Ethics briefings

Entertainment media and public health

Ethics briefings have previously drawn attention to ethical questions raised by the use of paternity testing in “true life” entertainment programmes, including where the proper limits to the use of medical procedures and information as entertainment might lie.¹ From a public health perspective the relationship between entertainment media and health is complex and interesting. In April 2001, for example, a storyline opened in the UK television soap opera *Coronation Street* in which a central character, Alma, developed cervical cancer and, within six weeks, died. Although the potential for entertainment media to promote positive health messages is recognised,² the effects of this particular storyline have yet to be fully understood.

While public health medicine can take advantage of the extraordinary reach of the entertainment media—*Coronation Street* is broadcast four times a week and regularly attracts 13 million viewers an episode—the effects of this influence need to be carefully considered, particularly when, as in this case, the story was not designed to deliver a particular health message. Researchers have estimated that an additional 14 000 cervical smears were performed in England’s North West as a result of the *Coronation Street* storyline, 21% more than the previous year.³ It may be argued that this presents an example of the positive influence of the media on health education and service uptake, although the reality is complicated. Of those estimated 14 000 additional smears, slightly less than 2500 were for women who were either overdue or had never had a smear test before.⁴ Although this resulted in a positive health benefit for the estimated 65 women who would otherwise not have had a “significant abnormality” detected, it did so at the cost of nearly 12 000 unnecessary or untimely smears. This increase in demand put considerable pressure on

the service providers, and meant that the time it took laboratories to report results increased beyond acceptable quality assurance limits.⁵ Furthermore, although entertainment programmes can raise the profile of health issues, in this case its effect was to generate a short lived burst of anxiety.⁶ The sustainability and long term effectiveness of entertainment programmes in promoting positive public health methods must therefore be questioned.

This highlights the complex relationship between entertainment media and public health medicine. Health stories can be attractive to programme makers, involving as they frequently do, questions of life and death. Responsible programme makers might justify dramatic storylines by reference to their educational impact, but their actual effect on service uptake, on long term awareness of health issues and, ultimately, on population health can be difficult to determine. For a truly symbiotic relationship between medicine and this form of media, more research on the long term impact of health storylines is needed.

Medical experts

Early in 2003, the role of medical expert witnesses in legal cases involving sudden infant death (“cot death”) was called in question.⁷ Sally Clark, a solicitor, was in 1999 found guilty of causing the death of her two baby sons, Christopher in 1996 and Harry in 1998, but was released when her conviction was ruled unsafe in January 2003. Professor Sir Roy Meadow, a paediatrician, appeared as an expert witness when she was convicted and gave evidence at the trials of at least five other mothers. His view was that, statistically, it was extremely unlikely that there would be more than one natural cot death in a family. His figures were subsequently questioned and were condemned by the Royal Statistical Society. Expert advice for the prosecution also came from a pathologist, Dr Williams, who said that Harry had been shaken to death or smothered but failed to disclose evidence that the child had suffered a brain infection. The General Medical Council said it would look at the doctors’ evidence to see if action should be taken against them. When Mrs Clark’s conviction was over-

turned, there was considerable media debate about the role and lack of independent appraisal of expert witnesses.⁸ Expert witnesses often begin this type of work by chance and are not obliged to be specifically trained or aware of legal requirements. As part of the general review of the criminal court system, training and registration of expert witnesses may now come under review. In addition, in March 2003, the Home Office published its review of forensic pathology services⁹ and announced measures for training and competence standards, both for evidence gathering and appearing as an expert witness (Home Office press release: Delivering a first class forensic pathology service: better regulation, improved performance, 17 March 2003).

Proxy consent for research involving incapacitated adults

In February 2003, the Department of Health published a consultation letter¹⁰ on the proposed regulations to bring the European Clinical Trials Directive into UK law. It included provision for proxy decisions makers to consent to incapacitated adults participating in drug trials. In England, Wales, and Northern Ireland, no one has had legal powers to consent to any intervention, including research, involving an incapacitated adult. The new government proposals for proxy decision making would apply only to clinical trials of medicinal products and not to other research or experimental therapy. The draft regulations require that the research is in that person’s best interests and any advance refusal of treatment made by the person prior to the onset of incapacity must be respected. They also require that some person should provide “consent” on the incapacitated person’s behalf although this seems to be a fairly meaningless ritual in cases where the patient is unknown to the proxy decision maker. Provision is made for two types of legal representative who could consent: “personal” representatives who have a relationship with the subject and “professional” representatives who can act if there is no suitable personal representative. A separate consultation spelled

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out in some detail how professional representatives would be chosen. They could be the treating doctor (as long as the clinician is not involved in the research), another health professional, or lay person such as a chaplain or social worker.¹¹ In Scotland since the implementation of the Adults with Incapacity (Scotland) Act 2000, a guardian, welfare attorney or nearest relative has been legally empowered to decide for incapacitated adults as long as the intervention agreed by the proxy meets the criteria set out in the act. Under the proposed new regulations, it would be acceptable for a "professional" legal representative to consent as in the rest of the UK. The government has promised to provide guidance for legal representatives.

Tightening controls on female genital mutilation

Ethics Briefings February 2003 reported that there was nothing in UK law to prevent families from taking daughters abroad for female genital mutilation.¹² The following month, a bill to do this was debated by the House of Lords.¹³ The bill uses the terminology female genital mutilation rather than female circumcision, which was the title of the previous act. It would make it an offence for a person in the UK to aid, abet, counsel or procure a person to perform an act of female genital mutilation outside the UK. It would also increase the maximum penalty from five to 14 years' imprisonment.

Although the aims of the bill are laudable, problems with it have been pointed out. If, for example, a family goes on holiday and when they come back the girl has been mutilated, a lawyer may be able to show that the parents had not been involved and were not there when it took place.¹⁴ Nevertheless, even if the bill is not perfect, its acceptance by parliament would show commitment to the UK's abhorrence of the practice.

Child protection

Eight year old Victoria Climbié died as a result of "the worst case of child abuse and neglect" the paediatric consultant responsible for her care immediately before she died had ever seen (p 1).¹⁵ Seven year old Victoria came to England from the Ivory Coast with her

aunt in April 1999, and within a few months Victoria was "transformed from a healthy, lively, and happy little girl into a wretched and broken wreck of a human being" (p 2).¹⁵ She died in February 2000. Victoria's aunt and the man she was living with were convicted of Victoria's murder.

The report into her death stated that protecting Victoria would have "required nothing more than basic good practice being put into operation" (p 1).¹⁵ Gross system failures were identified, with individuals and agencies failing to take responsibility to act to protect Victoria from horrific abuse. The inquiry sought to understand the many failings that led to Victoria's death, and to identify improvements that should be made at national and local level. Victoria had had contact with social workers and health professionals in the UK, and it was apparent that these professionals had been concerned about her. Evidence to the inquiry also suggested, however, that the health professionals who had come into contact with her, when she registered with a general practitioner and during two hospital visits, had not always made full notes of their concerns, or they had recorded concerns but not shared them with others. Necessary action was identified but not acted upon. The inquiry made 27 recommendations about health care aimed at improving communication, ensuring concerns are acted upon, record keeping, and attributing clear responsibility for child protection to a single hospital consultant. The inquiry set a tight timescale for implementing its recommendations.

Definition of an "embryo"

More than two years after the UK parliament passed regulations to enable the Human Fertilisation and Embryology Authority to license research involving embryonic stem cells, argument about the scope of the regulations has been settled. In March 2003 the House of Lords held that embryos created by cell nuclear replacement (CNR)—the technique used to create Dolly the sheep—fall within the legal definition of "embryo" in the Human Fertilisation and Embryology Act and are therefore subject to the act's regulatory mechanism.¹⁶ The Pro-life Alliance, which opposes all embryo research, had argued that since the creation of

CNR embryos does not involve fertilisation, their creation and use falls outside the act, which defines an "embryo" as "a live embryo where fertilisation is complete".¹⁷ The UK government had argued that the act was clearly intended to provide comprehensive control of human reproduction either by prohibiting or licensing particular activities. This purposive interpretation was accepted. Interestingly, had the House of Lords accepted the Pro-life Alliance's arguments, the creation and use of CNR embryos would not have been prohibited but, rather, would have been totally outside the UK's strict regulatory mechanism.

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