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Ethics briefings

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Legislation on euthanasia

The Netherlands has waited a long time for parliamentary endorsement of euthanasia, despite it being accepted practice for many years. Until recently, euthanasia and assisted suicide were technically illegal in the Netherlands, although court rulings during the 1970s and 80s indicated that a defence of necessity could be invoked by a doctor who ended the life of a patient. The situations in which that defence could be used were defined and became the Royal Dutch Medical Association's "rules of due care".

Many of the safeguards in the rules passed into statute in April 2001 with the passing of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act. The act decriminalised euthanasia and assisted suicide by doctors acting with "due care". Doctors will not face prosecution if they terminate the life or assist in the suicide of a patient who has made a voluntary and well considered request, is facing "interminable and unendurable suffering", understands his or her situation and prospects, and for whom there is no other reasonable solution. A second, independent, doctor must be consulted. There is no requirement for the patient to be terminally ill, and there are specific provisions that allow the euthanasia of young people between the ages of 12 and 16 if they and their parents agree. Parents of 16- and 17-year-olds must be involved in decisions about the young person's end-of-life care, but these patients are entitled to make their own decision. There is no requirement for the patient to be a Dutch resident.

The Dutch justice department's website has the English language text of the act and an explanatory factsheet at www.minjust.nl:8080/a_beleid/fact/suicide.htm.

In the light of the legislation, the World Medical Association (WMA) has reaffirmed its opposition to euthanasia and its strong belief that euthanasia is in conflict with basic ethical principles of medical practice. In a press release in May 2001, it called upon doctors worldwide to refrain from participating in euthanasia, even where it is permitted by national law.

Medical tourism

It has long been the case that individuals travel abroad for medical treatment or procedures not available at home. In 1973, 33.9% of the legal abortions carried out in Great Britain were for non-residents.[1] Fertility treatment is an area where "medical tourism" is particularly common. In two high profile cases in the UK, individuals travelled to other parts of the European Community for fertility treatments prohibited by the UK's regulatory body, the Human Fertilisation and Embryology Authority (HFEA). In 1997 Diane Blood won her legal battle to export her husband's frozen sperm to Belgium for insemination. Sperm had been taken from her husband shortly before his death but because he had not given valid consent for its storage and use, it could not be used lawfully in the UK. The HFEA initially denied permission for Mrs Blood to export the sperm but was forced to reconsider after the Appeal Court held that the authority had not taken sufficient account of her right to obtain medical services in another member state of the European Community.[2] This put the HFEA in the anomalous position of facilitating treatment that was unlawful in the UK. A subsequent review on behalf of the government recommended a change in the law to prevent this recurring by prohibiting the HFEA from authorising the export of gametes which have been unlawfully obtained.[3]

In the second case Mr and Mrs Masterton travelled to Rome for preimplantation genetic diagnosis to select a female embryo for implantation. The Mastertons had four sons and their only daughter had died, aged three, in an accident. They desperately wanted another daughter but clinics in the UK are prevented by the HFEA from offering sex selection for social reasons. They did have the support of a UK doctor, however, who is reported to have provided the necessary hormone treatment before the couple travelled to Rome.

Some clinicians have reportedly gone further to help patients overcome the rulings of the HFEA and the UK's legal restrictions. There was considerable disquiet in 1997 at reports that the medical director of a UK fertility clinic, Mr Paul Rainsbury, had set up a sex selection service in Naples, Italy. He offered couples at his UK clinic the opportunity of travelling to Naples for sex selection treatment, thereby avoiding the UK's restrictions.[4]

Things have now gone a stage further and rather than taking patients to the jurisdiction where the treatment is permitted, it has been suggested that the jurisdiction could be taken to the patient. Dr Philip Nitschke, an Australian doctor who helped four terminally ill patients to die when euthanasia was briefly legalised in the Northern Territory, is reported to have plans to take advantage of the Netherlands decision to legalise euthanasia, by buying a Dutch-registered ship to circumvent Australian law. Dr Nitschke asserted that "If this was a Dutch-registered vessel, it would be possible legally to provide access to voluntary euthanasia in international waters".[5] A Dutch doctor, Rebecca Gomperts, has also publicised her plans for a "floating abortion clinic" to be anchored off the coast of countries such as Ireland, where abortion is prohibited.[5]

Given that there are a range of issues, particularly around the beginning and end of life, on which international consensus is unlikely to be achieved, it is inevitable that individuals will travel to other destinations in order to take advantage of different laws. Whether it is appropriate for health professionals to encourage and facilitate such deliberate attempts

to evade local laws and regulations is another matter and one which requires further debate.

Human tissue retention in Australia

In October 2000 The Royal Children's Hospital in New South Wales identified a problem with its consent procedures. Prompted by the news of the British inquiries at Alder Hey and Bristol children's hospitals, it made public details of the extent of its collection of organs and tissue, and invited relatives to come forward.[6] In May 2001, the hospital's director of laboratory services reported at a conference of the Royal Australasian College of Physicians that of the families which found they had buried their children without some of their organs: "All . . . think they should have been given more information at the time of the autopsy and almost all of them thought their trust had been breached".[6] Half the families have chosen to have the organs returned to them for burial or cremation. The remaining families have allowed the hospital to keep them for educational purposes.[6]

Early in 2001 the chief medical officer of England published a complete audit of retained tissue and organs around the country. The census was conducted in response to public concern following reports, emerging from the Alder Hey and Bristol inquiries, that the practice of retaining organs was widespread in hospitals around the country.[7] Subsequently, the government has established the Retained Organs Commission[8] to oversee the return of organs and tissue to relatives if such requests are made. The federal government of Australia has announced that it has set up a working party as part of a nationwide audit of organ and tissue retention practices in the country, with a view to developing national guidelines on postmortem examinations and consent procedures (The Royal College of Pathologists of Australasia press release, 26 February 2001).

Helsinki Declaration on Medical Research

In October 2000, the World Medical Association (WMA) finally finished what had developed into an unexpectedly stormy three-year review of the Helsinki Declaration on Medical Research. The new version, however, contained some provisions which could be controversial if applied inflexibly in every instance. Questions were raised, for example, about whether any discretion could be exercised, in relation to military research, concerning the declaration's requirement that the design of all studies and the results of all research be made publicly available (paragraphs 16 and 27), and also about the obligation to provide, without time limit, the treatments developed from studies to patients who had participated in those studies (paragraph 30), without necessarily considering the implications for other patients. Pharmaceutical companies and governments wondered whether this meant they would be morally obliged to make an open-ended commitment to former participants of research without regard to the needs of other people. In reality, however, taking the WMA's statements literally in every respect is seldom expected. They are generally perceived more as an indicator of basic principles rather than rigid rules. Its statements are sometimes ignored by signatory medical associations or, at best, interpreted within the national context. Arguably, to perceive them as binding ethical rules is to misunderstand the role of the WMA.

Particular concerns were expressed about the declaration's prohibition on the use of placebos for conditions for which an effective treatment exists (paragraph 29), although some national legislation appears to permit placebos in such cases. There had previously been considerable ethical debate about the non-provision of antiretroviral regimes in HIV vaccine trials in developing countries. Pharmaceutical companies argued that patients in such countries needed cheap and effective alternatives to Western medicines and that it would be unrealistic and unhelpful to test new treatments against expensive–and locally unavailable–drugs.

Only seven months after having agreed this clause, the WMA was obliged to reopen the debate at its May meeting in 2001. The WMA is now setting up a new working group to harmonise its guidelines with those of other bodies. As yet, no timescale has been set for the conclusion of the project, which is expected to include wide consultation.

References

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7 At the end of 1999, a total of 54,300 organs, body parts or fetuses were being held in hospital or medical schools around the country. Department of Health. *Report of the census of organs and tissues retained by pathology services in England, conducted in 2000 by the Chief Medical Officer*. London: The Stationery Office, 2000.
8 The Retained Organs Commission (Establishment and Constitution) Order 2001, SI 2001/273.