End of life issues

End of life issues remain a cause for concern, debate, and Parliamentary action in several countries. In France, disagreement between doctors and nurses about the management of very ill patients led to an investigation into 18 deaths in Besancon hospital. It found that 14 patients had been illegally given euthanasia. The report, published in May 2004, found that deaths were caused by injections of potassium chloride, curare, painkillers, and sedatives resulting in cardiac arrest or paralysis of the respiratory muscles. In July 2004, a German nurse was charged with killing at least 12 patients and another 70 deaths were under investigation. He confessed to 10 killings, claiming he wished to end patients' suffering. Suspicions were only aroused when muscle relaxant drugs were missing and only 5% of suspicious deaths were subject to post-mortem examination. An expert on health professionals who kill in such circumstances noted that such murders often pass unnoticed. Such reports highlight the problems of identifying illegal killings in situations where unexpected death is common.

On the other hand, some patients experience significant difficulties refusing treatment. One of the biggest end-of-life debates took place in France following the death of Vincent Humbert in 2003, which caused controversy about the right to refuse treatment. Humbert was left tetraplegic, dumb and blind after an accident and sent a letter to President Chirac expressing a wish to die. His mother attempted to engineer his death by injecting him with barbiturates but this only pushed him into a coma. Subsequently, Dr Chaussoy, head of the intensive care unit, disconnected Humbert’s respirator causing his death, on the basis that this is what he would have wanted. In October 2003, Humbert’s mother was charged with poisoning him and Dr Chaussoy was also charged with causing his death by “premeditated poisoning”, carrying a life sentence. He admitted to withdrawing treatment but pointed out that he could easily have covered up his action had he not wanted to expose the hypocrisy associated with end of life decisions.

This stimulated public and political debate. The French Senate placed on its website information about the legal position and practice in relation to euthanasia in Germany, Denmark, England and Wales, Netherlands, Switzerland, Australia, and the USA. The French Language Resuscitation Society (SRLF) issued guidance on the factors to be considered for limiting or withdrawing treatment from adults (“Bases de reflexion pour la limitation et l’arret des traitements en reanimation chez l’adulte”). In the UK, a clear distinction is drawn between treatment withdrawal (as appears to have been Dr Chaussoy’s role) and active euthanasia and assisted suicide (which appears to have been the mother’s role). Also in the UK, a competent patient can refuse life-prolonging treatment and so Humbert’s published letter to President Chirac might have been regarded as an advance valid refusal of artificial respiration.

Following Humbert’s death, a French Senate committee examined the issues and considered whether any legal change was needed. In August 2004, it issued its conclusions recommending that “passive euthanasia” should be allowed in France. It made clear that this was limited to permitting terminally ill patients to refuse treatment in certain circumstances. Only patients with a serious incurable illness would be able to refuse active treatment. They would have to request non-treatment in writing and obtain a second medical opinion. The committee opposed the legalisation of any deliberate act to hasten death but also considered the possibility of patients making a “testament of life” to state in advance how they wanted to be treated at the end of life.

Nevertheless, there is clearly some support for going further at least in some jurisdictions. In January 2004 Lord Joffe introduced the Assisted Dying for the Terminally Ill Bill in the House of Lords in England. It had its second reading in March 2004 and was referred to a House of Lords Select Committee, which, in July 2004, called for evidence on the Bill. The BMA submitted written evidence in August 2004.

In Scotland in September 2004, Liberal Democrat MSP, Jeremy Purvis, announced plans to introduce a Bill into the Scottish Parliament to legalise “mercy killing”. The Parliamentarian said that it would be based on the Oregon physician-assisted suicide legislation and would be published in the next Parliamentary term. The Liberal Democrat party has policy supporting physician-assisted suicide and also gave evidence on the issue to the Joffe Committee in the House of Lords in September.

In September 2004, the Swiss group, Dignitas, reported it had assisted 22 Britons to die in Zurich over the previous 2 years. This was more than had been previously acknowledged.

Italian fertility law

In April, Ethics briefings reported on the new, very restrictive Italian law on fertility and reproduction that had been criticised as being “a potential disaster for women”. Among the Act’s provisions is the stipulation that only up to three embryos may be created during a treatment cycle and that all embryos must be transferred into the woman’s uterus simultaneously. Reports in summer 2004 highlighted some of the effects of this restriction.

Shortly after the law was passed, an infertile couple went to court to challenge this aspect of the legislation. Both were carriers of beta thalassaemia and wished to use preimplantation genetic diagnosis (PGD) in order to have only unaffected embryos transferred. Despite the couple making clear that they would abort any fetus affected by beta thalassaemia, the judge ordered that, under the terms of the legislation, all embryos had to be transferred. One month after the court decision and embryo transfer the woman suffered a miscarriage. Italian scientists had hoped that guidelines would prevent such cases in the future but instead they reinforce the ban on any form of preimplantation diagnosis “with eugenic purposes” and permit only observational study. Under the guidance, if observation shows irreversible defects in the embryo, implantation “will not be compulsory” and the embryo may be kept in culture until it dies.

In another reported case, a 26 year old woman sought a court ruling to permit fetal reduction of a triplet pregnancy after all three fertilised embryos had to be replaced. The court accepted that continuing the triplet pregnancy would
put the mother’s life at risk. This was the second reported case of fetal reduction before the courts since the new legislation came into force. In an earlier case fetal reduction of a twin pregnancy was permitted after it was found that one of the twins had thalassaemia. Commenting on such cases Dr Giovanni Monni said “These cases show what is wrong with this law. It was created to protect the embryo, but what it does is force the woman to choose abortion.”

Other concerns have focussed on the impact of this part of the legislation on the efficacy of treatment. It is usual practice in countries with less restrictive legislation to attempt to fertilise all oocytes collected. The best quality embryos can then be selected for transfer, increasing the likelihood of success. Any remaining good quality embryos can be stored for future transfer so that the woman does not need to go through a fresh in vitro fertilisation (IVF) cycle, including ovarian stimulation, for each attempt. As predicted, the early signs are that since the legislation has been in force there has been a decrease in IVF success rates in women over 35 and a steep increase in multiple pregnancies in those under 35.

Ironically, given that the legislation was passed in reaction to Italy being perceived as the “Wild West of assisted reproduction”, another effect has been an increase in “reproductive tourism” with couples travelling outside Italy for fertility treatment. Debate in Italy is complicated further by the fact that the birth mother has no genetic relationship with the child born.

The UK pro-life organisation LIFE has called for a ban on IVF in response to the US case. (LIFE press release. LIFE says it’s time to ban IVF, 5 August 2004.)

Internet training course for prison doctors

In summer 2004, the Norwegian Medical Association finished coordinat- ing the first Internet training course on ethics and human rights for prison doctors under the auspices of the World Medical Association. The BMA contributed several modules. The aim is to make such ethics guidance widely available, particularly in countries where doctors are generally unable to obtain such guidance and so translations of the material are the next priority. For example, discussions with Chinese authorities in Beijing in June 2004 resulted in a commitment for a Chinese version. The technical adjustments required to allow the material to be available in Chinese will also accept other scripts and so facilitate translation into other languages with different alphabets.

The course is free of charge and can be accessed at http://www.wma.net.

Prisoners at Guantánamo Bay

In June, Ethics briefings® highlighted the concerns regarding the dual loyalties experienced by doctors, and specifically the role of doctors providing examination and treatment for prisoners held for 2 years by American forces at camp Delta in Guantánamo.

In light of these concerns, at the BMA’s Annual Representatives Meet- ing in June 2004, an emergency motion was passed that the Association viewed “with dismay the illegal use of medical records during the incarceration of detainees in Guantánamo Bay and failure to report abuses of human rights by some doctors.” The Association called on all national medical associations to condemn the role of doctors and the misuse of medical records in perpetuating torture and the issue was raised for debate at the World Medical Association.

USA—embryo mix up

In August 2004, a woman was awarded one million US dollars compensation after an IVF mix up. The doctors treating the woman mistakenly implanted another couple’s embryo in to the woman. The doctors allegedly realised their mistake shortly after they implanted the embryo, but did not disclose the error believing that it would result in harm to one of the parties involved.

The US case mirrors a similar case in the UK in 2003. In that case, a black man undergoing fertility treatment with his wife had his sperm mistakenly used to fertilise the egg of a white woman also undergoing fertility treatment with her husband. The mistake was not identified until the birth of IVF twins, who were unexpectedly of mixed-race.

Both cases have thrown up legal disputes over custody and parentage, although in the US case it is arguably complicated further by the fact that the birth mother has no genetic relationship with the child born.

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