Bioethics

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The Medical Profession and its relations with the drug industry

Recent articles by Ray Moynihan in the BMJ (30th May, 2003), highlighted in the SYNAPSE website) deal with the relationship between the medical profession and the drug industry. In the United States, drug companies sponsor close to 300,000 events for doctors every year as part of their promotional efforts, it says. One could add that in Malta also one can hardly hope to organise a seminar for practitioners unless they are enticed to attend with the offer of a free lunch or other handouts.

The Article adds that the University of California at San Francisco (UCSF) is considering plans to end free lunches sponsored by drug companies and to remove drug representatives. Elsewhere, medical reform groups and student associations are also calling for dis-entanglement from drug companies, and foster independent education and sources of information.

One could question the ethical implications of sponsorship of drug companies. On purely management grounds, drug companies obviously think it is useful to support such meetings and provide free lunches with the information they impart. The feeling is growing, however, that this could influence prescribing practice to the benefit of the drug companies.

"In some ways we are all addicts to big pharma's money," argues Chief Executive Officer of UCSF Medical Center, Mark Laret, "but we are going to have to wean ourselves off a dependency that is generally inappropriate. This relationship is one of those things we need to clean up. The sooner the better."

In this Issue:

Ethics, Science and Society Conference

Villa Bighi provided an unusual backdrop for the one day conference on this topic, organised by the Bioethics Consultative Committee recently. It was open to all those interested in the impact of science on society. Speakers included Professor Judit Sandor from the University of Budapest, as well as several local speakers, including, Prof Alfred J.Vella, Dean, Faculty of Science, University of Malta, Prof Albert Leone Ganado (Computer Information Systems), Prof Alex Felice (Department of Physiology and Biochemistry), Dr Marion Mangion (Junior College), as well as ethicists Prof Rev Emmanuel Agius and Dr Pierre Mallia. The meeting was opened by the Hon Dr Louis Galea, Minister for Education, and concluded by the Hon Dr Louis Deguara, and was chaired by Professor Maurice Cauchi.

The range of topics included the role of the scientist in society, the restraints that need to be exercised, the role of the public in monitoring advances in science, and in particular the role of legislation in ensuring adequate standards and conformity with practice in Europe. The particular thorny problems of genetic diagnosis and protection of data emerging therefrom were of particular interest.

It is expected that, as in previous years, the proceedings of this symposium will be published soon, so that those who missed the opportunity of attending, might still benefit from the comments expressed there.

Biomedical Research - Council of Europe Protocol

At the latest meeting of this committee in Strasbourg in June, this Protocol was finalised. While the purpose of this protocol is to encourage biomedical research, it also ensures that bioethical issues are given due consideration.

As a general rule, research on human beings may only be undertaken if there is no alternative of comparable effectiveness. It may be carried out only if the research project has been approved by a competent body after independent examination of its scientific merit. The Research Ethics Committee must be an independent body, whose members must declare all circumstances that might lead to a conflict of interest.

Important sections of this Protocol deal with the subject of information and consent of the participants, as well as measures to be taken to protect them. Particularly important considerations relate to inclusion of persons not capable of giving consent where research regulations are particularly tight. Special situations where research has to be limited include research on pregnant and breast-feeding women, research in situations of clinical emergencies, and research on persons deprived of liberty, or unable to give consent, such as children and the handicapped.

Confidentiality has to be respected with all aspects of information derived from patients. Research participants are entitled to know about information collected on their health.

Researchers are expected to submit a summary of their results to the ethics committee and take measures to make the results available to participants as well as publish their research findings.

Other aspects of the Protocol deal with research performed in a country which is not a party to this protocol (which currently includes also Malta), and with compensation for damage.

Genetic testing and Paternity

This topic has emerged again in the popular press, with yet another private laboratory advertising its services for what has been called “adultery tests”.

Genetic tests are different from most other tests because of the permanency of the findings, as well as the impact they may have on the whole family and not just the individual patient.

In all such tests the welfare of minors is of particular importance. No genetic tests should be performed on children (including tests which might have a predictive/diagnostic significance). The general rule is that these tests should be performed on a child only if they have an immediate bearing on his health condition, otherwise they should be delayed until such time as the individual concerned reaches the age of maturity when s/he can decide whether to perform the test.

With regards to paternity cases, the courts are best placed to decide whether it is in the interest of the child to have genetic tests performed. The worst-case scenario is to have a situation where an irate husband demands that his children be tested with little or no counselling, simply because such a test is available on the market. It should not be left to the market to decide when to perform such tests.

One question that needs to be asked is whether the family doctor is in a position to be the person who gives such counselling, or whether such delicate decisions should be handled by expert geneticists and counsellors.

It is to be emphasised that no one may surreptitiously undertake to perform any test (and particularly DNA tests) without the knowledge of the person from whom the material originates. Even the performance of the most humble clinical test assumes that the person concerned has given his or her consent.

End-of-life decision-making in six European countries

Doctors from six European countries (Belgium, Denmark, Italy, the Netherlands, Sweden, and Switzerland) took part in a study to examine the type of end-of-life decision they are faced with.

Doctors in these countries were requested to give information about their practice. The number of patients varied from around 3000 to 5000 patients in each country, and a response rate of around 60-70% was achieved.

The study confirms the relatively high rate of euthanasia in the Netherlands, which at 2.59 % is about ten times higher than any of the other five countries examined. On the other hand, doctor-assisted suicide was highest in Switzerland with a rate of 0.36 per cent.

Of interest also is the finding that alleviation of pain and symptoms with possible life-shortening effect was found in over 20 per cent of all patients, a figure which varied only minimally from country to country.

(THE LANCET • Published online June 17, 2003 • http://image.thelancet.com/extras/03art3298web.pdf)

Publications by the Bioethics Consultative Committee

Bioethics: Responsibilities and Norms for those involved in Health Care (Ed. T. Cortis, 1989)

Informed Consent: Proceedings of a Symposium for Medical and Paramedical Practitioners. (Ed. M.N. Cauchi), 1998. ISBN 99909-68-68-3

Proceedings of the Conference on Bioethics and Disability (Ed. M.N. Cauchi) 1999. ISBN: 99909-993-0-9

Patients' Rights, Reproductive Technology, Transplantation. (Ed. M.N. Cauchi), 2000. ISBN: 999009-993-1-7

Inter-professional Ethics in Health Care. (Ed. M.N. Cauchi, 2001) ISBN: 99909-993-2-5

Bioethical Issues at the Beginning and End of Life. (Ed. M.N. Cauchi,2002) ISBN: 99909-993-3-3

Children and Maltese Legislation: Ethical Aspects

The recently introduced Bill namely, ***The Commissioner for Children Act***, enforces the articles of the ***Convention on the Rights of the Child*** adopted by the UN General Assembly, 1989 (and signed and ratified by Malta 1990). This Act will establish the post of Commissioner for Children to:

- Promote and advocate for the rights and interests of children,
- Ensure that children's opinions are given and considered,
- Protect family unity,
- Advocate adequate support for parents,
- Develop alternative care for children in need,
- Ensure that the rights and interests of children are taken into account by governmental and other organisations when decisions on policies affecting children are taken,
- Protect children from physical or mental harm, neglect and sexual abuse or exploitation,
- Promote the highest standards of leisure, play and recreational facilities for children,
- Ensure measures are taken to prevent and remedy poverty and social exclusion among children,
- Promote compliance with the United Nations Convention on the Rights of the Child as ratified by Malta.

In achieving these functions, the Commissioner should be guided by the general principles relating to achieving the best interests of children and the family, respect for the dignity of the child, with particular emphasis on children with disability or those from disadvantaged families, and that children are given the opportunity to participate in decisions that affect them.

The Commissioner is requested to monitor the situation and provide public education, collect information relating to breaches of the rights of children, encourage research, and in general ensure that services for children are adequate and relevant.

This Act also sets up a Council for Children with the specific aim of monitoring compliance with the UN Convention on the Rights of the Child.

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