance. Ethico-legal codes of professional practice, although emphasising communication skills, ethical behaviour, treating patients with dignity, and outlining legal boundaries of acceptable practice,[5 6] may neither provide sufficiently specific guidance nor resolve some unanswered ambiguities. The latter include the criteria for determining a patient's best interests, as well as indications of appropriate procedures to follow in the case of disagreement between professionals and patients.

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It is tempting to draw parallels between ethico-legal and clinical guidelines because the latter increasingly regulate clinical practice.[7] Both are intended to enhance good practice and to improve quality of care.[7] Although stringent criteria exist for testing the provenance and validity of clinical guidelines,[8] there remain reservations concerning their construction, implementation, and universality.[9] One criticism of clinical guidelines is that they might achieve reproducibility of outcome at the expense of flexibility and rigidity in their application.

Ethico-legal guidelines can attempt to avoid these criticisms by involving potential decision makers in their development, and having clearly defined mechanisms for dealing with dissent in both construction and implementation. Equally, the rigidity sometimes associated with clinical guidelines need not apply to ethico-legal guidelines. While defining moral and legal boundaries of acceptable practice, they positively invite latitude of interpretation and applicability. For example, in the management of withdrawal of ventilatory support from infants in respiratory failure some clinicians might disagree with the practice of continuing muscle relaxant treatment although still accepting the proposition that ventilation should be withdrawn because it is too burdensome.[1]

Because contemporary health care is delivered by multidisciplinary teams drawn from as diverse cultural, ethnic, and social backgrounds as the patients they serve, there is a need for ethico-legal guidelines to be multidisciplinary. Their drafting should accurately acknowledge and reflect different ethical perspectives of health care professionals, ethicists, lawyers, patients, families, and other appropriate members of the public. The working group that developed the RCPCH framework had representatives from all of these groups. The effective formulation of ethico-legal guidelines requires collaboration, communication, and mutual respect. Their successful implementation requires a clear understanding of individual professional roles and responsibilities and a sense of common ownership if tensions between team members and a sensation of under-representativeness are to be avoided.[10]

The construction of both clinical and ethico-legal guidelines is time consuming,

labour intensive, and expensive. As research better defines mortality and morbidity, and case law alters, the updating of both types of guidelines will be necessary. Therefore, mechanisms for re-evaluation and audit need to be built into both.[7 8]

Good ethico-legal guidelines should be multidisciplinary, open ended, and non-prescriptive but directed at an important issue. They should not advocate behaviour that is professionally unacceptable or potentially illegal. For the most part, the RCPCH framework meets these criteria.

The appropriateness of standards set by guidelines

Most ethico-legal guidelines acknowledge the difficulty of achieving a consensus for acceptable professional behaviour.[1] However, they do appeal to widely accepted moral principles which underpin the law. Thus, it is commonly agreed that clinicians must act in their patients' best interests.[1 4 5 6 8] This entails the following: (1) providing treatment that preserves life and confers net benefit over harm; (2) respecting the patient's right of self determination (autonomy); and (3) doing both (1) and (2) in a fair and just way. Disagreements may occur as to how these sometimes conflicting obligations might be fulfilled. For example, respecting the autonomy of a young person who refuses life sustaining treatment might dramatically conflict with the duty to protect their life and health to an acceptable standard.

In purely clinical terms, best interests are defined by medical outcomes based on scientific evidence or the considered opinion of a responsible body of medical practice. There is no moral obligation to offer treatment that cannot preserve life or whose burdens outweigh possible benefits. In certain clinical states (for example, brain death, severe brain damage, or multiple organ failure) treatment is clinically futile, burdensome, and therefore unethical. Thus, some defined clinical circumstances might preclude further life sustaining treatment, as the categories of the RCPCH document suggest.[1] There is an increasing openness about such practices in paediatrics and neonatology (and throughout medicine), no doubt stimulated by confidence about their ethical and legal appropriateness and the public's need for candour.

At the same time, inconsistencies in practice concerning withholding or withdrawing life sustaining treatment remain. These include differences in practice between adults and children. For example, some children suffering from the same conditions might receive life sustaining treatment whereas others do not. Moreover, children might receive more burdensome treatment than adults in similar circumstances because their clinicians feel that it is in their best interests.[11] There might also be a greater tendency to withdraw or withhold treatment in severely malformed babies than their normal looking counterparts.[12] When clinical facts neither determine outcome nor what treatment should be used, a broader consideration of best interests (including parental perspectives) is necessary.

Maximal respect for the right of self determination takes full account of the wishes, preferences, beliefs, and values of parents and those of the child according to their understanding, competence, and experience. Many codes of practice emphasise the latter.[1 13–15] For example, the Children Act provides a list of factors that should be considered in making decisions about a child's welfare. However, neonates and young children pose problems because of their vulnerability and the difficulty in ascertaining their wishes.

In these circumstances, the views of parents will carry great weight. Some parents might demand treatment that clinicians believe to be medically futile, whereas others may wish to discontinue treatment that professionals regard as being in a child's best interests. Resolving such disputes is not easy. Arguably, a reasonable child or parent would not want treatment that is medically futile or that prolongs a life in which self directed activity is impossible and/or in which pain and suffering are so great as to undermine any interest in remaining alive.[1 4 16] Similarly, a reasonable parent would not want to discontinue treatment that provides a good chance for the child of long term benefit over short term harm.

Even if clinical conditions for non-treatment decisions are carefully defined, what constitutes best interests involves normative values as well as scientific fact and, hence, may be controversial. For example, the "unbearable" situation in the RCPCH guidelines[1] invites consideration of withholding or withdrawing treatment when the "child and/or family feel that further treatment is more than can be borne". There can be little dispute if such a collective decision conforms to appropriate clinical criteria and there is agreement between the child of sufficient understanding and parents. However, it would be widely disputed that the wishes of parents should always override those of their children or that they would necessarily be the most appropriate final arbiters in these difficult circumstances. Clearly, different situations will lead to varying interpretations and potential disagreement.

Ethico-legal guidelines usually contain some guidance as to how such disputes are to be resolved, including those between parents or carers and professionals. Importance is placed on professional judgement, especially if it favours sustaining life. Although the burden of treatment upon families and society has be to acknowledged, it does not determine the action that should be taken. Moreover, some account should also be taken of the parental sense of impotence and despair, which may accompany such disputes, even at the expense of some clinical autonomy. Guidelines usually suggest that such disputes should be settled by discussion, use of second opinions, independent arbitration, and perhaps ethical review rather than court procedures.[17] Therefore, ethico-legal guidelines might advocate changes of goals of treatment as long as they are in the child's best interests, as determined by relevant

clinical and ethical standards. For example, a change in treatment plan from alleviation or cure to palliation[18] must be subject to valid consent, and the treatment offered should conform to a practice accepted as proper by a responsible body of medical opinion.[19]

Guidelines that include specific recommendations about treatments or those to whom they should be offered will always be controversial. For example, some regard artificial feeding as medical treatment that can be withheld or withdrawn, whereas others believe it is as essential component of care that ethically cannot be withdrawn.[10 16 20] In these circumstances, and others where disputes cannot be resolved, judicial review is necessary to determine the lawfulness or otherwise of the proposed course of action.

Role of the law

All recommendations made in guidelines must be lawful, notwithstanding the ambivalence that some professionals have about the role of the law in intensely personal decision making. Professionals require reassurance that their actions are lawful but may lack understanding as to what the law is or how it operates. Arguably the role of the law—be it criminal, statute, or case law—is to articulate minimum standards that professionals must achieve in the care of patients, or must apply to assess the competence of children to consent to medical treatment.[19 21] Of these, case law (which is formulated by the application of statute, precedents, and analogy in individual cases) is the most dynamic and flexible, at the cost of sometimes being piecemeal and over specific.

A number of principles can be articulated from case law about the legality of withholding or withdrawing treatment. Professionals should understand that these reflect decisions that a court would be likely to reach if similar cases were brought before it rather than their actual ruling on the case in question.

Any practice or treatment given with the intention to cause death—for example, euthanasia—is explicitly unlawful. In contrast, non-treatment decisions might be in a child's best interests, and therefore not unlawful, if they conform to acceptable clinical standards, are in accordance with the Bolam principle,[19] and therefore deemed to be in the child's best interests.[22 23] This is not to say that all important matters about the non-provision of life sustaining treatment have been legally resolved. For example, there is a lack of clarity about the role of artificial feeding and hydration in children who are severely brain damaged, but are neither dying[22] nor in a persistent vegetative state.[20] For this reason, some aspects of the RCPCH framework must be used with care, especially those pertaining to treatment classified as being "unbearable".

More specific clarification by statute law is unlikely to be forthcoming. This is because of the sensitivity of the issues involved and the difficulty in drafting legislation that is neither too specific and exclusive, nor too non-specific and inclusive. Yet, common law grants professionals and parents a great amount of leeway in making decisions in these difficult circumstances, while stipulating circumstances when it is necessary to involve it.[20] A strength of the RCPCH framework is that it recognises and publicises this fact.

Guidelines and the law

In that guidelines represent the views of a body of reasonable and competent professional opinion they satisfy the Bolam test.[19] Written guidelines cannot be cross examined and, hence, courts cannot decide what is reasonable and proper care simply by referring to them.[19] However, courts have called for the development of guidelines in ethically contentious areas—for example, the sterilisation of incompetent adults—or suggested that guidelines made by national bodies (such as the royal colleges) be carefully followed even in cases that come before them.[20] They have also considered recommendations from guidelines in deciding specific issues—for example, non-resuscitation in Re:R[24] and the RCPCH guidelines in Re:C (a case of withholding ventilator treatment in a patient with spinal muscular atrophy).[25] Courts will, by analogy with clinical guidelines, increasingly wish to examine the authority, provenance, and validity of guidelines closely.[26] There is general acceptance that guidelines do provide professionals with reference points and a series of procedures or consultations that should be gone through in individual cases. As such, they can be checked and they are likely to achieve increasing legal importance.

Conclusion

The construction of ethico-legal guidelines requires a careful balance between prescription and "laissez faire", over specificity and looseness. Lessons should be learnt from the process of drafting of clinical guidelines, messages from research, and input from practice, audit, and the law. The strengths and weaknesses of the RCPCH framework reflect the importance of such learning and provide important lessons for similar work in the future.

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