

Ethics briefings

Treatment decisions for children

In March 2004, the European Court of Human Rights (ECHR) awarded Carol Glass and her son David 10 000 Euros compensation after doctors treated David contrary to his mother's wishes, without a court order.¹ Although dismissed by UK courts, the ECHR held that David's article 8 right to privacy, and in particular his right to physical integrity, had been breached.

Born in 1986, David Glass is severely mentally and physically disabled, requiring 24 hour care. In July 1998 after surgery to alleviate an upper respiratory tract obstruction, David became critically ill and was put on a ventilator. Doctors thought he was dying. His condition improved briefly and he returned home only to be re-admitted a few days later when doctors discussed the option of morphine to alleviate his distress. His mother refused, believing it would compromise his chance of recovery. She also made clear that she wanted David resuscitated if his heart stopped. Although the doctor managing David's care noted the possible need for a court order in such cases of total disagreement, no order was sought. On 20 October 1998, diamorphine was administered to David and a DNAR (do not attempt resuscitation) notice placed on his medical notes. Relations between the Glass family and the doctors deteriorated rapidly, culminating in a fight in which two doctors were injured. Ms Glass applied unsuccessfully for a judicial review of the hospital's decisions and was refused permission to appeal. Subsequently, the General Medical Council (GMC) found the doctors innocent of serious professional misconduct and the Crown Prosecution Service declined to bring charges against them. Ms Glass then took her case to the European Court of Human Rights.

The Glass family argued that when the dispute arose, the hospital should have involved the courts to clarify whether, despite his mother's objections, the

treatment was in David's best interests and that doctors were wrong in believing the urgency of the case made that unnecessary. The ECHR rejected the hospital's argument of insufficient time to consult the court and held that there had been a breach of article 8. Good practice guidance^{2,3} already advises that in the event of continued disagreement between parents and doctors about whether treatment is in a child's best interests, a court declaration may be needed. This judgment made clear that failure to refer such cases to court is not only a breach of professional guidance but also potentially a breach of the Human Rights Act.

Mobile phone images and confidentiality

In February 2004, tension between technological innovation, clinical benefit, and confidentiality was highlighted in relation to the use of picture phones for diagnosing patients. The Medicines and Healthcare Regulatory Agency (MHRA) issued a warning that the use of telephone imaging systems not specifically intended for medical use could raise legal problems.⁴ The Medical Defence Union also issued guidance, reminding its members that any recording made for clinical purposes is part of the clinical record and subject to the same consent and confidentiality requirements as ordinary medical records.⁵

The MHRA alert followed media reports of doctors using digital cameras and picture phones to send x ray and other clinical images to specialists for interpretation. Although useful, the MHRA said that such technology was not subject to the rigorous tests necessary to license medical devices. Accordingly, "the consequent lack of verification of device performance means that it cannot be assured to be safe, suitable or effective. The use of a device in these circumstances exposes users and patients to unknown and therefore unacceptable risks".⁵ The warning coincided with the dismissal of a police officer for using a mobile phone to photograph bodies in a hospital mortuary.⁶

As the MHRA pointed out, however, provided the medicolegal implications are taken into account, the technology can give genuine benefits to patients and clinicians. Research suggests—for example, that photographic diagnosis could reduce dermatological referrals

by 25%, and therefore substantially reduce waiting times.⁷ Furthermore, a Welsh scheme using mobile phone technology appears to speed up the consultation process and reduce waiting times for orthopaedic patients.⁸ Nevertheless, the use of such technology in medicine must be governed by established ethical principles. Existing guidance from the GMC on making and using audio and visual recordings of patients emphasises the importance of informed patient consent for recordings and the obligation to ensure that patients' privacy and dignity are protected.⁹ It stresses that doctors should not use recordings for purposes outside the scope of the original consent and that appropriate arrangements should be made for safe storage and transmission.

Patient mobility and "health tourism"

The European Union (EU) expanded in May 2004 when ten central and European countries joined. These were Cyprus, the Czech Republic, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, the Slovak Republic, and Slovenia. The scale of the enlargement is unprecedented in EU history, involving a 34% increase in land mass, and an increase in population of 105 million.¹⁰

In March, a European parliament report had called on the commission to review patient mobility in the EU. It called for protection of national health systems so that the principles of solidarity and social cohesion would not be undermined by new demands. It also called for legal clarification of the rights of patients crossing borders to obtain treatment unavailable in their home country or if waiting lists at home were too long. The previous month, Peter Piot, executive director for UNAIDS, talking at an EU presidency conference, gave some indication of the scale of the problem. He called upon the European Commission to appoint a special commissioner to tackle the HIV/AIDS epidemic in Eastern Europe. According to Mr Piot, new cases in Eastern Europe and Central Asia had risen 50-fold. One and a half million people were living with HIV/AIDS in the region, and Estonia and Latvia, two of the accession states, were among the worst affected.

Concerns about the possible strain on public services following accession led

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all existing EU countries to impose “transitional” restrictions on members of the former communist countries, to limit their access to benefits and some public services. Ethically, accession raises questions of distributive justice and the extent to which states owe greater duties to citizens than to non-nationals. The willingness of taxpayers to contribute to systems of national risk pooling could come under stress if large numbers of non-contributors were perceived to have access to the benefits.

Solitary confinement: protection or punishment

In spring 2004 some UK prison doctors questioned their role in certifying prisoners “fit” for solitary confinement. New guidelines issued by the Prison Service in England and Wales in late 2003 drew the attention of prison doctors to their statutory obligations, under the Prison Act 1952, to certify that inmates are medically fit for “cellular confinement”.¹¹

In its human rights handbook,¹² the BMA had previously raised questions about medical involvement in such procedures. Longstanding BMA policy advises doctors against certifying prisoners as fit for punishment. In some jurisdictions, prolonged isolated confinement is a disciplinary measure and, when combined with other forms of sensory deprivation, can amount to torture. Certifying prisoners’ fitness to undergo isolation with this intention, would contravene the World Medical Association’s Declaration of Tokyo, which prohibits medical involvement in any kind of cruel, inhuman or degrading procedures.¹³ On the other hand, where inmates are placed in segregation units for their own benefit, either for medical treatment reasons or because they are at risk from other inmates, this is likely to be in their best interests.

Thus, the ethical acceptability of doctors’ involvement in the segregation of prisoners depends upon the nature and purpose of the segregation. All doctors are bound by professional codes but they are also by international standards of human rights which pertain even in war situations.

Dual loyalties

General concerns about the dual loyalties experienced by doctors working in detention centres have increasingly

preoccupied medical human rights groups.¹⁴ Media reports in 2002 and 2003, also drew specific attention to the role of doctors providing examination and treatment for prisoners held incommunicado for two years by American forces at camp Delta in Guantanamo Bay, in Cuba.^{15 16} Some British prisoners returned to the UK from Cuba in March 2004, and further questions may arise over whether medical advice had been sought about the psychological effects of detention and interrogation methods.

The choice to die at home

On 1 March 2004, the UK charity, Marie Curie Cancer Care, launched a major campaign “Supporting the choice to die at home” to promote terminally ill cancer patients’ right to choose where they die. Full details of the campaign can be found on the Marie Curie Cancer Care website.¹⁷ The charity currently provides care for 50% (15 000) of terminally ill cancer patients who die at home in the UK (Marie Curie Cancer Care press release: Health economist spells out cost of choice to die at home, 1 March 2004). At the same time as launching the campaign the charity publicised an economic study which they commissioned.¹⁸ The study found that fewer than 25% of terminal cancer patients die at home, despite 50–75% stating a preference that they would like to do so. Furthermore it was found that if funding were more readily available to support patients’ choice to die at home, this could “...free up twice that investment in hospital services. This could mean savings of up to £200 million a year”. (Marie Curie Cancer Care press release: Health economist spells out cost of choice to die at home, 1 March 2004).

The key principle underpinning the campaign—patient choice—could of course apply to all terminally ill patients, irrespective of diagnosis—for example, giving all patients the choice to die at home, in a hospice or in a local district general hospital. Often, however, patient choice is restricted due to limited resources or clinical factors. What the campaign and supporting study interestingly marries is the promotion of what many would consider to be ethically desirable—patient choice—with supporting economic research, which is arguably ethically desirable on more utilitarian grounds. Perhaps an

element of caution should, however, be exercised when utilising such an economic argument to ensure that the 25–50% of patients whose preference is *not* to die at home are not compelled to do so solely on the basis, either explicitly or implicitly, of economics.

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