International Journal of Risk & Safety in Medicine 11 (1998) 143–146
IOS Press

Hippocrates

The ethics of medical genetics

The broader the scope of medical practice becomes, the more frequently unanticipated questions of ethics seem to confront us. Genetics has been a thorny area from the moment that the possibility dawned of becoming involved with the natural course of heredity in any way, whether merely to make (sometimes unwelcome) predictions or actually to interfere in its course; the very prospect of human cloning has become the stuff both of sermons and of headlines, neither necessarily very helpful.

For the present, genetic testing and counselling is the issue most likely to challenge the practitioner's psychological and tactical abilities. In a thoughtful new paper in the *Canadian Medical Association Journal* [1], Burgess, Laberge and Knoppers consider among others the case of a woman who seeks DNA testing because she fears she may be a carrier of myotrophic dystrophy; the doctor takes a blood sample and merely suggests that she phone back in three weeks for the results – not the best way of learning what may be bad news. A second woman is afraid that she may have a familial risk of developing breast cancer; after genetic counselling and testing she is found to have the BRCA1 mutation; here too the outcome is wrongly handled – the counsellor presses her hard to tell her (hitherto healthy and happy) sisters, and succeeds in reducing her to a state of psychological distress.

A great many patients are now aware that genetic testing is possible. Most of them probably ask for it directly because of some apparent familial trait which they fear may affect either themselves or their offspring. In some situations a physician may himself have a duty to inform his patient that testing is possible; in Canada, as in several other countries, the courts have indicated that pregnant women must be informed that prenatal testing is possible [2,3]. In a very few situations indeed, a physician may feel that he should positively recommend the procedure, notably where the risk of a serious genetic condition in the offspring is present.

If serious psychological harm is to be avoided, the physician has to know and understand his patient as well as possible, and provide as much information as she (or he) needs and can digest in giving informed consent and understanding the outcome. How necessary is the test in this particular case? How reliable is the result likely to be? If the outcome is likely to be distressing, can the patient be helped to cope with it? What may the consequences be in terms of long-term health, insurability or employment? If the result suggests that other family members are at risk, who should inform them, when, and how? And if there is a need in the patient's own interests to withhold certain information, does the law allow for such a step?

Clearly, not every medical practitioner is well-equipped to tackle all these problems; some may wish to do so, but in that case they need more training in genetic counselling than they are likely to have received in their general profession education. For the moment, emphasis must surely be on ensuring that properly schooled genetic counsellors are available to handle these issues; as time goes on, they can only become more complex.

References

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Why do mothers still die?

In the World Bank's 1993 *World Development Report*, some positively frightening figures on maternal mortality across the world were lined up in tabular form [1]. Calculated for 1988 per 100,000 live births, the death statistics for low- and middle-income countries ranged from 60 in Europe and Central Asia to 686 in Sub-Saharan Africa. A table elsewhere in the report showed how dependent such figures were on specific changes in the social scene, with maternal mortality in Romania doubling between 1965 and 1989, largely as a consequence of a long period of prohibition of abortion for political reasons, then suddenly dropping back to pre-1965 levels when abortion was again made legal.

In Sierra Leone, no figures for maternal mortality were available in the eighties, though estimates had been made that it was as high as 450/100,000 for the whole country and perhaps in excess of 800 for selected hospitals or areas. At that time, however, a national plan for primary health care was approved, one of the aims of which was to reduce maternal mortality by 30% by the end of the century. Without a baseline for assessment, it is hard to evaluate achievements since then, but it is more than evident that they are highly disappointing. Virtually no change has been attained in fifteen years, and Sierra Leone is still probably in the worst possible situation of any country as regards maternal deaths. Why?

As a recent WHO review [2] concludes, "the overall philosophy of the programme, embracing preventive measures and community participation, was sound". A study in one particular chiefdom has, however, identified some of the causes for failure [3]. One seems to have been that the programme was not developed to the point where specific intervention techniques were selected and implemented. Most births were still conducted in homes poorly equipped to accommodate them, and in country areas too little was done to establish regular outreach clinics manned by travelling staff. At least as important, however, was a measure of indifference and even positive hostility to change. A vast number of women refused to use the services which were available, and failed to attend either antenatal or postnatal clinics on a regular basis. The primary health care services notably failed to make use of the existence of traditional birth attendants; experience elsewhere in Africa has shown how much can be attained by enlisting, encouraging and upgrading well-accepted traditional carers rather than spurning and competing with them. In other respects too, some staff attached to the official health services showed resistance to development and improvement.

This is an all too familiar story in health development programmes intended to provide better and safer care. They are too often devised behind the conference table, introduced with much aplomb, set into motion without sufficient thought, and then imposed upon a community and a health service which has not been motivated to accept them.

References

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Abdominal surgery and the airways

It is a well-recognized problem that upper abdominal operations are not uncommonly complicated by respiratory problems; depending on how one defines and classifies them (for they vary from mild hypoxia to severe pneumonia) the incidence of such complications may be as low as 10% or as high as 80%. For many years there has been a widespread belief that giving appropriate physiotherapy prior to operation could reduce the incidence of such problems, but the matter has never been adequately studied.

Happily, in the tradition of "evidence-based medicine", a Swedish group took upon itself the task of testing the approach methodically [1]. Fagevik Olsèn and his collaborators carried out a randomized clinical trial involving 368 patients whose ages ranged from 19 to 92 and who were due to undergo elective surgery of the upper abdomen. A subclassification distinguished between low- and high-risk subjects. After randomization, 174 patients received preoperative physiotherapy comprising respiratory exercises as well as training in coughing up sputum and in correct supine posture. High-risk subjects also underwent positive-pressure breathing exercises. Following operation, the treated patients were compared with the 194 who had received no physiotherapy or training; test measures used included oxygen saturation, forced vital capacity and maximum expiratory rate. Chest X-rays were taken prior to operation in patients with any known lung disorder and in those aged over 50; X-rays were taken post-operatively in any case where there was clinical evidence of pneumonia.

Two patients in each group had to be excluded from analysis for various reasons, but the findings were very clear. Respiratory complications were seen in only 6% of the patients who had received preoperative physiotherapy but in 27% of controls – a highly significant difference. What is more, patients given preoperative physiotherapy could be mobilized earlier and had better oxygen saturation than controls. In the high-risk subgroup, complications were noted in 6 of 40 patients receiving physiotherapy, but in 20 of 39 contrrols.

It takes some courage to carry out a study of this type. Surgery still lags rather behind internal medicine and pharmacology in carrying out randomized clinical studies to verify its methods. Such an investigation as this would in any case only be feasible in a centre (and in a situation) where there is real doubt as to the benefit of a particular prophylactic measure, so that no serious ethical objections to introducing a control group arise. Where such studies can be performed, they surely should be if we are to separate the prophylactic wheat from the chaff.

Reference

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Waking up to antibiotic resistence

How massive, how destructive, how menacing to humanity must a problem become before anyone cares about it? This *Journal*, in its ten volumes, has said much that can be said on the subject; Geoffrey Cannon's magnificent *Superbug* in 1995 documented the threat in a manner much more imposing than its title may have suggested [1]. Scandinavia's Tore Midvedt and Britain's Richard Lacey have hammered on the issue for years. And still, it seems, the people who matter remain apathetic. So do the media; we are all much more concerned, it would appear, about the infinitesimal risk of a meteor striking earth than

we are about the terrifying spread of multi-resistant microbes – a preventable problem if ever there was one.

This is not the place to document the drama all over again. Suffice it to point to the conclusions of a meeting of doctors convened by Uganda's ambitious National Drug Authority in September 1997 which showed that, in city hospitals, 75% of patients were no longer responding to the common antibiotics which the Ugandan community was able to afford [2]. At the other end of the world, Norway's Health Inspectorate rang the alarm bells in July 1998 with its finding that the rate of encounters with resistant antibiotic strains had already doubled in the course of the first six months of the year [3].

The difficulty is not under-recognition of the problem; everyone with any competence at all in the field knows that it is there. One suspects that the main reason for widespread indifference is that antibiotic resistance is for many people (whether professionals or patients) the other fellow's problem. Someone else will suffer, someone else is to blame. And still the world-wide trade in antibiotics flourishes largely because of unnecessary use and extravagant choice, egged on by shameless advertising and hard commercialism. Rumour at least has it that some praiseworthy initiatives behind the scenes of the World Health Organization have been sabotaged by the representatives of countries enjoying a profitable export market in antibiotic agents. This little column can do nothing about it except weep; those who raise louder voices in protest find themselves dismissed as agitators and scaremongers, if they are not altogether ignored. When will someone care sufficiently to put survival before money and open the doors to real action?

References

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