Ethics briefings

Medicine as entertainment

Many people gain much of their awareness of medicine and medical techniques from television. A regional survey in 1995, for example, indicated that local people primarily gained their understanding of postmortem examinations from television.[1] The popularity of factual series based in hospitals and documentaries following an individual's battle against illness illustrates the appeal of medicine as entertainment. But public knowledge does not come just from such serious portrayals. In the UK, fictional dramas and soap operas are increasingly seen as a useful tool for raising public awareness of the human dilemmas involved—for example in coping with infertility or requests for euthanasia. Programme makers frequently turn to medical advisors to ensure that the scope and limitations of medicine are accurately reflected. Such collaboration between health and media professionals is generally perceived as positive. The medical dilemmas of fictional characters can contribute to better public understanding of conditions such as HIV. Ethical problems can arise, however, when real rather than fictitious cases are presented as entertainment and where some of those involved cannot consent.

In June 2002, for example, the British Medical Association (BMA) complained about a sensationalist television chat show's call for volunteers to undergo paternity testing as part of the entertainment. For one of the programmes in the series, *Trisha Exposes Britain's Biggest Love Rats* (ITV, 17 Jun 2002) men who doubted their paternity of a young child were invited to air their concerns in front of an audience, with a paternity test being carried out either to confirm or deny their suspicion. Such use of genetic technology for entertainment is far from the responsible attitude espoused by the BMA and the Human Genetics Commission (HGC). Official guidance in the UK emphasises that paternity testing should only be carried out after careful consideration of the significance and possible irrevocable consequences of the test result for all those involved. In its report *Inside Information*[2] the HGC recommended that some degree of regulation be considered to ensure that paternity testing is not used "for frivolous or malign reasons". Such forms of entertainment have been pioneered in other countries, particularly the United States, where regulations and attitudes may differ. Ethical guidelines have perhaps not caught up with the ways that popular entertainment can blur boundaries so that something which is commonplace in fiction is unacceptable in real cases. Also the role of medical personnel may be peripheral even though a medical technique is a central feature. Given, however, the growing penetration of American formats as models for television programming in other parts of the world, health professionals are more likely in future to have to consider the ethics of their involvement in such entertainment.

This trend for "real life stories" is sometimes complicated by the involvement of people who cannot consent. The example above concerned young children, incapable of authorising the test or the broadcasting of the results. Wide dissemination of sensitive information about their paternity not only invaded their privacy but potentially carried lifelong implications for them. This case seemed particularly injudicious because the technology was purely for entertainment without any apparent educational or other justification. In other cases news programmes and documentaries featuring scenes with people who are unconscious, mentally ill or with fluctuating capacity can raise similar concerns about valid consent. In February 2002, for example, a programme showing the reactions of patients and their relatives when asked whether they wanted cardiopulmonary resuscitation included scenes of very distressed or incompetent older people (*The Trust,* The Age of Consent, Channel 4, 14 Feb 2002). In some such cases, relatives may consent on the patient's behalf but ethical questions may still be raised as to whether it is in the interests of the incompetent patient or the world at large to portray them in a situation of disarray. Although health professionals and health facilities have clear obligations in respect of confidentiality, the degree to which it may be justifiable for others to show identifiable patients in the media without their consent in order to make an important point has not been thoroughly clarified. The final decision often rests with the programme makers.

Sometimes disclosure without consent in the media can be argued as being in the "public interest". This was the argument put forward in spring 2002 in the case of an elderly patient allegedly neglected in hospital. The BMA strongly protested about the use of named patient data but her case was widely featured in all the UK media at the same time as the prime minister's family came under intense pressure to disclose the vaccination status of their youngest child "in the public interest". The BMA has drawn up principles concerning consent and confidentiality which, it is hoped, will eventually be adopted by politicians and other agencies when using confidential health material.[3]

Arguably, adult patients should be free to subject themselves to any kind of media exposure as long as they understand what is involved. But even programmes involving medical discussion of competent and consenting adults can cause some unease. Programmes, for example, featuring the clinically obese or people with eating disorders, raise concerns about obsession with body image. In some cases, an apparently unsympathetic or voyeuristic portrayal of those who participate may make the programmes appear as a modern day "freak show".

Similar complaints were made against Professor Gunther von Hagens's *Body Worlds* exhibition, which visited the UK from March to September 2002. Human cadavers with their skin stripped off and organs, arteries, and nerves exposed were displayed in a variety of ways including being sliced, splayed, and modelled in particular poses. Assurances that all donors had given their informed consent to their bodies being exhibited in such ways were met with incredulity by some and did not ease the concerns of those who considered the exhibition to be obscene and called for it to be closed down. Some health organisations, such as the BMA, were concerned

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about the possible implications for altruistic donation of human material for transplantation and research if bodies came to be accepted as artistic artefacts that could be bought and sold. The acceptable and unacceptable usage of human bodies and body parts is the focus of a continuing series of consultations by the Department of Health in England, the latest of which focuses on the import and export of all kinds of human remains.[4] One might ask where the boundaries lie between art, education, entertainment, and morbid voyeurism but also whether that question is of any relevance, if the individuals concerned have given genuine and valid consent to such exposure.

Confidentiality

A complex mixture of common (judge-made) law and statute form the legal basis for confidentiality in the UK. The 1998 Data Protection Act requires any processing of data to be "fair and lawful", which usually means that patients must be aware of the use and give their consent. Processing is also lawful if it is required "in the public interest" or by statute that sets aside the common law duty of confidentiality. Traditionally this has been limited to a few areas in which statute requires disclosure, such as notifiable diseases, health and safety, prevention of terrorism, investigation of suspicious or unexpected deaths by a coroner, or where a court orders disclosure. Since early 2001, debate has been around other uses of data which, in the absence of patient consent, have no sound basis in law. These include disclosures of information to cancer registries, public health surveillance and monitoring, and some general research purposes. Sometimes data are transferred automatically, while at other times patients' consent is not sought because of the administrative burden.

The UK government is aware that these issues need to be addressed. It agrees that in the longer term systems should be set up which allow patient choice to be respected. These uses of data should, generally, be controlled by patients, and authorised by their consent. Meanwhile, the government has introduced an interim legislative solution,[5] which sets aside doctors' duties of confidentiality and allows the disclosure of patient information without consent for: medical purposes relating to patients referred for the diagnosis or treatment of neoplasia; diagnosing, controlling, preventing, monitoring, and managing risks to public health; anonymising data; research into geographical locations at which disease occurs; identifying patients to approach for consent to the use of their data: linking data from multiple sources, validating its quality and completeness, and avoiding incorrect linkage or duplication; audit, monitoring, and analysing of health service provision of care and treatment.

The legislation applies only in England and Wales. The Confidentiality and Security Advisory Group for Scotland has proposed a solution that does not require legislation, but relies on government guidance which sets out situations in which a "legal defence" can justify overriding consent requirements.[6]

A statutory requirement to report colleagues?

The New Zealand government has retreated from plans to make it mandatory for doctors and other health professionals to report colleagues they believe are underperforming. During the development stages of the proposed Health Professionals' Competency Assurance Bill, the compulsion to report drew criticism from both inside and outside parliament, with accusations that it would create a culture of blame. Creating a balance between encouraging whistleblowing and avoiding the growth of a blame culture is a challenge for many jurisdictions. The New Zealand bill is designed to replace a multiplicity of competing and sometimes outdated statutes regulating standards of medical competence, with a single law.

The legislation took two years to develop and was drawn up following reports into the standard of care offered by surgeon to women in Northland. Initially the compulsion to report was supported by doctors' professional and regulatory bodies. Subsequently, however, it became clear that it would be very difficult to put into practice. The health minister announced that the clause had been changed after consultation. "We changed the 'shall report' to 'may report'", she said. "It was the 'mandatory' that was too difficult to be able to implement."[7] Instead, health practitioners will be encouraged to report their incompetent peers and will be protected if they do so.

Retained human material

Debate continues about retention of human material in pathology collections and museums. In March 2002 the Clinical Standards Board for Scotland issued draft standards on the topic. In June, the Retained Organs Commission finished a consultation[8] on the fate of material collected prior to 2000 that is unclaimed by relatives or unidentifiable. It suggested options which included continued respectful use, or destruction of all unclaimed material. The BMA argued strongly for the preservation of all unclaimed materials useful for research or education. Also in June, High Court action was initiated against 11 doctors from Alder Hey hospital by the mother of a child who died there in 1989 and whose organs were retained without her knowledge.[9]

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References

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