Bioethics

Newsletter issued by Bioethics Consultative Committee

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# Screening Programmes: Are they ethically justified?

The aim of a screening programme is to detect disease in a healthy population prior to its clinical manifestation. The aim, laudably enough is to prevent disease, to detect it at an early stage, or to be in a better position to give advice about risks to certain diseases and to treat them when detected. There are currently thirty-five screening programmes fairly widely used, ranging from mammography to cervical cancer screening. With the introduction of DNA testing this number could easily increase a hundred-fold.

Questions which many are asking now include the following:

- Will healthy people – the majority tested-benefit from such a procedure?
- Will the psychological trauma caused in the majority compensate for the benefit of the few?
- Could the money spent on such procedures be spent more profitably elsewhere (opportunity cost argument)
- What is the impact of false positive and false negative results?
- Is information given to patients adequate ?

A recent report by the Danish Council of Ethics (2001) shows concern that "the majority of screening programmes are initiated on an inadequate basis and with too great a degree of haphazardness in the decision-making process", and that the recommendations of WHO on the implementation of screening programmes are not being followed .

Before embarking on a screening programme, there should be a well-worked-out policy relating to aims and expected outcomes. Patients have to be informed adequately about the benefits and disadvantages of participation. In particular there should be a well-organised system of dealing with the results obtained from any such testing.

# Should the Courts prevail over the wishes of parents?

In normal circumstances there should be no interference with the wishes of parents, and these should prevail.

However, there are several situations where this is not desirable:

**1.** When parents are deemed incapable of good parenting: Examples include cases of neglect, battered babies, etc., The State has to intervene in the interest of the child

**2.** There are situations where the parents behave with the best of intentions but where their opinions are in conflict with the views of the majority within the community, and their actions (or inactions) will result in damage to the child. Most often these are based on religious convictions. The most obvious cases involve those children of Jehovah witnesses requiring a life-saving blood transfusion.

**3.** Where the parents' views conflict with those of a child, who, while legally under-age, still has rights which increase commensurate with age. Courts in the UK have decided for instance, that a 16 yr-old girl had the right for contraceptive prescriptions, against the knowledge (and presumably wishes) of the parents. It is interesting to note that the right to refuse treatment is more rigidly controlled, and parental wishes are usually required and often adhered to.

**4.** Where the wishes of one parent conflict with those of the other parent. Here the Courts have to decide whose wishes are in the best interest of the child.

**5.** There are situations where parents insist on treatment which is considered not in the best

interest of the child. For instance, some parents may insist on "extraordinary" and heroic treatment, in their effort to ensure that everything possible is done. A Court might rule that such treatment is not desirable –ie. nature should be allowed to take its course.

**6.** Refusal of treatment by parents. A number of situations have arisen where parents have requested that no treatment should be instituted for a severely malformed infant. Cases include surgery for Down's syndrome babies, or for hydrocephalus babies. The Courts have taken the view that when surgery can offer a reasonable quality of life, then treatment should be instituted. The criterion here is whether the child would have made such a decision "if he were in the position to make a sound judgement".

These are situations where Courts (particularly in the UK) have overridden the wishes of parents. Consensus in these areas is hard to achieve – even the final arbiter in the UK, the House of Lords, has been divided on a number of these issues.

It is essential that every effort should be made to ensure that parents are given the best information and advice available so as to avoid the possibility of such tragic conflicts. It is likewise crucial that the needs and long-term interests of the child are always held to be of paramount importance. This is the primary role of the Courts in such instances.

Cardinal Newman: knowledge and virtue are not identical, and the expulsion of ignorance by knowledge will not be enough to deal with the spiritual realities and moral challenges of the future.

## Genetic Testing: What precautions?

It is accepted today that the principle of informed consent should penetrate into every aspect of doctor-patient relationship. No procedure should be performed without the tacit, and often the explicit consent of the patient. This is essential not only in clinical diagnosis and treatment, but holds equally for the performance of laboratory tests on specimens taken from the patient.

The recent public outcry in the UK about pathology specimens kept in museums for teaching and research purposes highlights the issues and emphasizes the wide gulf that has separated medical practice from patients' knowledge. Time was when a post-mortem was performed automatically without the patients' relatives even knowing about it. What was tolerated a generation ago is no longer accepted nowadays.

This holds particularly for genetic testing. It is now possible to isolate DNA from a minute amount of blood or tissue, and to perform complex tests which identify a patient's genetic profile, including susceptibility to disease. This breakthrough has been hailed as the greatest achievement of science in the past century. But is it all a blessing?

Criteria which hold for ordinary diagnosis should be even more strictly enforced in the case of genetic testing. Not only is it essential that adequate information be given to the patient, but since such tests usually impinge on the family as a whole, this should also be taken into consideration. We should avoid the conundrum of having to explain to a patient that a husband or relative should be made aware of the results of genetic testing. Such information has to be given beforehand, and not after finding a potential disease-carrying gene.

Likewise, what is the ethics of testing for conditions for which there is no treatment in this country? Some would say that it is unjustifiable to proceed with tests which can serve only to increase the amount of anxiety in the patient.

DNA testing is a procedure which is here to stay. However, it would be a great pity if it was misused as many screening tests have been misused in the past. Above all, it should be made mandatory that all such tests were performed only when full information has been given to the patient by persons well versed in such procedures.

# Research Ethics: An Unsatisfactory Situation

Much lip service has been given to the value of research within an institution such as a medical school or a teaching hospital. Often research is seen as a necessary adjunct to clinical experience essential for advancement up the promotions scale.

More and more, we are reaching the stage where successful research is no longer the domain of dedicated individuals working is semi-isolation, but more and more a highly organised multi-team and often inter-national effort.

In such a scenario, the ethical control of research has become a very important aspect ensuring not only a high level of scientific value but also that the procedures are acceptable and that the patient is not instrumentalised, becoming merely an object of investigation. The emphasis placed by first-rank journals on ethical clearance of all papers submitted to them highlights the importance they give to this process.

Unfortunately, in Malta we are still labouring under conditions which would be unacceptable elsewhere. The Medical School has had a Research Ethics Committee now for the best of a decade. However its impact on medical research has been limited for a number of reasons:
There is no statutory obligation on researchers to submit their project to a Research Ethics Committee. The result is that the vast majority of research projects carried out in this country are not subjected to Research Ethics scrutiny at all. The current Research Ethics Committee has no power to oversee the progress of research. In other words, the onus of following the set protocol is put entirely on the research worker. There is no equivalent Research Ethics Committee to deal with projects from a variety of non-medical researchers, including psychologists, social workers, etc.

There is a tendency in this age of globalisation for inter-national organisations to gravitate to those areas where ethical control is least effective, and therefore where costs of research are reduced considerably. Malta should be aware of these developments and should not encourage them in any way.

# Doctors and Pharmaceutical Companies

In a recent article in the New York Review of Books (May 17, 2001) reflecting on the rise and fall and rise again of Thalidomide , Richard Horton has some hard comments to make about the medical profession. He says:
"the relationship between many doctors and pharmaceutical companies has now become close to corrupt. As of December 2000, twenty-seven members [of the Committee on Safety of Medicines in UK] had declared industry interests. These included shareholdings, fees, consultancies, non-executive directorships, grants, and financial support to attend meetings."

He continues:
"The research process itself is also immersed in a financial quagmire of conflicts of interest. A recent study at the University of California San Francisco found that a third of faculty investigators received payments from companies for delivering lectures and accepting consultancies. Ownership of shares in pharmaceutical companies and personal financial ties are common. Prestigious medical conferences organized by some of the world's most respected specialist societies - e.g. The European Society of Cardiology – are now packed with industry-sponsored symposia promoting a product, a company, or both.

"There is, moreover, convincing evidence that in some cases the opinions of medical experts can be bought by the highest bidder. Doctors who take money from drug companies are more likely to sing the company line – hidden anxieties about safety – than those who keep their hands firmly in their pockets. Such is the atrocious venality of modern academic medicine."

## Members of the Bioethics Consultative Committee:

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| Dr Paul Vassallo Agius | Paediatrician |

## 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

Interprofessional Ethics in Health Care. ( Ed. M.N.Cauchi, 2001) – In press

## Meeting of The European Society for Philosophy in Medicine and Health Care, Malta 2002

The European Society for Philosophy in Medicine and Health Care has chosen Malta to be its venue for its annual meeting in 2002. This society (ESPMH) is the largest structure of academics in Bioethics. It was started at the Catholic University of Nijmegen, Holland some ten years back and has since grown into a structure pursuing EU academic projects and having its own journal. The Bioethics Consultative Committee has appointed a subcommittee to organize this conference here.

Further information about this Conference will appear in this Newsletter in due course.

**Address for Correspondence:**
*The Bioethics Consultative Committee,*
c\o Ministry of Health,
15 Merchants St, Valletta.
Tel: (356) 246136
Fax: (356) 225028
E.mail: mcau1@um.edu.mt
Website: http://www.synapse.net.mt\bioethics

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