

FROM OTHER JOURNALS

*Ethics and medical technology*¹

In an earlier issue of the same journal, Professor ten Have of the Netherlands had discussed medical technology in general. The abstract of the paper starts with this sentence: 'The current model of technology assessment treats ethics itself as just another problem-solving technology.' The opening paragraph of the essay describes how the National Association of the Deaf in USA protested against widespread use of cochlear implants in children. The major objection was that this new technology threatens the hard-won respect for the deaf and that means by which they communicate.

Medical technologies expand without inherent constraints. Indeed, the only constraints are those of the availability of funds. Newly developed technologies prove irresistibly attractive to most in the medical profession and is often used even in the face of objective data that it is inappropriate, considerably more expensive than equally effective traditional measures and often in an attempt at being the first kid on the block to possess it.

Professor ten Have pleads for the incorporation of ethical principles in any assessment of technological 'advances'. Moral issues on the relevance of the technology and consequences of its usage must be raised and debated before general access to such technology is permitted.

*Distress at the thought of losing the uterus*²

A thirty-nine year old woman with three children was investigated for irregular vaginal bleeding and lower abdominal pain. A gynaecologist found multiple uterine fibroids and advised hysterectomy. As she was unwilling for the loss of her uterus she requested and was provided drug therapy. When this did not help, hysterectomy was recommended again. This caused acute distress, the patient claiming that without her uterus she would not feel like a whole woman. She sought extensive myomectomy with all the attendant hazards and despite the risk of recurrence of fibroids. Should the gynaecologist oblige?

This problem was posed to two teams. Both teams suggested that the consultant delve into why the thought of hysterectomy occasioned so much unhappiness. One team recalled a similar case where patient enquiry including the specific question, 'Do you know anyone who has had a hysterectomy?' elicited the answer. That patient recalled a friend who underwent this

operation. 'Overnight her hair turned gray, her skin became wrinkled, her husband left her - she wasn't any older than me!' Such natural fears must be allowed to surface. It may then be able to provide specific reassurance and permit an enlightened decision.

Should she continue to insist on the more hazardous operation, which the gynaecologist considers unjustified, he should ask the patient to seek another opinion and get the operation performed by another surgeon.

*Surgery in a Jehovah's witness: is great public expense justified?*³

A woman in her twenties had an ectopic pregnancy that needed immediate surgery. Since she was a Jehovah's witness, she refused permission for blood transfusion even after it was explained that failure to transfuse blood might result in death. During surgery her haemoglobin dropped to 3 G/100 ml. To save her life, extraordinary measures were used, including the use of expensive drugs. She survived but the hospital had to absorb the cost of \$100,000. Did she have a 'just claim' to this expense?

The problem was posed to two experts. Both pointed out that in refusing blood transfusion, she asserted a 'negative right' which did not create any correlative duty for nonbelievers to provide resources.

In a just health care system, it is incorrect to spend scarce resources on a person refusing a simpler, cheaper alternative which would have been equally or more effective. The hospital deprived others whose lives could have been saved using this large sum.

Either the community of Jehovah's Witnesses should have been asked to underwrite the expenses or the individual should have possessed an insurance policy that would have paid the bill.

*The 'unpatients'*⁴

Jonsen et al review the ethics of the application of molecular biology to diagnosis, prognosis and treatment. They point out that we have yet to determine whether and when to offer genetic screening, how to ensure optimal diagnostic validity and how to advise patients and family about testing, surveillance, prevention and therapy.

Genomic medicine will radically modify three features of medicine: the nature of the clinical transaction, the perspective of disease seen by clinicians and patients and

the social and cultural context in which clinical transactions occur. The clinical transaction has, historically, been prompted by curiosity about diagnosis and prognosis and expectations from therapy. Molecular medicine will bring in a novel, almost unprecedented form of prognosis through the identification of genes associated with susceptibility to diseases such as diabetes, cardiovascular diseases and cancer. Prognosis implies the consideration of possibilities of grave diseases at some future date on the basis of epidemiological studies and their statistical analyses. The novel prognosis is based on genes that confer innate risks. But the path from genotype to phenotype is complex and is influenced by a host of factors and such prognosis can be offered only by those understanding the ramifications of this complex series of events. How shall doctors and patients decide what constitutes truthful, accurate genetic information?

Further, the ability to test for susceptibility to disease has the potential to sweep into the world of medicine millions who experience no pain or discomfort or limitation. They will be made to wait and watch for early symptoms and signs of disease. They may be forced to organise their lives around mammographies and colonoscopies with their attendant risks. Are we encouraging the development of psychosomatic disasters and mental invalids?

Those carrying genetic susceptibility will, thus, constitute a new class - the unpatients. They will neither be patients under treatment nor free of medically relevant conditions. Already we see the psychological burdens carried by those testing positive for HIV.

Then there are insurers, employers and policymakers who await the information that will flow from genetic tests. Those identified as harbouring ill genes may fall off the map of concern and care, given the current political and economic realities.

*Have advance directives helped death with dignity?*⁵

When the US Congress passed the Patient Self-determination Act in 1990 it was hailed as advancing the rights of patients. Almost 40% of all deaths in the US follow withdrawal of life-sustaining treatment - often from a comatose or sedated patient - after protracted, agonising decision by family and physicians. To reduce such agony, the Act passed in 1990 required hospitals to inform patients being admitted to them of their legal right to refuse

life-sustaining technologies through advance directives such as living wills or documents authorising a spouse, relative or other proxy to make such decisions in the event of the patient becoming incapacitated.

Only 10-20% of American adults have, thus far, signed such advance directives. Conflicts and misunderstandings continue to arise over the proper treatment of the critically ill. A study of 9,000 patients reported in *Journal of the American Medical Association* in November 1995 found 'substantial shortcomings in care for seriously ill hospitalised adults'. Less than half the physicians whose patients had signed orders forbidding cardiopulmonary resuscitation were aware of the fact.

Some ethicists fear that this study might spur more calls for physician-assisted suicide of the kind offered by Dr. Jack Kevorkian. Dr. Joseph Fins, director of medical ethics at New York Hospital views suicide as a symptom of the problem, not a solution. Doctors, he says, must learn to view palliative care as an important part of their job. Court rulings, such as that in February this year, where a hospital that ignored a mother's plea not to put her comatose daughter on a respirator was ordered to pay damages of US\$ 16 million to the family, may force hospitals and doctors to pay more heed to the wishes of patients and their relatives.

Forms for advance directives ⁶

Hoffman et al discuss the forms in use in the US for advance directives and in a detailed review, point to inadequacies and problems posed by them to patients and relatives.

Examples are provided of forms demanding maximum treatment and those requiring only relief from pain under terminal conditions. Some forms took patients upto sixty minutes to complete. Under experimental conditions, up to 20% of subjects had difficulty with or needed some clarification on each question. Subjects showed inconsistency of response when tested under three different scenarios.

They conclude that there are significant risks in the use of 'standard' advance directive forms. Some are poorly designed. Filling these forms requires an educational level well above that of the average citizen. Forms used in many states have never been rigorously tested. 'With a poor form and a patient completing it under less than optimal circumstances, dangers arise that the form will be filled out incorrectly or in a way that does not reflect the individual's true preferences.'

Ethics of refusing life-sustaining measures ⁷

Powell and Lowenstein provide a case history of a thirty-seven year old woman with a brainstem stroke who went on to refuse all treatment, food and fluid and died. The various problems encountered are discussed in considerable detail. The role of stigma of permanent disability in provoking the desire to die is dealt with sympathetically and commands attention. 'Professionals can do everything that technology, creativity and hard work allows to open other options to (such) patients... to (help them) reach a quality of life that they find acceptable. If we truly accept the idea of independence for the disabled, we must also accept this choice.'

Rigged randomised trials ⁸

Kenneth Schulz and colleagues at the Center for Disease Control and Prevention question the equality of 'allocation concealment' - the process of hiding information about which patients will be assigned new treatment versus which will get conventional care. Doctors knowing that all patients registering on odd-numbered days will be given new treatment and those on even-numbered days conventional care may rearrange their appointment books - in the best interests of their patients - to undermine the intent of a randomised trial. Even when there is negligible evidence, doctors tend to believe that they know which treatment is most effective.

More sophisticated methods for allocation of patients make doctors go to even greater lengths to subvert concealment. Some doctors will open sealed envelopes, hold them over strong light or rifle a colleague's desk to learn the randomisation sequence. Trials with inadequate concealment numbered almost half of those studied and yielded estimates of effectiveness that were roughly 30% higher than those where allocation was properly controlled. Doctors convinced that the drug being tested would not work sneaked in their sickest patients into the treatment group instead of into the control group.

Schulz analysed a set of papers and found only 2% of tests indicated 'statistically significant' differences between controls and patients, putting the method used for the trial in doubt. Schulz and other statisticians will submit guidelines aimed at ensuring proper allocation later this year.

Ugandan symposium on bioethics of clinical trials ⁹

The summary of the proceedings of this

symposium make interesting reading. Uganda's current system of bioethical review developed, in part, in response to the increasing HIV research being conducted in that country. Uganda is plagued with social and economic inequality, a colonial past and the legacy of tyranny under Milton Obote and Idi Amin. We are provided a masterly understatement: 'Amin's actions were notably discordant with his words.' Uganda has found it difficult to follow the four principles - autonomy, beneficence, non-maleficence and justice -- wholeheartedly. The working group at the conference attempted to adapt these principles in a manner that would be culturally acceptable in Uganda. 'A significant amount of work remains.'

Moral issues of abortion ¹⁰

Abortion must be differentiated both from non-conception and from infanticide. This distinction is important as those favouring abortion suggest that when performed during the early stages of pregnancy, it can hardly be differentiated from non-conception. Those opposing it compare it to infanticide.

The main moral issue involved in abortion is: Can abortion be ethically acceptable at any point of fetal development? The author discusses when a fetus becomes a person, considering the range of views that a fetus is a person at conception, through the view that it is a person when it can exist independently to that which uses birth as the line of demarcation. Arguments against viability include its varying definitions under differing technological conditions.

The view that the fetus has no right to life independent of the wishes of its mother is also discussed. It is pointed out that a son cannot decide whether his aged mother, totally dependent upon him for survival, should die.

Mary Anne Warren postulated the following criteria for personhood: consciousness, reasoning, self-motivated anxiety, the capacity to communicate and the capacity to form concepts about oneself. Warren considers a fetus as not yet having developed into a person and therefore cannot be permitted to override its mother's right to obtain an abortion. The author of this essay appears to agree with Warren. If a woman has respect for the sanctity of human life, she should not support abortion but a woman also has duties towards herself, her family and society and in certain conditions, these duties might override the *prima facie* duty not to abort. The decision

should be left to each mother. 'I believe that every woman has the right to terminate an unwanted pregnancy.'

Paying participants in research¹¹

Dr. Moore discusses the thorny subject of whether subjects participating in research should be paid and, if they should, how much and in what form. Most ethics committees treat payment of participants with suspicion. Dr. Moore of the Philosophy Department, University of Otago, argues that 'it is ethically permissible for researchers to pay participants for their out-of-pocket expenses, participation, inconvenience and risk-taking.'

He considers the arguments against such payment - scientific integrity, community standards, inducement, exploitation, slippery slopes - and demolishes them. He concludes: 'Since there are good reasons to allow participant pay and no good reason to disallow it, ethics committees have some bad habits to change.'

Ethics in the professional curriculum¹²

During the last twenty years, the Centre for the Study of Ethics in Professions (CSEP) at the University of Illinois has been conducting 30-hour workshops for faculty members on how to integrate ethical values into their curricula. They have identified four objectives in the teaching of ethics:

- i) increasing the ethical sensitivity of students;
- ii) increasing the knowledge of relevant standards and codes of conduct;
- iii) improving their ethical judgements;
- iv) improving their ethical will power - their ability to live up to the highest ethical values.

They have used several techniques:

- i) providing the students literature on ethical values for independent study and then arranging discussions amongst them;
- ii) guest lectures;
- iii) showing films involving fine judgements about ethical values and asking them to react;
- iv) demonstrating during the course of regular teaching how even small deviations from ethical values may lead to harmful consequences for the profession and for mankind;
- v) developing and enforcing a code of conduct for students;
- vi) instituting regular courses on professional ethical conduct by a faculty that includes philosophers specialising in ethics;

vii) making ethics pervade the entire curriculum.

The Hippocratic oath (continued)¹³

Edmund Pellegrino is a distinguished and respected expert on medical ethics at Georgetown University Medical Centre in Washington D.C. He sounds a cautionary note. Whilst scientific and societal forces rightly subject the Hippocratic oath to critical review, the moral covenants at the heart of the oath must prevail if the interests of the patient are to be safeguarded. Pellegrino lists these covenants: the promises to act primarily for the benefit of the patient and not to do anything that will harm him; to protect confidences reposed in us by him; to refrain from having sexual intercourse with the patient or members of his family; to lead a life of moral integrity. Beneficence is central to medicine and does not conflict with autonomy. Trust cannot be violated. Those norms in the oath that are morally sound cannot be jettisoned.

Critics must counter moral precepts embodied in the oath with moral arguments and not those based on political, economic or social exigency. Pellegrino rightly goes one step further. Any ethic changeable by legal fiat ceases to be a viable ethic.

'No human being can escape the reality of being sick and being cared for. All must seriously contemplate what a divided profession without a common set of moral commitments would mean. Most important, we are obligated to ask how patients might fare in the hands of a profession with its moral fabric in tatters.'

Genetic screening and informed consent¹⁴

An editorial in *Nature* makes the astonishing claim that in the 'now-novel circumstances' of genetic testing, it is redundant to adhere to the ethical requirement to obtain a patient's consent. It suggests that genetic testing can only be a good thing even if nothing can be done about the disease susceptibilities thus identified.

Raffle discusses early diagnosis of cancer of the prostate and asks pertinent questions: What about the risk of revealing something spurious, irrelevant, untreatable or something that would never have troubled the person during their lifetime? Isn't testing people without fully informed consent an abuse of the right of individuals to make decisions concerning their own lives? 'Think of what you would feel if you

are told that you are amongst a substantial percentage of men with what a pathologist describes as early prostate cancer. You are well and are likely to remain so but now you are faced with the prospect of radical surgery of unproven value, which could render you impotent, incontinent or dead.' Is the powerful notion, that early detection must be a good thing, justified, especially since all methods of elucidating the consequences of early detection are fundamentally flawed? Finally, what about the cost? (Readers may also wish to refer to the essay by McCauley and Robin in *Issues in Medical Ethics* 1996;4:74-77.)

References

1. ten Have Henk AMJ: Medical technology assessment and ethics. Ambivalent relations. *Hastings Center Report* 1995;25:13-19.
2. Dwyer James, Cerfolio Nina, Murray Thomas H, Rosenthal Miriam B: Case study. The value of a uterus. *Hastings Center Report* 1996;26:28-29.
3. Post Stephen G, Fleck Leonard: My conscience, your money. Case study. *Hastings Center Report* 1995;25:28-29.
4. Jonsen AR, Durfy SJ, Burke W, Motulsky AG: The advent of the 'unpatients'. *Nature Medicine* 1996;2:622-624.
5. Horgan John: Right to die. *Scientific American* May 1996 p 12-14.
6. Hoffman Diane E, Zimmerman Sheryl I, Tompkins Catherine J: The dangers of directives or the false security of forms. *Journal of Law, Medicine & Ethics* 1996;24:5-17.
7. Powell Tina, Lowenstein Bruce: Refusing life-sustaining treatment after catastrophic injury - ethical implications. *Journal of Law, Medicine & Ethics* 1996;24:54-61.
8. Wallich Paul: Not so blind after all. *Scientific American* May 1996 p 20-22.
9. Loue Sana, Okello David, Kawuma Medi: Research bioethics in the Ugandan context - a program summary. *Journal of Law, Medicine & Ethics* 1996;24:47-53.
10. Chakravarti Koyeli: The moral issues of abortion. *Journal of Indian Council of Philosophical Research*, 1995;XIII:149-157.
11. Moore Andrew: The ethics of payment for research participants. *Otago Bioethics Report* 1996;5:2-4.
12. Kapur JN: Integration of ethical values in professional curricula. An American experience and what we can do. *Society for Scientific Values News and Views* 1996;4:2-4.
13. Pellegrino Edmund D: Ethics *JAMA* 1996;275:1807-1809.
14. Raffle AE: Trust me, I'm a scientist: will urologists set a lead for geneticists to follow? *The Lancet* 1996;347:883-884