Centre for Bioethics and Patient Advocacy

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The aim of having a Centre for Bioethics and Patient Advocacy (or Centre for Bioethics, for short) is to have a centre for academic excellence in bioethics, which is still lacking in Malta. The objectives are met by:

1. Providing scholars and health professionals with a forum for encounter and to sustain literature in the field;
2. To participate in local and international projects and seminars in the field;
3. Study local issues as they arise, including patient and research issues;
4. To provide good clinical practice standards with particular reference to research.

The Centre is an independent entity and although the board is composed mostly of university scholars, it remains independent from this institution. It is not therefore a University initiative, although one must admit that the board is studying whether it should be maintained under the aegis of the University or not. The board remains composed of people who are either experts in the field, or who have relevant experience to contribute.

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Scholars, up till now, have participated in the teaching of ethics, where this was approved either formally or informally; they have participated in debate only when requested to do so and through the limited forums of the country. However there are problems with this scenario - local ethics committees, for example, do not have the resources or remit to be a centre of academic excellence. Conversely a lot of debate goes on in the media. This is acceptable and also important. But certainly it is not the forum for scholarly research and where to express, debate and develop opinions.

Scholars, be they students or lecturers, in the field, need to participate in international meetings, especially those relating to their area of research. At the moment for example, the centre is participating with the European Forum for Good Clinical Practice on research in children and on children's medicines. Funds are necessary to participate in these meetings. The Centre thus uses its resources to be able to advance the professional development and involvement in such areas.

On the other hand there are local issues. These range from issues pertaining to patient rights, such as health insurance, to issues which may pose moral problems in the local context such as the recent attempt to legislate IVF regulation. When evaluating the outcome of this attempt, one should also consider that the lack of support for an academic forum at a tertiary level has contributed negatively to this effect.

Research (on human subjects and on animals) is an area not only of great interest, but of great importance to the advancement of health care. The awareness of ethical standards should not be there to hinder such research, but rather to aid it. Whilst researchers may have a need for clarification of issues such as how to obtain approval from an ethics committee, or how to properly obtain an informed consent, the public may need help in understanding the need for research and what they are gaining or giving up (if anything) in the process. This therefore does not only apply to research on humans, but also to research on animals. There is no legislation or framework to allow research on animals to go on unhindered. It is acceptable having people on committees from animal rights group. However it is not acceptable when these individuals are not acquainted with international guidelines on research on animals – which is in fact not prohibited, but regulated.

These issues are discussed in the courses on Research Ethics which the Centre has been offering. These courses are an end in themselves. Since the Centre is independent, they are not university courses; they are merely intended to provide knowledge in an area that needs dissemination.

What does the future hold? Certainly the first objective is to see whether the centre should remain independent or form part of the University of Malta. There are pros and cons to this. Independency must be maintained in order to respect the main aim and objectives. On the other hand, when it comes to teaching, a certain degree of mutual cooperation with our tertiary institution should be in place, for this to happen.

There is more to bioethics however than abortion, euthanasia or IVF. Bioethics is about bringing people from different areas together in order to reach solutions to individual rights and freedoms. What should primary care in the future hold for the patient? What is the position of patients who are informed by their insurance company that it wishes to have a look into their hospital file after they have made a claim? We can bring concerned parties together in a forum to discuss these issues and reach appropriate agreements. Although insurance companies must look into risk analysis, this must be balanced against the rights and freedoms of the individuals.

The Centre is certainly in its embryonic stage, but the work it has done has already generated interest and concerns. Important courses such as Research Ethics, and Law and Medical Ethics have already been offered and a course on Genetic Counselling and other topics are in preparation.

The Centre already has links to various organisations and is handling a joint conference between the University of Malta and the University of Montpellier on bioethics. Of course there are those who would have reservations, and those who may frown upon such initiatives. But perhaps that is a characteristic of our island nation. Certainly there is an academic void. Certainly as well, our survival naturally depends on the good will of those involved.