Ethics briefings

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International debate about 'the right to health'

All international statements of human rights comprise a mixture of liberty rights (such as freedom of expression, freedom from unjustified arrest or detention) and positive claims to social support. In general, the latter have received far less attention than the former although this now seems set to change. The 1948 UN Universal Declaration of Human Rights included "the right to a standard of living adequate for health and wellbeing, including food ... medical care and necessary social services" (article 25). In the ensuing fifty years, however, this human right rarely seemed to be centre-stage even though it was reflected in the constitution of the World Health Organization (itself a specialised agency of the UN) which famously defined health as "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity".

One of the reasons for the apparent dismissal of the notion of a right to health in much previous ethical debate has been that while such a right is clearly a good thing, what is actually entailed, whether it is practically deliverable and from whom has long remained unclear. Now, however, concrete guidance is gradually emerging, leading to increased emphasis on this area of human rights, not just by specialised human rights lawyers and pressure groups but also by ethicists and medical organisations. The Commonwealth Medical Association, working with the American Association for the Advancement of Science, recently completed a report on the meaning and content of "the right to health". The British Medical Association (BMA) has also recently compiled a major report on how the interface between medicine and human rights is changing, devoting much attention to the right to health, a right to a minimum standard of health

care and the concept of an ethical duty to respond to need.¹ It sets out to chart, among other things, changing trends in how medical groups and organisations approach human rights issues.

One such area of change has been the development, during the last decade of the twentieth century, of an international movement focused specifically on health and human rights. The late Jonathan Mann, first Director of the American Francois-Xavier Bagnoud Center for Health and Human Rights was a prime mover in this field, which continued to grow after his death. In July 2000, the UN Committee on Economic, Social and Cultural Rights gave a boost to the debate about a right to health by providing long awaited guidance on the meaning of the right to the highest attainable standard of health. It recognised that health is closely dependent upon the realisation of other human rights. Governments should take note of this guidance since they have obligations under the International Covenant on Economic, Social and Cultural Rights to demonstrate the steps they are taking to implement the right to health. The guidance also emphasises the crucial importance of the community at all levels and is likely to impact on debates about public health ethics, equity and justice. Medical human rights groups in countries such as Israel are already beginning to use the guidance to argue for an extension of health care through insurance schemes to formerly excluded groups such as migrant workers and nomadic people.

For medical human rights groups, such as the International Physicians for Human Rights movement and the Dutch Johannes Wier Foundation, the traditional focus on the medical role in torture and judicial punishments such as the death penalty, has expanded to include debate about the human right to health and by extension the right to health care. In the sphere of medical ethics, the multidisciplinary Tavistock group, initiated by the American Academy of Arts and Sciences, has

conducted a series of international consultations in a pioneering effort to draw up a code of shared ethical principles for everybody working in health care, including managers. Its first core principle defined health care as a human right. This came in a period when a spate of articles by international lawyers analysed the meaning of the right to health in international law and speculated about its legal enforceability. Taking the debate forward will certainly involve interdisciplinary collaboration between lawyers, health professionals, ethicists and human rights experts to clarify not only pragmatic monitoring standards but also the corresponding scope of individuals' rights and duties.

Electronic communication

Electronic communication is impacting in many ways on the provision of health care, each of which raises ethical issues about patients' interests. It is often noted that the internet is changing health care, an observation most frequently illustrated by the new opportunities for patients to have access to up-to-date information about illness and its management. This in itself can bring problems if information is unreliable or inaccurate, but it is the proliferation of on-line pharmacies and consulting services which presents the most pressing need yet for regulation and standards. Can it be safe for doctors to diagnose without seeing patients? How clear a picture of the patient's health is it possible to get from an e-mail exchange? How can doctors be sure they have appropriate consent?

In May 2000, the eHealth Ethics Initiative published a code of ethics which aimed "to ensure that people worldwide can confidently and with full understanding of known risks realise the potential of the internet in managing their own health and the health of those in their care".² The

code identifies key ethical principles: candour; honesty; quality; informed consent; privacy; professionalism (including respect for these ethical obligations and incorporating a duty to inform and educate patients about the limitations of the medium); responsible partnering with other organisations, and accountability.

The BMA is working with indemnifying organisations and providers of on-line consulting services to produce its own guidelines offering practical ethical advice on the issues. Also in the UK, the General Medical Council (GMC) is shortly to consult on a revision of its guidance, *Good Medical Practice*, the document which describes the standards of competence, care and conduct to which doctors must adhere. The GMC will be asking whether, save for exceptional cases, it is acceptable to prescribe drugs or treatment where there has been no face-to-face consultation. At present, the council stresses that any on-line services must serve patients' best interests.

The increasing use of new media led the UK government to give the police new powers to intercept communications and undertake covert surveillance operations. The Regulation of Investigatory Powers Act 2000 puts these covert policing measures on a statutory footing but, medical bodies argue, possibly at the expense of doctor-patient confidentiality. The act is unclear in the extent of its applicability to hospitals providing high security psychiatric facilities, for example. It also allows information to be sought for the purpose of protecting public health, or to prevent death, injury or damage to health. These are familiar limits to the duty of confidentiality, but only where the risks outweigh the harms of breaching a person's privacy. Hopefully, explanatory codes of practice will offer advice on the careful interpretation of these sections.

Commercialisation of human tissue samples

After a year-long consultation, and building on the 1995 recommendations of the Nuffield Council on

Bioethics,³ the Medical Research Council (MRC) recently finalised its report on the use of tissue samples in research. The aim of the MRC report is to give researchers practical guidelines on using stored tissue samples. The advice comes at a time when reports from the United States reveal that some academic hospitals are forming partnerships with biotechnology companies to provide them with human tissue for research purposes. Companies who buy the tissue will bank the biological samples and sell both the data and tissue to interested parties. The aim is to create large tissue samples in relation to their particular research. Commercial factors affect both the legality and the ethical issues of the use of donated tissue, and the MRC guidelines address these issues. The BMA is also looking into the subject.

Sex offences

In July 2000 the UK Home Office, following a detailed review of the law in England and Wales, published a report, *Setting the Boundaries. Reforming the Law on Sex Offences*. The proposals emanating from the review group have been issued for consultation.

One proposal is the introduction of a new offence of breach of a relationship of care. This would make it a criminal offence for doctors, or others who provide therapeutic services, to have a sexual relationship with any patient or client in their care. Consent would be irrelevant: a sexual relationship falling within the terms of the law would be an offence. The report says this would not prevent genuine relationships between doctor and patient provided the caring relationship was broken before a sexual relationship developed. Although this reflects the sentiment of existing good practice guidelines, which strongly discourage such relationships, it goes further. The current guidance from the GMC states that doctors must not use their position to establish "improper personal relationships" with patients or their close relatives.⁴ Although it is

known that the GMC takes very seriously any sexual relationship between doctors and patients, its current guidance does not explicitly forbid them. One of the questions open for consultation is whether professional regulation offers sufficient protection or whether the criminal law would be a more appropriate way of protecting patients from exploitation.

The review group also considered the age of consent for sexual intercourse, recommending that this should remain at 16. The report proposes, however, the introduction of a "no defence" age below which a young person cannot give an effective consent to sexual activity; it recommends age 13. Specific attention is given to the importance of not deterring those under 16 from seeking help, advice, treatment and support in matters of sexual health. The report makes clear that those involved in providing such services should not be regarded as aiding and abetting a criminal offence and questions whether this should be made explicit in any new statute. The report also addresses the capacity of vulnerable people to consent to sexual relationships.

The consultation period ends in March 2001.

References

- 1 British Medical Association. *Medicine and human rights: handbook for a changing agenda*. London: Zed Books (in press).
- 2 eHealth Ethics Initiative. *eHealth code of ethics*. Internet Healthcare Coalition, May 2000. www.ihealthcoalition.org/ethics/ehcode.html (accessed 20 September 2000).
- 3 Nuffield Council on Bioethics. *Human tissue: ethical and legal issues*. London: Nuffield Council on Bioethics, 1995.
- 4 General Medical Council. *Good medical practice*. London: GMC, 1998: para 22.