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“The principle of justice must be safeguarded in the application of new biomedical advances”

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Why bioethics and not simply ethics? What does it involve exactly?

In fact the word itself, bioethics, defines its own meaning. We are talking about ethical reflection applied to the field of the biomedical and life sciences in general: bio. Bioethics is a discipline the main characteristic of which is to create a dialogue between the fields of knowledge of biomedical and biological sciences and the humanities (philosophy, ethics, theology, law), along with the social sciences (sociology, politics, economics...), beginning at the point where the application of new advances in these sciences collides with established values in a given social and cul-

tural context. At this point we must stop and reflect as to whether such applications are compatible with certain ethical values, and what channels of consensus can be achieved in order to resolve these conflicts (life vs. knowledge and research, life vs. quality of life, etc.).

How and when do ethical reflections concerning health arise?

It is medical and healthcare practice itself which gives voice to this need for reflection in response to the actual conflicts which doctors raise in cases of the specific treatment of patients. The greatest impetus came from medicine in the second half of the 20th century, with the development of technologies such as dialysis, life support machines, new surgical techniques, etc., leading doctors to ask themselves what was best for the patient, if all that could technically be done should actually be done, how to establish fair principles for access to technology when it is scarce and demand is particularly high, etc. This whole debate, which began at the major American hospitals, moved on to the academic world at universities, and that is where the need was raised for such reflection to be enriched through the perspectives of philosophy, ethics and the different theologies (Christian, Muslim...).

This is what gave rise to the term bioethics itself, and the foundation of the world's first centres for bioethics, specifically the Hasting Center (1969) and the Kennedy Institute of Ethics (1971), which remain the benchmarks worldwide. Following on from this, some years later, bioethics arrived in Europe and gradually developed across the world, focusing not only on the field of new biomedical advances and

research, but also making inroads into the field of the recognition of patient rights, gradually leading to a complete paradigm shift as to what healthcare represents.

How does bioethics impact on the daily work of doctors and nurses?

I would prefer to talk about the impact it should be having, as we are unfortunately still a long way off the level of awareness of such issues which would be desirable among the professional healthcare fraternity. I understand that doctors and nurses (including nursing assistants) are the individuals closest to the patient, in a situation of vulnerability, and that they are required to demonstrate both technical and human excellence. Given this context, many of the actions and decisions taken day-to-day in a hospital or healthcare institution, whether or not we are talking of extreme clinical situations or cases, have a bioethical aspect. This is because the impact they have on the patient in a given situation, which may be more or less serious, is for them, the patient, the most important factor, and also has an impact on their physical or psychological integrity. Questions such as information, personal treatment, confidentiality, respect for the patient's freedom of choice, etc. form part of daily life, and so represent a constant presence in everyday affairs.

Unfortunately, our healthcare professionals begin caring for patients without having received training in clinical relationships and communication, the rights and duties of patients, the ethical conflicts of life and death, or principles for the limitation of treatment and appropriate palliative care when a cure is no longer possible, etc. Right now, the only way to improve these aspects is to provide post-graduate training as part of lifelong learning in the healthcare professions, providing these essential elements as a supplement to their technical knowledge. That is one of the tasks we perform at the Institute.

How is its presence organised within healthcare structures?

The presence of ethical reflection within healthcare structures can be established by means of various mechanisms. On the one hand, teams must themselves promote dialogue and reflection as to clinical cases in those aspects which go beyond the specific medical problem or pathology, including in their discussions every aspect of the patient's case in personal, holistic terms, not considering simply the illness.

Meanwhile, we have for some years now in Catalonia and the rest of Spain seen the gradual development of healthcare ethics committees. These are consultancy and advice bodies for professionals, of a multi-disciplinary nature (with a rotating presence on the part of doctors, nurses, social workers, experts in ethics, lawyers...), who perform an important and helpful task of analyzing complex cases involving ethical conflicts which are difficult to resolve. This is not yet the case at all hospitals and healthcare institutions here, but more and more are being set up, and those which have been in operation for some years are developing their experience and track records, with positive results. It is also very important to highlight the fact that such committees can never serve to provide final resolution or binding judgements, but simply advise, with the ultimate decision always lying with the doctor involved.

I believe that considerable progress has been made in this field over recent years. Although traditionally references to ethics in the field of health have assumed aspects of morality and religion, we have now succeeded in making the appropriate distinction between one thing and the other, and can now see ethics forming part of the *modus operandi* of healthcare... but I do feel we still have a long way to go...

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And how can patients be helped when making bioethical decisions?

Every individual has his or her own personal ethics, although they may not at times recognise or be able to express this... Our personal history, our cultural and educational baggage gradually shape us as people over the course of our lives, and we build up our own ethics, more or less guided by the upbringing we have received. If a person is in a weakened state, suffering an illness, any action affecting their physical or psychological integrity is experienced as an intrusion which must be undertaken with care and respect. Such procedures can lead to ethical conflicts, because the values of

the patient may not coincide with those of the professional, or the ethical justification of the measure or treatment proposed by the medical team. It is in such situations that patients will particularly appreciate appropriate handling of the resolution of such ethical conflicts, which involves listening to their opinions, taking the utmost efforts to respect their values and, in the event of an irreconcilable conflict, through recourse to other support mechanisms, such as committees or team meetings.

If the professional set-up dealing with the patient deals properly with these aspects, the perception is positive and the individual feels

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respected and well cared for. If we do not observe such respect and instead attempt to impose our own judgement and value system, we are not acting with a bioethics mentality this should be based on dialogue and the quest for consensus, with the result that patients may feel they have not been properly tended to and that their rights have been violated.

What are the main current concerns within this discipline?

In academic terms, I would say that one of the main challenges, as I mentioned earlier, is that of ensuring that the discipline of bioethics is included as a subject or core module on all professional healthcare courses, meaning that individuals would begin their professional career with a good knowledge of the subject.

This is a difficult goal to achieve, as a number of different attempts have been made to revise medical degree programmes, as yet without success, and here we still lag some considerable way behind the training seen in other European countries, where bioethics has been an integral aspect for some years.

From our perspective, as a university institute we feel particular satisfaction that our Master's in Bioethics has received accreditation as an official university master's course within the European higher education framework (known as the Bologna Plan), meeting the very high standards of pedagogical and academic quality. Although it remains a post-graduate training course, it does form part of

the lifelong learning of practising professionals, and therefore at least it is one way of providing essential knowledge within the formal university structure.

Does the media focus too much on one-off, dramatic cases?

I believe that the media have enormous power over society, and consequently great responsibility when they deal with such issues affecting the life and health of people. In this regard, I do not view the fact that certain events make it into the media sphere as always a negative, provided that the issue is properly handled, the information is unbiased, there is no attempt at sensationalism or a focus on the more gruesome aspects, and that the media are not skewed by a particular ideological stance, although this is a rather utopian desire in today's society.

I do believe that bioethics deals with issues of general popular interest, as we all live and die, and so could all find ourselves prey to an illness, needing assistance from science, at any point in our existence. One good example of this would be the fact that the major social debates in bioethics (when life begins, abortion, euthanasia, AIDS, etc.) clearly do arouse popular interest and grab people's attention, becoming the subject for everyday conversation as soon as a case is published in the press. Everyone has an opinion, a personal view, based on multiple factors: culture, upbringing, beliefs... That is why it is important to spread knowledge in order to create informed public opinion, and that is why I also feel that we should demand that the media operate in accordance with clear ethical principles and with social responsibility in the task which they perform.

Meanwhile, I feel that today's society has lost its values, its capacity to reflect and think beyond the immediate moment and the one-off situation, and that this is a major problem which often prevents us from reflecting seriously about issues of general interest, as other neighbouring countries have done when, for example, legislation has been proposed to decriminalise euthanasia or abortion...

Autonomy, beneficence (to do good), non-maleficence (avoiding doing harm) and justice... are these still valid principles?

I would say so. The principle of non-maleficence is as old as the ancient Hippocratic tradition of *primum non nocere*, and could be viewed as a universal or principle of the first

order. The other principles are also up-to-date, as they were initially drawn up as a result of the research involved in the Belmont Report, with its proposal for beneficence, autonomy and justice. We cannot, however, claim that these principles are fully integrated within our healthcare world, since for example there is still some considerable way to go before professionals have a clear idea of what the principle of personal autonomy means, beyond legal informed consent forms, or to ensure that the principle of justice is taken into consideration in their clinical decisions. Meanwhile, we must not overlook other proposed principles based on concepts of vulnerability or the dignity of the individual, which have also been created by a more European healthcare model, not based so much on the contract mindset of Anglo-Saxon countries governed by the law of the market, but the values of a welfare state... We must also continue our work along these lines.

How does the legal framework affect bioethics? Are we looking at recommendation or regulation?

It would be fair to say that both apply, recommendation and regulation, although over the last 25 years a great many legal provisions have been drawn up to cover issues which had previously been the subject of self-regulation by the professions or which, at the most, were included simply in scientific protocols or broad declarations of principle, with no binding power. In Spain specifically, after the transition to democracy lawmakers became very busy in areas of bioethics, in fields such as transplants and assisted reproduction, the clear definition of patient rights, biomedical research, etc. The main reason for this is the difficulty in reaching an ethical consensus as to what is right and wrong in a plural and incre-



asingly global society, with the risk of extremism, meaning that the law would seem to be the only way of establishing one common yardstick and inviolable limits.

I do, however, feel that lawmakers often attempt to cover everything by regulation, without leaving space for reflection and ethical consensus within professional bodies themselves. This has been harmful in that it has often led to defensive medicine, a call on the part of professionals for a regulatory framework providing them with security, and undermining their own initiative or innovation.

Although it is true that the law and vision of legal theorists must play its part in the bioethical dialogue, this must be to an appro-

priate extent, without allowing the law to replace ethics or the capacity for reflection in value conflicts. Unfortunately, ethics and the law do not always go hand in hand...

Stem cells, cloning... what will be the main problems of the future?

The issues which have always aroused the greatest attention in bioethics, since its very outset, have been those connected with the two essential moments of existence: the start of life and the end of life. Although we have been reflecting on all this for some 40 years now, we have not yet achieved a clear consensus as to these issues, and continue to debate the value of the human embryo, what is ethically



acceptable and what is not in the field of human reproduction, research, etc. The same situation arises when we consider the end of life, where we have gradually made slow progress in establishing criteria for the quality of life, the limitation of treatments to avoid unnecessary prolongment, to develop palliative care for terminal situations, etc. There is still, though, a more philosophical debate as to control over life itself, to what extent a person can choose when and how he or she is to die.

Beyond these core issues, one of the most cutting-edge aspects on the table involves genetics. Our knowledge of the human genome and the therapeutic applications of this for humanity is one of the fields arousing most

concern today. In particular to ensure that proper use is made of our knowledge and that the application of genetics is not biased by personal or commercial interests.

Meanwhile, increasing globalisation demands that we engage in bioethical reflection in order properly to apply the principle of justice in the implementation of new biomedical advances, in order to ensure that they do not simply benefit a number of wealthy countries, but that international organisations can also safeguard North-South solidarity... This is a challenge which goes beyond the professional and individual sphere of each person and which is the responsibility of the great established powers in the mightiest states.



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What role does the Borja Bioethics Institute play?

It is a University Institute, the first of its kind in Europe, established as a bioethics centre in 1976 by Dr Francesc Abel. It is a partner centre of the Ramon Llull University, with university recognition for its teaching work, its main aims being to:

- Analyse the problems raised by biomedical progress and their repercussions for society and its system of values.
- Promote interdisciplinary dialogue between scientists and humanists as a working methodology allowing us to seek out reasoned routes for the resolution of conflicts based on respect for human rights.
- Serve as a platform for dialogue between the Christian faith and other world views, exploring the scientific, philosophical and legal basis of ethics as applied to the health sciences.
- Provide a service for society at large, highlighting bioethical issues in publications and other formats.

In order to achieve these purposes, we focus on three main operational areas: **teaching**, delivering a range of courses, along with our formal Postgraduate Courses in Bioethics and the Official University Master's in Bioethics, the latter delivered in person and also virtually via our online campus (www.campus.ibbioetica.org); **research**, as the Institute has its own forum for studying the subject, and is also involved in national and international research projects where the ethical consideration of issues of biomedical research plays a key role; **consultancy and publication on bioethical issues**, through membership of healthcare and research ethics committees and various institutions, taking part in central and regional government commissions and various working groups, and developing a range of activities to spread the word and raise the profile of bioethical issues, including single-issue publications and our quarterly journal *Bioètica & Debat*, the constant updating of our bioethics portal (www.bioetica-debat.org), and the maintenance and updating of our specialist Library and Documentation Centre. All the above is furthermore supplemented by the Institute cooperating upon request with the media and large-scale information platforms regarding issues of bioethics (magazines, newsletters, etc.).



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