

Ethics briefings

Mandatory disclosure of HIV status

In 2002, the Scottish Police Federation called attention to the growing number of assaults on police officers by drug addicts and people infected with blood-borne viruses, including HIV, hepatitis B, or C. In cases where officers were deliberately exposed to attackers' bodily fluids, the federation argued that they should be able to find out the infection status of the assailant.¹ In February 2005, the Scottish Executive published a consultation, setting out new legal proposals to achieve this.² Going further than the police federation's petition,¹ the consultation proposed that any victim of assault or rape involving bodily fluids should be able to apply to a sheriff to allow disclosure of the assailant's infection status.² The proposal required that voluntary consent to disclosure be sought from alleged perpetrators and, in the absence of any relevant results in their medical record, it allows them to be asked to have a voluntary blood test. There would be pressure to agree since refusal could result in a large fine but it was emphasised that no blood sample would be forcibly taken.

The advantages of mandatory disclosure were claimed to be reduced anxiety for assault victims and an opportunity for them to make an informed choice about whether to discontinue postexposure prophylaxis (PEP) for HIV and hepatitis B. There is no PEP for hepatitis C but for HIV, prophylaxis is stressful and unpleasant and people would generally prefer to stop if enough information about their actual risk were promptly available.

In Scotland, procurators fiscal can already apply for a warrant to access the medical records of accused people or require a blood sample to be provided for testing for bloodborne diseases but they do not disclose those results to victims. The new proposals would permit disclosure if judged to be warranted and allow for an application for disclosure to be made on behalf of a victim

who is a child or is mentally incapacitated. Decisions would be made on a case by case basis and would involve a judgment being made between the human rights of the two individuals.

Similar legislation exists in Queensland Australia and in most Canadian provinces. The Queensland disease test orders cover sexual offences and assaults against adults, children, and incompetent people where transmission of bodily fluids appeared likely. Victims must approach a magistrate for an order for a blood or urine test from an assailant but the disclosure of results is tightly regulated. The Queensland legislation carries up to 6 months imprisonment for any "public disclosure" of the test results. The victim and suspect can choose to share information with people close to them but are prohibited from public disclosure through the media. The Queensland legislation is also more draconian than that proposed for Scotland. It authorises the police to take a suspect to hospital, once a magistrate has given permission and health professionals can use "reasonably necessary force" to obtain a sample. Test results appear to be obtained quickly: within the 72 hour window for prophylaxis in case of hepatitis B and within days for HIV. It is argued that this allows the victim and the treating doctor to make better informed decisions about whether to continue with early prophylactic treatment.

Antisocial behaviour orders and mental disorder

In February 2005, the BBC reported the story of a woman who had attempted suicide four times and was given an antisocial behaviour order (ASBO) barring her from rivers, multistorey car parks, train tracks, and bridges in England and Wales. She had been rescued three times from the River Avon in Bath in 2004, and had also been found hanging from a railway parapet.³ She could be jailed for breaking the order.

Antisocial behaviour orders are civil orders designed to protect the public from behaviour that causes or is likely to cause harassment, alarm, or distress. An order contains conditions prohibiting the offender from specific antisocial acts

or entering defined areas. According to the Home Office: "The orders are not criminal penalties and are not intended to punish the offender".⁴

Although there is very little background information available, the story raises the question of whether ASBOs are appropriate tools with which to manage individuals who may be suffering from mental disorder. Restrictions are imposed upon the individual, but there is no corresponding provision for care or treatment.

Duties to future children

What duties, if any, we owe to future children has been the topic of much debate in medical and academic circles over recent months. This has been prompted by the Human Fertilisation and Embryology Authority's (HFEA) review of the "welfare of the child" provision of the Human Fertilisation and Embryology Act.⁵ The act requires that "a woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of treatment (including the need of that child for a father) and of any other child who may be affected by the birth".⁶

Although the consultation was based on the scope and interpretation of this section in order to provide clear guidance for clinics, there has inevitably been debate about whether such a requirement has any validity at all. Given that we do not stop fertile people from having children, irrespective of the level of harm or neglect we may foresee, it is unreasonable, it is argued, to make those who require assistance to conceive demonstrate their fitness as parents. Reproductive liberty requires that people should be free to make their own decisions about reproduction unless there are powerful reasons for the state to override the wishes of the individuals concerned. Others argue that where a professional third party is asked to assist a person to have a child, that third party has some moral obligations toward the future child. The extent of these moral obligations is also open for debate, with some setting a minimum standard threshold—a duty to protect the child from clearly foreseeable serious harm—and others setting a very high threshold requiring assessments akin to those undertaken for adoption.

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Until now the HFEA has taken a “middle of the road” view but one that arguably puts unreasonable demands on clinics. Factors they are required to take into account include, not only factual questions about the health of the parents or evidence of past harm to children, but also factors such as the stability of the family environment and the patients’ commitment to having children. These latter points, if they are to be meaningfully assessed, inevitably involve intrusive questioning, speculation, and subjective judgments. The risk of such assessments tipping over into arbitrary and discriminatory decisions about who will be a “good parent” is clear. Little surprise then that practice among clinics varies quite considerably, with some adhering closely to the guidance and carrying out detailed assessments, while other clinics’ assessments are far more superficial.

Review of the guidance on this controversial part of the act should be welcomed. With much speculation about new legislation in this area in the next few years, clear guidance now will provide an opportunity to see whether an appropriate balance can be achieved between reproductive liberty and the duties toward future children of those providing treatment. Standard assessments based on factual information would be a good starting point.

The HFEA aims to publish new guidance in the late summer.

Politicians and patients’ stories

Margaret Dixon, Rose Addis, and Jennifer Bennett may be familiar names to anyone who has kept an eye on the British media for the last few years. All of them have had their stories of “unsatisfactory” interactions with the National Health Service (NHS) publicised in the mass media at the instigation of politicians eager to win political points based on their stories. The most recent case, that of Margaret Dixon, was brought to light when Michael Howard, leader of the British Conservative Party, raised her case in the House of Commons in March 2005 as election preparations heated up. Mrs Dixon had a shoulder replacement operation postponed on a number of occasions because

she required a high dependency bed due to multiple pathologies.

Whether one story of unsatisfactory care can truly reflect deeper widespread failings in the NHS is questionable. Nevertheless, what is clear is that healthcare professionals involved in these individual cases can sometimes be put in the difficult position of having a duty to maintain confidentiality while being approached by the media seeking comment on the cases. Such stories can often be misrepresented in the media either through inaccuracies or incompleteness of the information presented. Some healthcare professionals feel that once a patient has gone to the media, he or she forfeits certain rights to confidentiality and his or her case can be discussed openly via the media to clarify the facts of the situation. The General Medical Council’s rules about disclosure to the media are, however, clear. Normal rules regarding confidentiality and privacy, irrespective of whether or not the information is also in the public domain, should be maintained.

As the past chairman of the BMA Council, Dr Ian Bogle, stated at the time of the Rose Addis affair: “Is it too much to ask that for those who are dissatisfied with the care they or their relatives receive from the NHS, a swift, transparent and robust NHS complaints procedure should be the preferred route to Prime Minister’s question time or the front page of a tabloid newspaper?”

Euthanasia and newborn babies with intolerable and incurable illnesses in the Netherlands

Decisions surrounding the care and treatment of newborn children with painful incurable illnesses are among some of the most difficult and emotive decisions that health professionals, families, and society are called upon to face. Doctors respond to the ethical challenge of these cases by trying to assess the best interests of the newborn.

In the Netherlands, public debate has recently focused on “the (deliberate) termination of the life of a newborn”

(or, as it would be typically termed in the UK, non-voluntary euthanasia—that is, mercy killing of incapacitated patients); with calls for the Dutch government to clarify the legitimacy of the euthanasia of babies in these circumstances.

The Groningen University Hospital department of paediatrics, which is taking the lead in this call for clarity, has already drafted the “Groningen protocol” (University Medical Center Groningen press release: Paediatricians call for nationwide protocol for the ending of life of unbearably and incurable suffering newborns, 10 December 2004), which outlines five criteria that need to be taken into account when deciding to end life in these circumstances:

- the suffering must be so severe that the newborn has no prospects of a future;
- there is no possibility of a cure or alleviation with medication or surgery;
- the parents must always give their consent;
- a second opinion must be provided by an independent doctor who has not been involved with the child’s treatment, and
- the deliberate ending of life must be meticulously carried out.

At the time of writing the Dutch government had not yet formally responded to the appeal for clarification.

References

- 1 **Scottish Executive.** *Blood testing following criminal incidents where there is a risk of infection: proposals for legislation.* Edinburgh: Scottish Executive, 2005, appendix A.
- 2 **Scottish Executive.** *Blood testing following criminal incidents where there is a risk of infection: proposals for legislation.* Edinburgh: Scottish Executive, 2005.
- 3 **Anon.** Suicide woman banned from rivers 25 Feb 2005. BBC Online. <http://news.bbc.co.uk/1/hi/england/somerset/4297695.stm> (accessed 14 Mar 2005).
- 4 **Home Office.** *A guide to antisocial behaviour orders and acceptable behaviour contracts.* London: Communications Directorate, 2003, 9. <http://www.crimereduction.gov.uk/asbos9.pdf> (accessed 14 March 2005).
- 5 **Human Fertilisation and Embryology Authority.** *Tomorrow’s children. A consultation on guidance to licensed fertility clinics on taking into account the welfare of children to be born of assisted conception treatment.* London: HFEA, 2004.
- 6 *Human Fertilisation and Embryology Act 1990*, s 13(5).