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Ethics briefings

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Human Rights Act

This month, October, the Human Rights Act 1998 comes into force, bringing the rights and freedoms enshrined in the European Convention on Human Rights[1] into domestic law. The act applies to the whole of the United Kingdom, although to some extent the convention has already been incorporated into the law in Scotland, Wales and Northern Ireland. Under 1998 legislation,[2] neither the Scottish Parliament, nor the Welsh and Northern Ireland Assemblies, may act in contravention of the European Convention on Human Rights. It has been possible for some time, therefore, for the exercise of a function by one of those bodies to be challenged as not being within its powers, by virtue of that function being incompatible with the convention rights.

Under the Human Rights Act, all action by "public authorities" must be compatible with the convention rights. National Health Service (NHS) trusts and health authorities are public authorities in this context and it is possible that individual NHS doctors will also fall within that definition. Whilst hospital doctors may appear to be more affected than general practitioners, who are independent contractors, other doctors may also be caught within the terms of the act. Acting in accordance with the Human Rights Act is also a matter of good practice. All doctors, therefore, need to be aware of their obligations and would be well advised to take account of the new legislation in making treatment decisions.

One of the primary changes that will occur, in practical terms, is that, in addition to considering whether a proposed action would be lawful, it will be necessary also to consider whether someone's human rights are involved and, if so, whether it would be legitimate to interfere with them.

It is envisaged that the introduction of the convention rights into domestic law will lead to an increasing number of challenges to medical decisions. The articles most likely to be used in such cases include: article 2—right to life; article 3—prohibition of torture and of inhuman or degrading treatment; article 5—right to liberty and security; article 6—right to a fair trial; article 8—right to respect for private and family life; article 9—right to freedom of thought, conscience and religion, and article 14—prohibition of discrimination.

The type of decisions that may, potentially, be open to challenge using the Human Rights Act include the cessation of life-prolonging treatment, rationing decisions, particularly where these are made on the basis of age (as is often the case with the provision of fertility treatment) and do-not-resuscitate (DNR) orders. The courts began to bring discussion of convention rights into their deliberations in the months leading up to October, considering specifically whether, and if so how, an individual's human rights were involved in the cases being considered. An example of this is in the case of "I"[3] which was considered in July 2000. "I" was 19 months old and suffered from a severe, chronic, irreversible and worsening lung disease. A declaration was sought, by the NHS trust, that "I" could be treated as advised by his paediatrician which could include non-resuscitation in the event of a respiratory and/or cardiac failure, and palliative care to ease "I"'s suffering and to permit his life to end peacefully and with dignity. "I"'s parents opposed the application. The application was granted and, referring specifically to the convention rights, it was held that there was no infringement of article 2 (right to life) in making the declaration as the decision was in "I"'s best interests. Furthermore, under article 3, which requires that a person not be subjected to inhuman or degrading treatment, it was held that a person had a right to die with dignity.

In many cases, as with that described above, rights may conflict and arguments can be made both in support of and against a particular course of action using convention rights. The situation is further complicated by the fact that not all articles have the same weight. Some, such as article 3, are absolute rights allowing no derogation by the state. It is therefore helpful that the court has made clear that this does not entail prolongation of life in all circumstances. Other articles, such as article 8, are qualified rights. A government task force has produced general guidance on the Human Rights Act[4] and many individual trusts are also taking legal advice. Professional organisations such as the British Medical Association are reviewing their existing guidance to ensure compatibility with the Human Rights Act and to include reference to convention rights.

The level of impact the Human Rights Act will have on medical practice is impossible to predict. The process by which decisions are currently made, involving a balancing of benefits and burdens and of conflicting duties and rights, will take on greater importance because the concept of proportionality is one of the key principles underpinning the act. What is now good practice will, in some areas, become obligatory and decisions are likely to be open to far greater scrutiny. Whilst the outcomes of many cases will be the same, the way in which they are argued and decided will be different. There will be a steep learning curve and, until a body of case law develops, a lot of uncertainty but one thing is clear: doctors simply cannot afford to ignore the new legislation.

Confidentiality

The General Medical Council (GMC) has published new guidelines on confidentiality[5] to replace those issued in October 1995. The new guidelines have been the subject of intense debate and controversy during their many months' gestation. The basic principles have not changed: all patients are entitled to expect that information about them will be kept confidential, to be asked about its disclosure or use, and that confidentiality

will be breached in only the most exceptional of circumstances. For the first time, however, the GMC has given detailed advice about the nature of consent required for disclosures of information. Consent must be "express" where patients may be personally affected by the disclosure, for example to their employer or insurance company. Where disclosure of information is unlikely to have personal consequences for patients, for example in epidemiology, public health or administration of the health service, the GMC advises that express consent should be sought wherever possible, but acknowledges that this is not always practicable. In such cases, patients should be informed of the nature and purpose of the disclosure, and given an option to refuse.

Another change is in relation to the publication of material. Where information about an individual is to be used in media to which the public has access, the new guidance says that express consent is *always* necessary whether or not the doctor believes the patient can be identified from the information. This does not apply to aggregated or statistical data, but is relevant for the publication of case histories or photographs.

With that exception, the GMC has held on to the general principle that anonymous information is not confidential, and in general may be used freely without consent although this issue cannot be considered as settled in UK law. There is an ongoing legal case between a commercial organisation wishing to buy anonymous health data from pharmacists, and the Department of Health, which advised that this is unlawful without consent.[6] The Court of Appeal ruled for the commercial company, but the Department of Health may seek to take the matter to the House of Lords. The GMC may, yet again, have to review its guidelines if the Appeal Court decision is overruled.

New research guidelines

In May 2000, the Griffiths Inquiry published its report into controversial research carried out at North Staffordshire Hospital.[7] The inquiry considered the use of two procedures involving babies and children: continuous negative extrathoracic pressure as a technique for respiratory support and the use of covert video surveillance to detect Munchausen syndrome by proxy in carers. Considering the research framework within which the procedures had been carried out, the inquiry concluded that "considerable clarification is now urgently required of the roles and accountabilities of the different bodies involved in research and its management—in short, a framework of research governance". A central concern of the inquiry was how valid consent could be obtained for the involvement in research or innovative treatment of vulnerable subjects, such as young seriously ill children, when parents were likely to be severely psychologically or emotionally stressed. The same point had been made earlier in the year by the Royal College of Paediatrics and Child Health which published in January 2000 specific guidance on *Safeguarding Informed Parental Involvement in Clinical Research involving Newborn Babies and Infants*. (The college subsequently also issued its revised general *Guidelines on the Ethical Conduct of Medical Research involving Children*.) In July 2000, the Department of Health announced that it would be establishing a group to look at some aspects of Griffith's recommendations, namely the need for guidance about the use of covert video surveillance in the care of children. The Royal College of Psychiatrists has also prepared new *Guidelines for Researchers and for Ethics Committees on Psychiatric Research Involving Human Participants* (in press).

May 2000 also saw publication of the interim report of the *Inquiry into the Management of Care of Children Receiving Complex Heart Surgery at the Bristol Royal Infirmary* which drew attention to the lack of clarity concerning the law on the removal, retention, use and disposal of human material. This echoed other complaints about the unauthorised retention of deceased children's tissue and organs for research at Liverpool's Alder Hey Hospital and elsewhere. The Royal College of Pathologists published *Guidelines for the Retention of Tissue and Organs at Post-mortem Examination* in March 2000, partly in the hope of pre-empting further criticism as well as to guide pathologists and researchers. The Medical Research Council has also drawn up new guidance on *Human Tissue and Biological Samples for use in Research* (in press).

Helsinki Declaration

The World Medical Association's (WMA) consultation is progressing on the Declaration of Helsinki, which provides international guidance on research on humans. The latest draft removes references to a distinction between "therapeutic" and "non-therapeutic" research and provides a glossary of terms to avoid ambiguity about what is intended by frequently used words such as "benefit" and "risk". A final revised text will be submitted for agreement at the WMA's October meeting in Edinburgh.

References

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